



Expert meeting on experiences in applying a human rights-based approach to address mortality and morbidity among newborns and children under-five

Final Report

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I. Overview

Following the 2016 Human Rights Council resolution on preventing mortality and morbidity of children under 5 years of age,¹ the United Nations Office of the High Commissioner for Human Rights (OHCHR) hosted an expert meeting in collaboration with the World Health Organization (WHO) to discuss experiences in applying a human rights-based approach to address mortality and morbidity among children under five. The meeting focused in particular on the implementation of the <u>Technical Guidance</u> on a human rights-based approach to reduce and eliminate preventable mortality and morbidity of children under 5 years of age, taking account of the specific challenges in respect of the newborn child.

II. Background

The expert meeting built on a body of existing work to address child mortality and morbidity from a human rights perspective undertaken on the basis of mandates arising from the Human Rights Council and the World Health Assembly. These have included Council resolutions inviting OHCHR and the WHO to prepare reports on under-five mortality as a human rights concern,² and calling for the preparation of Technical Guidance on a human rights-based approach to reduce and eliminate preventable mortality and morbidity of children under 5 years of age,³ as well as an initial report on the implementation of the Technical Guidance.⁴

The first of these reports lays out the foundation of why preventable morbidity and mortality among children under five is a human rights concern. It describes the main health issues that affect children, and contains an analysis of the obligations of States and other duty-bearers with regard to children's right to health as well as recommendations to ensure the realization of that right. The report stresses that the survival, protection, growth and development of children in good physical and emotional health are the foundations of human dignity and human rights.⁵

The Technical Guidance itself is designed to assist States and non-State actors to improve the realization of the rights of the child by providing guidance on addressing mortality and morbidity of children under 5 years of age in accordance with human rights standards. It outlines the key elements of a human rights-based approach to reducing child mortality and morbidity⁶:

- A participatory, inclusive, non-discriminatory, transparent and responsive process for working towards achieving human rights and public health goals;
- The need to engage and build the capacity of relevant duty bearers and rights holders;
- Equality and non-discrimination as a framework to ensure that the most vulnerable and marginalized are given due attention;
- Ensuring that mechanisms exist to hold those responsible to account for their actions (or lack thereof); and

¹ Human Rights Council resolution 33/11

² Human Rights Council resolution <u>22/32</u>

³ Human Rights Council resolution <u>24/11</u>

⁴ A/HRC/33/23

⁵ Human Rights Council resolution 22/31

⁶ For definitions of the human rights concepts captured in this description of a human rights based approach and throughout this report, see Appendix 1.

 Promoting the availability, accessibility, affordability, acceptability and quality of facilities, goods and services related to health; and addressing its underlying determinants, such as poverty, poor education and lack of access to other social services.⁷

In addition, the Technical Guidance provides guidance for operationalizing a human rights-based approach, and includes an illustrative example of how it can be applied.

The report updating the Council on implementation of the Technical Guidance was submitted in July 2016. It highlights the emergence of collaboration between the communities working on child rights and child health, including the prevention of mortality, and provides clear examples of such work at the global level across different United Nations mechanisms.⁸

This substantive work has been complemented by the related work of the Independent Expert Review Group on Accountability for Women's and Children's Health, as well as the establishment of the Independent Accountability Panel and the Global Strategy for Women's, Children's and Adolescents' Health (2016-2030). In addition, the adoption of the Every Newborn Action Plan in 2014 at the World Health Assembly has been crucial in bringing attention to the particular needs of the newborn child. The High-level Working Group on the Health and Human Rights of Women, Children and Adolescents, convened following the 2016 World Health Assembly, presented a report of its findings and recommendations in May 2017 entitled 'Leading the Realization of Human Rights to Health and Through Health'.⁹

Opening the Meeting

During the opening session of the meeting, Kate Gilmore, United Nations Deputy High Commissioner for Human Rights, highlighted some key findings from the report, including the toxicity of certain social norms in relation to child marriage, child mortality, violence and exploitation. She noted the need for increased focus on the voice of people to realize rights, drawing attention to the Universal Declaration of Human Rights and a human rights-based approach as keys to helping overcome powerlessness.

Anthony Costello, Director of Maternal, Newborn, Child and Adolescent Health at the World Health Organization (WHO), drew attention to the importance of human rights based approaches to child morbidity as well as child mortality, especially in the context of humanitarian crises, access to health information and services, and protection from harmful substances. He also highlighted that health professionals may need additional capacity building to understand how human rights relate to child health and the services they provide.

Imma Guerras-Delgado, Adviser on Child Rights at the Office of the High Commissioner for Human Rights (OHCHR), recalled that while the evidence base around effectiveness of human rights-based approaches is crucial, international human rights law is in its own right an imperative regardless of the availability and quality of evidence. She underscored the importance of access to remedies in claiming children's health-related rights.

A human rights based approach to addressing child mortality is a critical cornerstone of a holistic, life cycle approach to addressing health. Furthermore, intergenerational poverty and inequalities contribute

⁷ Human Rights Council resolution 27/31

⁸ Human Rights Council resolution 33/23

⁹ Leading the realization of human rights to health and through health: report of the High-Level Working Group on the Health and Human Rights of Women, Children and Adolescents. Geneva: World Health Organization; 2017.

to child mortality and should thus be addressed within this context, especially for the most marginalized communities among whom mortality rates are highest.

The Special Rapporteur on the Right to Health, Mr. Danius Puras, noted the remarkable achievements regarding the rights to health and survival globally but also highlighted the need for more work to ensure the right to holistic development. Over-dependence on medicalized models has led to underprioritization of the determinants of health as well as psychosocial interventions. Recent retrogressive measures with respect to women's rights are of grave concern, and it is critical that the international community renew commitment to women's rights and children's rights moving forward.

Mr. Leo Heller, Special Rapporteur on the Right to Safe Drinking Water and Sanitation, also highlighted the need for greater attention to the underlying determinants of health, particularly access to water and sanitation. He underscored the importance of the availability, accessibility, affordability and acceptability of water and sanitation facilities to reduce child mortality.

The Special Rapporteur on the Environmentally Sound Management and Disposal of Hazardous Substances and Wastes, Mr. Baskut Tuncak, underscored the contribution of toxic waste to child mortality as well as morbidity. He recommended that states should assess the hazards of toxic threats to children, conduct human rights due diligence of non-state actors operating in their territories, and create a stronger and more effective global framework of treaties on hazardous substances and wastes.

III. Current knowledge on human rights based approaches to addressing preventable morbidity and mortality among children under 5

Background research

In preparation for this expert consultation, background research was carried out to provide an overview of the current state of knowledge with regard to applying a human rights-based approach to address preventable morbidity and mortality among children under five. Searches were carried out of the peer-reviewed literature as well as grey literature available online but they yielded very little relevant information. It is unclear if this is because people are not publishing work on human rights-based approaches to addressing preventable mortality and morbidity of children under 5 or if the search terms used (e.g. human rights, participation, quality) are too generic to efficiently find appropriate literature. In the case of the peer-reviewed literature, part of the challenge is that academic databases are not indexed in a way that is amenable to this type of search.

In addition to these searches, meeting participants sent documentation of their own work in this area. Participants were asked to submit case studies relating to one of the following areas:

- 1. Ensuring a supportive legal and policy environment;
- 2. Increasing access to health interventions, services and life-saving drugs; or
- 3. Establishing accessible, transparent and effective mechanisms for monitoring and accountability.

Many of the case studies submitted by meeting participants cut across more than one of these areas.

Report structure

The purpose of this report is to provide examples of how a human rights-based approach to addressing mortality and morbidity among children under five has been approached to date. This provided a grounding for discussion at the expert consultation by ensuring that participants were aware of the range of approaches that exist to applying a human rights-based approach in this context.

This report constitutes a compilation of case studies, each of which has been synthesized and reformatted in an effort to provide similar types of information within each one. Case studies are divided into two groups: those case studies that explicitly framed the work as human rights based (14 case studies), and those that are aligned with at least some elements of a human rights based approach (6 case studies). The difference between interventions that are explicit or implicit with regard to human rights has implications for how duty-bearers understand their roles and obligations, and for legal accountability, which is why they are presented separately. Explicit use of human rights standards and principles in policy making, service/intervention design and delivery, and monitoring and evaluation adds value in terms of legal accountability and individual and community empowerment where legal remedy and redress are available and accessible to all, and where individuals and communities are sufficiently sensitized to both their legal entitlements and means to claim said entitlements. If those elements are not present, using explicit human rights language can highlight these shortcomings and the need to strengthen such mechanisms. There may be very good reasons why human rights language is not explicitly used in some places but it is important to understand whether or not rights were part of the conceptualization of the work as without this caution, many public health programs could be framed as aligned with human rights without rights ever having been part of their design, implementation, monitoring or evaluation. It will be useful to further explore this question for the case studies currently categorized as aligning with some elements of a human rights-based approach.

Within the sub-section on work that is explicit in its adoption of a human rights-based approach, the case studies are organized into three different categories that emerged from the range of case studies received:

- 1. Health facility (self-)assessment for quality improvement (5 case studies)
- 2. Capacity building of duty-bearers and rights-holders (4 case studies)
- 3. 'General' human rights based approaches (3 case studies)

The last of these categories includes case studies that took a very broad approach to applying human rights to address child mortality that did not fit in either of the other categories presented.

A preliminary analysis is provided of patterns emerging from the range of case studies presented such as which elements of a human rights based approach are most and least often addressed within the work. In addition, a few potential questions for discussion, based on the information compiled in this report, are proposed that might be further explored. A short conclusion draws together the document.

The overarching vision is that this report can contribute towards strengthening the evidence base on the implementation of human rights based approaches to addressing preventable mortality and morbidity among children under five.

IV. Case studies explicitly grounded in human rights

This section includes all case studies that are explicitly grounded in human rights. They do not all address every aspect of a human rights-based approach to addressing mortality and morbidity among children under five, but each one includes explicit mention of human rights.

Health facility (self-)assessment for quality improvement

1. The European Association for Children in Hospital (EACH) Charter¹⁰

Background

EACH is an umbrella organisation of European NGOs and non-profit associations involved in the welfare of children in hospital and other healthcare services. It was founded to respond to the acknowledged need for conditions for children in hospitals to be improved as they were detrimental to children's emotional and psychological wellbeing. EACH has worked to develop a universally applicable set of standards for quality paediatric care in hospitals that can be implemented throughout Europe and beyond.

Applying a human rights-based approach

EACH developed a simple, 10-article Charter that explicitly "recognizes and endorses the rights of the child as stipulated in the UN Convention on the Rights of the Child (CRC), and in particular the key principles that, in all situations, the best interests of the child should prevail". An annotated version exists to help health workers understand what each article means and how they can implement it.

As one example of this, Article 2 of the Charter is that "Children in hospital shall have the right to have their parents or parent substitute with them at all times". The annotated version explains the practical implications of this right, an extract of which is included below:

"Children have the right to have their parents with them regardless of the child's age, 24-hours a day. This applies to all situations where children need, or possibly might need, their parents, e.g.:

- whether or not the child is being treated or examined, with or without local anesthesia or sedation;
- o during the induction of anesthesia and during recovery;
- during periods of coma or semi-consciousness and during resuscitation (At such times, parents must be offered full support);
- o after birth, whether the newborn child is healthy or needs special care.

It also includes:

children in neonatal or paediatric intensive care units, accident & emergency departments, isolation rooms, medical imaging rooms, recovery rooms, maternity services, ambulant transport services, or other healthcare settings in or outside of hospitals."

The Charter is simple and easy to follow, but a useful reminder to systematically pay attention to these issues.

¹⁰ An additional case study examining children's participation in decisions in healthcare decision-making from a human rights perspective has been carried out recently. Further information is available on the EACH website at: https://www.each-for-sick-children.org/best-practices/quality-of-paediatric-hospital-care/360-quality-of-paediatric-hospital-care.html

Lessons learned

The Charter has been used to inform legislation and professional guidelines in countries across Europe and it has been used as a reference in many scientific studies and publications. Additional documentation is being sought on this.

The Council of Europe adopted in 2011 Guidelines on Child Friendly Healthcare (see below for more information on this), where the EACH Charter was listed as one of the documents of reference.

2. The Maternal and Child Friendly Healthcare Initiative

Background

The aims and objectives of the Maternal and Child Friendly Healthcare Initiative (MCFHI) are to improve the quality of health care given to women and girls, particularly those who are pregnant, children and families across the world and to reduce unnecessary fear, anxiety and suffering during and because of a healthcare experience. The MCFHI involves (self-)assessment of the quality of care being provided in a hospital with a view to informing quality improvement interventions. It builds upon the Child Friendly Healthcare Initiative (CFHI), expanding this to also include attention to women.

The MCFHI manual describes the rationale, concept and details of women- and child-friendly health care. It discusses reasons for sub-optimal care and suggests simple and practical ways in which health providers and individual health workers can assess their care and make improvements.

Applying a human rights-based approach

The MCFHI builds on the previously-developed 'Child Friendly Healthcare' Standards, translating the articles of the CRC into every day health practices relevant to children as well as women and girls who are or may become pregnant. Sixteen articles of the CRC are highlighted as particularly relevant, including the right to health, the right to non-discrimination and the best interests of the child.

The standards were developed following global consultation that ensured the participation of a range of stakeholders. The MCFHI assessment process is also highly participatory, seeking ideas and possible solutions from health workers, women, and children and their parents/care-givers thereby giving them a voice in how services are provided. This promotes a sense of ownership of health services, and any improvements thereto, among these groups.

Taking into account limitations in resource availability, the standards promote high quality care that is accessible (including financially accessible) and acceptable to women and children.

One of the Standards "Recognises, protects and supports vulnerable and/or abused women, girls, infants and children" thereby promoting equality and non-discrimination, which are key elements of a human rights based approach.

Overall, the MCFHI aims to improve institutional accountability for the provision of quality health services for maternal, neonatal and child health by promoting self-awareness among hospital managers and staff about strengths and weaknesses in their service delivery to inform quality improvement efforts.

Lessons learned

Although it has since been implemented in an even wider range of countries, CFHI was pilot tested in Kosovo, Pakistan, Uganda and the United Kingdom. ¹¹ Initial assessments resulted in developments by health workers in several areas of care including: development and integration of therapeutic play in multiple hospital units (Mulago Hospital, Uganda); parental participation in clinical care and ward rounds (Gjilan Hospital, Kosovo); and multidisciplinary working committees, including parental representation for the first time (PIMS Children's Hospital, Pakistan). All of these constitute important improvements to quality of care.

The project revealed similar causes of frustration, anxiety and distress in parents, children and health workers at all sites. Two of the factors that hindered appropriate care were poor systems for disseminating and implementing new knowledge and defensive hierarchical management structures that prevented change or progress. This has implications for commonly perceived solutions to poor practice: while training can sometimes be necessary, alone, it can be insufficient to improve service quality.

The CFHI toolkit was seen to be universally applicable and to enable health workers to identify, prioritise, and make realistic improvements to care or the systems that contribute to care. The same process also enabled change to be measured. There are strong indications that the approaches developed were beneficial to the ability of health workers to effect positive change in the care received by children and families.¹²

The Guidelines on Child Friendly Healthcare were endorsed by the health ministers of 47 European nations in September 2011 in Lisbon.

3. Health care driven by children's rights in Santiago, Chile: 'Hospital Amigable' program

Background

Infant mortality in Chile was reduced from 120 to 7 deaths per 1000 births between 1950 and 2014. This achievement was based on good policies, plans and approaches, the foundation of which was political will. Supportive laws and public policies, including a legal guarantee of the right to health, led to high coverage of public health services, increased human resources and, ultimately, reduced mortality.

Within this context, Hospital Dr Luis Calvo MacKenna is a large government children's hospital in Santiago, providing general and specialist services to children and families from Santiago and other parts of Chile. In 2008, the hospital recognised that a new approach was needed to improve the experience and quality of care, to foster the development of a culture that recognises children as rights-holders, and to integrate a rights-based approach throughout the design, systems and delivery of care.

Applying a human rights-based approach

¹¹ For further information on country-specific improvements and lessons, see: http://www.cfhiuk.org/pilot/index.htm

¹² Clarke A and Nicholson R. The Child-Friendly Health Care Initiative – An Update. Paediatric Nursing. 2007. 19(8):36-7.

The team, working together with children and families, adapted the Child Friendly Healthcare Initiative (CFHI) model, a child-rights framework for guiding, assessing, implementing and monitoring change (see above), to become 'Hospital Amigable'. The model is a 'quality of care' improvement cycle focused on 12 standards and criteria that translate the CRC into daily practice for health workers.

A triangulated approach enables health workers, children and parents to assess the quality and experience of care against each standard, identifying where rights and quality of care are good or should be better, and providing a framework for making and then measuring improvements.

A multi-disciplinary committee was established for planning and coordinating the program. The psychosocial team led the process but all clinical teams were included, with full and continuing senior management support and institutional commitment at strategic and 'mission-level'.

Initial implementation included the training and sensitisation of hundreds of hospital staff about child rights; a qualitative study about children's rights within the hospital; an initial assessment of three standards (Communication, Pain, Play); and activities across the institution to engage workers in a 'Friendly Hospital Community'.

Following this, a structured approach was applied along two lines; one line of actions at the institutional level, and a second line in specific units (Oncology, BMT, Cardiology, and Critical Care) including assessment and grading against all 12 standards and implementation of improvement plans.

Lessons learned

At the hospital level, this work has led to improvements in facilities and support for families; new protocols and systems for protecting children from abuse and maltreatment; increased focus on play and education; changes in human resource management and induction training for all staff; information and awareness about rights across the institution; and inclusion of child rights in the institutional strategy and mission. In addition, within specific units, changes have included: introduction of routine assessment and improved pain management; children and parents now remain together 24 hours; weekly meetings between parent groups and staff; increased value and use of play within clinical practice and more play spaces (including in the Operating Room); improved privacy for children and adolescents; spaces for sensitive discussions; information booklets for children and families; and greater integration of education.

This has been captured through a range of quantitative and qualitative information. For example, with regard to the standard of 'information giving and participation', the following improvements were noted:

Indicator	Baseline (2008)	2014
% children and carers receiving enough information	83%	98%
% children and carers who report understanding all information received	63%	95%
% children and carers who report being listened to and having their views taken seriously	63%	77%

There has been much learning, building on the earlier lessons and implementation experience from Hospital Amigable and CFHI. Revisions have been made to streamline the tools and simplify the process,

and work done to promote a rights-based model and supportive links with other hospitals interested in adopting this approach. Better structured mechanisms for collating cyclical assessment findings are also in advanced stages of development, adding statistical consistency to the model for wider applications.

Most applications of this model to date have been at localised levels or piggy-backed onto other things when opportunities have arisen. They have been able to demonstrate an ability to catalyse the types of changes in systems, health worker practice and user experience, that are already associated or evidenced as contributing to improved outcomes. However, an important gap remains to gather evidence from a controlled trial, to isolate and measure the impact on higher level outcomes such as mortality or others (e.g. utilization, equity-reach, recovery rates/times, failed treatments/compliance, re-admissions, risk behaviours, measurable anxiety or post-care mental health, cost etc.).

4. The 'Task Force on Health Promotion for Children and Adolescents in and by Hospitals' self-evaluation tool — lessons learned from Kyrgyzstan, Moldova, Tajikistan and Uzbekistan

Background

While efforts to increase the accessibility of health services have been underway for many years, it is only recently that similar attention is being given to the quality of these health services. Children's rights provide a useful framework for quality assessment and improvement efforts, particularly focusing on improving children's experience of health care and enhancing children's and parents' involvement in their own care and in the development of services. This has been recognized in recent strategies and policies. However, guidance is required for health professionals to understand and translate their obligations as duty bearers into the provision of quality health services for children.

Applying a human rights-based approach

The Task Force on Health Promotion for Children and Adolescents in and by Hospitals developed a self-evaluation tool based on the CRC's guiding principles. There is also an accompanying Manual on Children's Rights in Hospital and Health Services and a set of tools for assessment and improvement. The task forced recognized "the respect of children's rights as a key component of health promotion, of child- and family-centred care".

The domains of the tool map directly to specified articles in the CRC. All components of a human rights based approach are explicitly encompassed (see Table 1)¹⁴.

Table 1: Elements of a human rights based approach captured within the tools

HRBA element	Assessment within the tools
Quality	The overall aim of the tools is to assess children's right to health and other related rights as a means to improve the quality of healthcare.
Participation	The tools assess children's participation in their own care and in the design, development

¹³ See for example: Investing in children: the European child and adolescent health strategy 2015–2020; WHO Regional Office for Europe's Health 2020 policy framework and strategy.

¹⁴ Table is adapted from Guerreiro et al. Assessing and Improving Children's Rights in Hospitals: Case Studies from Kyrgyzstan, Tajikistan and Moldova. *Health and Human Rights*. 2016; 18(1):235-248.

	and assessment of services. The process of implementing the tools is designed to include participation of children, parents, health professionals and health managers in the		
	assessment of standards and identification of gaps for improvement.		
Availability	The tools assess the existence, implementation and appropriateness of a range of		
	paediatric services such as pain management and child protection.		
Acceptability	The tools assess acceptability generally as well as the elements of friendliness, safety,		
	cleanliness and appropriateness of hospital infrastructures.		
Accessibility,	The tools assess accessibility as well as the delivery of patient-centred care that		
Equality and non-	recognizes the child's individuality, diverse circumstances and needs.		
discrimination			
Accountability	The tools assess the implementation of national programmes and hospital policies in		
	place against actual delivery of care for children. They also facilitate a monitoring and		
	evaluation system for quality of paediatric care.		

Tool implementation involves training on child rights relevant to health care and on how to use the CRC as a framework to assess, monitor and improve paediatric health services.

Since 2012, the European Regional Office of the WHO has supported the use of these self-evaluation tools in a range of countries including Kyrgyzstan, Moldova, Tajikistan and Uzbekistan. "In Moldova, the Ministry of Health used the findings and recommendations from the first round of assessment to develop a national plan of actions to improve quality of care in pediatric hospitals but did not proceed with a second round of assessment of children's rights in hospital...

In Kyrgyzstan and Tajikistan, the tools were used to assess improvement results approximately one year after the first assessment... Between the first and second round of assessment, hospital managers initiated changes in several areas. For example, some of the hospitals reorganized children's wards in a way that allowed parents or caregivers to stay overnight. Substantial improvement was also noted in the number of hospitals that displayed and disseminated a Charter on Children's Rights. Hospitals also reported that after the first assessment they ensured that in waiting areas different videos with health messages such as prevention of acute respiratory infections, diarrhea, support and promotion of breastfeeding and proper care seeking were shown to enhance parents' knowledge of child health."

Lessons learned

Highlighting the importance of children's and parents' participation in assessments of paediatric health services, these perspectives provided crucial information about the fulfillment of certain rights, which would have been difficult to gather otherwise. The process of the assessment was educational for everyone involved as it raised stakeholders' awareness of rights and obligations. A national multistakeholder steering committee can help raise awareness of and commitment to ensuring a human rights-based approach to child health both within and beyond the hospital setting.

The areas where least improvement was seen between assessment rounds in Kyrgyzstan and Tajikistan related to renovation of hospital infrastructure including to improve children's privacy as well as to ensure access to play areas and facilities. This work would require substantial financial investment. Engagement of children for the development and improvements of health services was another area where little change was observed; this is likely a challenge as it will require capacity building and behaviour change, and more importantly a culture in which children's views are properly respected.

Even where repeat assessments were carried out, little information was generated about equality and non-discrimination, highlighting the need to ensure appropriate adaptation of the tools and capacity building of researchers to attempt to capture local nuances wherever implemented. Triangulating responses from different stakeholders (e.g. health workers and service users) is useful to minimize (or at least understand) desirability bias in responses.

5. Assessing conduciveness for quality of care in hospitals in Zanzibar¹⁵

Background

For many years, the Ministry of Health of Zanzibar has been trying to reduce the neonatal and under 5 mortality rates. Recent government statistics on the neonatal mortality rate are not available but in 2010 it was 29 per 1,000 live births. Improvements have been documented in under 5 mortality in Zanzibar, which decreased from 141 per 1,000 live births in 2002 to 67 per 1,000 live births in 2012, but remains unacceptably high.

A study was carried out to examine the current situation in five hospitals in Zanzibar providing maternaland child health care, with the aim of assessing how conducive those hospitals are to achieving high quality of care. While older studies examining the performance of health facilities in Zanzibar have focused on technical aspects, this study also looked into issues such as participation of patients and respect for the dignity of the patients and their families. It has become increasingly clear that many aspects of human rights could and should be addressed to help achieve high quality of care. This was the first study in Zanzibar to assess these aspects of quality of care.

Applying a human rights-based approach

The hospital assessment included WHO's 8 standards of quality of care: evidence-based medicine, health information system, referral system, communication system, respect and dignity, emotional support, competent and motivated staff, and physical environment. In addition, it assessed the level of patient participation in decisions regarding their health, health workers' perspectives of the availability of the supplies that they need to provide services, and visual inspection of the hospitals' infrastructure (including availability of appropriate rooms and supplies as well as physical accessibility for people in wheelchairs) and cleanliness. This provided additional insight into the experiences of patients and health providers.

Lessons learned

Shortcomings were found with regard to many of the standards including communication, dignity and respect, emotional support and the physical environment. The most needed changes identified by participants all relate to health systems challenges (ensuring supplies, adequate staffing, adequate infrastructure), highlighting the need for intervention at the level of the health system to ensure quality services at the facility level.

¹⁵ This material is synthesized from the evaluation report: Conduciveness for High Quality of Maternal- and Child Health Care in Hospitals in Zanzibar. (Tarek Meguid, Fatma Mrisho Haji, Tanneke Herklots, Mubina Rajhy, Nihfadh Issa Kassim) 2016.

All respondents in the assessment had ideas for improving the quality of care within hospitals, suggesting that a participatory planning exercise might be useful. Lack of mechanisms for redress, transparency and accountability were highlighted as areas of concern where concerted action is required.

Capacity building of duty-bearers and rights-holders

6. Promoting Child and Women's Rights in the Health System and Services

Background

In Argentina, health care has traditionally been carried out from the biomedical approach without regard to the social determinants of health, which limits the possibility of recognizing all people equally as subjects of rights. The lack of consolidation of a culture of rights in the health sector perpetuates human rights-blind policies that limit accessibility and quality of services, and foster health service delivery that does not protect rights as evidenced through discrimination, violence and other rights violations with negative health consequences. Fragmented service delivery prevents adoption of a person-centred, life-course approach to health and recognition of the interdependence and indivisibility of human rights.

Applying a human rights-based approach

Collaborative multi-country efforts to promote the child's right to health have been ongoing for over a decade, with some work particularly focused on how to translate child rights frameworks into practical tools to be applied to health policy formulation, health programmes and interventions. An overarching strategy for the training of health professionals¹⁶ was tailored to the Argentinian context by the Program of Social Sciences and Health at the Latin American School of Social Sciences (FLACSO) in Buenos Aires. It is grounded in child rights, particularly Article 12 of the Convention on the Rights of the Child (respect for the views of the child).

With regard to ensuring a supportive legal and policy environment, the project has worked with policy makers, ministries of health, local health authorities and hospital directors advocating for the rights of children and women. Access to health interventions, services and drugs has been promoted through: translating the empirical evidence of rights based interventions on the health of newborns and children; generating arguments for health teams on the added value of introducing a child rights perspective in their professional practices; training health care teams to integrate a rights perspective into the health care model; promoting the participation of children in health services and informed decision making in those aspects that involve them; and working with scientific societies and UN agencies to reduce existing gaps between discourses and practices. Through the project, tools have been developed to assess knowledge and perceptions about rights, to characterize care settings, and to capture qualitative and quantitative indicators that illustrate the extent to which a child rights perspective is incorporated into healthcare delivery.

Lessons learned

A range of areas for strategic action have been identified through the project:

 $^{^{16}}$ This was based on original work by T Waterston, G Lansdown and J Goldhagen.

- Integrating the agenda of the rights of the child with the rights of women from a life course perspective
- Recognizing that changing institutional cultures takes time, creating long-term collaborations with health professionals and organizations within the health sector as well as with other sectors so as to deepen the inclusion of a child rights approach in services and policies
- Developing models of accountability that capture states' commitment to child rights
- Promoting activities to empower children and their caregivers in order to achieve higher levels of agency in relation to their health, development and quality of life.
 - 7. Stimulating demand and improved supply of maternal and newborn health services by gender empowerment, increasing equity, access, quality of care and accountability in Nepal

Background

Social and gender-based discrimination is a barrier to the health-related rights of young women and newborns in Nepal, who face a patriarchal and caste-based social structure, low levels of influence, participation and self-determination, with most decisions at household level made by men and mothers-in-law. Progress made nationally towards reducing maternal and newborn mortality and morbidity is not reflected among marginalised populations and rates of antenatal care and skilled birth attendance are significantly lower.

A rights-based maternal mobilization and access programme was implemented between 2012 and 2016 in Rupandehi District, Nepal, in rural areas in the south and west along the border with India and in urban slums.

Applying a human rights-based approach

The Improved Mother and Infant Health Project worked in partnership with communities and government health services to improve the health-related rights and empowerment outcomes of marginalized women and newborns through mobilizing and leveraging women's groups, behaviour change, and capacity building of both community and government health structures. It focused on the capacity building of duty-bearers and rights holders as well as promoting equality and non-discrimination by targeting the most marginalized.

The project covered a population of 380,000 people targeting 109,000 women of reproductive age and approximately 9,000 pregnant women and newborns each year, also engaging dominant influencers such as men, mothers-in-law and older women.

There were four project outcomes, each of which reflects certain elements of a human rights based approach, including participation, accessibility, quality and accountability:

- 1. Improved health seeking behaviours to protect and promote maternal and newborn care and community knowledge of women's health rights
- 2. Reduced barriers to accessing maternal care and improved referral systems
- 3. Strengthened and more responsive health services
- 4. Increased sustained participation of women rights-holders in local decision making and resource allocation

Evaluation data showed encouraging improvements in many indicators (Table 2).

Table 2. Results related to selected project indicators

Result	Indicator	Baseline %	End of Project %
			(sample n. 710)
Outcome 1	% of pregnant women attend four times for antenatal care	51.9	73.5
Outcome 1	% of women attend at least once for postnatal care	33.3	67.6
Outcome 1	% of newborns examined by a health worker	46.9	93.3
Outcome 1	% of infants exclusively breastfed to 6 months	64.5	90.6
Outcome 2	% of women delivered last baby at a health institution	38.5	64.5
Outcome 2	Traditional Healers and Female Community Health	0	256 Trad Healers
	Volunteers trained in community referral systems		540 FCHV
Outcome 2	% of health facilities operating basic written referral	0	100
	pathways related to their specific geographical location		
Outcome 3	Newborn Care Corner established at Birthing Centres	0	100 (8)
Outcome 3	Functioning Health Facility Management Committees		
	% of HFMC members regularly attend	Invalid data	84.5
	% of HFMC with development plan	0	100
Outcome 3	% of health facilities comply with minimum government	Drugs: 13%	Not assessed due
	levels of equipment and essential drugs	Equipment:	to blockade
		29%	82.5
Outcome 4	Outcome 4 % of women participants in local government planning		37
Outcome 4	% of local administrative areas with devolved budget for	10	77
	maternal and newborn health activities		
Outcome 4	% of Women Dialogue Groups evolved into formal	0	73
	cooperatives and local CBOs		

In particular large changes were seen for disadvantaged groups of Madhesi, Dalit and Muslim women and newborns, closing the equity gap between women from advantaged and disadvantaged castes (see Table 3 for an example of this).

Table 3. % of pregnant women accessing antenatal care at least four times (by caste/ethnic group)

	Brahmin / Chhetri	Terai Madhesi	Dalit	Muslim
Baseline	70	45	47	43
End project	80	73	72	64
Change + / -	+10 (14% rise)	+28 (62% rise)	+25 (53% rise)	+21 (49% rise)

The graduation of most Women's Dialogue Groups into cooperatives and CBOs, and the development of community-managed emergency funds supports their organizational and financial sustainability. The approach for strengthening the referral systems within government health services in the area has also been embedded.

Lessons learned

Public health strategies to improve maternal and newborn health outcomes in some settings are likely to struggle unless interventions to improve health care supply are integrated with interventions that

address societal barriers that prevent rights-holders (pregnant adolescents and young women) from enacting their rights to information and self-decision-making, and that include women in local accountability mechanisms.

Increasing women's empowerment, influence and access to maternal and newborn health services (demand), has to be matched with interventions to improve rights-respecting practice inside health facilities (supply). Health worker attitudes and behaviours are a major factor in use of maternal and newborn services.

Barriers faced in supporting change differ within and across different social and ethnic groups. Blanket strategies need to be combined with more tailored actions to bring inclusion, equity and improved outcomes for all.

8. Fulfilling the right to information: IAP HealthPhone, India

Background

Although under-five mortality has decreased in recent years in India, it remains unacceptably high. The Indian government has put in place a range of initiatives to reduce child mortality but there remains a knowledge gap, both for health workers and for parents, that limits their effectiveness. The IAP HealthPhone aims to impart information on maternal and child health through mobile phone technologies targeting woman and health workers. It was founded on the principle that "informing, educating and supporting society in child healthcare knowledge is a right" and it seeks to uphold the right to health.

Applying a human rights-based approach

Available in 18 languages, accessibility and acceptability of messages to different communities have been central to project design. The project is intended to promote women's participation in decisions relating to their health, with the ultimate aim of improving women's health and children's health. The project targets the rural poor and other excluded groups in order to overcome pre-existing inequalities: conditional cash transfers are given to women from poorer districts along with free talk time so they can watch the educational videos.

A decentralised training programme targets a range of stakeholders including state governments, NGOs and health workers to improve the quality of health services. These stakeholders in turn educate adolescent girls and women up to 35 years of age as well as husbands and grandparents. This can serve to galvanize duty-bearers to understand and fulfil their related human rights obligations.

Lessons learned

Limitations in the health workforce and infrastructure may limit implementation in some places. Furthermore, coordination of multiple stakeholders across sectors has been a challenge.

Low levels of literacy, including health literacy, shape the ways in which messages must be conveyed.

Data on the number of times that different messages are viewed has been collected but has not yet been connected with data on health outcomes. By 2025, the project hopes to have reached 20 million

women with online messages as well as 17 million through revitalization of the health worker training programme.

The rapidly growing mobile phone market in India constitutes a platform with immense potential for disseminating health information tailored appropriately to local languages and literacy levels.

9. A child human rights judgment that saved half a million lives in South Africa *Background*

In 1999, it was established that a single dose of nevirapine administered to a mother during labour could reduce mother to child HIV transmission by almost half (47%). Yet, in South Africa, in 2000, 75 000 infants and young children died of HIV infection because these drugs were not available. About one in three children of HIV-positive mothers were infected with HIV.

Despite nevirapine being cheap and registered in the country the South African government limited its use to 18 pilot sites with no timeline for expansion. Although framed as a capacity issue, this was driven by the president's negative perception of anti-retroviral therapy. Paediatricians, child health advocates and other civil society organizations carried out a range of activities to pressure the government to act but the government refused to change its stance.

Applying a human rights-based approach

Political action took place at a grassroots level. There were demonstrations at hospitals. A meeting was conducted with the Health Minister. Email campaigns took place. Memoranda were distributed. Legal action to enforce doctors to prescribe these drugs became inevitable. A Court case was filed.

In August 2001, the Treatment Action Campaign (TAC), together with Save Our Babies and the Children's Rights Centre filed a constitutional action against the government claiming a violation of the constitutional right to basic healthcare. The parties sought a declaration that the current policy was unconstitutional and asked that the government be ordered to make nevirapine available to pregnant women and their babies in the public health sector where this was medically indicated. The state opposed the case on grounds that the relief was unaffordable, that the efficacy and safety of nevirapine was not fully proven and that its widespread use risked a public health catastrophe.

The High Court found in favour of the civil society groups but the decision was appealed by government and referred to the Constitutional Court, the highest court in the land. During this time, TAC and Save our Babies engaged in intensive public mobilisation, attracting enormous support and media interest. In July 2002, the Constitutional Court found the government's policy to be unconstitutional. The Court noted that nevirapine should be more accessible and ordered the Minister of Health and all nine provinces to lift restrictions on the availability of nevirapine 'without delay'. Following the judgment, the Department of Health included programmes for the prevention of mother to child transmission of HIV in their budgets and the public health system began rolling out treatment to adults and children living with AIDS.

In the decade following the court's decision, it is estimated that HIV infection was averted for 327,000 infants as a result of having access to services to prevent mother to child HIV transmission. The South African under-5 mortality rate halved from 80 per thousand live births in 2003 to 41 in 2011, primarily

because of efforts to prevent mother to child HIV transmission and the provision of antiretroviral therapy to children. In 2016, with better drug regimens available, mother to child transmission of HIV has been reduced to 1.3%.

Lessons learned

Regrettably, despite the example highlighting the potential that litigation may have for attainment of human rights, access to courts for the poor and pro-poor organisations remains limited owing to the scarce resources directed to providing public legal services. The South African government has continued to appeal human rights-related cases and to question the Constitutional Court's jurisprudence on socio-economic and other rights.

Civil society has learnt the importance of social mobilisation dedicated to ensuring that people's rights are upheld. It was the efforts, advocacy and dedication of civil society and health-care workers that ensured that the judgment did not remain mere words on paper. However, access to courts for economically disadvantaged groups and the organisations working for them remains limited.

The case demonstrates the key elements for successful realisation of human rights - including respect for the rule of law, an active civil society addressing more than health care, effectively resourced propoor legal organisations, and a government willing to put the constitution at the forefront of all policymaking decisions. It vividly shows the power skilful litigation can offer in taking advantage of human rights and constitutional promises.

'General' human rights based approaches

10. Enabling sustainable access to essential basic paediatric medicines in urban poor primary health care in Nepal

Background

Government urban primary health care is very limited in Nepal in terms of coverage, quality and utilisation, following its initiation only five years ago. Nepal has committed to Universal Health Coverage, particularly targeting the poor and underserved. Primary health services and medicines are free and the country retains a strong policy focus on maternal and young child health. However, this is undermined because the government supply of 35 essential medicines and items includes only three medicines in an appropriate form for young children, none of which are antibiotics.

As a consequence, families, including the poor, bypass the government urban health services to use private providers, incurring increased out of pocket expenditure, unnecessary exposure to unregulated practice or advice, and avoidable polypharmacy.

Applying a human rights-based approach

Asha Health Care has been providing urban pro-poor primary health care for women, children and adolescents at central and satellite sites in Kaski District for over a decade, with services, facilities design, systems, values and care practices based on a child-rights framework. As an NGO service, it filled a large gap in provision, its services achieving high reach and acceptability to poor and marginalised groups, utilized over 700,000 times, and an integrated part of the district and regional health system.

Assurances about rational prescribing and rights were also re-affirmed in the service's rights-based Charter that was promoted and displayed.

In June 2016, following a staged period of preparatory scaling down, re-structure and capacity building of health facility governance, Asha Health Care was mainstreamed and adopted into the government health service as Asha City Clinic, a Municipality primary health service and as a resource unit to support improvements of quality of care at Urban Health Centres.

Community consultations and dialogue with key stakeholders in the period leading up to hand-over to the government, highlighted concerns about the future availability of paediatric medicines and the impact that would have. To address this, preparation included establishment and capacity building of the Health Facility Management Committees (HFMC), now with more devolved power in Nepal, that promote community participation. A non-profit community drugs programme was established with the HFMC, operating alongside the government supply within the central health facility to enable continued access to essential paediatric medicines within the facility. Essential paediatric medicines are sold at wholesale price enabling cheaper access and removing the need to visit other providers. The administration costs of the programme are covered by the bulk-buy discount provided by the supplier.

The community drug programme has been running for less than a year but uptake has been good, with 2,047 recorded users during the last 6 months, almost all under 5 years. Daily management, re-ordering cycles and Health Facility Management Committee oversight have worked as effective accountability mechanisms. The activation of the community drug programme (together with better quality of care factors) is cited by service users as one of the reasons for high attendance and utilisation rates at Asha City Clinic; they continue to be 2-3 times the level of any other urban health service in the city.

Lessons learned

The sustainable functioning of a community drug programme in the current Nepali context is reliant on having devolved, competent and locally accountable governance – in this case study in the form of a Health Facility Management Committee. Investment in strengthening local health service governance and transparency creates the platform for locally owned interventions such as this, which can provide a cheaper source of medicines than retail, increasing accessibility for poor populations.

11. Addressing preventable mortality among newborns and children under five in Togo *Background*

Despite concerted efforts at the national level to reduce neonatal and child mortality in Togo, these rates remain high: 89 and 27 per 1000 live births respectively. Underlying causes contributing to this mortality include: poor sanitation and lack of access to clean water; low quality of services to address malaria, pneumonia and diarrhoea; insufficient coverage of vaccinations and services to prevent mother-to-child HIV transmission; and financial barriers to accessing services.

Applying a human rights-based approach

A favourable legal and policy environment has been created in Togo within which to address child mortality. National health policies prioritize the health of women, newborns and children under five

years of age, and multisectoral interventions on neonatal and child health are coordinated by the Ministry of Health's maternal and child health department.

Efforts have been made to ensure the availability of structures, appropriate human resources and services for children and neonates. Some services such as malaria, neonatal care and paediatric HIV services are free while all services for children under five are subsidized through a social protection scheme that is designed to ensure the financial accessibility of services to all. However, public awareness of available services and when they should be sought remains low.

Accountability is promoted through the use of performance indicators with national data disaggregated by age and sex. Surveillance of maternal and neonatal deaths is also carried out and there is an annual review of neonatal and child health interventions.

Lessons learned

Despite the favourable legal and policy environment, challenges exist in relation to mobilizing sufficient resources to implement the necessary interventions in a sustainable manner. In addition, ensuring engagement of all appropriate stakeholders including the health workers themselves can be a challenge. Additional efforts on public awareness and education appear critical to generating demand for services and holding duty-bearers accountable for their obligations.

To effectively reduce neonatal and child mortality, it is important to institute and implement a policy of free or subsidized services for diseases that cause a high burden of mortality such as malaria, diarrhoea and pneumonia. Ensuring the availability of essential medicines and blood products is also key.

12. Access to essential healthcare services in emergency-affected and fragile settings *Background*

In fragile and very low-income settings, health facility services are inaccessible to large portions of the population even in normal times. During emergencies, access to these services is reduced even further. When humanitarian relief services are provided, it is often only to populations that are easy to reach, such as around urban centres or in camps for refugees or internally displaced persons, leaving the majority of the affected population without access to any services.

UNICEF, IRC and Save the Children conducted case studies in Liberia, Sierra Leone, Guinea, South Sudan and Bangladesh looking at the use of community health workers (CHWs) to increase access to essential healthcare services in different types of emergencies.

Applying a human rights-based approach

A human rights-based approach is key to the design of effective community health interventions. In this work, the human rights principles and standards of availability and accessibility of services, participation, non-discrimination and accountability were considered particularly central. Services at the community level aimed to overcome inequalities in access to services by bringing care to those with the most need and least access. Additionally, community engagement in the selection of CHWs and for community accountability was key to ensuring successful outcomes.

Lessons learned

Key challenges included weak government capacity and ownership of programs, lack of flexible funding mechanisms to quickly respond to the changing situation, health system weaknesses that led to stockouts of commodities and weak supervision, and a lack of trust in government and the health system.

The projects' experiences highlighted the importance of having strong health services at the community level provided by known and trusted members of the community during emergencies. These services proved to be more resilient and accessible than health facility services. Engagement of CHWs and other community members was also key to mounting an effective response, particularly during the Ebola outbreak. However, stronger commitment from governments, donors, and implementing partners is needed to strengthen community health services in stable times and to provide continued support during emergencies.

13. Regulating the inappropriate marketing of breast milk substitutes and other foods for infants and young children, including through human rights frameworks

Background

Improving the breastfeeding rate globally would result in the lives of 800,000 children under the age of 5 being saved, 87% of them at less than 6 months old. In addition, there were would economic gains of over \$300 billion annually due to increased productivity from higher intelligence; and women's risk of developing invasive breast cancer would decrease. However, women worldwide lack the support needed to initiate and maintain breastfeeding, partly due to insufficient investment in this area. Alongside this there is an emerging trend of promoting breast milk substitutes on social media, and global sales of substitutes are expected to rise for \$44.8 billion currently to \$70.6 billion.

Applying a human rights based approach

The International Code of Marketing of Breast-milk Substitutes was adopted by the WTO in 1981. The code prohibits inappropriate marketing, but does not prohibit sales. The code is thus voluntary. Since its adoption, the code has been strengthened to include provisions on: non-necessity of follow-up milks, prohibition on making nutrition and health claims, prohibition of free and low cost supplies, avoidance of conflicts of interest, risk of contamination and need for strict guidance on preparation and use. Furthermore, a longstanding loophole has been closed. The code is very specific now on any kind of milks presented as suitable to children up to the ages of 36 months.

Countries are expected to translate the code into national legislation. However, only 32 countries have a monitoring system for monitoring implementation of code legislation.

Lessons learned

There is a lack of political will, interference from manufacturers and distributors, lack of sufficient data and expertise, absence of coordination among actors and limited resources for legislation, or for monitoring enforcement of legislation. Companies exploit complexities with regard to breastfeeding very well. For example, Nestle is digging water wells in many countries so that breast milk substitutes can be used safely.

This has to be framed as a violation of children's right to health and mother's right to unbiased information. Then international human rights instruments, such as the CRC, CEDAW and the CESCR, can be used as a framework for accountability. International human rights institutions need to be a part of the solution. Women have the right to choose whether or not to breastfeed, but that choice has to be an informed one. The international code of marketing should be renamed and seen as a tool that expresses a violation of the rights of the child.

In addition, it is important to be more innovative and aggressive in terms of calling out code violations; to broaden the network to identify code violations and aid countries in eliminating code violations. WTO could usefully create a list of code violators as part of a 'naming and shaming' approach. In the Philippines there was huge community mobilisation, with breastfeeding mothers leading large public demonstrations, and this worked.

14. Health economics as a child rights issue

Background

Economics is a means through which we can target core child rights challenges, including mortality and morbidity among children under five. In practice ideas on entitlements such as universal health coverage can conflict with economic ideas on fiscal prudence but it is critical to promote dialogue in such a way that economic stakeholders appreciate the rights aspect and the struggle involved.

There is a positive correlation between increased health expenditures and reduced child mortality. Through fiscal policies, access, availability and affordability of services can be enhanced. Budgets should therefore be informed by appropriate data so that resources can be appropriately targeted and efficiently used. Currently, 20-40% of health resources are wasted through inefficiencies and corruption.

Cost effective analysis is fundamental but it is not done enough. In Malawi, basic things such as toilets and community healthcare are largely underfunded. Even procurement systems are wrongly managed, creating unnecessary overspending: budgets for procurement are often higher than prevention budgets.

A human rights based approach

Strengthening the link between plans and budgets enhances allocative efficiency and effectiveness of investments. Attention to human rights principles in these processes can contribute to this. For example, health and expenditure policies are more affective when they reflect age and gender, issues to which non-discrimination draws attention. Investing in decentralisation has the potential to improve access to health services. There is much need for work at the local level. Globally the evidence on child participation in budgeting is mixed. However, participation usually takes place only once, which is not enough to challenge adults and existing power dynamics. Children are able to monitor utilisation of budgets better than adults in some cases. Fiscal transparency and budget monitoring improve accountability and effectiveness in child health expenditures.

Lessons learned

A legal framework without a financial plan cannot be effective. Policies in most countries are already compliant: it is implementation that falls short. Ensuring resource allocation is key, and there should

always be a forum where children can contribute to this process. Consideration of the political economy is also critical to these processes.

Domestic Resources are the most sustainable source of health financing as most governments are more prudent with their own resources, than with donor resources. One can generate as much as 5-6% of the health budget by tackling inefficiencies.

More can be done on efficiency, effectiveness and equity, including assessing and influencing expansion of the fiscal space for health, ensuring that community healthcare gets an equal share, and strengthening fiscal transparency and accountability mechanisms. The child health and rights sectors should engage budget actors to ensure appropriate attention to human rights throughout these processes, with special attention to children's health and rights in emergencies.

Furthermore, human rights can contribute to addressing corruption, which can also increase the budget available for work on child health and rights. There are three pathways of change to address corruption:

1) informal, community, grassroots: How do we get citizens to speak out? 2) State apparatus: Social accountability has to be linked to formal processes, and perpetrators arrested and taken to court. 3) Formal international: Cross-border cooperation is required. Illicit financial flows have to be tackled at the international level: there is cross border collusion between elites, but not between the people.

V. Case studies of work aligned with human rights

15. Community-based management of acute malnutrition in urban informal settlements of Mumbai, India

Background

Worldwide, 16 million children under five suffer from severe acute malnutrition (SAM) or severe wasting;¹⁻² India is home to one-third of these children.³ The WHO recommends the Community-based Management of Acute Malnutrition (CMAM) approach which involves community outreach for the screening of acutely malnourished children; outpatient management; provision of ready-to-use therapeutic food; and in-patient treatment of medical complications.⁶ While CMAM has been adopted worldwide, India is yet to formulate national guidelines for a CMAM strategy.

The CMAM intervention in this case study was run by a non-profit organization, the Society for Nutrition, Education and Health Action (SNEHA). Established in 2011, the SNEHA CMAM program provided a continuum of care for pregnant women and children up to age three in *Dharavi*, one of South Asia's largest informal settlements located in Mumbai. The SNEHA CMAM program partnered with the Integrated Child Development Scheme (the government-run programme to address underweight children), the local health post and the Nutritional Rehabilitation and Research Centre, both run by the Municipal Corporation of Greater Mumbai.

Intervention alignment with human rights

Focused on bringing to household level interventions to prevent and address malnutrition, the SNEHA CMAM programme aligns closely with the rights standards of availability and accessibility of health services. There appears to also have been substantial attention to the acceptability of the intervention with one of the critical success factors noted to be the tailoring of information provided to care-givers. The programme adopted a participatory approach: workshops were held with administrators, doctors and nurses; and an appreciative inquiry approach was taken with shared strengths in case stories

disseminated. This was seen to contribute towards health workers' motivation to improve quality of care. Targeting an urban informal settlement, the programme also aligns with the principles of equality and non-discrimination.

Lessons learned

The programme has not achieved sustainability as quickly as planned. Moving forward, there are plans to focus on intensive involvement of community volunteers (aligned with participation) as well as institutional capacity building to enable the Integrated Child Development Scheme to take on the activities (capacity building of duty-bearers).

16. Addressing child malnutrition in the impoverished rural Transkei region, South Africa *Background*

Young child malnutrition is a major contributor to the burden of disease globally and in South Africa, a middle-income country. At the time of this initiative, chronic malnutrition and Vitamin A deficiency affected almost a third of the country's young children, significantly contributing to continuing high morbidity and mortality. Recognition of this in post-apartheid South Africa resulted in the development of a new policy: 'the integrated nutrition strategy'.

In an attempt to develop a replicable model of nutrition policy implementation the School of Public Health at the University of the Western Cape, the Health Systems Trust, a large national NGO, the Public Health Nutrition Unit of the London School of Hygiene & Tropical Medicine and the Eastern Cape Department of Health, commenced in 1998 the implementation of a research and service development project to address child malnutrition in the impoverished rural Transkei region.

Intervention alignment with human rights

An initial participatory research exercise involving staff from two district hospitals was key to understanding the baseline situation with regard to fatality rates for severe acute malnutrition as well as hospital practices for managing malnutrition. This helped to inform required actions to reduce fatality rates, which were also actions to improve the quality of care provided.

By targeting a poor and rural area, the project contributed to the promotion of equality and non-discrimination. Furthermore, significant efforts were made to understand the project's differing levels of success in different hospitals, which highlighted the importance of leadership, management and accountability mechanisms for this work.

A concern for the indivisibility of rights and the need for multisectoral action can be seen in the project's attention to interventions outside the health facility. The project identified several barriers that participants were experiencing to accessing the government-administered child welfare grant to which they were entitled. Working in alliance with other NGOs, it mounted a large advocacy campaign, which included a television documentary, to promote access to these grants. This resulted in a sharp and sustained increase in grant distribution nationally, and greater attention to household food insecurity as a causal factor in malnutrition.

Lessons learned

An important gap was noted between laws and policies on paper, which are supportive of child rights and appropriate management of child malnutrition, and implementation efforts. This highlights the importance of assessing not only the existence and content of laws and policies but also the degree to which they are implemented, budgets allocated and expended, and how their impact is captured.

The participatory nature of this work is seen as fundamental to its success and a first step towards promoting quality of care. By engendering a sense of ownership and responsibility among hospital staff of how the hospital was performing created in them a sense of investment in improving quality.

Hospitals operate within the broader health system and it is essential that the larger system be functional in order for hospitals to address noted weaknesses. For example, inappropriate management of malnutrition was found to be due to knowledge and skills deficits, inadequate resources and staff, and poor supervision and support from managers. Responses included additional resources (drugs, micronutrients, testing equipment, ingredients for special feeds, and extra night staff) and sustained training and supportive supervision, together with ongoing monitoring, all of which depend on the broader health system through appropriate allocation of human resources, a functional supply chain etc.

17. Improving professional standards and the ethical behaviour of health workers in hospitals in Liberia

Background

As a result of many factors including extreme poverty, lack of education, an Ebola epidemic and armed conflict, professional standards and medical ethical behaviour in the public hospitals of Liberia have been difficult to achieve. To address this, the Ministry of Health, the Liberian Medical and Dental Council (LMDC) and Maternal and Childhealth Advocacy International organized a three-day conference on the subject.

Intervention alignment with human rights

The training was participatory in nature with short presentations followed by interactive discussions. Following the conference, documents outlining ways in which each hospital could develop better professional standards as well as a more ethical approach to patient care were prepared and the LMDC has started to implement these in two hospitals. This creates an opportunity for improving the acceptability and quality of care, and for holding duty bearers accountable for their actions in this regard.

18. Improving the management of pain control and palliative care in The Gambia *Background*

Despite the great importance of pain control and palliative care in managing illnesses, major injuries and incurable diseases such as cancer in low resource countries, there have been few advances in the development of effective systems for their provision to women and children attending public hospitals

in The Gambia. This has resulted in children with severe injuries undergoing painful treatments with wholly inadequate pain management, leaving them screaming in pain.

To address this, Maternal and Childhealth Advocacy International, in partnership with the Ministry of Health and the WHO, prepared a training course for hospitals on the use of morphine for treating severe pain in children and pregnant women. Large quantities of oral and injectable morphine were provided.

Intervention alignment with human rights

This intervention was designed to improve the availability of morphine and the quality of child health services. Furthermore, in addition to the drug provided through the government pharmacy to the hospitals involved, special lockable drug boxes and logbooks were also provided to ensure that a record was kept of the treatments given by trained staff in the hospital to promote accountability.

19. Attempts to reduce the physical and mental health consequences of child abuse in low resource countries

Background

Most low resource countries do not have adequate child protection systems. Serious health consequences exist for children subject to child abuse or neglect, especially their severe forms. In response to this, Maternal and Childhealth Advocacy International worked with paediatricians and social welfare departments in Pakistan and The Gambia to develop documents/guidelines/protocols that highlight and help to manage the health consequences of abuse. They have also carried out courses in the recognition by health workers of the major physical signs of both serious physical and sexual abuse of children.

Intervention alignment with human rights

This intervention was designed to improve the quality of child health services by increasing health worker capacity to recognize and respond to child abuse. This can also be considered to have increased the availability of these services, which were previously severely lacking. Children who have experienced abuse are particularly vulnerable members of society and therefore any efforts to reach them and improve their health are aligned with the principles of equality and non-discrimination.

Lessons learned

The project has had mixed levels of success, with political support and leadership a critical component for this, particularly in The Gambia. In Pakistan, the greatest benefits have been seen in cities rather than rural regions, which warrants further exploration.

20. Community health workers in emergency situations

Background

During the Ebola outbreak in West Africa, community health workers continued their work. Integrated community case management was limited by lack of support and guidance for community health

workers and for everyone on whether they could continue to treat or not. There was a reduced utilization of the services, but less in the maternal, newborn and child health services. Mistrust of outsiders, including health workers and fear of referral led to an increase in home treatment. Community health workers carried out social mobilization, contact tracing, etc. and were absolutely key to the Ebola response.

During the conflict in South Sudan, international staff were evacuated, leaving only local staff and community health workers to respond to the community's health needs. There was an initial drop in community health worker services during displacement, which was then restored, and then the community health workers' caseload increased as they sought to address the needs of internally displaced people as well as the host communities.

Intervention alignment with human rights

As community health workers reside in the communities they serve, they can continue to make services available even during the crises. Services provided by community health workers were more acceptable since they are part of the community. The use of community health workers also aligns with the principle of participation as local community members are critical to the health response.

Lessons learned

It can be challenging to ensure a continuous and sustainable supply of health commodities to community health workers during emergency situations. However, preliminary results show that community health workers can continue to provide health services, that they are a key workforce who can reach the heard to reach and that they need continued support from governments and NGOs to continue to deliver these services as effectively as possible. As many crises are predictable, greater investment is needed in peace time to build resilient systems for when crises arise.

It might be useful to consider a mechanism through which minimum standards for addressing child health in emergencies could be developed and mainstreamed into humanitarian health plans.

VI. Analysis

The breadth of interventions covered in this selection of case studies is encouraging as it showcases the wide range of different ways that a human rights-based approach can effectively be applied to addressing child mortality. Child rights invite strategic thinking in order to reach the goal of adequate health for all. However, one of the challenges that this brings is a fragmentation among stakeholders: human rights-based approaches require truly multi-sectoral action and it is complex to bring together all of the relevant stakeholders for a collective response. Within the health sector, action is required from the community level, up through all levels of health service delivery, to health policies and laws; and alongside this, many other sectors must also be involved to help address the underlying determinants of child mortality.

The quality of health facilities, goods and services is a focus for the vast majority of the case studies. This is unsurprising given that 5 of these case studies involve some form of facility assessment that is designed to inform improvements in quality of care, and a further 4 of the case studies involve capacity building of duty bearers to ensure that they can provide quality services. Given the increasing global focus on quality of care (following years of disproportionate focus on promoting the availability and

accessibility of health services to the population), the existence of these rights-based assessment tools that have been shown to be effective constitutes an opportunity for expanding attention to a rights-based approach to improving quality of care.

There is differing attention to participation across the case studies. However, reforming discourse about vulnerability to promote empowered participation for social justice is critical to ensuring meaningful participation of all stakeholders, including those who might need additional support and capacity building in order to effectively participate. Among the case studies that are explicitly grounded in human rights, substantial attention is also given to participation, which was not as often central to the other case studies, suggesting that this might be an area that to which human rights-based approaches have brought more systematic attention.

Many of the explicitly rights-based case studies also focus on accessibility of services, and, even as little detail on actual mechanisms is provided, accountability. These are elements that are also found in most public health approaches to improving child health services even if they are not grounded in human rights, which might be why they most commonly permeate work on paediatric health service provision.

Across all of the case studies, least attention is given to the acceptability of health facilities, goods and services, although the Child Friendly Healthcare Initiative (Case study 2) and the Task Force on Health Promotion for Children and Adolescents in and by Hospitals self-evaluation tool (Case study 4) are important exceptions from which useful lessons can be drawn. In any work moving forward, it will be key to understand why some elements of a human rights-based approach are more often addressed in this work than others e.g. quality vs. acceptability?

In addition, with the exception of EACH (Case study 1) and the South African case study on litigation for access to medicines (Case study 9), no case studies included information about the national legal, regulatory and policy context within which the work took place. Although most case studies noted their grounding in the CRC, given the centrality of legal accountability in human rights based approaches, it is the national frameworks that should provide the legal foundation. Perhaps linked to this, the case studies included relatively little information on concrete mechanisms for redress, transparency and accountability.

While the case studies that implicitly align with elements of a human rights-based approach may contribute to the realization of child rights (alongside the improvement of child health), it might be useful to consider how an explicit grounding in rights might boost their effectiveness. It may be that some of these case studies were indeed explicitly conceptualized from a human rights perspective, in which case it would be interesting to re-visit their documentation. There is ongoing, useful debate around the advantages and disadvantages of explicitly grounding public health efforts in human rights that it would be valuable to explore further in the context of addressing child mortality and morbidity.

It is important to recognize that health workers who may be violating children's rights might be working within health systems that constrain their actions (due to resources, staffing, capacity constraints etc.) and working conditions that may constitute a violation of their own rights. While there is a definite need to build the capacity of health workers to help them engage with human rights and see how adopting a rights-based approach can strengthen their work, it is also important to tackle the broader system within which they work and to ensure that they have the information and protections to in turn deliver quality care.

Within health services, the focus is on treatment rather than human rights. However, human rights based approaches can guide health planners and support health workers, improve quality and experience of care, and reduce suffering. It is important that tools to improve quality of care capture human rights dimensions; existing human rights tools are often complex and not practical for routine health service use so new simplified tools, written in accessible language, may be needed to support health workers to adopt a human rights based approach.

Human rights based approaches draw attention to regulatory barriers that exacerbate child mortality, such as restrictions of drug availability and regulations about which cadres of health workers can administer certain interventions. Social mobilization around these issues may be required to exert pressure on duty-bearers to improve national regulatory environments.

Addressing gender inequalities is noted as a central dimension of a human rights based approach to reducing child mortality: women must be engaged and empowered at all stages, and gender-based violence should be tackled, particularly violence during pregnancy (when it is known to increase). These inequalities may be exacerbated in the context of conflict or migration, which constitute situations that receive disproportionately little funding and action in the context of mortality among children under five. Beyond attention to mortality among children under five in these contexts, greater investment in the long-term health consequences arising from these situations (PTSD, anxiety, depression) is needed.

Most of the case studies do not include evidence on the basis of concrete data to illustrate how applying a human rights-based approach has specifically contributed to decreases in child mortality. The strategic litigation case from South Africa (Case study 9) is a notable exception where this contribution is clear. The maternal mobilization and access project that was implemented in Nepal (Case study 7) and the 'Hospital Amigable' work in Chile (Case study 3) also showed clear improvements across a range of health indicators (even if not child mortality) between the baseline and project end. In most of the other case studies, improvements have been shown in, for example, quality of care or participation in health-related decision-making, which it might be assumed should have a positive impact on the uptake of services as well as child survival and child health.

The evidence base of how a human rights-based approach to addressing preventable mortality and morbidity among children under five remains scattered, but it exists and it is growing, which suggests increasing appreciation of the value of these approaches. While a human rights based approach is a legal obligation in its own right, there is a strong need to strengthen the evidence base of its impact on outcomes in order to convince health system decision-makers and practitioners to implement a human rights based approach to addressing child mortality. Additional data to document this link would be useful. In particular, where appropriate, randomized study designs would help strengthen the evidence base in this regard.

Alongside this, better use can be made of routinely collected health data: if analysed using a human rights lens, important insights can be gained into the extent to which a human rights based approach is being applied. Qualitative data collected alongside this can help illuminate pathways of change as well as barriers along these.

Politics and power play key roles in the implementation of human rights based approaches to addressing mortality among children under the age of five. Case study 9 illustrates how, even in the presence of a supportive constitution that could be used as a legal instrument for action, political struggle was required before progress with its implementation could be made. Case study 13 shows how commercial interests influence political will to implement rights-based breastfeeding laws and policies. Health

issues, such as child mortality, provide an entry point for examining broader societal inequities and challenging the underlying power dynamics, for which political commitment is required. This highlights the need to take account of and work effectively with broader political and power structures; including in particular political leaders and policymakers, & commercial interests (e.g. stronger legal and regulatory approaches to prevent marketing of breast milk substitutes).

A continuum of child rights-related activities might help effectively address child mortality:

- 1. Generating arguments by translating scientific evidence into rights-based action to prevent rights violations and promote rights across the life course;
- 2. Use epidemiological data to inform human rights based policy and training for health workers;
- 3. Explicitly address barriers, biases and discrimination that exist within health facilities and the health system more broadly; and
- 4. Advocate for additional resources for human rights based approaches to addressing child mortality.

Across this continuum, it will be important to link expertise at country level with human rights mechanisms including OHCHR, the Human Rights Council, Special Rapporteurs and the UPR. There currently exists fragmentation among actors working on addressing mortality among children under five and useful synergies could be created by bringing together the vast expertise, experience and evidence of impact on positive user experiences. A forum for continued discussion and collaboration would be welcome.

VII. Moving forward

The collation and preliminary analysis of the case studies presented here raises a range of questions pertinent to moving forward work on implementing and documenting a human rights-based approach to mortality and morbidity of children under five. Participants at the expert meeting was asked for recommendation of how best to move forward this work to apply human rights based approaches to mortality and morbidity in children under five. Below is a selection of the group's recommendations. This is a non-exhaustive list but it is designed to stimulate further thoughts, discussions and actions.

Legal and Policy Environment:

- Develop legally binding regulations for child health, including palliative care, and international protection systems
- Increase attention to national legal, regulatory and policy environments including redress mechanisms and legal accountability
- Develop tools to assess and improve legal and policy environments to support child health and rights
- Increase attention to national legal, regulatory and policy environments in human rights based work to address child mortality and morbidity, including attention to redress mechanisms and legal accountability

Community Involvement & Participation:

- Empower communities to demand rights in line with the right to health at all health facilities, during home visits and from community health workers and facilitate feedback
- Research the role of citizen involvement in ensuring child rights and create an appropriate mechanism for this
- Encourage UN agencies or mechanisms to systematically and uniformly support health professional-led initiatives to generate sustainable change
- Explore the possibility of linking health professionals with community groups (e.g. women's groups)
- Research how best to capture participatory assessment

Quality of Care:

- Document how human rights advance quality of care and what human rights metrics should be included in the paediatric quality of care standards
- Use the wealth of information in these case studies on a human rights-based approach to improving paediatric quality of care to identify common gaps, challenges and successes – from a human rights perspective – that can be utilized to further ongoing work being led by WHO on the paediatric care standards
- Promote awareness of human rights principles among medical and allied health professionals through mandatory human rights training for health workers, guidance and training syllabi into academic and professional curriculum
- Promote health knowledge in relation to child rights and access to information through health standards, benchmarks, codes of conduct, hazards and budgets, and how best to capture nonbiased information on equality and non-discrimination within the context of child healthcare provision
- Train health care workers and create awareness of health needs of pregnant women and young children
- Clearly articulate the human rights of health care workers and incorporate this into human rights based approaches for health systems
- Explore the possibility and repercussions of integrating a family-centred philosophy instead of only baby friendly ideology at hospital and health facilities

Country Implementation:

- Building on existing work by the OHCHR, WHO, the Human Rights Council, the Committee on the Rights of the Child and others, develop a uniform human rights framework to facilitate national implementation of a right to health.
- Facilitate a global civil society network for child rights

Monitoring and evaluation:

 Analyze how 16 key indicators (and broader 60 indicators) of the WHO Global strategy captures human right considerations

- Analyze how child health indicators capture elements of human rights based approaches –
 participation, non-discrimination, transparency and accountability, availability, accessibility,
 acceptability, quality, and best interests
- Develop tools and child right indicators to guide and measure impact of human rights intervention in countries
- Develop tools to capture non-biased information on equality and non-discrimination within the context of child healthcare provision
- Make human rights based monitoring and evaluation tools for routine use shorter and harmonize existing tools to avoid duplication and overlap
- Develop a website as a repository of tools and information
- Facilitate collection of systematic disaggregated data, including in financing, for child health
- Promote a culture of data use instead of just data collection
- Form an expert review group to work on appropriate methodologies for advancing implementation, monitoring and evaluation through regular meetings with member States and donors

Research:

- Research evidence of impact on health through selected case studies and evaluate the impact of a human rights based approach on health outcomes
- Model human rights based approach in a few countries through controlled trials or a range of small trials to demonstrate specific impact of a human rights model in health settings, for both assessment and improvement
- Create additional data on how a rights based-approach contributes to reduced child mortality and morbidity

Finance & Budgeting:

- Research the implications of human rights budgeting and the changes it will lead to in resource allocation and health outcomes
- Reorient fiscal policies and budgets towards a rights based approach
- Need to develop tools for costing exercises on interventions

Healthcare in Conflict/Emergencies:

- Pursue a UN internal protection system that overcomes the veto problem regarding health in conflict
- Convince the UN about the necessity of safe schools, orphanages and hospitals to protect both children and medical staff
- Utilize both top down and bottom up approaches in fragile States

VIII. Conclusion

The case studies included in this report exemplify the range of work that can constitute a human rights-based approach to addressing preventable mortality and morbidity among children under five, which is very promising. It demonstrates the flexibility of this approach and its applicability to a range of different strategies to address child mortality and morbidity, including efforts at the national level, within health facilities and within communities. Furthermore, for some of these projects there are data

available to concretely demonstrate their effectiveness with regard to effecting positive change at both the process and outcome levels. While the implementation of a human rights-based approach to health care and the prevention of child mortality is a legal and moral imperative for all countries, more systematic documentation of the benefits of a human rights-based approach to child health is needed to strengthen the evidence base as a means of further promoting their uptake, both to realise children's rights and to improve their survival and health.

Appendix 1: Glossary of human rights terms¹⁷

1. Non-discrimination

The human rights principle of non-discrimination obliges States to guarantee that human rights are exercised without discrimination of any kind based on race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status such as disability, age, marital and family status, sexual orientation and gender identity, health status, place of residence, economic and social situation.¹⁸ This obligation in connection with health programmes means countries are to ensure the availability, accessibility, acceptability and quality of services and information without discrimination.

2. Participation

Under international human rights law, countries have an obligation to ensure active, informed participation of individuals in decision-making that affects them, including on matters related to their health.¹⁹ Participation of affected populations in all stages of decision-making, implementation and monitoring of policies, programmes and services is a precondition for sustainable development and the highest attainable standard of health.²⁰ Laws, policies and programmes better reflect the needs and perspectives of affected populations when members of these populations take part in their development, thus helping to secure improvements in health outcomes and the quality of health care.²¹ Under international human rights law, countries have an obligation to ensure active, informed participation of individuals in decision-making that affects them, without discrimination, including on matters related to their health.²² They also have the obligation to ensure the meaningful participation of adolescents in all policies and programmes affecting their health.²³

(CESCR); 2000.

¹

¹⁷ Adapted from: WHO. Ensuring human rights within contraceptive service delivery: Implementation guide. Geneva, Switzerland: World Health Organization; 2015.

¹⁸ United Nations Committee on Economic, Social and Cultural Rights. General comment No. 20 (2009): Non-discrimination in economic, social and cultural rights (article 2, paragraph 2, of the International Covenant on Economic, Social and Cultural Rights). Geneva, Switzerland: United Nations Economic and Social Council; 2009. ¹⁹ United Nations Economic and Social Council. General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant). Geneva: UN Committee on Economic, Social and Cultural Rights

²⁰ UNDP. Investing in development: A Practical plan to achieve the millennium development goals. Report to the UN Secretary-General. New York (NY): UN Development Programme; 2005. Bradley SEK, Schwandt HM, Khan S. Levels, trends, and reasons for contraceptive discontinuation. DHS Analytical Studies No. 20. Calverton (MD): ICF Macro; 2009.

²¹ Ferguson L, Halliday E. Participation and human rights: impact on women and children's health. What does the literature tell us? In: Bustreo F, Hunt P, Gruskin S, Eide A, McGoey L, Rao S, et al. Women's and children's health: Evidence of impact of human rights. Geneva, Switzerland: World Health Organization, 2013. Potts H. Participation and the right to the highest attainable standard of health. Colchester: University of Essex Human Rights Centre; 2008.

²² See supra 19.

²³ United Nations Committee on the Rights of the Child. General Comment No. 15 (2003): The right of the child to the enjoyment of the highest attainable standard of health (article 24 of the Convention on the Rights of the Child). New York (NY): United Nations; 2003. (CRC/GC/2003/4).

3. Right to Health

a) Availability

Functioning health and health-care facilities, goods and services, as well as programmes, have to be **available** in sufficient quantity within the State.²⁴ The characteristics of the facilities, goods and services will vary depending on numerous factors, including the State's developmental level. Countries must, however, address the underlying determinants of health, such as provision of safe and potable drinking water, adequate sanitation facilities, health-related education, hospitals, clinics and other health-related buildings, and ensure that trained medical and professional personnel are receiving domestically competitive salaries. As part of this core obligation, countries should ensure that the commodities listed in national formularies are based on the WHO Model List of Essential Medicines, which guides the procurement and supply of medicines in the public sector.²⁵

b) Accessibility

Under international human rights law, countries are required to ensure that health-care facilities, commodities and services are **accessible** to everyone. This includes physical and economic accessibility, as well as access to information.²⁶ Human rights bodies have called on countries to eliminate the barriers people face in accessing health services, such as high fees for services, the requirement for authorization by spouse, parent/guardian or hospital authorities, distance from health-care facilities, and the absence of convenient and affordable public transport.²⁷

c) Acceptability

All provision of health-care facilities, commodities and services must be **acceptable** to those who are their intended beneficiaries. They must be provided in a manner respectful of medical ethics and of the culture of individuals, minorities, peoples and communities; sensitive to gender and to life cycle requirements; must be designed to respect confidentiality, and improve the health status of those concerned.²⁸ Countries should place a gender perspective at the centre of all policies, programmes and services including planning, implementation and monitoring of such policies, programmes and services.

d) Quality

Fulfilment of human rights requires that health-care facilities, commodities and services be of good quality, and scientifically and medically appropriate. This requires, among other things, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment,

²⁴ See supra 19.

²⁵ See supra 19.

²⁶ See supra 19.

²⁷ UN General Assembly. General recommendation No. 24 (20th session): Article 12 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) — women and health. Report of the Committee on the Elimination of Discrimination against Women, Fifty-fourth session of the General Assembly, Supplement No. 38 (Chapter I). New York (NY): United Nations; 1999 (A/54/38/ Rev.1).

²⁸ See supra 19.

safe and potable water, and adequate sanitation.²⁹

4. Accountability

Countries are accountable for bringing their legal, policy and programmatic frameworks and practices in line with international human rights standards.³⁰ Further, effective accountability mechanisms are key to ensuring that the agency and choices of individuals are respected, protected and fulfilled, including when seeking and receiving health care. Effective government accountability includes monitoring the use of mechanisms for reporting, remedy and redress in the case of violations of human rights relating to child mortality and morbidity and ensuring their accessibility and functionality.³¹

5. Duty bearers

Duty-bearers are those actors that have a particular responsibility to respect, promote and realise human rights and to abstain from human rights violations. The term is most commonly used to refer to state actors, but non-state actors can also be considered *duty-bearers*. Depending on the context, individuals (e.g. parents), local organisations, private companies, aid donors and international institutions can also be *duty-bearers*.³²

6. Rights holders

Rights-holders are individuals or social groups that have particular entitlements in relation to specific duty-bearers. In general terms, all human beings are rights-holders under the Universal Declaration of Human Rights. In particular contexts, there are often specific social groups whose human rights are not fully realised, respected or protected. A human rights-based approach does not only recognise that the entitlements of rights-holders need to be respected, protected and fulfilled, it also considers rights-holders as active agents in the realisation of human rights and development – both directly and through organisations representing their interests.³³

³⁰ Commission on information and accountability for women's and children's health. Translating recommendations into action. First progress report on implementation of recommendations: November 2011–June 2012. Geneva, Switzerland: World Health Organization; 2012.

²⁹ See supra 19.

³¹ Human rights-based approach to reduce and eliminate preventable mortality and morbidity of children under 5 years of age: Technical Guidance. Report of the Office of the United Nations High Commissioner for Human Rights (A/HRC/27/31). Human Rights Council (27th session). Geneva, Switzerland: United Nations General Assembly; 2014.

³² Gruskin S, Bogecho D, Ferguson L, Raad Z, Melo Castilla LA, Toure A. 'A Human Rights-Based Approach to Programming: Practical Information and Training Materials', Program on International Health and Human Rights, Harvard School of Public Health and the United Nations Population Fund (UNFPA), New York, 2010.

³³ See supra 32.