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**Mental health workers' perceptions and perspectives on
the right to health and a human rights-based approach to
mental health: A case study of the Chitwan District in Nepal**

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LONDON SCHOOL OF HYGIENE AND TROPICAL MEDICINE

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STATEMENT OF ORIGINALITY

I, Ingrid Gunilla Backman, have read and understood the School's definition of plagiarism and cheating given in the Research Handbook. I declare that this thesis is my own work and that I have acknowledged all results and quotations from published and unpublished work of other people.

Signed:

London, 30 January, 2018

ABSTRACT

Over the last decade, there have been increasing calls for respecting and integrating human rights into health, including into mental health policies, plans, and programmes. The convergence of mental health and the right to health has implications for health workers, as they are the key translators of policy- and programme-related decisions into practice.

This thesis is a qualitative research study which follows a case-study approach situated in the Programme for Improving Mental Health Care in Nepal. It aims to explore the perceptions and perspectives of health workers in the Chitwan district in Nepal on the use of a human rights-based approach (HRBA) to mental health. The specific objectives are to (1) examine existing evidence on the use of an HRBA to advance health; (2) explore perspectives on the right to health among mental health workers in Nepal; (3) explore health workers' perceptions of the application of an HRBA to mental health in planning and service provision; and (4) develop a conceptual framework regarding the use of an HRBA to mental health.

The literature review identified some plausible positive evidence on the use of an HRBA to advance health, but also highlighted the very limited quantity and quality of the evidence and the difficulty in determining with certainty the direct influence of an HRBA to health. No studies were identified that explored an HRBA to mental health in low- or middle-income countries. The qualitative research highlighted that participants were aware of human rights, but faced difficulty in understanding their meaning and application, including an HRBA.

An HRBA to health and related plans requires an understanding of both the health system context and involvement of health workers. A conceptual framework was developed of an HRBA to mental health to help guide the application of an HRBA in mental health planning and service provision. Recommendations are provided.

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ABBREVIATIONS

AAAQ	Availability, accessibility, acceptability, and quality
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CPA	Comprehensive Peace Agreement
CRC	Convention of the Rights of the Child
CRPD	Convention of the Rights of Persons with Disabilities
DALY	Disability-adjusted life years
EMERALD	Emerging Mental Health Systems in Low- and Middle-Income Countries
GAVI	The Global Alliance for Vaccines and Immunisation
GDP	Gross domestic product
HRBA	Human rights-based approach
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
LSHTM	London School of Hygiene and Tropical Medicine
MDG	Millennium Development Goal
mhGAP	Mental Health Gap Action Programme
NGO	Non-governmental organisation
NHRC	National Human Rights Commission
OHCHR	Office of the United Nations High Commissioner for Human Rights
PHC	Primary health care
PHR	Physicians for Human Rights
PRIME	Programme for Improving Mental Health Care
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RBA	Rights-based approach
RTHBA	Right to health-based approach
Sida	Swedish International Development Cooperation Agency
TPO Nepal	Transcultural Psychosocial Organisation Nepal
UDHR	Universal Declaration of Human Rights
UN	United Nations
WHO	World Health Organization

GLOSSARY

AAAQ

The AAAQ framework is a right to health tool and can be used to evaluate governments' compliance with the right to health, as well as to help design projects and programmes to ensure compliance with the right to health. The AAAQ stands for availability, accessibility (which has four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility, and information accessibility); acceptability (respectful of medical ethics and culturally appropriate); and good quality.

Committee on Economic, Social and Cultural Rights

The United Nations Committee on Economic, Social and Cultural Rights is the body responsible for monitoring state parties' compliance with the International Covenant on Economic, Social and Cultural Rights. *See General Comment 14; human rights treaty bodies; International Covenant on Economic, Social and Cultural Rights.*

General Comment 14

In 2000, the Committee on Economic, Social and Cultural Rights published General Comment 14, which interprets the content of "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" (right to health), as laid out in article 12 of the International Covenant on Economic, Social and Cultural Rights. *See Committee on Economic, Social and Cultural Rights; general comments; human rights treaty bodies; right of everyone to the enjoyment of the highest attainable standard of physical and mental health.*

General comments

United Nations human rights treaty bodies publish "general comments" that further interpret the content of human rights provisions in international treaties. With the exception of the Committee on Migrant Workers, all treaty bodies have issued general comments. The Committee on the Elimination of Racial Discrimination and the Committee on the Elimination of Discrimination against Women refer to their comments as "general recommendations." *See General Comment 14.*

Human rights-based approach

A human rights-based approach is a conceptual framework that is normatively based on international human rights standards and operationally directed to promoting and protecting human rights. It seeks to analyse obligations, inequalities, and vulnerabilities and to redress

discriminatory practices and unjust distributions of power that impede progress and undercut human rights. “Human rights-based approach” is the official term used by the Office of the United Nations High Commissioner for Human Rights, although many also use the term “rights-based approach.” (This research uses the term “human rights-based approach,” or “HRBA.”)

Human rights treaty bodies

United Nations human rights treaty bodies are committees of independent experts that monitor the implementation of the core international human rights treaties. They are created in accordance with the provisions of the treaty that they monitor. They also issue “general comments” interpreting rights within their respective treaties. There are currently nine human rights treaty bodies. These bodies are also referred to as “committees,” “treaty bodies,” and “treaty monitoring bodies.” *See Committee on Economic, Social and Cultural Rights; general comments.*

International Bill of Human Rights

The International Bill of Human Rights encompasses the Universal Declaration of Human Rights (1948); the International Covenant on Economic, Social and Cultural Rights (1966); and the International Covenant on Civil and Political Rights (1966) and its two protocols. *See International Covenant on Civil and Political Rights; International Covenant on Economic, Social and Cultural Rights.*

International Covenant on Civil and Political Rights

Adopted in 1966, this international treaty protects individuals’ civil and political rights. *See International Bill of Human Rights.*

International Covenant on Economic, Social and Cultural Rights

Adopted in 1966, this international treaty protects individuals’ economic, social, and cultural human rights. *See International Bill of Human Rights.*

Right of everyone to the enjoyment of the highest attainable standard of physical and mental health

More often referred to in the shorthand – generally either “the right to the highest attainable standard of physical and mental health” or “the right to health” – this fundamental human right is enshrined in a number of international human rights treaties, as well as many national constitutions. The right to health encompasses not just health care but also the underlying determinants of health, both of which should be affordable to all without discrimination. In

addition, this right is concerned with disadvantaged groups, participation, and accountability. For the right to health to be realised, there needs to be a functioning health system, accessible to all without discrimination.

“Where, after all, do universal human rights begin? In small places, close to home – so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere...”

– Eleanor Roosevelt

CHAPTER 1: INTRODUCTION AND BACKGROUND

1. INTRODUCTION

The World Health Organization's (WHO) Mental Health Action Plan for 2013–2020 highlights the centrality of human rights in addressing mental health globally. It notes the need for services, legislation, plans, strategies, and programmes to protect, promote, and respect the rights of persons with psychosocial disabilities in line with relevant international and regional human rights treaties and conventions as one of the steps to address the widespread stigma surrounding and discrimination against people with psychosocial disabilities [1 p. 3].

The interrelationship between health and human rights and the possible implementation of the right to health is an issue I have explored through my work in service delivery and policy in low-, middle-, and high-income countries, as well as through my academic studies. After completing a Master of Public Health and a Master of Human Rights, I worked as a senior research officer for the first United Nations (UN) Special Rapporteur on the Right to Health, Professor Paul Hunt. During this work, I focused on two main tasks. The first task was to examine the role played by the right to health in health systems; this was written up in UN Report A/HRC/7/11 [2], as well as a number of book chapters [3-6]. This task also involved exploring the practical application of this report, through the identification of indicators to measure the right to health features of health systems in 194 countries. This work was written up in a special issue of *The Lancet* in 2008 (see appendix 1) [7]. The second main task was to develop a course on the right to health for post-graduate law students at the University of Essex, which Studentlitteratur later asked me to turn into a book for medical and public health students [5, 8]. Based on my experiences and discussions, there appeared to be limited focus on the practical application of the right to health – particularly in the mental health arena – by both the health and human rights communities. Furthermore, there seemed to be a dearth of research exploring the role of health workers and their perceptions and perspectives regarding the integration of human rights into mental health services (or health services in general). Finally, although I considered myself part of the health and human rights community, I was uncertain about the meaning and impact of a human rights-based approach (HRBA) to health. This uncertainty hampered me in my efforts to explain why we should or should not apply an HRBA to health. I felt I only had the legal arguments, and my personal experience of having applied the right to health (though at that time I did not know it was referred to as an HRBA to health) was at the service delivery and management levels. As a result, I sought to examine the application of an

HRBA in more depth for my PhD studies. It was important for me to carry out this research at a public health school, as it was among people working in the health sector that I most frequently encountered hesitations and questions, such as, *How can the right to health practically be applied? What is an HRBA, and what is the added value of the right to health and an HRBA to health? What does the right to health or HRBA do that we are not already doing in public health and medicine?* Even those who seemed to be part of the health and human rights community tended to talk about human rights only after violations had already taken place, and not in the context of using an HRBA to prevent violations from happening.

The convergence of mental health and the right to health has implications for health workers, who must try to integrate the two fields into a coherent set of principles, plans, and practices. Health service providers' perceptions of the right to health are pivotal, since these individuals are the main translators of policy- and programme-related decisions into practice and are often the first point of contact for health seekers. Attempting to implement the right to health, and other health-related rights, into practice without the understanding and support of health workers, particularly health service providers, could be extremely problematic and potentially counterproductive. Divergent interpretations and approaches might result in limited or flawed policy implementation, which could worsen health service delivery and patient health outcomes [9-12].

Considering my experience and interest, I decided to focus in depth on the right to health specifically. The right to health is a shorthand version of "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" [13 para 43(f)]. To make the research manageable, and to obtain depth, as it is a qualitative study, every effort has been made to narrow this research. As such, I looked at mental health specifically and focused only on one study population, health workers. Initially I considered including users of the mental health services as part of the study population, but it was not possible due to ethical concerns such as risk of potential distress among users of mental health services. Furthermore, in order to keep the research sufficiently focused on the role of the front-line providers and to maintain sufficient quality, it was felt preferable not to include people living with psychosocial disabilities. This limitation is highlighted in Chapter 7, specifically sections 7.5 and 7.6.

My thesis is a qualitative case study, situated within Nepal's Programme for Improving Mental health care (PRIME) (see Chapter 2 section 2.5 for further details) that explores mental health workers' perspectives on the right to health and the rights of persons with psychosocial disabilities, as well as their perception of the integration of an HRBA into mental health plans and services in

the district of Chitwan in Nepal. Although my study was situated within PRIME, this programme did not delineate the boundaries of my research. The data were collected in country between June and August 2013. More details about data collection can be found in chapter 3, and specifically table 2.¹

I recognise all human rights are important and very relevant for the realisation of the rights of persons with disabilities. To have focused this research on 'health and human rights' broadly could have been beneficial as some actors prefer the term human rights rather than the right to health, and as such the term 'health and human rights' would ensure protection from a range of national and international laws and might lead to that the research would obtain greater support.[14] However, focusing on 'health and human rights' would also risk the research becoming too broad, since a number of human rights would be included.

To make the research manageable, and to obtain the depth required for a qualitative study, the research was narrowed down to focus on the core human right in respect to health, the right health, stipulated in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ESCR).[15] The right to health is also recognised in the Constitution of the WHO, all states have ratified one or more treaties which include this right, and it has been recognised by the UN on a number of occasions in a wide array of international human rights treaties and declarations.[16, 17]. There are also a number of General Comments and Recommendations on the right to health which explicitly focus on the right to health, such as General Comments 14 on the right to health, General Comment 15 on the right of the child and the right to health[18], and General Recommendation 24 on the right to health and women[19], and reports of the UN Special Rapporteurs on the right to health and thematic and mission reports, which provide insights into the interpretations and application of the international right to health. According to Sofia Gruskin, Edward Mills and Daniel Tarantola, "the right to health forms the legal basis for much of the present work in health and human rights"[20p.451].

To focus on the right to health is still a very large right, as it includes rights such as To focus on the right to health is still a very large right, as it includes rights such as: privacy; prevention, treatment and control of diseases; and freedom from inhuman or degrading treatment. I narrowed the right to health further, and decided to look at mental health specifically and then to focus on mainly three priority disorders, depression, alcohol use disorders and psychosis (mainly schizophrenia). These priority disorders are identified by WHO[21].

¹ The data collection was completed before the 2015 earthquake in Nepal.

Nepal has explicitly incorporated the right to health into its interim constitution as well as in its national health plan. This was another reason for focusing on the right to health. Chapter 3 looks in more detail to the Nepali laws, policies and programmes and relation to the international human rights treaties, including the right to health and rights of persons with disabilities, specifically mental health.

The overall aim of my research was to explore the perceptions and perspectives of health workers in Nepal regarding the use of an HRBA to mental health. It had the following specific objectives:

Objective 1: To examine existing evidence on the use of an HRBA to advance² health

Objective 2: To explore perspectives on the right to health among mental health workers in Nepal

Objective 3: To explore health workers' perceptions of the application of an HRBA to mental health planning and service provision

Objective 4: To develop a conceptual framework regarding the use of an HRBA to mental health

This thesis has seven chapters. Chapter 1 provides background information for the thesis. Chapter 2 presents the case study of Nepal, specifically its PRIME mental health programme. Chapter 3 outlines the methods used in my research. Chapter 4 presents the results and analysis of my systematic literature review concerning evidence on the use of an HRBA to advance health. Chapter 5 presents Nepali mental health workers' perspectives on the right to health. Chapter 6 presents the health workers' perceptions of the application of an HRBA to mental health in mental health planning and service provision. Finally, chapter 7 offers my findings and recommendations.

² "Advance" refers to aspects that support the protection and improvement of health.

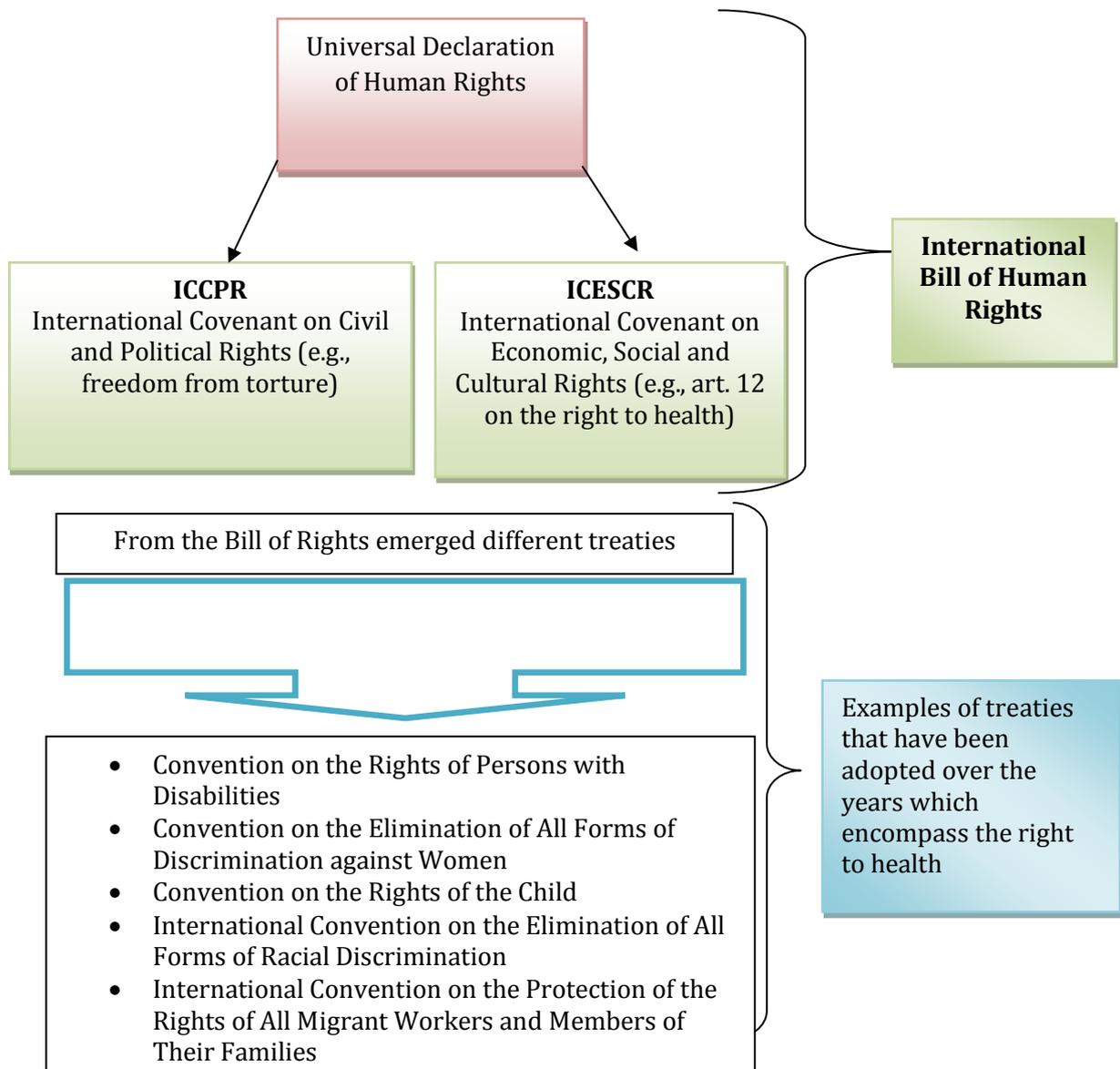
This chapter, Chapter 1, provides the theoretical background for this thesis. The first section explores the right to health, and the second looks specifically at mental health. The third section then combines the right to health and mental health, highlighting how they are interrelated and interdependent. The fourth section presents the rationale and aim of this thesis.

1.1 RIGHT TO HEALTH

The right to health, which is shorthand for the right of everyone to the highest attainable standard of physical and mental health, was first recognised in 1946 in the WHO Constitution [16] and has since been recognised in a number of public health documents, such as the Alma-Ata Declaration (1978) (see box 1) [22]. In 1948, all human rights, including the framework for the right to health were included in the Universal Declaration of Human Rights (UDHR) [23]. UDHR is an aspirational document that it is not legally binding on states. The initial plan was that a year after the adoption of the UDHR a legal document would be adopted, a document that would be legally binding upon states that ratified it. However, UDHR was developed during the cold war and national particularities and various historical, cultural and religious backgrounds led to that the UDHR came to be divided into two documents, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR), which emerged from the UDHR. In 1966, the ICCPR and the ICESCR were adopted by the UN General Assembly and opened for signatures. Both ICCPR and ICESCR entered into force in 1976. Both covenants are legally binding for the states that have ratified them [15]. The right to health is stipulated in the ICESCR. The ICCPR and the ICESCR came to be seen as two distinctly aimed instruments. Although there are now two separate covenants, attempts have been made to underline that all human rights are universal, indivisible and interdependent and inter-related. For example, the final document agreed to at The World Conference on Human Rights in Vienna in 1993 was endorsed by the forty-eighth session of the General Assembly in 1994 and is referred to as the Vienna Declaration. This declaration further reaffirmed the principles that had evolved during the previous 45 years of the universality, indivisibility and interdependence and inter-relation of all human rights, refuting those who argued that human rights were not universal but historically, socially and politically contextual and contingent and further strengthened the foundation for additional progress in the area of human rights[24]. The recognition of interdependence between democracy, development and human rights, for example, prepared the way for future cooperation by international organizations and national agencies in the promotion of all human rights, including the rights to health and to development. Together, the UDHR, ICESCR, and ICCPR are referred to as the International Bill of Human Rights and are considered the backbone of human rights (see figure 1).

The right to health is enshrined in the majority of international human rights treaties that have emerged from the Bill of Rights, such as the Convention on the Rights of Persons with Disabilities (CRPD). It can also be found in regional treaties.

FIGURE 1. THE INTERNATIONAL BILL OF HUMAN RIGHTS AND OTHER TREATIES



Every country in the world has ratified a treaty encompassing the right to health and, in doing so, has legally bound itself to the implementation of this right within its national territory [25]. In 2000, the UN Committee on Economic, Social and Cultural Rights adopted General Comment 14 on the right to health.³

³ The Committee on Economic, Social and Cultural Rights is a body of independent experts appointed to monitor the implementation of the ICESCR.

Though not legally binding, this document explains what the right to health is and what its features mean (see box 2) [13]. The Alma-Ata Declaration (see box 1) had a great influence on the development of General Comment 14. The declaration is situated on the common ground between medicine, public health, and human rights. This convergence is reinforced in paragraph 43 of General Comment 14, according to which “the Declaration of Alma-Ata provides compelling guidance on the core obligations arising from” the right to the highest attainable standard of health [13].

Box 1. ALMA-ATA DECLARATION (1978)

Principal themes

- Equity
- Community participation
- Multisectoral approach to health problems
- Effective planning
- Integrated referral system
- Health promotional activities
- Sustainable training of human resources
- International cooperation

Essential health interventions

- Education on prevailing health problems
- Promotion of food supply and proper nutrition
- Adequate supply of safe water and basic sanitation
- Maternal and child health care, including family planning
- Prevention and control of locally endemic diseases
- Appropriate treatment of common diseases and injuries
- Provision of essential drugs

Source: [22].

The right to health is sometimes understood to imply that everyone has a right to be healthy. This is not the case. Rather, the right to health means that each country must have the appropriate conditions in place for a person to live a healthy life, without discrimination. For example, everyone should have access to health services, preventive amenities (such as access to health information), and curative care. Thus, the right to health encompasses both public health and medical care. It also includes underlying determinants of health, such as education, housing, and water [13]. Moreover, it encompasses freedoms (such as the right to be free from discrimination) and entitlements (such as the right to essential primary health care, or PHC) [13]. At the centre of the right to health is a well-functioning health system that is available, accessible, acceptable to all without discrimination, and of good quality (see box 3) [13]. The

right to health can also be broken down into more specific elements, such as mental health services and maternal, child, and reproductive health [13]. Although the right to health is a self-standing international human right, it is dependent on other human rights, such as the right to education and the right to life. The right to health is subject to progressive realisation and resource availability, meaning that a country is obliged to improve its human rights performance steadily. In this way, it is essential for the country to have a health plan with indicators, benchmarks, and a budget, in order to demonstrate what the country is planning and promising to provide, and how progress is being made to realise these promises. The plan must also be transparent – in other words, accessible to the public. If there is no progress and the right to health has not improved, the government of that country has to provide a rational and objective explanation. While more is expected of countries with greater resources, some obligations of the right to health – known as *core obligations* – are of immediate effect, meaning that every country must fulfil them, irrespective of resource availability. These core obligations include, for example, non-discrimination; establishment of a national health plan; essential PHC; provision of essential medicines, including psychotropic medicines; and accessible health facilities, goods, and services, particularly for vulnerable and marginalised people and groups, such as people with psychosocial disabilities [13, 15]. The right to health, like all human rights, is interested not only in outcomes but also in the processes related to these outcomes. For example, it is concerned with how individuals and communities participate in a health decision that affects them, such as the development of a country's mental plan and the organisation of PHC services and the health system more broadly[13].

The right to health also has an international dimension, such as the control of infectious diseases and the dissemination of health research and regulatory initiatives (e.g., the WHO Framework Convention on Tobacco Control) [26]. The human rights responsibilities of international assistance and cooperation can be traced to the Charter of the UN, the UDHR, and some more recent international human rights decisions and binding treaties [27]. High-income countries have additional responsibilities to provide health-related international assistance and cooperation for low-income countries and to help such countries fulfil their core obligations [13].

BOX 2. KEY POINTS FROM GENERAL COMMENT 14

Article 12 of the ICESCR briefly sets out the right to health. General Comment 14 provides the UN Committee on Economic, Social and Cultural Rights' interpretation of article 12. Although not legally binding, this general comment is highly authoritative. Key points from General Comment 14 include the following:

- The right to health encompasses physical and mental health.
- Governments have obligations in relation to health care and the underlying determinants of health, including the provision of clean water, adequate sanitation, nutritious food, adequate shelter, the protection of liberty, education, a safe environment, health-related information, and freedom from discrimination.
- Governments should ensure that both public and private health providers comply with the principle of non-discrimination in relation to persons with disabilities.
- Governments have obligations regarding maternal, child, and reproductive health; mental health; the prevention, treatment, and control of diseases; health facilities, services, and goods; and healthy workplace environments.
- Countries should have physical and mental health facilities, services, and goods that are available in sufficient quantity, accessible (including affordable) to everyone without discrimination (including children, adolescents, indigenous people, and men and women), culturally acceptable (e.g., respectful of medical ethics and sensitive to gender and culture), and of good quality.
- Governments should ensure that their countries' health systems provide timely access to basic preventive, curative, and rehabilitative health services and health education; regular screening programmes; and appropriate treatment for prevalent diseases, illness, injuries, and disabilities, preferably at the community level.
- The right to health is subject to progressive realisation and resource availability. Nonetheless, governments must take deliberate and targeted steps to ensure the progressive realisation of this right as swiftly and effectively as possible.
- However, core obligations of the right to health are subject to neither progressive realisation nor resource availability. They include primary health care; access to health facilities, goods, and services for everyone without discrimination; essential medicines, as defined under the WHO Action Programme on Essential Drugs; the equitable distribution of all health facilities, goods, and services; and, on the basis of a participatory and transparent process, the adoption and implementation of a national public health strategy and plan of action with indicators and benchmarks by which progress can be closely monitored.
- Governments have an obligation to ensure that non-state stakeholders are respectful of the right to health (e.g., that they do not discriminate against certain health care users).
- High-income states, as well as others in a position to assist, should provide international assistance (e.g., economic and technical assistance) to help developing countries fulfil their core obligations.
- The right to health is closely related to, and dependent on, numerous other human rights, such as the rights to life, education, and access to information.
- In narrowly defined circumstances and as a last resort, some human rights might be temporarily curtailed to achieve a public health goal (e.g., limiting the right to individual freedom of movement through quarantines in order to contain the Ebola virus).

For the right to health to be realised, states must *respect, protect, and fulfil* the right [13]. In short, the obligation to *respect* means that the state has to refrain from denying or limiting equal access to preventive, curative, or palliative care services. The obligation to *protect* means that the state must prevent third parties (e.g., private companies) from intervening in the health sector in ways that could pose a threat to the realisation of the right to health. A concrete example of this can be seen in a court case in India (*Ratlam Municipality Council v. Vardi Chand*) in which the Supreme Court held that municipalities had a duty to protect the environment in the interest of public health [28]. This feature of protection also means that health workers are required to meet appropriate standards, such as those regarding education and skills. The obligation to *fulfil* means that the state must give sufficient recognition to the right to health in its political and legal systems and take appropriate measures to facilitate, provide, and promote the right to health. Ultimately, the aim is to assist individuals and communities in enjoying the right to health, such as through programs that help people make informed choices about their health [13].

Determining whether the right to health has been violated requires consideration of the distinction between the state's inability and its unwillingness to comply with its obligations under, for example, article 12 of the ICESCR [13]. The commitment a state makes by ratifying a human rights treaty – in this case, a treaty encompassing the right to health – should be reflected in (i) the state's national constitution; (ii) the national health plan or strategies; (iii) the structure and development of the health system; and (iv) all health programmes and projects. While the ratification process is generally a top-down process, it could also be a bottom-up one in which other actors, such as civil society groups, pressure the state to ratify a treaty or make changes to its laws.[29].

To ensure that the right to health forms part of the planning, implementation, and evaluation of programmes and projects, the conceptual framework, frequently referred to as a “human rights based approach” or a “rights-based approach” to health can be used.

1.1.1 The interrelationship between the right to health and a human rights-based approach to health

In 1997, the then UN Secretary-General, Kofi Annan, launched the UN Programme for Reform, which called on all entities of the UN system to mainstream human rights into their activities and programmes. Following this was the adoption of the UN Common Understanding in 2003, marking a further shift towards the operationalisation of human rights. The operationalisation is referred to as an HRBA [30]. The application of HRBAs to a variety of fields, beyond or within the realm of cooperation and development resulted in different formulations of the substantive content of a HRBA. Many Official

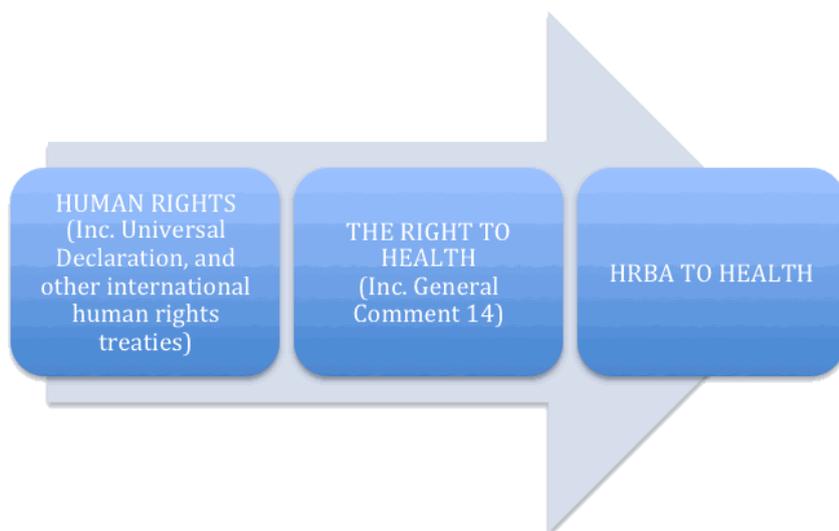
Development Assistance (ODA) agencies and international non-governmental organisations (INGOs) have formulated HRBAs that suits specifically their institutional objectives and scope of work. For example, the Swedish Development Cooperation Agency (Sida) defines an HRBA by at least the HRBA human rights features: non-discrimination, accountability, transparency and participation.

Klasing et al. (2011) reviewed different organisations' definitions of a Rights Based Approach (RBA) in humanitarian settings, observing that "an organisation's 'rights based approach' is determined not only by the legal framework, but by the organisation's founders, governors, stakeholders, and others, rendering the term somewhat relative to the organisation or group one happens to be addressing" [31 p. 11].

What, then, is the difference between human rights and an HRBA? Human rights law describes certain standards aimed at protecting individuals and groups against actions and omissions that interfere with fundamental freedoms, entitlements, and human dignity, such as non-discrimination and the right to health. Human rights law obliges governments and other actors to do certain things and to refrain from doing others [32]. An HRBA is described by the Office of the United Nations High Commissioner for Human Rights (OHCHR) as a conceptual framework that is normatively based on international human rights standards and operationally directed to promoting and protecting human rights. Under this approach, plans, policies, and programmes are anchored in a system of rights and corresponding obligations established by international law [32].

An HRBA to health specifically aims at realising the right to health and other health-related human rights. Health policy making and programming are to be guided by human rights standards and features with the aim of developing the capacity of the government and other actors who have committed to realising human rights, to meet its obligations. Further, an HRBA also aims at empowering those who are to benefit from the realisation of human rights, and be able to claim them if they are not realised. An HRBA to health is as such is both a top-down and -bottom up approach [30, 32, 33]. An HRBA to health encompasses a number of human rights features, such as availability, accessibility, participation, non-discrimination, and accountability. An HRBA to health makes explicit reference to rights from the outset of programmes, policies, and projects, as a way of preventing violations from happening in the first place. The introduction of an HRBA to health into public health is essentially about approaches and processes, as well as maximising public health gains [34]. Figure 2 shows the interrelationship between human rights, the right to health, and an HRBA to health.

FIGURE 2. THE INTERRELATIONSHIP BETWEEN HUMAN RIGHTS, THE RIGHT TO HEALTH, AND AN HRBA TO HEALTH



To date, however, there is still no common and universal definition of what constitutes an HRBA or an HRBA to health [35] (see chapter 4 and chapter 7). This research focuses on an HRBA to health and uses the understanding of HRBA adopted by WHO and the UN High Commissioner for Human Rights (OHCHR). This approach aims at realising the right to health, and other health related human rights. The definition encompasses the principles of availability, accessibility, acceptability, quality, non-discrimination, participation, and accountability (see box 3) [36]. These features arise from human rights and the right to health and are explained in General Comment 14.

BOX 3. SEVEN FEATURES OF AN HRBA TO HEALTH

Availability	<i>Availability</i> implies that functioning public health and health care facilities, goods, services, and programmes are available in sufficient quantities. The precise nature of the facilities, goods, and services will vary depending on numerous factors, including the country's development level. Availability also includes underlying determinants of health, such as potable drinking water, adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs (as defined by the WHO Action Programme on Essential Drugs).
Accessibility	<i>Accessibility</i> is a core obligation of the right to health and includes the overlapping aspects of non-discrimination and physical, economic, and information accessibility. The importance of accessibility is also demonstrated in the CRPD, where it is included in a number of articles, and also featured in a stand-alone article.
Acceptability	<i>Acceptability</i> implies that all health facilities, goods, and services must be respectful of medical ethics and be culturally appropriate – that is, respectful of individuals, people, and communities, sensitive to gender and life cycle requirements, and designed to respect confidentiality and improve the health status of those concerned.
Quality	<i>Quality</i> means that facilities, goods, and services must be scientifically and medically appropriate and of good quality. This requires, among other things, skilled personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation.
Non-discrimination	<i>Non-discrimination</i> is a core obligation of the right to health and is the foundation of all human rights. No one should be denied access to health care or the underlying determinants (e.g., water, sanitation, education) of health, or to entitlements of procurement. Even in times of severe resource constraints, vulnerable members of society must be protected by the adoption of relatively low-cost targeted programmes. To prevent discrimination, the state has an obligation to provide those who do not have sufficient means with the necessary health insurance and health care facilities. Primary and preventive health care should be prioritised over expensive curative health services, which are not accessible to all.
Participation	<i>Participation</i> is a core obligation of the right to health and is also highlighted in the preamble and article 3(c) of the CRPD [37]. It is also a feature that health systems must include to be respectful of the right to health – in other words, health systems must make institutional arrangements to ensure citizens' active and informed participation in planning, strategy development, and accountability [2].
Accountability	<i>Accountability</i> is central for the realisation of the right to health, and all other human rights. As the right to health and CRPD give rise to legal obligations, independent monitoring and accountability mechanisms are of critical importance. The significance of this feature is reflected by the fact that it has its own article in the CRPD (art. 33) [37] and is highlighted by other authors as pivotal [36].

Source: [13, 37]

Applying an HRBA to health is not a radical departure from what the majority of contemporary health sectors highlight as important for improving the health and well-being of individuals and populations, including those with psychosocial disabilities [38]. Clinicians and other health professionals should already be familiar with the values of an HRBA to health, even if the language might seem unusual [33]. An HRBA to health is thought to contribute to the fulfilment of the right to health and to improve health outcomes [35]. The major difference between an HRBA to health and the features generally mentioned in public health is that the features of an HRBA to health are anchored in international human rights law and are thus legally binding.

The practical application of the HRBA features are subject to active and rich debates [38]. Despite the increasing emphasis placed on human rights and the integration of an HRBA into mental health policy and practice, [21, 39-42] the impact of an HRBA to health on health practice is unclear (the evidence base is explored further in chapter 4).

1.1.2 The interrelationship between the right to health and public health

Jonathan Mann, one of the pioneering experts on health and human rights, noted in the 1990s that the “promotion and protection of rights and health are inextricably linked [and that this] requires much creative exploration and rigorous evaluation” [43, 44]. Until recently, the health and human rights communities largely worked in parallel, rarely engaging with each other. However, a number of major challenges in global health altered this. One such catalyst was women’s health issues, including the human rights violations that took place in the conflicts in the Balkans and the Great Lakes region in Africa [44-46]. Another catalyst – and arguably the most significant one for spurring connections between health and human rights – was the HIV/AIDS pandemic [44]. The enormous discrimination and suffering associated with this pandemic contributed to an improved understanding and practical application of human rights within public health discourse and practice [47]. It was increasingly recognised that when human rights are protected, fewer people become infected and those living with HIV, as well as their families, can better cope with the disease [48]. Over time, public health officials were thus encouraged to systematically ensure that policies and plans respected human rights. Other areas in public health, such as sexual and reproductive health and maternal and child health, have followed suit. For example, increasing demands have been placed on public health professionals and policy makers to apply an HRBA to health when developing plans and programmes for reducing maternal mortality, with a particular focus on economic, social, and cultural rights and on a functioning health system [49-53].

My research will concentrate on mental health, an issue that remains neglected in the discourses on human rights (including the right to health) and global public health [54-57]. It is increasingly being recognised that when mental disorders are treated effectively, and human rights are respected, many positive secondary benefits result – not only for individuals but also for their relatives and the community [58]. Yet, to my knowledge, no research has explored health workers’ experiences and perspectives on the right to health in mental health and their perceptions of the application of an HRBA to health in mental health planning and service provision in the global South. This is despite the fact that recent years have seen an increased emphasis on mental health and human rights, such as the adoption of the CRPD [37] and *The Lancet’s* 2011 Series on Global Mental Health, which highlights the need for human rights to be placed at the foreground of global mental health [57, 59]. Furthermore, the WHO’s Mental Health Action Plan for 2013–2020 highlights the centrality of human rights in addressing mental health globally. It notes the need for services, legislation, plans, strategies, and programmes to protect, promote, and respect the rights of persons with psychosocial disabilities in line with relevant international and regional human rights treaties and conventions as one of the steps to address the widespread stigma surrounding and discrimination against people with psychosocial disabilities [1].

Although there is a clear interrelationship between public health and the right to health, there can be times when the two fields interpret differently such issues as legitimate derogations on human rights, for example as they apply to the restriction on the right to liberty of movement (e.g.; quarantine), on the right to privacy (e.g.; confidentiality) or on the right to information (e.g.; informed consent) and on several—although not all—human rights. It is therefore important for both health and the right to health to reflect how best human rights standards and public health measures act in synergy rather than in opposition to one another and try to find a solution best suited to the realisation of both human rights and public health goals. As another example, with the HRBA feature of accountability it is important to understand its meaning so as to ensure that health workers are not used as scapegoats for deeper institutional failures [9, 60].

Although health workers have contributed to the integration of the right to health and health-related human rights, some have (knowingly or unknowingly) violated human rights. For example, they have denied treatment to marginalised groups, such as immigrants or undocumented migrants; disclosed confidential medical records; and denied sexual and reproductive health information to women and adolescents. Health workers have also, at times, been pressured to participate in human rights violations, including torture, forced sterilisations, and female genital mutilation [12]. Health providers’ inadequate compliance with human rights standards is often the result of complex and interrelated circumstances, including political pressures and societal influences [12]. There may also be problems stemming from

differences in the professional language and culture between the legal and health communities [60]. Another issue may relate to inadequate or non-existent training in human rights, resulting in uncertainty around what human rights mean, both conceptually and operationally. Different understandings and approaches will potentially result in limited or flawed implementation of policies and plans, or they will worsen the situation [9-12]. For example, a study by Vernooij and Hardon (2013) on HIV testing and counselling practices in a rural Ugandan antenatal clinic demonstrated how the practice of counselling in the prevention of mother-to child HIV transmission was influenced by two hegemonic discourses: the health of the child should be protected, and health workers know best. As a result, counselling in these settings focused on the health of the baby, silencing women's right to opt out of HIV tests [61]. Public health scholars have emphasised the need to understand the implementation system and actors involved, including health workers, in order to understand why policies and plans frequently do not achieve their expected outcomes [10, 11]. According to these and other scholars, increased attention needs to be placed on the manner in which health workers implement policies and plans [10, 61]. Thus, health workers are at the centre of my research.

Health systems are a central element of the right to health and fundamental to improving the overall health of the population. Today, there is widespread consensus that strong health systems are critical for improving all health outcomes, including among people with psychosocial disabilities. For example, health systems have been highlighted as necessary for achieving national and international health goals, including the Millennium Development Goals and the Sustainable Development Goals [62-64]. The importance of strong health systems has recently been reinforced with the Ebola crisis [65].

In 2006, the UN Human Rights Council passed a resolution (2/108) requesting the then UN Special Rapporteur on the Right to Health to identify and explore the key features that an effective, integrated, and accessible health system should have in order to be respectful of the right to health, bearing in mind the level of development of countries [66]. The report was presented to the Human Rights Council in 2008 [67]. I was centrally involved in the development of this report, which later also included the development of indicators to measure these identified right to health features and provided an assessment of them in 194 countries. A summarised version of the report, including the assessment, was subsequently published in *The Lancet* [7] (appendix 1).

The identified right to health features that a health system should possess should be applied consistently and systematically across the numerous elements, or "building blocks," that the health sector has identified as necessary for a functioning health system [68]. These "building blocks" serve not only the health system but also the right to health. Like health systems, the right to health requires health workers,

health services, health information, medical products, financing, and stewardship. This thesis focuses specifically on health workers.

1.1.3 The right to health and health workers

The report on health systems by the UN Special Rapporteur on the Right to Health provides examples of the way in which the right to health relates to the health workforce:

- The state should have an up-to-date development plan for human resources in preventive, curative, and rehabilitative health; this plan should encompass physical and mental health.
- Recruitment of health workers must include outreach programmes for disadvantaged individuals, communities, and populations, such as indigenous peoples.
- Effective measures are required to achieve a gender balance among health workers in all fields.
- The state should ensure that the number of domestically trained health workers is commensurate with the health needs of the population, subject to progressive realisation and resource availability. In this context, appropriate balances must be struck between, for example, the number of health workers at the community or primary level and specialists at the tertiary level.
- The number of health workers should be collected, centralised, and made publicly available. The data should be broken down by category – for example, nurse, public health professional, and so on. The various categories should be disaggregated, at a minimum, by gender.
- Health workers' training must include human rights, including respect for cultural diversity, as well as the importance of treating patients and others with courtesy.
- After qualifying, all health workers must have opportunities, without discrimination, for further professional training.
- Health workers must receive domestically competitive salaries, as well as other reasonable terms and conditions of employment. Their human rights must be respected (e.g., the freedoms of association, assembly, and expression). They must be provided with the opportunity for active and informed participation in health policy making.
- The safety of health workers, who are disproportionately exposed to health hazards, is a major human rights issue.

There should be incentives to encourage the appointment and retention of health workers in underserved areas [2 p.20].

According to the Special Rapporteur's report:

“Human rights do not provide neat answers to such questions, any more than do ethics or economics. But human rights require that the questions be decided by way of a fair, transparent, participatory process, taking into account explicit criteria, such as the well-being of those living in poverty, and not just the claims of powerful interest groups” [2 p.17].

1.2 MENTAL HEALTH

Mental health is one part of the right to health and is a core focus of this research. The WHO broadly defines mental health as “a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community” [1, 69]. As such, mental health refers to a broad array of activities directly or indirectly related to the mental well-being component included in the WHO’s definition of health: “a state of complete physical, mental and social well-being, and not merely the absence of disease.” Mental health is related to the promotion of well-being, the prevention of mental disorders, and the treatment and rehabilitation of people affected by mental disorders [70]. Mental disorders are defined by the WHO (2016) as comprising a broad range of problems, with different symptoms, characterised by some combination of abnormal thoughts, emotions, behaviour, and relationships with others. Examples are schizophrenia, depression, intellectual disabilities, and disorders due to drug abuse. Most of these disorders can be successfully treated [71]. Mental disorders are estimated to affect approximately one in four people around the world [39]. Mental and behavioural disorders accounted for 5.4% of the global disability-adjusted life years (DALYs)⁴ in 1990, rising to 7.4% in 2010 (global, both sexes, all ages) [72].

For this research, I will generally use the term “psychosocial disabilities.” According to the WHO (2011), disability is the umbrella term used for “impairment, activity limitations and participation restrictions, denoting the negative aspect of the interaction between and individual (with a health condition) and that individual’s contextual factors (environment and personal factors)” [73]. Common definitions of the term “psychosocial disabilities” tend to include everything from major ill health and disorders (such as schizophrenia, depression, and substance abuse disorders) to intellectual disabilities (such as brain damage occurring before, during, and after birth). The disability can be permanent or transitory [74, 75]. According to Drew et al. (2011), the term psychosocial disabilities is used to refer to people who have received a mental health diagnosis and who have experienced negative social factors, including stigma, discrimination, and exclusion. People living with psychosocial disabilities include former and current users of mental health services [57].

⁴ The disability-adjusted life year (DALY) is a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death.

There are four reasons why I use the term psychosocial disabilities. First, it is the preferred terminology of the World Network of Users and Survivors of Psychiatry [76]. Second, the term “disabilities” is the legal term that has been codified in the CRPD, where persons with disabilities are defined as “those who have long-term physical, mental, intellectual or sensory impairments which in interactions with various barriers may hinder their full and effective participation in society on an equal basis with others” [37 Art.1]. Third, during the 2001 World Health Assembly, the WHO urged states to use the classification of disabilities stipulated in the International Classification of Functioning, Disability and Health [77, 78]. The term disabilities also encompasses the three WHO priority conditions which are the focus of this research (see below) [75].

While this research mainly uses the term psychosocial disabilities, the terms mental health, mental disorders, and mental disabilities are commonly used in the global mental health discourse; thus, at times, I will use these terms interchangeably where appropriate, such as where cited studies and reports have referred to those terms.

In order to make this research more focused and feasible, I focus largely – but not exclusively – on three priority conditions in global mental health: depression, alcohol use disorders, and psychotic disorders (mainly schizophrenia). These are priority conditions for WHO, as they present a high burden of mortality, morbidity, and disability; have high economic costs; and are associated with widespread human rights violations [79]. They are also priority conditions for the Programme for Improving Mental Health Care (PRIME) in Nepal, where this thesis’s field work was situated (see chapter 2).

Depression is a common illness worldwide, with an estimated 350 million people affected. More women are affected by depression than men. Depression is different from usual mood fluctuations and short-lived emotional responses to challenges in everyday life. Especially when long-lasting and when of moderate or severe intensity, depression may become a serious health condition. At its worst, depression can lead to suicide. Over 800,000 people die from suicide every year, with suicide the second leading cause of death in 15- to 29-year-olds [80]. Although there are known, effective treatments for depression, fewer than half of those affected in the world (in many countries, fewer than 10%) receive such treatments [80]. The 2010 Global Burden of Disease study estimated in 2009 that depression alone would likely be the second highest contributor to the global burden of disease by 2030, accounting for 2.5% of total DALYs (global, all ages, both sexes) [72].

Alcohol abuse causes a large disease, social, and economic burden in societies. Alcohol affects people and societies in many ways, depending on the volume of alcohol consumed, the pattern of drinking, and, on

rare occasions, the quality of alcohol consumed. In 2012, about 3.3 million deaths, or 5.9% of all global deaths, were attributable to alcohol consumption [81]. Overall, 5.1% of the global burden of disease and injury is attributable to alcohol, one of the leading causes of DALYs among the adult population [81]. Alcohol consumption causes death and disability relatively early in life. Among people aged 20–39, approximately 25% of all deaths are alcohol attributable [81].

Schizophrenia is characterised by distortions in thinking, perception, emotions, language, sense of self, and behaviour. Common experiences include hearing voices and delusions. It is a severe mental disorder that affects more than 21 million people worldwide, with men being more affected (12 million) than women (9 million) [82]. Worldwide, schizophrenia is associated with considerable disability and may affect educational and occupational performance [72, 82]. It is estimated that people with schizophrenia are 2–2.5 times more likely to die prematurely than the general population. Schizophrenia is treatable, but there is a major treatment gap – approximately 90% of people with untreated schizophrenia live in low- and middle-income countries [72, 82].

There are a number of commonly recurring risk factors for mental disorders. Gender plays a large role in the prevalence of mental disorders, with women reporting higher rates of mood disorders, depression, and anxiety compared to men. On average, women report 1.5–2 times higher rates of such disorders [83–86]. This skewed gender distribution of mental disorders has far-reaching implications, including, for example, the fact that mothers may have a reduced ability to care for their children [86, 87]. Poverty, low education, low socioeconomic status, stress, and limited access to resources can also increase the risk of mental disorders. People with mental disorders are also more likely than those without mental disorders to be pushed into poverty through the loss of employment, the loss of housing, stigma and discrimination, and increased health costs [86, 88–92]. Mental health is a key public health concern for conflict-affected populations, where exposure to stressful events, impoverishment, and other daily stressors can trigger or worsen mental health problems, often at the same time that the mental health infrastructure is weakened [93, 94].

People with mental disorders have an increased risk of suffering from non-communicable diseases, such as cardiovascular disease, and communicable diseases, such as HIV and malaria. The reasons for this may include diminished immune function, poor health behaviour, poor adherence to medical treatment, and social barriers (such as discrimination and stigma that impede treatment) [39, 95].

Beyond recognising mental health as a fundamental aspect of health, studies indicate that high levels of mental disorders present a major barrier to the socioeconomic development of low-income countries [96]. Numerous studies have shed light on the economic burden and impact of this neglect, showing the

loss of productivity attributable to mental disorder and the resulting negative impact on a country's development [39, 90, 96-99].

Effective, low-cost treatments are available for a range of mental disorders [39, 98], and evidence shows that interventions for mental disabilities can improve clinical outcomes and break the cycle of poverty, thereby facilitating economic growth and progress towards important global development goals, such as the Millennium Development Goals and Sustainable Development Goals [84, 88, 100].

However, surveys in low- and middle-income countries reveal a large treatment gap for mental health, with more than 75% of those with mental disorders receiving no care at all [101]. The consequences of this unmet need include, among others, long-term disability, ill health, increased mortality, and diminished outcomes for other health conditions. Numerous studies and programmes have brought attention to this neglect, such as *The Lancet's* 2007 series entitled "Scale up services for mental disorders: a call for action" [41]. In this series, the authors argue for a basic, evidence-based package of services for core mental disorders, along with the strengthening of human rights protection for people with mental disorders and their families [41]. In a response to this call, the WHO established its 2008 Mental Health Gap Action Programme (mhGAP) [102] with the aim of providing health planners, policy makers, and donors with a set of clear and coherent activities and programmes for the scaling up of mental, neurological, and substance use disorders (discussed in more detail in section 1.3). There has been some belated recognition of the importance of mental health. For example, the World Health Assembly resolution from May 2013 calls for a comprehensive, coordinated response to mental disorders at the country level [80]. In addition, sub-goal 3.4 of the Sustainable Development Goals includes mental health [103].

1.3 MENTAL HEALTH AND THE RIGHT TO HEALTH

Mental health was one of the first health issues to attract the attention of the human rights community, which adopted a strong focus in the 1970s and 1980s on abuses in psychiatric institutions and the mental health claims were initially firmly grounded in the ICCPR, but are today based on both ICCPR and ICESCR [6]. Indeed, health care settings from the community level to large psychiatric hospitals continue to be places where people with psychosocial disabilities experience some of the worst human rights violations and discrimination [40]. In addition, people with mental disorders frequently face widespread discrimination and obstacles to claiming their rights, such as a lack of access to mental health services both in the health care sector and beyond [57, 74, 104]. The reasons for these continued human rights violations are many and are frequently systemic in nature, including the lack of a functioning health system that is respectful of the right to health, poor legal frameworks, and weak or non-existent

accountability mechanisms (such as an ombudsperson that monitors a state's implementation of its health and human rights commitments).

The marginalisation of mental health services in many health systems, particularly in low- and middle-income countries and post-conflict settings [39, 74, 105, 106], has been highlighted in research and by the WHO [39, 42, 63]. In the face of the expected increase in the absolute number and share of the global burden of disease attributable to mental and behavioural disorders in the future, practical strategies for managing these disorders in low- and middle-income countries, including investment in manpower and medical education, are urgently needed [72]. Presently, many health systems have scarce financial resources, trained personnel, infrastructure, and drug supplies, leading to treatment gaps [63, 101]. In addition, many low- and middle-income countries lack mental health care plans, policies, and legislation to guide the direction of their services and programmes [63]. Both treatment gaps and the lack of plans, policies, and legislation are concrete examples of violations of the core obligations of the right to health [13]. There has been an overreliance in many low- and middle-income settings on psychiatric institutions and even jails to house those considered to be mentally ill. In many of these institutions, human rights violations have been widely reported [57]. As a result, those in need of care are often reluctant to seek help [57, 107].

The WHO recommends that mental health care be integrated into PHC,⁵ as this approach has been demonstrated to improve access to care and the detection and treatment of mental disorders [39]. This PHC treatment needs to be supported by effective referral systems to secondary and tertiary care levels, as well as by formal and informal community-based services [39, 42, 63, 106].⁶

To be able to implement the WHO's recommended service organisation for mental health, limitations in the health system must be addressed. For example, to deal with human resource concerns, task shifting is recommended; this means that with brief training and appropriate supervision by health care specialists, non-specialist health professionals, such as lay workers and occasionally caregivers, can assist

⁵ Primary health care encompasses any health clinic that offers the first point of entry into the health system.

⁶ *Formal community-based mental health services* include community-based rehabilitation services, hospital diversion programmes, mobile crisis teams, therapeutic and residential supervised services, home help, and support services. Community mental health services work best if closely linked to primary health care and informal community care providers. *Informal community-based mental health services* may be provided by local community members other than general health professionals or dedicated mental health professionals and paraprofessionals. Informal providers are unlikely to form the core of mental health service provision but can be important in improving the outcomes of a person with a mental disorder. However, there are concerns of human rights violations by some traditional healers and faith-based organisations (106. WHO, *Mental Health Policy and Service Guidance Package. Organization of Services for Mental Health* 2003, WHO: Geneva. p. 92.).

with detecting, diagnosing, and monitoring people with psychosocial disabilities [108]. Another aspect to consider with regard to the deinstitutionalisation of mental health services to the community level is limited resources. More often than not, community mental health service provision is undermined by inadequate resources, and donors are often reluctant to fund mental health programmes [105]. This may be addressed through the efforts of policy makers and health workers, including health service managers, to ensure that additional resources are secured [39, 109]. The successful implementation of community-oriented mental health care services is underpinned by self-determination, equal access, and respect for the human rights of people with psychosocial disabilities [110].

To address the many and varied barriers that exist at the different health system levels, the WHO's mhGAP develops integrated packages of care focusing on specific priority conditions. The priority conditions are depression, schizophrenia and other psychotic disorders, suicide, epilepsy, dementia, and alcohol and illicit drug disorders [79]. The focus of the interventions is on low-income and lower-middle-income countries. The intervention packages are based on their efficacy and effectiveness, including cost-effectiveness, equity, ethical considerations (including human rights), and feasibility [79].

The incorporation of human rights into mental health plans, policies, and laws is considered fundamental for responding to the global burden of disorders, including psychosocial disabilities [1, 75, 111]. To ensure respect for people's human rights – including their right to health – an HRBA to health should be integrated into mental health services.

1.4 RATIONALE, AIM, AND OBJECTIVES

1.4.1 Study rationale

Over the last decade, there have been increasing calls to integrate human rights into health, including mental health policies, plans, and programmes [1, 41, 112, 113]. For example, the 2013 WHO mental health action plan (2013–2020) highlights the centrality of human rights in improving and advancing mental health [1 p. 3].

There appears to be a gap in the research about the role of health workers and their perceptions regarding the integration of human rights into mental health services specifically and health services in general. The convergence of mental health and the right to health has implications for health workers, who must try to integrate the two fields into a coherent set of principles and practices. Health service providers' perspectives and perceptions concerning the right to health are pivotal, given that these actors are key translators of policy- and programme-related decisions into practice and are often the first point of contact for health seekers. Attempting to implement the right to health and other health-related rights

in practice without the understanding and support of health workers, particularly health service providers, would be extremely problematic and potentially counterproductive. Different understandings and approaches could result in limited or flawed policy implementation, which could worsen health service delivery and patient health outcomes [9-12].

1.4.2 Aim and objectives

The overall aim of this research was to explore the perceptions and perspectives of mental health workers in Nepal regarding the use of an HRBA to mental health. It had the following specific objectives:

Objective 1: To examine existing evidence on the use of an HRBA to advance⁷ health

Objective 2: To explore perspectives on the right to health among mental health workers in Nepal

Objective 3: To explore health workers' perceptions of the application of an HRBA to mental health planning and service provision

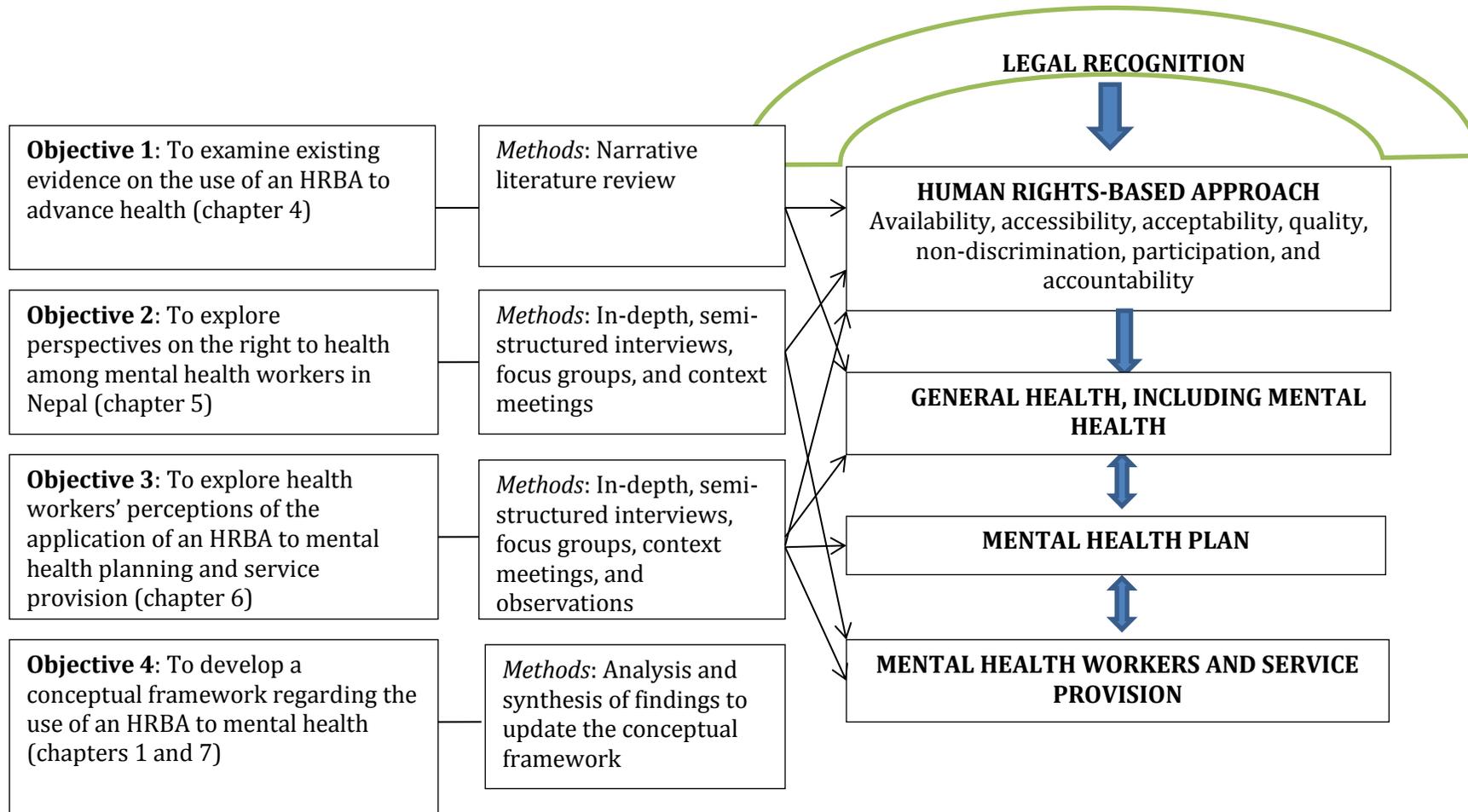
Objective 4: To develop a conceptual framework regarding the use of an HRBA to mental health.

⁷ "Advance" refers to aspects that support the protection and improvement of health.

1.5 CONCEPTUAL FRAMEWORK AND THEORETICAL APPROACH

The conceptual framework outlined in figure 3 provided the foundation of this research and informed my research methods, analysis, and interpretation. It was developed through a consideration of both the right to health and public health. It relied on the right to health as its basis, while also drawing on public health theory, particularly the work of Lipsky (1980).

FIGURE 3. CONCEPTUAL FRAMEWORK FOR THIS THESIS



At the top of the framework is the legal recognition of the right to health, as enshrined in international human rights treaties and national law by a government. A government's legal commitment to human rights law is vital to understand as it sets out the state's legal obligations and commitments. It is from human rights treaties that the features of an HRBA emerge, as outlined in the second box. A state's human rights legal commitments, including the HRBA, should be reflected in the state's health system, including mental health activities and approaches, as well as in its mental health plan, which are the two subsequent layers. Finally, the mental health plan should be trickled down to subordinate levels and be reflected in the mental health system (from tertiary to primary and community care levels) and to mental health workers, who are the ones who will be realising the health plan.

General Comment 14 stipulates that "the right of individuals and groups to participate in decision making processes, which affects their development, must be an integral component of any policy, programme or strategy developed to discharge governmental obligations under article 12 [the legal article referring to right to health in the ICESCR]" (CESCR, 2000 para 54[13 para 54]. Individuals and groups also include health workers, and not just users of health services [13]. Furthermore, although human resources for health have attracted increased attention in recent years, the human rights dimensions of the issue rarely receive significant attention. Health workers are key in translating human rights and health policies into practice, but their human rights have received little attention despite health workers being central in realising the right to health [2]. The importance of paying attention to health workers in policy implementation has also attracted research attention in public health. Lipsky (1980) has found, for example, that well-meaning policies could (albeit unintentionally) make things worse, such as by increasing staff workload. This could lead to negative behaviour towards the implementation of the policy by, for example, altering the meaning of the policy's content, thus exacerbating existing problems [11]. Lipsky uses the term "street-level bureaucrats" to refer to professionals who are the interface between citizens and the government, such as social workers, police, teachers, and health workers. Street-level bureaucrats are the ones who deliver a policy that has been constructed elsewhere [114]. Although his research was carried out mainly in the United States, it still seemed applicable and relevant to my research, as Lipsky's theoretical framework has been used in other low-income settings [10, 115]. My research has expanded Lipsky's definition of street-level bureaucrats to include health workers who provide services directly and those who are decision makers in service provision.

According to Lipsky, workers in public services are vital, as they are in direct contact with citizens, who are the beneficiaries. For example, in the context of this thesis, although the ratification of human rights treaties is the responsibility of the government, health workers at the facility level play a crucial role in the implementation of human rights and public health policies. They have some power to decide about

the quality of services provided to health care users [11]. Moreover, another aspect of street-level bureaucracy is that clients – who, for this thesis, are service users – often do not have a choice as to where to access the services. As a result, street-level bureaucrats, including health workers, do not lose anything by not providing good-quality service to users. Most of the time, users have little information to compare or assess their treatment, and they are unable to easily hold service providers to account. The limitations of not having all the information required or not being able to assess treatment and holding service providers to account have an important impact on the relationship between the health workers and service users as the power is with the health service providers. As such, it could potentially lead to neglect and abuse of the users. Moreover, some health workers may prioritise one group over another [11].

Workers, including health workers, may not always share the same objectives and preferences as their supervisors or policy makers, and thus may not always work towards the same goal. Their priorities may be to minimise discomfort in their job and maximise income and personal gratification [11]. Furthermore, health workers' compliance depends on the extent to which they consider their managers to be legitimate leaders. Moreover, workers at the delivery level often have personal standards regarding whom should receive the service. The fact that workers might not share the same objectives as policy makers highlights the need to understand health workers' working conditions, as well as the context under which the health workers are working [11].

As described by Lipsky, studies indicate that workers may directly or indirectly alter policies, adjusting these policies to their working conditions and priorities. This does not, however, imply that workers do not want to apply the prescribed policy; rather, due to, for example, limited working conditions, they may be unable to apply the policy. This may then lead to discrepancies between policy declaration and policy implementation. One example of this is shown in the study by Walker and Gilson (2004), who used Lipsky's work to explore how nurses in a PHC clinic in urban South Africa responded to the 1996 national policy mandating the removal of user fees. The results showed that nurses agreed with the policy in principle but that the policy increased their workload without simultaneously increasing overall staff levels or drugs available. Moreover, many of the nurses felt that some patients abused the system when it was free. As a result, a number of nurses distorted the policy by not always giving free access to services for certain groups of patients [10]. Recent research by Petit (2013) has also applied Lipsky's theoretical approach in exploring health workers' perception of the implementation of Liberia's Basic Package of Health and Social Welfare Services [115].

The next chapter will describe the context of Nepal, which is the case study for my thesis, and the subsequent chapter will then describe the methods used to realise the objectives and to develop the conceptual framework.

CHAPTER 2: THE CASE STUDY OF NEPAL

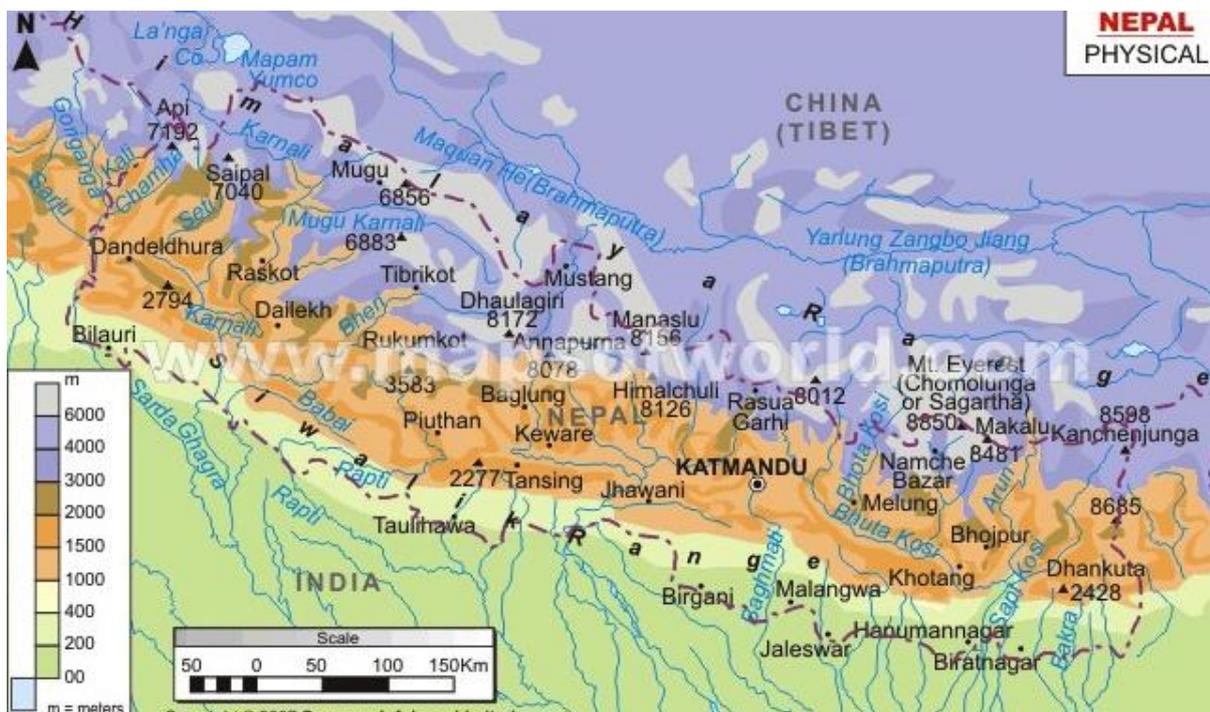
This chapter presents the case study of this research: Nepal and its Programme for Improving Mental Health Care (PRIME). Nepal has received significant international attention for its commitment to the adoption and implementation of human rights and the right to health in the field. The rationale for choosing Nepal and PRIME is discussed further in section 2.5.

This chapter begins by providing a brief overview of Nepal. It then looks more specifically at the right to health in relation to mental health in Nepal, the health system in Nepal, and the mental health situation in Nepal. The last section looks at PRIME.

2.1 THE COUNTRY CONTEXT

Nepal's population is estimated at 28.17 million people [116]. A small, mountainous country located in South Asia, Nepal shares its borders with India and China. The country is, in the words of Nepal's founding father, Prithvi Narayan Shah, "a yam caught in between two boulders" [117 p.1]. Geographically, it is divided into three regions: the lowland Terai plains in the south, the middle hilly parts, and the northern Himalayan Mountains that culminate in the Tibetan plateau (see map 1). The country is landlocked and heavily dependent on India for transit facilities to the outside world.

MAP 1. PHYSICAL MAP OF NEPAL



Nepal's geography and limited infrastructure makes accessing certain parts of the country difficult. Some villages are accessible only by foot or by air (see map 2). Population density varies widely across the regions, where the mountainous northern part is the least populated and the low-lying Terai is the most densely populated. It is estimated that 84.1% of the population lives in rural areas and 14.2% in urban areas[118]. The difficult terrain and varied population density influence both the cost and the benefits of providing infrastructure to many remote areas[119].

MAP 2. ROAD STRUCTURE IN NEPAL



For the past several decades, Nepal has faced an internal struggle for peace, development, and justice. There were failed attempts at democratisation in the 1950s and after, with Nepal instead ruled for 30 years of monarchical dictatorship. Between 1996 and 2006 there was a civil war [117] in which over 16,000 people died, and many more were subject to torture, intimidation, extortion, abduction, and rape [120]. The civil war is also referred to as the “people’s war” by the Communist Party of Nepal (Maoist)[121]. The war was initiated in 1996 by the Maoists with the aim of forcing the king to hand power over to the country’s political parties and declare a “People’s Republic”[117].

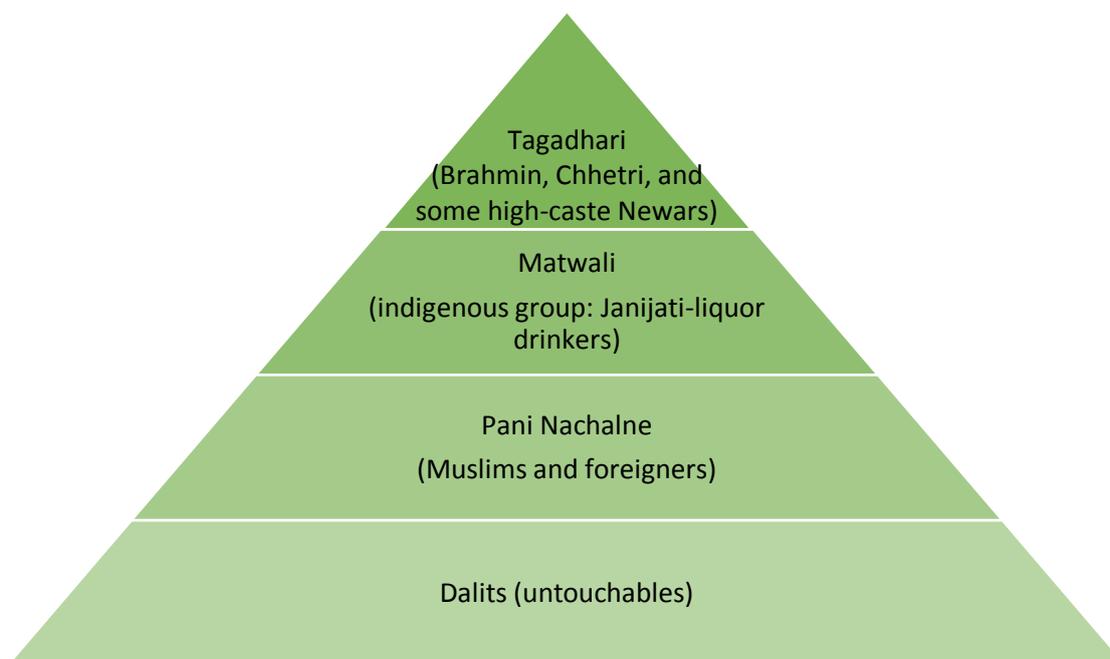
Endemic poverty and social inequality and injustice have been highlighted as two of the main long-term causal factors that led to the conflict[117]. According to von Einsiedel et al. (2012), the conflict must also be understood in the context of Nepal's status as one of the most ethnically diverse and socially stratified countries in the world, with 36% of its population belonging to one of the over 100 different indigenous nationalities with their own language and traditions[117]. Earlier in the 1990s, the Maoists had called for an end to "discrimination against people living in the Terai and remote areas ... end discrimination against oppressed people and the Dalits ... and equal opportunity in the media, including the radio and TV, for all languages"[122p.53], but without success. Examples of social inequality included the fact that in 1996, 42% of the population was living below the national poverty line, with poverty levels in rural areas twice as high as those in urban areas [119]. While this rural-urban division can, to some extent, be explained by geography, it is also a reflection of the Kathmandu ruling elite's neglect of the rest of the country throughout Nepal's history[117]. This division has been compounded by the largely feudal nature of land ownership and the agricultural sector, where a small elite owns vast portions of the land[116] (see figure 6 for a simplified description of the Hindu caste system).

Gender inequality in the country was also a key point among the Maoists, who stated, "Whereas this state has been treating women as second class citizens for long, now it has intensified rape, trafficking and the process of commoditisation through advertisement, against them"[121 p. 16]. Gender inequality was present throughout the whole country but was considered worst in the western hills. Two examples of unequal treatment between men and women – which women still faced in the 1990s and, to some extent, today – were their inability to inherit after the father and to receive an abortion. Indeed, any woman who carried out an abortion was subject to a lengthy jail sentence. Another example of disadvantages faced by women was the need to move out of the house whenever they had their periods, a traditional practice referred to as *chhaupadi*,⁸ which is documented to cause physical and psychological harm[123]. Finally, the preference for a girl child meant that girls would most likely not receive the same education as the boys, at least not for girls living in the hills. Another pressure on hill villages was the danger of parents selling their daughters to brothels. It is estimated that tens of thousands of girls were sold in this manner[124]. The Maoists promised, if given power, to end gender inequality. They argued that women should be given equal rights as men (such as the right to marriage by mutual consent), that they should enjoy the right to abortion, and that they should receive special consideration in divorce proceedings[121].

⁸ Some sources spell the practice as *chaupadi*.

Although the 1990 Constitution acknowledged, for the first time ever, the country’s multifaceted ethnicity and culture, it continued to define the country a “Hindu kingdom,” which, as such, continued to separate people according to groups and class[117]. The Maoists drew heavily on caste and ethnic grievances to mobilise popular support[121]. The unification of Nepal in 1700 was based on the Hindu caste system. The Hindu caste system was consolidated in 1800 by the Rana rulers with the introduction of the Muluki Ain (Civil Code), which codified Hinduism’s caste structure and incorporated all groups, whether Hindu or non-Hindu, within its hierarchical structure[119]. In this way, the Muluki Ain codified the system and gave different privileges and obligations to each caste and sub-caste. The code also reproduced the patriarchal view of women as subordinate to men and economically dependent on them[125]. The Hindu caste system is based on the idea that certain groups, depending on their ancestry, occupation, and practices, have different levels of purity, where the highest caste is the purest and the lowest is the least pure[119] (see figure 4).

FIGURE 4. SIMPLIFIED HINDU CASTE SYSTEM



Source: [125].

Only when the Muluki Ain was revised in 1963 was Nepal’s caste-based discrimination formally abolished[119]. Yet, according to Thapa (2012), “there seems to be a clear link between group status in the 1854 Muluki Ain and positions of influence of Nepal today because caste status continues to affect social mobility and individual accomplishment”[122p. 13]. The Hindu caste system resulted in official discrimination on a massive scale, which marginalised large parts of the population[117]. The fostering

of a Nepali identity based on Hindu culture and practice was further reinforced in the 1960s and 1970s by its political leaders, resulting in deeper exclusions of already marginalised groups.

However, in 1979, students in Nepal revolted. These protests are often considered to be the precursor to the 1990s People's Movement[117]. The then government's inability to create change led to rising frustration and increased support for the Maoists and their charismatic leader, Prachanda, with Baburam Bhattarai as his assistant and Ram Bahadur Thapa as chief of his "People's Liberation Army" [117]. Having seen no political improvements in the country, the Maoists repeated their earlier demands in their charter, known as the 40-Point Demand, which they delivered to the government on 4 February 1996. They requested that the government take immediate steps to fulfil these demands, threatening to take up arms if it did not take action by 17 February 1996 (see box 4 for a summary of the 40-Point Demand)[122, 126].

BOX 4. SUMMARY OF THE 40-POINT DEMAND

- Regional discrimination against Terai by the hill-based elites should be eliminated.
- Backward areas should be awarded regional autonomy. Rural and urban areas should be treated equally.
- All racial exploitation and suppression should be stopped. Where ethnic communities are in the majority, they should be allowed to form their own autonomous governments.
- Discrimination against downtrodden and backward people should be stopped. The system of untouchables should be eliminated.
- All languages and dialects should be given equal opportunities to prosper. The right to education in one's mother tongue should be guaranteed.
- Girls should be given equal property rights as those of their brothers.
- Everyone should be given free and scientific medical care and education, and education at private schools should be completely stopped.
- Arrangements should be made to provide drinking water, good roads, and electricity in villages.

Source: [121, 122p. 53, 126].

The failure of the ruling elite to accede to these demands resulted in war breaking out in 1996. This war lasted until 2006, when the Maoists led the reinstatement of Parliament in April 2006, followed by a ceasefire agreement and, later the same year, the signing of the Comprehensive Peace Agreement (CPA) between the government of Nepal and the Maoists[127].

The CPA called for political, economic, and social change in the country, based on adherence to humanitarian law and human rights principles, including through the establishment of a national human rights commission, a truth and reconciliation commission, and a national peace and rehabilitation commission. The agreement also called for the election of a constituent assembly and requested that the UN observe and assist the electoral process. In addition, it called for the nationalisation of all property belonging to the royal family and for the decision – by simple majority in the first constitutional assembly meeting – whether to retain the monarchy as an institution [127]. Two years after the CPA, the monarchy was abolished and Nepal became a federal democratic republic. With the election of Dr. Ram Baran Yadov as the nation’s first president, Nepal ended its 247-year-old monarchy[117].

Although Nepal is still a fragile country, it has progressed in recent years, even during the conflict [117]. For example, the percentage of people living on less than US\$1.25 a day dropped from 53% in 2003–2004 to 25% in 2010–2011. Several social indicators in education, health, and gender have also improved[116].

However, despite this progress, the country still faces many challenges. Nepal ranks 145th out of 187 on the Human Development Index[128] and is one of the poorest counties in South Asia. In 2014, Nepal’s gross domestic product (GDP) was estimated at US\$19.77 billion[116]. While the country’s economy grew steadily during the height of the conflict and then yielded a budget surplus in 2013–2014, growth in 2015 was documented at 4.8%, which was a decrease from its 2014 level of 5.4%[116]. The weakened economy has led to a reliance on donors and the private sector. According to the World Bank (2016), current growth levels are too low to reduce poverty, and Nepal remains too dependent on remittances from Nepali workers overseas [116].

2.2 RIGHT TO HEALTH IN NEPAL: AN OVERVIEW

In 1978 Nepal affirmed the Alma-Ata Declaration (1978) which encompasses the right to health. Yet in the 1970s and 1980s, many of the country's national laws were explicitly discriminatory towards people with psychosocial disabilities.

During the ten-year civil war in Nepal, both sides of the conflict were criticised for violating human rights. Yet during this period of intense political instability, approaches to health programming changed from a focus on basic needs to poverty reduction strategies and the emergence of a more explicit HRBA [36]. Further, Nepal ratified many of the human rights treaties relevant for the right to health and mental health, such as the ICESCR and the CRPD [129, 130].

Mental health also received more specific attention during this time. Officially, Nepal made significant progress, shifting from a mixture of protective and explicitly discriminatory national laws and policies towards people with psychosocial disabilities to an explicit human rights focus in the 1990s, with overt protection of psychosocial disabilities (see table 1). For example, in 1996, Nepal adopted a detailed national mental health policy, which proposed the integration of mental health into the overall health system and stressed the importance of protecting the fundamental human rights of people with psychosocial disabilities [131]. However, the plan is yet to be implemented [131]. Further, in 2006 a draft Mental Health Treatment and Protection Act (2006) was presented. However, it has yet to be approved. This proposed law has been criticised for being too medical.

In recent years, there has also been an increased focus on the realisation of economic, social, and cultural rights, including the right to health. The 2006 CPA encompassed civil, political, economic, social, and cultural rights, leading to constitutional recognition of all human rights [132 Para. 7.1.3.]. Further, the Interim Constitution, which was adopted in 2007,⁹ included the right to health, stipulated the right of all Nepali citizens to free basic health services [134 Art. 16.2], and explicitly recognised the rights of people with psychosocial disabilities. That same year, the Right to Information Act (2007) came into force, which gives citizens the right to access information on government programmes and policies.

In 2010, Nepal ratified the CRPD[37] and presented the country's national health plan (2010–2015), which is in line with the Interim Constitution and international treaties the country has ratified, with the

⁹ The plan was for political parties to present Nepal's first Constitution in May 2012. Unfortunately, politicians failed to reach agreement, leading to increased political instability in the country 133. Parajuli, J.N. *Nepal enters crisis mode as constitution talks fail*. [BBC News] 2012 28 May [cited 2012 21 September]; Available from: <http://www.bbc.co.uk/news/world-asia-18234114>.

aim to provide free basic health care to everyone [135]. The plan further stresses the inclusion of psychosocial disabilities within existing and future health and social programmes, prioritises essential health care services, and highlights the need to implement the mental health policy of 1996 [135]. Key principles in the health plan include decentralised delivery, user participation, accountability, equal access, community services, prioritised essential health care services, and access to essential medicines [135]. Many of these principles are also right to health features.

In 2011, Nepal was the first country in South Asia to launch a UN-sponsored user's guide on indicators for monitoring economic, social and cultural rights[136]. Nepal further agreed to implement a number of recommendations made by other UN member states, including redoubling its efforts to promote and protect the rights of people with disabilities and ensuring the development of an independent national human rights commission [137 para 106.17,43,46; para 107.5]. Indeed, the National Human Rights Commission, Nepal's national human rights body charged with monitoring the implementation of human rights in the country, stipulated in its 2011–2014 Strategic Plan that mental health was a priority area of work[138].

TABLE 1. THE LACK OR PRESENCE OF A HUMAN RIGHTS FOCUS IN POLICIES, PLANS, AND LAWS (1960s–2014)

	1962–1981	1982–1990	1991–1996	1997–2006	2007–Present
International human rights treaties	International Convention on the Elimination of All Forms of Racial Discrimination (1971)	Convention of the Rights of the Child (CRC) (1990)	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1991)	2:nd Optional Protocol to the ICCPR aiming to the abolition of the death penalty (1998)	Convention of the Rights of Persons with Disabilities (CRPD) (2010)
			International Covenant on Civil and Political Rights (ICCPR) (1991)		Optional Protocol to the CRPD (2010)
			Optional Protocol to the ICCPR (1991)		Optional protocol to the CRC on the Sale of Children, Child Prostitution and Child Pornography (2006)
			Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) (1991)		Optional Protocol to the CRC on the Involvement of Children in Armed Conflict (2007)
			International Covenant on Economic, Social and Cultural Rights (1991)		Optional Protocol to CEDAW (2007)
National law	General Code (1963): Chapter on Court proceedings No. 11* <i>Explicitly discriminatory against people with psychosocial disabilities.</i>	The Protection and Welfare of the Disabled Persons Act (1982)**	Social Welfare Act (1992). <i>No explicit mention of psychosocial disabilities – only the term “disability” is used. Explicitly mentions assisting people with drug and other addictions.</i>	Local Self-Government Act (1999) <i>No explicit mention of psychosocial disabilities. Explicit mention of disability.</i>	Nepal Interim Constitution (2007) <i>Explicit protection of people with psychosocial disabilities.</i>
	Marriage Registration Act (1971) <i>Explicitly discriminatory against people with psychosocial disabilities.</i>		Children’s Act (1992) <i>Explicitly mentions psychosocial disabilities and establishment of homes for orphans with psychosocial disabilities.</i>		

			The Disabled Persons (Protection and Welfare) Rules (1994) <i>No explicit mention of psychosocial disabilities – only the term “disability” is used.</i>		
Policy			National Health Policy (1991) <i>No mention of psychosocial disabilities.</i>	Second Long-Term health Plan (1997-2017) <i>No explicit mention of psychosocial disabilities.</i>	Free Health Care Policy (2007) <i>No explicit mention of psychosocial disabilities.</i>
			National Mental Health Policy (1996)	The Ten Point Health Policy and Programmes (2006) <i>No explicit mention of psychosocial disabilities - highlight the Alma-Ata Declaration (1978)</i>	
Strategies and plans					Three Year Interim Plan 2007/08 – 2009/10 <i>No explicit mention of psychosocial disabilities – only the term “disability” is used.</i>
				National Human Rights Action Plan (2004) <i>No explicit mention of psychosocial disabilities.</i>	Nepal Health Sector Programme Implementation Plan II (2010-2015) <i>Explicit inclusion of people with psychosocial disabilities and emphasis on the need to implement Nepal’s 1996 mental health policy.</i>
					Health Sector Gender Equality and Social Inclusion Strategy (2007)

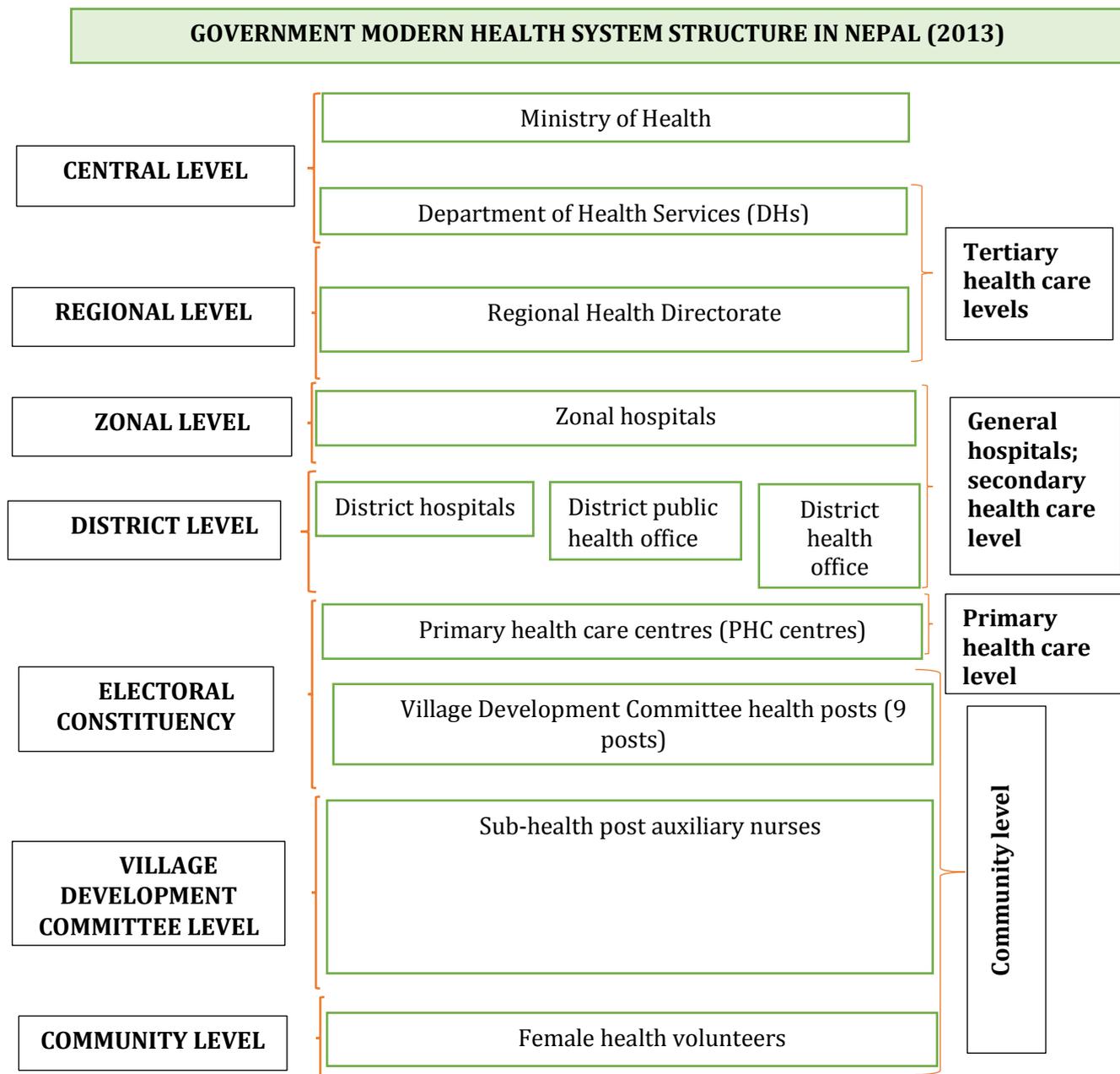
				National Health Sector Programme, Implementation Plan (2004-2009) <i>No explicit mention of disability or psychosocial disabilities.</i>	National Human Rights Commission Strategic Plan (2011-2014) <i>Explicit focus on psychosocial disabilities as a priority area.</i>
				Vulnerable Community Plan for Nepal Health Sector, Implementation Plan (2004-2009)	National Health Development Partnership (2009) <i>No explicit mention of psychosocial disabilities. Explicit mention of the need to implement the Nepal Health Sector Programme Implementation Plan II.</i>
<p>* The Supreme Court has given directives to amend this provision, but as of August 2014 it remained untouched.</p> <p>** Recognises psychosocial disabilities as a disability, but also contains some discriminatory provisions against people with psychosocial disabilities.</p> <p>*** There is a draft Mental Health Treatment and Protection Act (2006), which had yet to be approved 2014. This proposed law has been criticised for being too medical.</p>					
The colours in the table should be interpreted in the following manner:					Absent rights focus
					Implicit rights focus
					Explicit rights focus

Source: Adapted from figure 1 [139]

2.3 HEALTH SYSTEM IN NEPAL

Nepal's health system is divided into two parts: a traditional system and a "modern" system. The traditional/alternative system, in turn, includes two parts. The first is treatment based on the spiritual belief that illness arises when gods are displeased or when devils are at work. The second part consists of approaches such as Ayurveda, homeopathy, and Greek/Unani medicine, which each has its own treatment system. The modern health system consists of a mix of public and private sector health care providers, including national and international non-governmental organisations (NGOs). The modern health system (which I will refer to hereinafter as "the health system") is structured around seven levels, as presented in figure 5.

FIGURE 5. NEPALI HEALTH SYSTEM



Source: Adapted from [140].

At the community level, female health volunteers are often the first point of contact, and they are also there to ensure community participation. Sub-health posts monitor the female health volunteers and provide essential health packages. They are also the first point of institutional contact for basic health services. Health posts, which are also located at the community level, provide the same services as the

sub-health posts, with the addition of birthing centres. Sub-health posts and health posts are not staffed with a medical doctor.

After the community level are primary health care centres (PHC centres). PHC centres are available in each electoral level and are the first referral point in the health system. In addition to basic health services, they offer family planning, maternal and child health packages, and basic laboratory exams. PHC centres are also staffed with a medical doctor. One of the key aims of the National Health Policy of 1991 was to upgrade the health standards of the country's rural population by extending basic primary health services[141]. PHC centres are delivered through health posts and health centres, which in turn are managed by district public health offices. The district hospital is the highest level of service provision within a district, and the district public health offices/district health offices are responsible for coordinating the health activities in a specific district [120].

Nepal's health system was affected by the armed conflict[120]. Community health posts were destroyed, health workers lost their lives, and many fled. In addition, the provision of essential commodities, drugs, and vaccines was not sustainable. Although the conflict interrupted or weakened the provision of health services throughout the country, rural areas were particularly affected[142]. However, with the assistance of donors, the government of Nepal has made great efforts to improve the health sector. For example, the government has developed specific programmes and policies on safe motherhood and other health areas to effectively guide programme interventions. Nepal received a "Child Survival Award" from the GAVI Alliance (formerly the Global Alliance for Vaccines and Immunization) for its progress in meeting MDG 4, and an award from the UN for its progress in meeting MDG 5 on maternal health. Nonetheless, neonatal mortality has remained stagnant at 24/1,000 live births since 2006[143].

Other efforts to improve service provision, made by the Ministry of Health, include the introduction in 2007 of free essential health care services throughout the district health system. Initially, these services were offered only to poor and vulnerable citizens visiting PHC centres and district hospitals (which have a capacity of up to 25 beds). However, in January 2008, the Ministry of Health expanded free essential health care services to all citizens, regardless of their economic situation, through health posts and sub-health posts throughout the country[144]. Under this system, there are no fees for patient registration; for 40 essential medicines; or for outpatient, emergency, and inpatient services. In January 2009, free essential health services were expanded to PHC centres and district hospitals [145]. At the same time, the country's policy ensuring free institutional deliveries in government hospitals – a policy that goes by the name of Aama, or "mother" – was launched[146]. With the introduction of free health care, the Ministry of Health documented a 35% increase in 2007–2008 in new outpatients, including poor and

disadvantaged groups[144]. Similar findings have been documented by other studies, which also conclude that the removal of user fees appears to have had an especially positive impact for poor and marginalised people[145, 146]. At the same time, however, this rise in the use of health care services has led to concerns in relation to systemic issues, particularly understaffing and dwindling general revenues.

With respect to health workers, there are an estimated 0.042 doctors per 1,000 inhabitants and 0.25 nurses per 1,000 inhabitants in Nepal[144]. Chen et al. (2004) have estimated that health worker density must exceed 2.5 workers per 1,000 inhabitants in order to achieve 80% measles vaccine coverage, and enhance skilled birth attendance at birth, in order to reduce maternal, infant and child mortality[147]. According to the Ministry of Health, the deployment and retention of human resources is a major problem in the health sector.

In 2010, the Ministry of Health estimated that the health workforce had increased by only 3.4%, compared to the population's growth of 45% between 1991 and 2011[144]. It is estimated that only two-thirds of the positions for doctors and nurses have been filled. Another recognised problem is staff attendance and low morale, with many public health workers moving to the private sector. An additional issue of concern is the need to increase the number of health workers in rural areas and to increase the representation of Dalits and other marginalised groups in the health workforce [135]. Finally, other challenges include decreased general revenues for health facilities, caused by the loss of revenues from user fees, which may explain some health facilities' continued implementation of these fees[146], as well as emerging diseases, such as non-communicable diseases [144].

Despite restructured laws and the development of health plans and policies, there are significant challenges in the implementation of these plans and policies and the delivery of health services. Nepal's health system faces difficulties in implementing universal health care, with large discrepancies between rural and urban areas and among ethnicities and castes [135]. There are a number of contextual factors explaining the lack of universal coverage, such as political and economic instability; long-term underinvestment in public health infrastructure; socioeconomic, ethnic, and cultural inequalities; and inaccessible terrain (road density in Nepal is among the lowest in South Asia, and over one-third of residents in the hills are estimated to live more than four hours away from an all-weather road) [148] (see map 2). As a result, the most disadvantaged groups require an estimated four to six times more time to travel to a health facility than the most well off [149]. There are also fundamental structural problems in the health sector, such as health worker shortages and limited financial allocations by the national government, with just 5.9% of the GDP allocated to health in 2004/2005. However, according to the Ministry of Health, there has been a steady increase in health allocations each year, and 8% of the total

GDP was allocated to health in 2010[150].¹⁰ But according to the WHO, in 2014 the health allocation was just 5.80% of the total GDP[151]. The same year, neighbouring countries such as China, Bangladesh, India, and Pakistan, allocated 5.6%, 3.7%, 4.0%, and 2.8%, respectively, of their total GDP [152-155]. Nepal's weak state-funded health infrastructure has led to an increased reliance on the private sector. It was estimated that the private share of total health expenditure in Nepal 2014 was nearly 60% of which about 80% came from out-of-pocket payments[156]. Further, the number of private hospitals increased from 69 in 1995 to 147 in 2008, whereas the number of public hospitals increased from 78 to 96 during the same period[145]. Similarly, it is estimated that the private sector provides between 40% and 50% of the total hospital beds in the country[140, 145]. The private sector includes a diverse range of agencies and organisations, including for-profit organisations, non-profit organisations (such as voluntary organisations and missionaries), and traditional faith healers. The private sector is currently subject to scant regulations and is available only to those who can afford its services[140]. Karkee and Kadariya (2013) highlight that information on private facilities and the services they offer is scarce[145].

2.4 MENTAL HEALTH IN NEPAL

Mental health services in Nepal began only in the early 1960s[157]. Today, mental health is a growing concern in the country, where the prevalence of priority mental disorders (schizophrenia, bipolar disorder, major depressive disorders, epilepsy, and alcohol dependence) is estimated between 8% and 10% [158].

This burden is attributable to a number of factors. First, armed conflict undoubtedly has profound effects on those who experience it directly. Second, daily stressors such as poverty, social marginalisation, and changes in family structure (e.g., husbands leaving to work in neighbouring countries) are common in Nepal and are highly correlated with psychosocial disabilities [84, 159]. Third, gender-based and domestic violence are ubiquitous and have resulted in high rates of suicide among women of reproductive age, which is now the leading cause of death among women in this age group [135]. Fourth, Nepal has limited human and physical resources for mental health. In 2011, Nepal had no child psychiatrists, counselling psychologists, or school psychologists, and it had only 0.18 psychiatrists, 0.25 nurses, and 0.04 psychologists per 100,000 inhabitants [160]. In 2015, it had 0.22 psychiatrists and 0.06 psychologists per 100,000 inhabitants[120]. Mental health facilities are also limited, with just one mental

¹⁰ Health allocations vary around the globe – from, for example, Singapore, with around 3% of its GDP, to the United States, with 17% of its GDP. However, high-income countries often allocate between 7% and 10% of their GDP. WHO Department of Health Statistics and Informatics (May 13, 2011). "World Health Statistics 2011". Geneva: WHO. <http://www.who.int/whosis/whostat/2011/en/index.html>. Retrieved 2012-11-7.

health hospital, three day-treatment facilities, and 25 mental health outpatient facilities in the country [160].

Nepal has integrated international norms and standards into its national laws and health policies, which is vital to the realisation of the right to health and an HRBA to mental health (see figure 6). Yet, the country's 1996 mental health policy has not been revised since its adoption, and the degree to which it has been operationalised is limited, which has contributed to the limited functioning of the mental health system[131, 161].

Moreover, Nepal's budget for mental health is less than 1% of the total health budget [161, 162], and these funds are spent mainly on mental health hospital services[120]. According to a study by the Lancet Global Mental Health Group, Nepal would require a tenfold increase in its total health expenditure (from new and existing allocations) to about US\$2.00 per person per year by 2015 – in order to increase the coverage of schizophrenia and bipolar affective disorder to 80% in Nepal [41]. International support focusing on mental health is also scarce, with only a few pilot projects around the country. Of the estimated 27,400 national and international NGOs in Nepal, 19 work in mental health[163].

2.5 PRIME

The field work for this thesis was situated within Nepal's Programme for Improving Mental Health Care, or PRIME. I chose Nepal and PRIME because both the Nepali government and PRIME had expressed a strong commitment to realising the right to health. In the case of PRIME, the program was keen to explore how the right to health and an HRBA to health could be operationalised through the program's work. It was thus supportive of hosting my research.

PRIME is a six-year programme which aims to adapt, implement, scale up, and evaluate the integrated package of mental health interventions designed by the WHO's mhGAP [21] for the priority disorders of alcohol abuse, depression (including maternal depression), psychosis (notably schizophrenia), and epilepsy in maternal and PHC systems [164, 165]. PRIME is linked to a sister project – Emerging Mental Health Systems in Low- and Middle-Income Countries (EMERALD) project – which is a five-year project that also builds on the WHO's mhGAP. EMERALD focuses on the overall health system, aiming to identify key barriers to, and solutions for, the scaled-up delivery of mental health services in low- and middle-income countries. One identified fundamental need is to enhance local capacities and skills to plan, implement, evaluate, and sustain health system improvement.

PRIME and EMERALD are consortiums of research institutions (e.g. the London School of Hygiene and Tropical Medicine (LSHTM), and the Institute of Psychiatry, Psychology & Neuroscience at King's College London), the WHO and ministries of health in a handful of pilot countries: Nepal, South Africa, India, Ethiopia, and Uganda (EMERALD has also included Nigeria).

I selected PRIME and EMERALD since my research aims fell squarely within the intersection between the two projects, and the expected results would be valuable to both. However, to tighten my research, I decided to focus mainly on PRIME's PHC activities and its mental health plan. This decision was a pragmatic one. My research had to be focused – and in the right to health, PHC and health plans are core obligations. In addition, from a health systems and mental health perspective, PHC and health plans are key priority areas.

PRIME has three phases:

- *Phase I:* Formative research for the development of district Mental Health Care Plans;
- *Phase II:* Mental Health Care Plans are implemented in districts and evaluated;
- *Phase III:* Mental Health Care Plans are adapted and improved based on evaluation findings, then scaled up to other districts [166].

PRIME's and EMERALD's programmes in Nepal are both located in the Chitwan District, which is one of the 75 districts in the country. Chitwan is located in the zone of Narayani, 132 kilometres from the capital city of Kathmandu in southern Nepal, in the Terai valley, which borders India (see map 3). PRIME selected Chitwan for its programming because (i) the population reflects the multi-ethnicity of Nepal; (ii) it has an established referral system between primary, secondary, and tertiary health services; (iii) health workers at the PHC centres have basic education; and (iv) Chitwan is not far from Kathmandu.

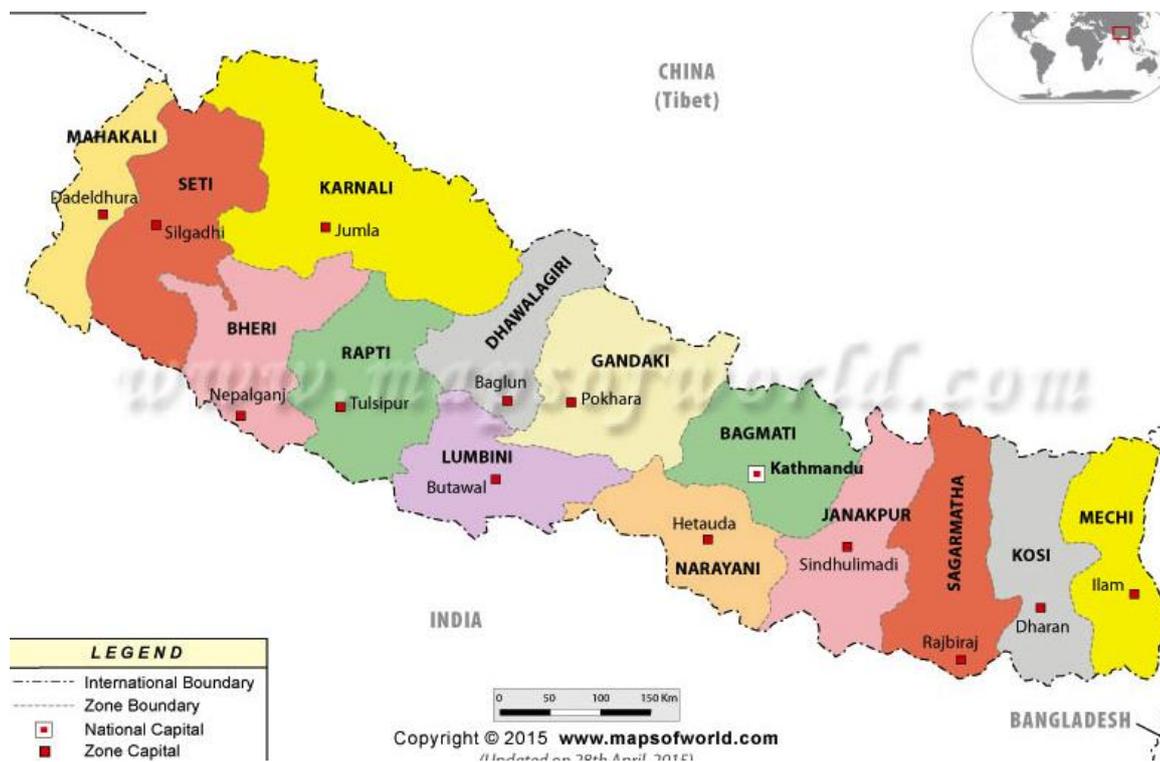
The implementing partner of PRIME in Nepal is the NGO, Transcultural Psychosocial Organization Nepal (TPO Nepal), which is one of Nepal's leading psychosocial organizations. It was established in 2005 with the aim of promoting psychosocial well-being and mental health of children and families in conflict affected and other vulnerable communities. TPO Nepal is affiliated with HealthNet TPO, an Amsterdam based international organization that works in conflict and disaster settings, with the aim of re-establishing and improving public health and mental health care systems.

At the time of this research PRIME is in phase I, and only the staff in two PHCs in Chitwan, Divyanagar and Meghauli, have received mental health training and began to treat patients.

In total there are 11 health workers in the two PHCs, but there are also staff at that work at the district level, in the referral chain, who are part of the PRIME programme that will be include in the research. In

addition, new staff who were receiving training from PRIME were included in the study. However, at the time of the study, health workers at the community level, e.g. female health volunteers, were not yet included in PRIME and so were not included in this research. For more details of the sampling, number of participants, location and time/frame see Chapter 3, section 3.2 and table 2.

MAP 3. NEPAL'S ZONES, INCLUDING NARAYANI, WHERE CHITWAN IS LOCATED



This chapter has provided background information on the case study of Nepal and PRIME. The next chapter describes the research methods used for this thesis.

CHAPTER 3: METHODS

This thesis uses a narrative literature review and qualitative methods in Nepal consisting of in-depth, semi-structured interviews; focus groups; observations; and context meetings.

This chapter aims to demonstrate the intellectual logic of the study, from concept to operation. It outlines the epistemological influences; methods used; translation, transcription, and analysis of data; synthesis of research; and ethical concerns of the research. Before describing the specific methods employed, I briefly touch on the epistemological assumptions underpinning this study and, relatedly, the forms of reflexivity undertaken. The epistemological assumptions and issues are particularly important in public health, as they help shape the kinds of data collection and analytical methods that are employed. These decisions can be traced throughout the study design.

The only way to capture health workers' perspectives and perceptions of the right to health and of an HRBA to mental health is by applying qualitative research methods, which begin with epistemology.

3.1 EPISTEMOLOGICAL APPROACH

Epistemology is the theory of knowledge [167 p.303]. It structures ideas around how we know the world, what the basis for our knowledge is [168], and the validity of that knowledge [167]. Furthermore, one's epistemological position also influences the methods that one chooses and the ways in which one interprets and validates data. The specific intellectual pursuit produces practical knowledge, which is valuable for understanding the perception of epistemology. It is therefore important to be explicit and transparent about what we can learn through this study. In this research, I was interested in the space between written human rights law – i.e., right to health law – and the possible implementation of the right to health by mental health workers. However, it is very difficult to conform to just one philosophical position, as every approach has its limits.

This research adopted an analytical approach which Hammersley refers to as “subtle realism” [169, 170]. Subtle realism is a middle way between the various realist and interpretive epistemological approaches. Hammersley agrees with the realists who assert that there is a reality “out there” which is independent of our knowledge of it. But he is also in consonance with an interpretive phenomenological position which proclaims that we can know this reality only from our own perspective [Hammersley (1995) cited in 169].

My research conceptualises the right to health as an inherent actuality. But rather than referring to it as “reality,” I see human rights law as the “reference” or “benchmark.” Freeman (2003), on the other hand, refers to human rights law as the conclusion of certain arguments and argues that human rights theories are arguments[171]. Thus, my position taken in this study is that all humans have equal rights and that these rights derive from the inherent dignity of the human person. However, human rights are more than just moral and political rights – they are also legal, implying that they cannot be taken away by ordinary political processes [172]. But how the law becomes available and accessible – i.e., operationalised in health – and how health workers access it is more problematic, and this is the subject of this research.

Although I take a subtle realist position, I am fully aware that this does not fit neatly within the human rights paradigm. As Donnelly (2013) explains, human rights have no single philosophical or religious foundation. Rather, human rights have multiple foundations [173]. However, in this research, I will use the law – specifically the right to health – as my reference. I recognise that all human rights are interrelated and interdependent (to realise one human right, you cannot exclude another)[23, 24], but for practical reasons, my focus is on one human right: the right to health, and specifically to mental health. Furthermore, I am not interested in how human rights law and related phenomena came about, which is something that a more constructivist position would seek to explore[167]. Rather, I affirm and take as my starting point that there is a human rights law. This theoretical stance is justified, as most countries have acknowledged the existence of human rights through their signatures and ratifications of various treaties. It is also supported by international consensus on human rights, which is based on overlapping moral and religious theories [173]. In this study, although I take my starting point in human rights law, i.e. the HRBA to health features are part of the human rights law and I have revised Nepal’s legal commitments. Yet my main interest is in how affirming the right to health might be translated into practice by the health sector, and what such a move might mean. As a result, this research focuses specifically on the position of mental health workers in Nepal, with an in-depth focus on the district of Chitwan.

I appreciate that for the right to health to be realised – i.e., for legal obligations to be translated into practice and applied in the health sector – certain conditions must be in place. In accordance with a subtle realist approach and its interpretivist strands, this study rejects the positivist notion that there is a potential “correct” explanation, one which is value free and thus independent of any subjective and political standpoints[169]. On the contrary, this study claims that knowledge is always mediated by pre-existing ideas and values, whether explicitly captured by the researcher or merely implied[170].

This study sought to comprehend health workers' perspectives on the right to health – including overarching human rights and, more specifically, the rights of persons with psychosocial disabilities – as well as their perceptions of the application of an HRBA to mental health planning and service provision. Thus, in accordance with subtle realism, this study tried to understand reality rather than the “truth”[174]. I employed a variety of research methods, as it is recognised that different methods foster different views and perspectives among participants[175]. I also reviewed documents and laws in order to understand relevant national and international human rights legal provisions and policies, strategies and plans. The documentary and legal review informed my interviews, as well as the legal possibility of implementing an HRBA. The status of ratifications by states forms the backbone of human rights law. States' commitments must then be reflected in national law, such as in constitutions and health policies and programmes, including mental health plans. Individuals, including health workers at the PHC centre level, may be influenced by the contexts in which they live and work, at both the macro and micro levels, which has an effect on their understandings and perceptions of human rights and the human rights of persons with psychosocial disabilities. As a result, the opportunities and obstacles in implementing an HRBA to health will be affected by the context.

By using different data collection methods (a narrative literature review and then qualitative methods that consisted of semi-structured interviews, focus groups, observations, and context meetings), I also tried to capture the context – for example, history, politics, and legal, cultural, social, and economic forces – which might have shaped participants' perspectives, perceptions, and experiences around human rights and mental health, and how this might have direct relevance to practice.

In order to increase the validity of my qualitative research – something which is strongly encouraged by a subtle realist's analytical approach – I applied different processes [169]. In claiming that we can know reality only from our own perspective, this study appreciates that it is not possible to assert validity as certainty. Thus, in accordance with Hammersley, this research redefines validity with the notion of confidence[169]. To be able to judge the confidence of a particular qualitative research project, the analytical approach of subtle realism encourages different procedures aimed at increasing validity. These different procedures each have value but together can give us greater confidence. They include, for example, reflexivity, respondent validation, clear exposition of methods of data collection and analysis, attention to deviant cases, and triangulation[169, 174]. The section below looks at reflexivity in more detail, while in the subsequent sections and following chapters elucidate the other procedures.

3.1.1 Reflexivity

Reflexivity is a way of trying to *understand* the world from the view of the participants, rather than *explaining* their views per se [167]. It implies a need to critically reflect on the research itself – both the broader political and social fields and the researcher’s own assumptions – and how these might have helped shape the findings[167, 174]. It also requires unpacking how the role of the researcher and translator might have influenced the manner in which data was collected and analysed. Ultimately, reflexivity, including openness and honesty, is an important part of ensuring the certainty and reliability of the research[176].

Thus, researchers’ values and perspectives influence their work, meaning that their research cannot be value free. Subtle realism explicitly acknowledges the influence of the researcher in this regard. It claims that the researcher and research community are no different from the rest of the society in terms of the division of status and power[170]. Therefore, acknowledging and unpacking these possible influences is important. The researcher should explain his or her underlying assumptions and be transparent about them[177]. The aim is to make the researcher (and interpreter) visible in the research [169, 178]. The researcher needs to be explicit about the epistemological position of the research, how the data was analysed, and how conclusions were reached. Although this is the ideal of reflexivity, it may not always be achieved. Some authors warn that reflexivity can be understood as self-confession, where the researcher provides personal information that may not inform the research (such as his or her sex, age, and race) while failing to reflect on how these attributes may have influenced the data collection or findings[179, 180]. Therefore, in this study, by being transparent, I tried to balance the visibility of the researcher (i.e., myself) with the aim of reflecting on how my background and beliefs may have influenced this research. Further, each phase of the study was described and I have been explicit in the process of this research by outlining the methods, data collection, sampling, and analysis of the research throughout the research. I also tried to pay attention to the context in which this research was carried out and which might have shaped people’s understandings of the world [177]. Further reflection on the role of the researcher in the research design, data collection, and data analysis, as well as the different approaches used to increase confidence in this study, are provided in subsequent chapters. I hope I have managed to be transparent throughout this research, thus helping the reader determine the plausibility, relevance, and importance of this topic.

3.2 METHODS, DATA COLLECTION, AND SAMPLING

This research is an exploratory study situated within the PRIME initiative in Nepal. PRIME’s sister project, EMERALD, was also included in this research. However, my main focus is on PRIME. More details about PRIME, EMERALD, and Nepal (including the exact location of the research) can be found in chapter 2.

This qualitative research used a case study, as case studies are well suited to exploratory, descriptive, and explanatory research, and are useful in providing a response to *How?* and *Why?* [181-183]. They are also useful for understanding a real-life phenomenon in depth. Traditionally, case study research has been criticised for lacking rigour, validity, and objectivity [181, 184] and for providing little basis for generalisation [183]. However, a number of authors have described how case studies can contribute to the collective development of knowledge. For example, a case study can be used to test a theory for generalisation [183] or to test what is referred to as “falsification” – in other words, whether a theory fits with a particular proposition, which is part of critical reflexivity in social science [184]. For this research project, I chose to employ a case study because there was no other way to look at the tension between global commitments and national design. The only way to document the local implementation of the right to health among mental health workers, as well as their experiences, perspectives, and perceptions regarding the right to health and its possible operationalisation, was to use qualitative research methods, and thus a case study, at the local level.

A case study should not be confused with ethnographic qualitative research. Unlike the latter, a case study relies on the use of multiple data sources, can be both quantitative and qualitative, and can be conducted over a relatively short period of time [181, 183, 185, 186].

Table 2 presents an overview of the objectives of this thesis, the methods used to realise them, sample, location and time frame. As seen in the table, the methods overlap and inform one another, especially regarding objectives 2 and 3.

TABLE 2. OVERVIEW OF OBJECTIVES, RESEARCH METHODS, SAMPLE SIZES, LOCATION AND TIME FRAME¹¹

Aim: To explore the perceptions and perspectives of mental health workers in Nepal on the use of a human rights-based approach to mental health			
Objectives	Methods	Sample	Location/Time frame
1. To examine existing evidence on the use of a human rights-based approach to advance ¹² health	<i>Literature review</i>	High-, middle-, and low-income settings globally. See details under objective 1 below.	Gobal
2. To explore perspectives on the right to health among mental health workers in Nepal <i>AND</i> 3. To explore health workers' perceptions of the application of an HRBA to mental health in planning and service provision	<i>In-depth, semi-structured interviews</i>	<i>Pilot (non-PRIME health worker)</i> N=1 (1 man)	Chitwan June 2013
		<i>Present stakeholders of PRIME</i> Mental health workers and policy makers N=7 (5 men & 2 women)	Chitwan June–August 2013
		<i>Present stakeholders of PRIME</i> Mental health policy makers N=4 (men)	Kathmandu July–August 2013
		<i>Future service providers of PRIME</i> Service providers N=4 (3 men & 1 woman)	Chitwan July–August 2013
	<i>Focus groups</i>	<i>Pilot</i> N=3 (3 men)	District-level hospital in Chitwan
		<i>Prescribers</i> N=4 (3 men & 1 woman)	Divyanagar and Meghauri PHC centres (located in Chitwan) June–August 2013

¹¹ “The data collection was completed before the 2015 earthquake”.

¹² “Advance” refers to aspects that support the protection and improvement of health.

		<i>Non-prescribers</i> N=6 (2 men & 4 women)	Divyanagar and Meghauri PHC centres (located in Chitwan) June–August 2013
	Context meetings	<i>Mental health stakeholders</i> National and international NGOs, mental health service providers, donors, and policy makers N=21 (14 men & 5 women)	Kathmandu and Chitwan June–August 2013
		<i>Human rights stakeholders</i> (national and international NGOs, donors, policy makers) N=8 (5 men & 3 women)	Kathmandu June–August 2013
3. To explore the health workers' perceptions of the application of an HRBA to mental health in planning and service provision	Focus groups	<i>Policy makers and researchers of EMERALD</i> N=6 (5 men & 1 woman)	Kathmandu August 2013
	Observations	<i>PRIME's PHC centre 1</i> Approx. 30 hrs	Divayangar (located in Chitwan) June–August 2013
		<i>PRIME PHC centre 2</i> Approx. 20 hrs	Meghauri (located in Chitwan) June–August 2013
4. To develop a conceptual framework regarding the use of an HRBA to mental health	Analysis and synthesis of a conceptual framework for an HRBA to mental health		London 2016

Details on the realisation of each objective are provided below.

Objective 1: To examine existing evidence on the use of an HRBA to advance health

The specific aims of this overall objective were as follows:

1. Describe the contexts, research methods, and health outcomes used in studies on HRBAs.
2. Describe the range of HRBAs used to advance health.
3. Explore evidence on how an HRBA may advance health.
4. Examine the strength and quality of the evidence on the use of an HRBA for advancing health.

I employed a narrative literature review to address these aims. This involved a review of published literature and grey literature, review of additional sources referred by experts, and snowballing from reference lists. I applied systematic review techniques in that I used traditional methods of qualitative systematic review for searching, summarising, and analysing. However, I adjusted the inclusion and exclusion criteria to include studies with secondary data, as a handful of such studies were of great relevance for my research. Robson (2011) emphasises the importance of relevance over comprehensiveness if material is found to aid the research, design, and questions. Relevant works are defined as those with “important implications for the design, conduct, or interpretation of the study, not simply those that deal with the topic, or in the defined field or substantive area, of the research”[187 p.51-52]. The various steps of this methodology are explained below.

i) Eligibility criteria

The initial intention of the systematic review was to include only those studies whose data could demonstrate or indicate an explicit health impact and evidence of the use of an HRBA on mental health. This was carried out year 2011 and 2012. However, preliminary research suggested that this would yield virtually no studies. I therefore decided to use more generous inclusion criteria to include all studies that had carried out primary research, outlined an HRBA to health or a rights framework regarding health, and presented at least some results of the use of this approach, even if the study did not encompass empirical evidence on how it advanced health or mental health.

The populations of interest were all people in high-, middle-, and low-income settings globally. The intervention of interest was the application of an HRBA to health. The outcomes of interest were any health-related outcomes, including processes and outputs. All primary research studies of any study design were included. The end search date was June 2013, when the field work

began. The outcomes of interest were individual and population-level health outcomes, as well as health services, programmes, and policies, including processes and outputs. Further details are provided in table 3.

TABLE 3. INCLUSION AND EXCLUSION CRITERIA FOR THE ADJUSTED SYSTEMATIC LITERATURE REVIEW

	Included	Excluded
Population	High-, middle-, and low-income settings globally	
Intervention	Applied right to health based approach or HRBA or rights-based approach to health or rights based approach	Studies that made no specific reference to “human rights-based approach/framework,” “rights-based approach/framework,” or “right to health-based approach/framework” in their title or abstract
Outcome	The outcomes of interest were individual and population-level health outcomes, as well as health systems, programmes, and policies (including processes and outputs)	
Publication type	Primary research studies, including evaluations and secondary research studies Published literature in the health and legal fields Grey literature in the health and legal fields Any date of publication Any language	Recommendations, judicial decisions and analyses, human rights declarations and analyses, treaty analyses, conference proceedings, book reviews, press releases, editorials, commentaries, and advocacy reports
Study design	All quantitative and qualitative designs	

ii) Information sources and search strategy

Bibliographic data sources included published literature, grey literature, snowballing techniques, and sources referred by experts.

The databases used for published literature were MEDLINE, Embase, PsycINFO, Social Policy and Practice, Global Health, the International Bibliography of the Social Sciences and Web of Science databases. See table 4 for the search term and further details.

TABLE 4. SEARCH TERMS FOR THE BIBLIOGRAPHIC DATABASES

Database	Search terms	Limitations
MEDLINE, Embase, PsycINFO, Social Policy and Practice, and Global Health	(right* adj2 health*) .ab,ti; rights based approach .ab,ti; human rights approach .ab,ti	None
International Bibliography of the Social Sciences	“rights based approach,” “human rights based approach,” “rights based approach,” “human rights based approach”	Only peer reviewed literature. Excluded literature on migrants, food aid, sex offenders, development, education, and democracy.
Web of Science	“rights based approach,” “human rights based approach,” “rights based approach,” “human rights based approach”	Search terms applied only to titles, not full text of article. Only English-language literature. Excluded literature on climate change, education, terrorism, counter terrorism, court cases, migrants, food, development, fishery, global justice, moral responsibility, multinational cooperation, forestry nature reserves, whaling, special management, poverty, contract law, and programming.

The data sources used for the grey literature included the databases PsycEXTRA, Google, and Eldis- Global Health and the websites of Health and Fragile States Network, Eldis, the Centre for Global Mental Health, Movement for Global Mental Health, JSTOR, International Network for Economic, Social and Cultural Rights, Human Rights Watch, Amnesty International, People’s Health Movement, and International Federation of Health and Human Rights Organisations.

I also used a snowballing approach, which involved reviewing the reference lists of the final selected studies to identify additional studies for review; this yielded no additional studies. Finally, in order to ensure as comprehensive a review as possible, I contacted twenty-seven experts working on human rights and health with the aim of identifying additional studies not yielded through the bibliographic databases, web searches, and snowballing. These experts were people familiar with or working in the field of human rights and health. Specifically, I sent an email to each expert requesting the names of reports or studies which provide examples of and evidence-based recommendations on best practices involving an HRBA to health programmes, projects, policies, or research. Seventeen experts responded with suggestions. Details on these expert respondents are provided in box 5.

BOX 5. RESPONDENTS FOR THE EXPERT REVIEW

- ✓ **Judith Bueno de Mesquita**
Lecturer, Law School, University of Essex; member of the Human Rights Centre, University of Essex, United Kingdom; former Senior Research Officer to Paul Hunt, UN Special Rapporteur on the Right to Health
- ✓ **Natalie Drew**
Technical Officer, Mental Health Policy and Service Development, Department of Mental Health and Substance Abuse, World Health Organization, Geneva
- ✓ **Laura Fergeuson**
Assistant Professor, Keck School of Medicine Program on Global Health and Human Rights, Institute for Global Health, University of Southern California, USA
- ✓ **Lisa Foreman**
Lupina Assistant Professor, Dalla Lana School of Public Health; Director, Comparative Program on Health and Society, Munk School of Global Affairs, University of Toronto
- ✓ **Sofia Gruskin**
Professor of Preventive Medicine, Keck School of Medicine; Professor of Law and Preventive Medicine, Gould School of Law; Director, Program on Global Health and Human Rights, Institute for Global Health, University of Southern California, USA
- ✓ **Rachel Hammonds**
Post-Doctoral Researcher, University of Antwerp
- ✓ **Hans Hogerzeil**
Professor, Robert Gordon University, Aberdeen; former Director, Department of Essential Medicine and Pharmaceutical Policies (2004–2011), World Health Organization, Geneva
- ✓ **Paul Hunt**
Former UN Special Rapporteur on the Right to Health (2002–2008)
- ✓ **Leslie London**
Professor, University of Cape Town, South Africa
- ✓ **Gorik Ooms**
Professor of Global Health Law & Governance at the London School of Hygiene & Tropical Medicine, Adjunct Professor at the Law Faculty of Georgetown University, and Visiting Professor at the Faculty of Medicine and Health Sciences of Ghent University.
- ✓ **Helen Potts**
Principal Adviser, Disability Rights Team, Australian Human Rights Commission, Australia
- ✓ **Maria Stuttford**
Senior Research Fellow, Division of Health Sciences, Warwick Medical School, United Kingdom; Honorary Senior Lecturer, University of Cape Town, South Africa; Honorary Lecturer, University of St Andrews, United Kingdom
- ✓ **Susan Timberlake**
Former Chief, Human Rights and Law Division, UNAIDS Secretariat, Geneva
- ✓ **Javier Vasquez**
Regional Human Rights Law Advisor, Office of Gender, Diversity and Human Rights, Pan American Health Organization/World Health Organization
- ✓ **Alicia Ely Yamin**
Visiting Professor of Law and Director, Health and Human Rights O'Neill Institute for National and Global Health Law, Georgetown University Law Centre

iii) *Study screening and selection*

Six stages were used for the study screening and selection: stage 1 – bibliographic database search, along with grey literature; stage 2 – removal of duplicates; stage 3 – review of titles and

abstract; stage 4 – review of full text; stage 5 – snowballing of reference lists of the final selected studies, and consultations with experts; stage 6 – full review and data extraction of the final selected studies.

iv) Data extraction and analysis

Information from included studies was extracted using a standardised form with the following domains: geographic location, year of the study, sample, human rights-based approach (e.g., HRBA vs. right to health-based approach vs. rights-based approach), human rights features included in the approach, health outcomes and outputs, research methods, and methodological quality. The data screening and extraction were conducted by me alone.

For the analysis of the final selected studies, I used an adjusted version of what is referred to by Marston and King (2006) as comparative thematic analysis [188]. This involved reviewing and identifying codes that represent themes and then identifying overall themes. I structured the analysis by following themes based on an HRBA to health (see chapter 1, box 3) and this thesis's conceptual framework (see chapter 1, figure 3), with additional sub-themes then identified within this broad structure.

To review the quality of the final selected studies, I used the RATS quality assessment guidelines, as all these studies were qualitative studies [189]. RATS assesses the *relevance* of the study question; the *appropriateness* of the qualitative methods; the study's *transparency* procedures (sampling, recruitment, data collection, role of researcher, and ethics); and the *soundness* of its interpretive approach (analysis, discussion, and presentation) [189]. Although aware of concerns about trying to apply standardised quality criteria to qualitative research [188, 190, 191], I felt that the use of RATS provided an indication of the overall levels of quality in the research being used with regard to HRBAs to health and that such an assessment would provide a useful contribution to the field of human rights and health. I reported the findings based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting guidelines [192].

Objective 2: To explore perspectives on the right to health among mental health workers in Nepal

To realise objective 2, I used three qualitative methods: (i) semi-structured interviews; (ii) focus groups; and (iii) context meetings. The participants were all part of PRIME, with the exception of the participants in the context meetings. Table 2 summarises the methods and sample sizes.

Although described separately, the methods used to realise objectives 2 and 3 overlapped, with the exception of observations, which were included to realise objective 3 (see section 2.2.3).

i) In-depth, semi-structured interviews with PRIME's stakeholders

I chose this particular method because it is a valuable tool for capturing the context and for tapping into potentially sensitive issues which the respondents might have felt uncomfortable mentioning in a group setting [167].

Sampling, target group, and information required

I used purposive sampling, with help from my PRIME partners in terms of identifying respondents. The respondents (N=16) (see table 2) had all been part of developing PRIME and its plan in Chitwan. Of the participants, 13 were men and 3 were women. This gender imbalance reflected the gender imbalance in the overall workforce [144]. Two men did not want to participate. One declined because he was no longer working with mental health or with PRIME, and the other declined because he had been reallocated. However, the latter of the two agreed to be interviewed on the condition that he would be paid. But given that no one else was reimbursed for their participation in the interviews, I decided not to include him.

The respondents were a mix of psychologists, psychiatrists, medical doctors, midwives, managers, coordinators, researchers, and policy makers – all of whom were part of the PRIME project and had been involved in developing PRIME's Mental Health Care Programme. They were representatives from the Ministry of Health, the district hospital in Chitwan, the mother and child health clinic in Chitwan, and local and national NGOs.

I wanted to understand how the respondents understood human rights, the right to health, and the rights of persons with psychosocial disabilities, specifically the rights of persons with depression, alcohol use disorder, and psychosis. I also wanted to explore whether and how they thought it would be possible to implement a plan that incorporated an HRBA, and what would be required to do so. I constructed a detailed topic guide which brought together the key areas of investigation, rationale, themes, questions, and an explanatory note. Next to each broad theme was a list of questions. Table 5 presents examples of the themes and questions. The complete topic guide can be found in appendix 2.

TABLE 5. EXAMPLES OF THEMES AND QUESTIONS IN THE SEMI-STRUCTURED INTERVIEWS

<i>Broad themes</i>	<i>Examples of questions asked</i>
<i>General understand of mental health</i>	Can you please tell me a bit about your work?
<i>Human rights</i>	How do you think human rights are understood in Nepal? How are they talked about in Nepal?
	What do you think the right to health means in Nepal? How would you explain the right to health in Nepal?
	How do you think other people understand the rights of persons with psychosocial disabilities?
	What is your experience with human rights in your work?
<i>PRIME's mental health care plan</i>	Can you tell me about the process of developing PRIME's mental health care plan?
<i>Integration of an HRBA into PRIME's mental health care plan</i>	Do you think it is possible to integrate human rights into a mental health care plan and into your work?
	If yes, why is it important? What could be the challenges? If not, why? Not to think it is important to integrate the right to health is equally important as a "yes" answer. I want to learn from you.

Implementation

The topic guide was piloted in Nepal. It was not possible to pilot the topic guide on any of the PRIME staff, as the sample was so small. As a result, the NGO Transcultural Psychosocial Organisation Nepal (TPO Nepal) assisted with the selection of a health worker at the public hospital in Chitwan who was familiar with PRIME but did not work directly with mental health. The topic guide did not directly change from the piloting, but it became a test of the coordination between translator/research associate and researcher. The topic guide was influenced by my observations in the clinic and the context meetings. It was also adapted on an ongoing basis to accommodate emerging analysis and the different respondent types.

The location of the interviews was selected by the participants. Although I originally anticipated that the interviews would last for one hour, in reality they ranged from thirty minutes to three hours, depending on participants' availability and what needed to be said. The short interviews were with participants who worked for the Ministry of Health and who held director positions. All the interviews were audio recorded.

The interviews were conducted in English and Nepali. Seven (N=7) were carried out in Nepali, six (N=6) in English, and three (N=3) in a mixture of Nepali and English. The issue of translation is explored in section 3.3 of this chapter.

ii) Focus groups with PRIME's PHC workers

Focus groups are used to stimulate discussion, generate ideas, explore participants' thought processes, and gain an understanding of what participants perceive to be the priorities¹³ of different health issues [193]. The group dynamics can help generate questions among participants that might have been difficult to raise during in-depth interviews [193].

For this research, one of my aims in using focus groups was to understand participants' experiences and perspectives regarding human rights, the right to health, the rights of persons with psychosocial disabilities, and the rights of persons with alcohol use disorder, depression, and psychosis. A second aim was to explore the perception of the application of an HRBA to mental health in planning and service provision. My initial intention was to follow the focus groups with in-depth, semi-structured interviews to allow further exploration of key comments or issues raised in the focus groups. However, the health workers were very pressed for time, so I instead tried to follow-up on key issues when I was in the clinics for observations. The group dynamic of the focus groups was crucial, as it captured the interactions between participants when questions were asked and helped explore the diversity of participants' views and opinions, as well as interpersonal dynamics with the group.

Sampling, target group, and information required

The health workers were sampled from PRIME's two PHC centres, Divyanagar and Meghauli health posts, in Chitwan District (N=11), and divided into two focus groups: prescribers (N=4) and non-prescribers (N=11). The main difference between a prescriber and a non-prescriber is that prescribers are authorised to prescribe medicine to mental health users, while non-prescribers are not. Prescribers and non-prescribers are not medical doctors but auxiliary health workers. Some of the non-prescribers were also administrators (see chapter 2 for more information about Nepal's health system structure). Prescribers and non-prescribers are also distinct from each other in terms of the additional training they receive from PRIME and, as a result, their responsibilities in the clinics. Prescribers receive a total of nine days of training by PRIME, which include two days of basic training on mental health and mhGAP, two days of basic training on psychosocial support, and five days of specific training on five disorders: depression, alcohol use disorders, psychosis, epilepsy, and behavioural problems. Non-prescribers receive four days training by PRIME, including two days of basic training on mental health and mhGAP and two days of basic training on psychosocial support.

¹³ The purpose of questions on priorities was simply to explore health workers' perspectives on what they perceive as priority activities, and how that mirrors the core obligations of the right to health.

TPO Nepal, the implementing partner of PRIME in Nepal, helped set up the focus groups. TPO Nepal took me to the clinics and introduced me to staff, and also helped explain the nature of my research – namely, the key aims and objectives and the different research methods being employed. In each case, the heads of the clinics determined the date, time, and location of the focus groups. I constructed a detailed topic guide before going to Nepal. The topic guide brought together the key areas of investigation, rationale, themes, questions, and an explanatory note. I sent the topic guide to TPO, Nepal for comments and piloted it once I was in the country. Table 6 presents an example of the topic guide; the definitive version can be found in appendix 3.

TABLE 6. EXAMPLES OF THEMES AND QUESTIONS IN THE FOCUS GROUP DISCUSSIONS

<i>Themes</i>	<i>Examples of questions asked</i>
<i>Dynamics in the clinic/challenges</i>	How long have you worked with people with mental disability? Can you please tell me what a typical day looks like?
	What do you think is needed to provide good care for, e.g., alcohol use disorders, depression, and psychosis?
<i>Human rights</i>	How do you think human rights are understood in Nepal? How are they talked about in Nepal? What do you think the right to health means in Nepal? How would you explain the right to health in Nepal? How do you think other people understand the rights of persons with psychosocial disabilities? Has human rights been used or applied in other areas of health? If so, how has it impacted the health sector? What do you think other people think the rights are of people with mental disabilities? Do you think people with alcohol use disorders, depression, and psychosis have the same rights as other people with mental disorders? (added after context meeting)
<i>PRIME's mental health care plan</i>	Can you tell me about the process of developing PRIME's mental health care plan?
<i>Integration of an HRBA into PRIME's mental health care plan</i>	Do you think it is possible to integrate human rights into a mental health care plan and into your work? If yes, why is it important? What could be the challenges? If not, why? Not to think it is important to integrate the right to health is equally important as a "yes" answer. I want to learn from you.

Implementation

It was not possible to pilot the topic guide on any of the PRIME staff given that the total number of PRIME mental health workers was so small; therefore, TPO Nepal's office in Chitwan identified three health workers from the public sector for this purpose. Although these health workers did not work directly with psychosocial disabilities, they were familiar with PRIME. The purpose of the piloting was to test the topic guide questions; test the collaboration between translator, facilitator, and note-taker; and test my presence in the focus groups. Prior to undertaking the pilot focus group, I discussed with my PRIME partners in Nepal whether I should participate in the focus groups. On the one hand, we felt that my presence could help clarify questions and comments that might arise from participants, something which would be harder for the facilitator to do since he was less familiar with the research. On the other hand, we wondered whether my presence might hamper the flow of the focus groups and interviews. In order to test these concerns, we held pilot focus groups where I was included. This piloting did not alter the questions but rather affected the manner in which we presented and carried out the focus groups, such as the coordination of the translation. There were no objections to me running the focus group, and so we agreed that I would run the focus groups in collaboration with a translator and note-taker.

I proposed running the main focus groups twice, as I felt this would give participants an opportunity to familiarise themselves with the topic and allow us to build rapport. However, the health workers in the clinics disagreed with this proposal and suggested that we instead conduct one long (five-hour) focus group with each health worker group. The rationale for their argument was that the services were disrupted when the health workers were taken out of the clinics, and given that the participants were already included in PRIME's research, there was a risk of too much disturbance in the clinics. The health workers decided the date, time, and location of the focus groups. According to Nepali government standards, per diems and transportation costs were paid.

iii) Context meetings

Qualitative research needs to convincingly show that the research findings were based on a critical and genuine investigation to avoid accusations of "anecdotalism" and bias [180p. 276]. In this regard, one of the concerns of this particular research relates to the fact that all of the participants were part of PRIME, a project which indeed highlights the importance of human rights in their work to improve the health and lives of people with mental disabilities. As a result, the participants might have felt that it would be politically incorrect to question human rights, the rights of persons with psychosocial disabilities, or the difficulties of operationalising the right

to health, as alluded to in section 3.1 on epistemology. Other research has shown that human beings want to present themselves in the best possible light and that respondents are often unwilling or unable to report accurately to sensitive questions for “ego defensive” or “impression management reasons” [Maccoby and Maccoby(1954) cited in 194]. This can mean data are systematically biased towards respondents’ perception of what is “correct” or “socially acceptable”[194 p.303]. To address this, I decided to meet with stakeholders in mental disability and in human rights law in Nepal who did not work at PRIME. I came to refer to these meetings as “context meetings” aimed at better contextualising the individual interviews.

Through these context meetings, I wanted to obtain a better understanding of human rights law and the right to health in the context of Nepal, as well as the context of mental health in Nepal. I was interested in participants’ interpretation. Considering reflexivity, which was underpinned by my epistemological position, I wanted them to tell me what they considered important and to use their different views to help me understand the context better and inform my topic guides. I also anticipated that these more informal meetings would help me pay attention to potential nuances that could arise within the interviews. Meeting with representatives from different levels of society and from both the legal and public health fields (and specifically mental health) assisted my interpretation of the data and ultimately my understanding of human rights, specifically the right to health and mental health in the Nepali context outside of the participant-presented worldview.

Sampling, target group, and information required

The sampling method for the context meeting was purposive in that I began with an initial seed group of respondents who worked in mental health and in human rights law in Nepal and then used the snowballing technique to increase the number of respondents. In my sampling criteria, I ensured that participants came from both Chitwan and Kathmandu, that there was a balance of participants from different levels of society (i.e., international, national, district, and local levels), and that the sample included Nepali respondents, as I quickly realised when I arrived in Nepal that there was a gap in collaboration and information sharing between many national and international stakeholders. In total, I met with 29 (N=29) stakeholders. I met with the following stakeholders in Kathmandu: mental health advocacy organisations established by mental health users (N=2); mental health professionals working in academia as well as service provision (N=2); a child psychiatrist (N=1); director of Nepal’s mental health hospital (N=1); medical youth associations working in mental health and human rights (N=3); Ministry of Health and Population (N=2); Ministry of Justice and Law (N=1); National Human Rights Commission (N=2); international NGOs providing mental health services (N=2); international NGOs providing legal

assistance (N=3); UN agencies (N=3); and donors (N=4). In Chitwan, I met with mental health professionals working in the district's private medical teaching hospital (N=2).

Access to participants was sensitive to how the study was represented. While the study needed to be consistent with LSHTM and the ethical principles of transparency, upon reflection, I found it helpful to wear different "hats" at different times in order to emphasise different aspects of my experience so that I could obtain access to certain people. So, for example, in addition to telling people that I came from LSHTM, depending on the situation, I sometimes also added specific aspects of my background – for example, that I was on leave from the Swedish International Development Cooperation Agency (Sida) and that Sida was funding my research, or that I had worked for certain UN agencies or the former UN Special Rapporteur on the Right to Health. These hats were useful, as they enabled access to certain organisations more easily and proved that I could also access certain ranks. They also helped the conversations become more collegial, open, and relaxed, possibly helping me elicit different perspectives on human rights, mental health, and psychosocial disabilities. This in turn may have helped me access views that were potentially less socially acceptable, or views that I subsequently realised were outside of the norm.

Although there were many advantages to using these different hats, there may also have been certain limitations to this approach, as with all research approaches. For example, Green and Thorogood (2011) highlight how there can be assumptions of shared meanings between parties [167], and that one may overlook certain statements. Wearing different hats also shows how a range of personally and socially constructed characteristics can influence how we view ourselves and how others view us, a phenomenon often referred to as the "insider/outsider" debate[195]. In order to minimise the potential effect of this, I tried to take a critical stance to what was said, often prompting interviewees to clarify their statements.

Implementation

The participants chose the meeting locations. The meetings were very relaxed, and although I reiterated my motivations at the beginning of each meeting, I also encouraged participants to tell me what they wanted, without interruptions. The meetings were extremely informative, playing a crucial role in helping me better understanding the complex Nepali context with its unstable politics; history of war; influence of religion, caste, and gender; emerging human rights (both civil and political rights and later economic, social, and cultural rights); large community of national and international stakeholders; and tensions within the groups working in mental health.

I did not audio record the meetings; rather, after each meeting, I took field notes according to the format presented in section 3.6. My research associate attended many of the meetings and also asked questions. After each meeting, we discussed and reflected upon themes or issues that had been raised, again following the format outlined in section 3.6.

Objective 3: To explore health workers' perceptions of the application of an HRBA to mental health planning and service provision

Four qualitative data collection methods were used for this objective: (i) in-depth, semi-structured interviews; (ii) focus groups; (iii) observations; and (iv) context meetings and studies. The context meetings fully overlapped with those used in objective 2 and therefore are not described in further depth here. Since there was some distinction between the semi-structured interviews and focus groups for objective 3, these are described further here.

i) In-depth, semi-structured interviews; and

ii) Focus groups

My selection of respondents and implementation of the semi-structured interviews and focus groups were the same as in objective 2, with the exception of one focus group, which included staff only from the EMERALD project.

The piloting of the topic guides was the same as in objective 2. For the realisation of this objective, I used an HRBA checklist as a guiding tool to complement the topic guides when talking about an HRBA to mental health. I drafted the HRBA checklist for mental health planning, using the first UN Special Rapporteur's report on what features a health system should have to be respectful of the right to health, the more detailed version published in *The Lancet*, and WHO's checklist for a mental health plan as the foundation [2, 7, 196].¹⁴

In addition to the features of an HRBA to health (see chapter 1, box 3), I wanted to explore health workers' working conditions, as they are central to this research. They also have a significant bearing on the protection and realisation of health-related human rights, particularly the right to health. However, in many countries, health workers' human rights are not fulfilled (for example,

¹⁴ For the checklist itself see: https://lshtm-my.sharepoint.com/personal/lsh291090_lshtm_ac_uk/_layouts/15/guestaccess.aspx?docid=15307509e82314985a123c32c40db9aeb&authkey=AT64qqgX8NQmtpHQUJUZO00 AND https://lshtm-my.sharepoint.com/personal/lsh291090_lshtm_ac_uk/_layouts/15/guestaccess.aspx?docid=15de750e7994a40cda31e3b3678414593&authkey=AYkHuJKtFpnaYS0H78KB70c

Or contact Dr. Bayard Roberts, supervisor of this research, should the links not work.

inadequate pay), contributing to several problems in the health sector, such as emigration and the transfer of health workers to the private sector, which depletes the public health system. Health workers themselves are also victims of discrimination and can have their opinions, speech, and movement restrained [197]. The personal views of health workers may influence the way they understand and perceive human rights, which may be inconsistent with the rights of health service users. To explore health workers' perceptions of the application of an HRBA to mental health in planning and service provision, it was critical to understand how they, as health workers, saw their rights and obligations, and the reasons for these understandings. Other authors have emphasised the need to understand the implementation system and its actors (in this case, health workers) in order to understand why policies (and also, in this case, ratifications of international laws and the implementation of Nepal's Constitution) do not achieve expected outcomes [10, 11].

iii) Observations from PRIME's PHC centres: A focus on health workers

Observations are based on ethnographic principles. Classical observational studies are often defined by anthropologists as studies where an extensive amount of time is spent living in small-scale communities in order to understand the communities' social structure and beliefs. The observer tries to see the world through an "insider" perspective [167]. The general explanation of observational studies is that they produce a description of a social setting that is trustworthy to the participants. Frequently, the researcher also learns the local language. However, observational studies can also entail short-term field work [198], and ethnography can also be defined as any "small scale social research that is carried out in everyday settings; uses several methods; evolves in design throughout the study; and focuses on the meanings of individuals' actions and explanations"[199]. Furthermore, since it can be difficult to learn a new language during short-term research, translators can be used [200].

For this thesis, the application of observational research was limited in scope and involved spending time in Chitwan's two PHC centres. Rather than attempting an in-depth ethnographic piece of research, I used the observational method to complement the other methods and inform my interviews by aiding interpretation and understanding the everyday life of health workers in the PHC centres.

Spending time in the clinics allowed me to build rapport and helped the health worker interviewees feel more relaxed. It also permitted me to note backstage details – in other words, things that the interviewees did not consider worth mentioning in the interviews or information that they possibly took for granted. In addition, the observational method allowed me to discover

issues that I might have otherwise overlooked had I carried out only semi-structured interviews. This method also helped me gain a greater “insider” perspective and, as a result, question my own perspectives and assumptions. Ultimately, the observational method helped deepen the overall quality of my research, interviews, and analysis, while also strengthening the bottom-up perspective.

Sampling, target group, and information required

Through the observational study, I wanted to examine the everyday running of the PHC centre from the perspective of health workers, particularly with respect to patients with mental disabilities. I focused on the implicit use of the right to health, without asking about it unless it was directly brought up or observed. Access to clinics, medicine, and information without discrimination was a specific issue that I looked for. Access is a core obligation of the right to health and is also critical to public health. I also attempted to look at the HRBA from health workers’ perspective. For example, if a patient was treated in the waiting room, rather than condemning the lack of patient confidentiality, I tried to understand why health workers treated this specific patient, and not others, in the waiting room. The challenge with in-depth interviews is that they access only what people say about what they do. Observations counter this limitation. The questions that emerged through my observations were followed up within the semi-structured interviews and focus groups. I also included questions in the context meetings if I felt there might be broader issues that could be relevant, such as understandings of consent and confidentiality.

Implementation

My research associate and I travelled for one to two hours by motorbike from the city of Chitwan, where we were staying, to PRIME’s two PHC centres in Divyanagar and Meghauri. In each clinic, we sat in the waiting room, trying to be as discrete as possible. Given that the two PHC centres were relatively small, sitting in the waiting room allowed us to observe each clinic’s pre-opening routine, patient registration, the consultation rooms, the dispatch area, and the entire waiting room. Photos below depict the two clinics. There were moments when I think the health workers forgot or did not really care that I was sitting there – but initially they seemed very aware of my presence, as they constantly wanted to inform me of what was going on.

PHOTO 1. PRIME'S PHC CENTRES: DIVYANAGAR AND MEGHAULI

A: DIVYANAGAR (OUTSIDE)



B: DIVYANAGAR (INSIDE)



C: MEGHAULI (OUTSIDE)



D: MEGHAULI (INSIDE- COUNSELLING ROOM)



When introduced to staff in the PHC centre, I quickly noticed that they were not used to being observed in their work; thus, there was a sense of suspicion around my role, as I wrote in my field notes:

“When we came in, even if I had been there a couple of days earlier and been introduced and they had agreed ... , there was tension ... The belief appeared to be that I was there to evaluate their work, even if they did not say that directly. They read through the consent forms again very carefully. There was tension in the air and not really any enthusiasm.”
(O1 300613)

I think this tension was reduced as time passed and that the workers better understood what I was doing, even if they might not have fully understood my research topic. The service users appeared to have very mixed attitudes towards my presence – some noticed it and were curious, while others did not seem to care, simply coming in, registering, sitting down, having their visit with the health worker, getting their medicine, and leaving. Given my unfamiliarity with the local language, I worked with the research associate I had hired as my gatekeeper. As the clinic was very small and for practical reasons, at times he initiated the translation when he felt I should properly understand what was being said. On other occasions, I prompted him to translate when something was happening, such as a discussion at the registration desk or if patients came up to talk. I also took detailed field notes.

After the clinic had closed for the day, we often stayed to talk with the health workers, drink tea, and eat bananas or mangoes that we had brought with us. Those moments gave us an opportunity to build rapport, ask questions, and talk about the day and reduce suspicion. They also provided a chance for us to talk about other things in life unrelated to the clinic, such as politics in Nepal. Attempts – though futile! – were also made to try to teach me Nepali. I was conscious of how I was perceived and how this influenced the data, in terms of both actual data and what was perceived to be data.

Throughout the day, my research associate and I took detailed field notes. When we had finished for the day, we debriefed and wrote down impressions and emerging themes. These debriefings informed the interviews and alluded to key issues that would be important to pay closer attention to when observing the clinics during subsequent days. Issues that arose, for example, were confidentiality, consent, gender, and caste. This was then integrated into the topic guides for the in-depth interviews. Each of us wrote up our field notes separately. These notes were also integrated into the framework analysis.

Objective 4: To develop a conceptual framework regarding the use of an HRBA to mental health

A conceptual framework is a way of explaining key factors, concepts, variables, or relationships[201]. This objective sought to present a framework, in a simplified form, describing the key elements involved in understanding the use of an HRBA in implementing mental health plans and services.

The framework was also developed as a response to the limitations that I had observed in existing frameworks in both public health and human rights. These limitations include the fact that there is a limited number of conceptual frameworks on the right to health and that these frameworks focus on users, leaving out service providers. There are also no frameworks that include human rights law, the features of an HRBA to health, and a focus on health workers and mental health.

My conceptual framework does not include a number of aspects that I felt to be beyond the scope of this thesis. For example, the framework does not include mental health users, as their role was not included in the thesis. Moreover, the framework does not include detailed arrows demonstrating how certain factors might influence one another, as it is intended to present a simplified version of linkages between the different components rather than a detailed logic model of relationships.

The framework's components were designed to reflect the key issues and actors relevant to the study. They are based on the aim and objectives of the thesis, as well as my prior experience and knowledge. They were then further developed throughout the thesis, based on findings from the literature review (chapter 4) and from the field work consisting of qualitative data collection on health workers' perceptions of the right to health (chapter 5) and their perspectives of an HRBA to mental health planning and service provision (chapter 6). The updated framework is presented and discussed in the discussion chapter (chapter 7).

3.3 TRANSLATION

Rigor and transparency in the analysis of qualitative research has been highlighted by a number of authors[177, 187]. The linguistic challenges one may face, as well as the importance of describing the relationships and methods used to address such issues, also need to be highlighted. These pertain to, for example, the fact that three languages were involved in this research, leading to the risk of loss of meaning [202]. English is not my first language (Swedish is). This use of third

parties – or what might be referred to as “triple subjectivity,” which is the interaction between the researcher, interpreter, and participant – has significant implications for qualitative research [203]. Such a scenario requires reflecting on the interaction between the researcher, the interpreter, and the participants [204]. Moreover, I did not use professional translators, instead relying on Nepali individuals who were fluent in English, had done their academic studies in English, and had experience working in research and mental health. Therefore, it was not possible to fully control for bias in the translation [202]. Being aware of the risk of bias in translation, I paid attention to this possibility and attempted to minimise it, as explained below.

Paying attention to translation was important not only for determining whether the sentences had been “correctly” translated but also for acknowledging the power dynamics between the researcher, the translator, and the participant, as well as the role of data translation more generally. According to authors such as Larkin et al (2007), there are approaches that allow for more rigorous qualitative research involving two languages that are carried out via a translator [204]. Following the recommendations of Larkin and Dierchx de Caterle, I adopted the following strategies:

- I used the same translator at every stage of the data collection (baseline, follow-up) including translation and transcripts. The translator also participated in extensive discussion prior to and after the interviews, discussing the interactions within and content of the interviews, with a specific focus on emerging themes and cultural understanding and expressions. This implied that the translator was a visible presence and a co-partner, rather than a silent partner, thus strengthening the rigor of the work [205]. For example, the translator questioned his own culture: “It appears as the service users with mental disorders are served last – could this be the case? If, could it be that they are Dalits?” (O1 300713). Although he was fully aware of the inequalities between higher and lower castes (Dalits being low caste, or untouchable) and had worked in mental health, when sitting in the clinic and observing it first-hand, it appeared to affect him. Also, being from Nepal and thus having an insider view allowed him to pick up on differences, such as different castes, that I as an outsider did not initially notice.
- During the focus groups, I hired a note taker in addition to the main translator in order to take note of non-verbal clues. This allowed me to capture participants’ feelings towards the questions and the group process more generally [177, 202]. The note taker also played an active role during the discussions about the interactions within and content of the

interviews, with a specific focus on the body language that took place during the interviews. In this research, it was important to take note of and talk about the body language in the focus groups in general and, more specifically, with respect to the group dynamics and specific questions. This was important, as a particular concern of this research was that people might merely pay lip service to the usefulness of human rights without actually believing in its importance. Thus, the study of body language was an additional way to tap into people's responses and assess their genuineness. It was also a way to take additional note of hierarchical structures – not just when one person dominated when speaking but also when different body language influenced other participants' responses, whether verbal or through silence, to certain questions.

- This practice of active participation of the translator was also applied with the transcriptions and translations. An additional translator was hired to assist with the translations. In the initial translations, differences and apparent difficulties arose when attempting to identify the conceptual equivalence of some words and meanings in Nepali and English. This, according to Temple et al. (2002), can be explained by the fact that language is often related to local realities, so when a word is translated, it can take on a different meaning from its original usage[203]. Thus, for example, “accountability” is a word which does not exist in Nepali, and so it was translated into “responsibility.” In order to clarify different understandings and minimise the potential differences in interpretation of the transcripts, the translators (one male and one female) rechecked each transcript together by re-listening to the recordings and re-reading the transcripts. In the transcripts for the focus groups, non-verbal communications were also incorporated. We all then talked over the completed transcripts, which frequently led to further discussions between me and the translators.

It is important to acknowledge that there are limitations to this approach, as context and culture always play a part in language and translations[203, 206]. The translators might not have always precisely captured participants' views or meanings, thus leading to the omission of valuable information and data. Unfortunately, the nature of this approach makes such a possibility unavoidable.

Furthermore, there were trade-offs to my carrying out the interviews. Because I could not speak the language, it was not possible for me to control every situation. So, for example, I was unable to monitor the way in which the translator explained a question from the topic guide in

participants' mother tongue. As highlighted by other authors, there was therefore always a risk that an incorrect elaboration or misinterpretation of the question was made [202].

3.4 ETHICAL ISSUES

No ethical approval was sought for the literature review, as it used only literature in the public domain and did not involve human subjects.

I received ethical approval from the Ethics Committee of the London School of Hygiene and Tropical Medicine and from Nepal's Health Research Council (see appendix 4). My ethical application formed a part of PRIME's ethics application, given that our research overlapped and we interviewed many of the same people.

Before the interviews were carried out, I sought interviewees' informed consent. For the semi-structured interviews, potential participants were contacted by phone, and the research was explained to them in Nepali. If they agreed to take part, they set the date, time, and place where the interview was to be carried out. For the focus groups, the heads of the respective clinics determined the date, time, and location. Prior to the semi-structured interviews and focus groups, an information sheet and consent form was provided in Nepali (see appendix 5). Before participants were asked to sign the form, the project was explained again in Nepali, or in English and Nepali, and participants were asked again if they accepted being interviewed and recorded. They were also encouraged to ask questions or give comments prior to signing the consent form. Because of participants' busy schedules, it was not practical to meet and sign the consent forms on separate occasions.

When interviews were conducted via Skype, the information sheet and consent forms were sent electronically and consent was received via e-mail. Prior to starting the interviews, as with the face-to-face interviews, participants were informed about the project and encouraged to ask questions. The respondents were also informed when the recorder was turned on and off. I did not use a web camera, as this significantly weakened the Skype connection, which in turn would weaken the quality of the interviews. When interruptions took place because of poor-quality connections, the participants sometimes grew frustrated and speeded up their responses to the questions. However, because I could not see them, I could not read facial expressions; rather, I had to pay greater attention to their voice and tone. I tried to include "expressions" – such as extended silence or laughter – in my notes. On the other hand, interviewing by Skype gave

participants more freedom to quit when they felt like it, and thus required a high level of commitment by the participant.

For the observational study, I provided health workers with an information sheet and a consent form (see appendix 6). At the clinics, the directors decided that they would sign the consent form on behalf of everyone. The information sheet, however, was given to everyone, and on the first day of the research it was placed on the table in the waiting room for all to read. I also provided an information sheet and a consent form to the users of the services (see appendix 7). In my discussions with health workers at the PHC centres, it was agreed that the nurse at the registration desk would be in charge of informing service users about the research and giving them the options of consenting to or refusing our presence. We emphasised the importance of obtaining consent when they came to the clinic.

Although the health workers had agreed to inform and obtain consent from the service users, we quickly realised that in one of the PHC centres, the service users had not received the information and had not consented until they had left. In the other PHC centre, although the information was thoroughly explained to each person upon arrival, only one of the health workers had provided it. In both clinics, I was always unsure whether the users with mental disabilities had been given the information at all; it appeared as though they did not receive it. Although we addressed the issue of information and consent with health staff on a number of occasions, and it appeared to improve over time, the situation always depended greatly on which of the health workers was registering the patients. This became a concern for me, as I felt it ethically important that the patients have the right to agree or disagree. However, the service users did not seem to mind having me there; as one of the health workers explained, “The patient will be impressed seeing white people in the health facilities” (O1:2). But I was never completely sure what the service users really thought. Further discussion on the ethical aspects of this research is provided in chapter 7.

Together with the health workers, we agreed that children, who often came on their own to the PHC centres, should also be informed about our presence and given the opportunity to consent or not, which is in line with the rights of the child [207 Art. 12 and 13.] If the parents were with the children, we felt it sufficient if the parents were informed and gave their consent on the children’s behalf.

Formal ethical approval and informed consent are important and necessary, but they are not sufficient. My personal behaviour in the field was equally important. A pertinent example of this was with respect to the issue of consent in the clinics. Even if everyone was told that their participation was voluntary, I do not think it would have been easy for them to refuse participation, as I am a white foreigner and this has a perceived status, as was expressed by one of the health workers. Also, if this was the only health clinic close to them, they might have been reluctant to complain, out of fear of possibly losing access to the service. With that said, I do not think that I was perceived as a threat, given that many of them asked my translator about the research and who I was, and openly invited me to their homes. Yet is it possible that my visiting their homes would have had a positive influence on their status in the village, or that they might have invited me in hopes of gaining access to other resources? I reflect on this question in more detail in chapter 7.

When PHC centre users and mental health users learned about my research, they often approached me at meetings and in the clinics, and occasionally invited me to their homes to “talk” or to their NGO to show me their work. Initially, I was reluctant due to ethical concerns, but turning someone down who wished to talk felt morally wrong. I talked this issue over with one of my supervisors, and we agreed that it was a privilege for me that people wanted to talk with me – and given that the overall aim of this research was to provide evidence that could inform policy and practice, we felt that such an opportunity was important. I therefore decided to meet, when possible, with the people who asked, but for ethical reasons I chose not to record or report these conversations as findings.

In order to respect the anonymity of focus group and interview participants, I did not record their names in the transcripts, instead using letters (such as R, for Respondent). For the focus groups, I assigned respondents a letter and a number, such as R1, R2, or R3. I also gave each transcript a separate code, such as T1, C1, or O1. The list explaining which code belonged to which participant was saved separately from the transcripts, making it impossible to link the participants to their respective codes. The list of codes was saved in Dropbox, and the coded transcripts were saved separately on my private computer. Both were password protected. Once I returned from the field, I kept the printed transcripts in a locked drawer. Once I finished listening to the interview recordings, I deleted them.

Confidentiality, anonymity, and data storage were discussed at length with my translator and research associate. Despite such conversations, there were times in practice when the transcripts

included both the code and the person's name. When this happened, we talked it over. I have come to realise, based on the experience I gained, that this was not done on purpose but rather was due to the fact that confidentiality was not perceived as a particularly pertinent issue. We all agreed, however, that the recorded transcripts should be deleted once each transcription was completed, something which the translators and research associate assured me they had done. This topic is discussed in more detail in chapter 7.

3.5 TRANSCRIPTION OF DATA

The data collected and translated from the qualitative methods was transcribed into written form for closer analysis, as is the common next step in qualitative research [208]. Data transcription is an interpretive process and a first step in the analysis of the data.

I took the following steps:

The data that had been audio recorded in Nepali – which constituted the majority of the data – were transcribed from the audio recording into a notebook by my research associate. I had initially requested that the transcripts be transcribed on a computer so they could be stored and backed up. However, I quickly realised that Nepali, an Indo-Aryan language that is written with the Devanagari alphabet, does not have corresponding letters on a computer keyboard. As a result, in order to write in Nepali on the computer, one must type a number corresponding to a respective Nepali letter. Unless the transcriber is used to transcribing in this way, it is a very tedious process that involves looking up each letter for its respective number. When I talked with other research NGOs and transcribers, they told me that they usually transcribed by hand. My research associate and I talked about what would be the best for him, and he preferred to transcribe each audio recording by hand into a notebook. The transcripts in the notebook were structured as if transcribed on the computer, with line numbers and margins. We agreed that he should transcribe everything that had been audio recorded, including non-verbal communications such as laughter and silence. Although I could not analyse the data at this stage, the researcher began to ask me about certain issues, a curiosity that appears to have been prompted by the transcripts. This was a very stimulating experience for me because, sometime later – and after a lot of encouragement – he questioned my reflections. This helped me in my thinking and prompted me to ask more questions about context and culture, as well as encourage him to ask questions in the meetings.

Once the data were transcribed into Nepali, the transcripts were given to the translator, who translated the data. She translated from the written transcripts, while also re-listening to the

tapes to ensure nothing had been missed. Besides the issues that arose regarding translation, which has already been discussed in section 3.3, some of the cultural expressions, even if correctly literarily stated, were sometimes difficult for me to understand. In such cases, we agreed that she would briefly explain what particular expressions or words meant.

We tried to transcribe as soon as interviews had been carried out, but the process took time from the first transcription to the translation. Therefore, I received some transcripts when I was back in London. Furthermore, two interviews were also carried out once I was back in London.

3.6 ANALYSIS OF DATA

I analysed the data using qualitative analysis principles. Specifically, I applied a thematic analysis approach to elicit key findings from the transcribed material [187]. I followed the overall framework based on the conceptual framework (see chapter 1, figure 3) and study objectives. The analysis sought to identify themes emerging within this framework (e.g., the combination of deductive and inductive approaches). Thematic analysis is flexible in that it allows a large range of themes to emerge but can be narrowed down by selecting material relevant to the objectives and the HRBA features (see chapter 1, box 3). The steps typically used for thematic coding are: familiarise oneself with the data, generate initial codes, identify themes, construct thematic networks, integrate the themes, and interpret [187]. I used the NVivo software programme to organise transcribed material and to assist with the justification of themes and the identification of deviant cases [177, 180].

Prior to starting the research, particularly the interviews, my research associate and I reflected on our respective expectations. Together, we also discussed and wrote down, in an analytical memo, our thoughts on what the early findings of the research might indicate. A brief analysis took place after each of the data collections (interviews, context meetings, and observations). The field notes were structured in the following manner:

- Summary (participants' background and summary information)
- Interview arrangements
- Interview settings and dynamics
- Reflection on methods and accounts (context)
- Reflection on emerging themes (pointers for analytical thinking)
- Points for follow-up
- Additional information[209]

Before I left the field, I provided brief feedback on the preliminary findings to the participants in the PHC centres. In Chitwan, I gave brief feedback after each focus group to the coordinators of district hospital in Chitwan. In Kathmandu, I gave brief feedback to all the staff at TPO, and time allowed for comments and reflections by the staff.

Once back from Nepal, my analysis continued, taking place in five main stages, as recommended elsewhere [177]:

- (i) Familiarisation with the data
- (ii) Coding of the data
- (iii) Development and application of an analytical framework
- (iv) Charting the data into framework matrix
- (v) Interpretation of the data.

Although the course of qualitative research analysis is often conceptualised as linear, in reality the process is much more unruly, characterised by a back-and-forth process between original data, memos, and new literature [177]. This was particularly the case with this research, as it included a diverse range of data sources – focus groups and semi-structured interviews, observational field notes, field notes from context meetings, and legal and health data. The analysis drew primarily on what is known as the Framework Method, which is derived from a “thematic framework” [177]. This is a “matrix-based analytical method” which, when carrying out multidisciplinary research, helps reduce the amount of data [177]. The charted nature of the data is useful because it allows other people, such as supervisors and advisors, to provide constructive criticism throughout the process without having to be part of every stage of the data analysis (such as reading all the transcripts or engaging in the more technical aspects of the analysis) [210].

i) Familiarisation with the data

This first step of the analysis allowed me obtain an overview of the data and create the thematic framework [177]. This was done by re-reading the transcripts and re-listening to the interviews (the ones in English), as well as reviewing my journal notes, field notes, and transcripts from the semi-structured interviews and focus groups, in addition to the legal documents. Whilst re-reading, I noted my impressions and analytical observations in the margins using track changes, which enabled the initial coding, comments, and reflections. I communicated frequently via Skype with my translator and research associate in order to share thoughts and reflections. This helped me take a step back from the data and examine it from a slight distance. Although it is recommended that at least two researchers (or at least one from each multidisciplinary team)

independently code each transcript[210], this was not possible for this research project, since both translators had moved on to continue their university degrees and begin new jobs.

ii) Coding

The second step of the analysis focused on the coding of material. The coding of transcripts was carried out in steps. Each step included the coding of four or five transcripts from different times and methods of the data collection. Each transcript was coded line by line. Yet the coding process was more deductive than inductive, something which is common when the research has a predefined and specific area of interest[210]. In my case, the right to health and the possible application of an HRBA was the predefined topic of concern. The first-level codes were initially predesigned according to the themes in the topic guide, with new first-level codes emerging out of the participants' discourses. The second-level codes emerged from the participants' discourse when they explained the first-level codes. For example, the second-level code "tension and critique" was created because some of the participants grappled with the tensions around successfully achieving the tasks they needed to do within the context of limited resources and confrontations with patients demanding their "rights." This second-level code was therefore created in an attempt to further understand the potential obstacles or possibilities of using the right to health. When an important code emerged (first or second level), and I was uncertain how it should be coded, it was placed under the subcategory "other." This was done in order to not forget it, as it was anticipated that a more formal category might emerge once all data had been analysed[210]. See figure 6 for an example of what this looked like. These codes were developed into a "coding framework," which is stage 3 of the analysis.

FIGURE 6. AN EXAMPLE OF PARTS OF THE ANALYTICAL FRAMEWORK

Themes
Sub-themes
RIGHTS-BASED APPROACH
RIGHT TO HEALTH
ACCESS
Treatment
Medicine
Kept away/locked up/tied away
Awareness
Services
Transportation
Other
ACCOUNTABILITY
Responsibility
Mechanism
Punishment
Monitoring, supervision
System
Other
QUALITY
Training
Service user/patient
Big thing/everything
Others
RIGHTS OF PERSONS WITH PSYCHOSOCIAL DISABILITIES
Gender, caste, and religion
Different rights
Same rights
Stigma and discrimination
Other
PSYCHOSOCIAL DISABILITIES
Prioritisation
Gender, religion, and culture
Government
Health worker
Psychosis
Alcohol use disorder
Depression
Other

iii) Developing and applying a coding framework

The coding framework was developed by coding a small number of transcripts. I tried to identify second-level codes that participants used when explaining the first-level codes, such as the rights of persons with disabilities (see figure 6). Each extract that was picked was compared and contrasted with previous extracts. I explored whether similar or new codes or themes emerged. This framework was not permanent; it was constantly revised as transcripts were analysed.

For each set of transcripts that had been analysed, I wrote an analytical memo. Such memos are considered “the intermediate step between coding and writing” [177, 211]. The analytical memos were informal and creative. They helped me feel less overwhelmed by the data and helped me organise my thoughts. The memos also helped me develop working hypotheses and crystallise my ideas and thoughts about what the data were saying. Through these memos, I was also, to some degree, able to step back from the data in order to explore how different categories might be connected, how they might compare against existing piles, and whether similar or new codes or themes might be emerging. In certain cases, writing the memos also allowed me to move beyond the descriptions of particular cases in order to unpack the potential rationale underpinning the emergence of a phenomenon or certain expressions or explanations. Relatedly, at other times, writing the memos helped me explore whether existing ideas contradicted or confirmed ideas from the literature, both scientific and legal, and whether the cases might have differed from the norm. In this research, an example of such an “unusual” case was the view, expressed by certain participants, that people with different mental disabilities had different human rights. The analytical memos also helped clarify when there was an organisational problem as opposed to an objective issue [211], such as the repeated comments by the non-providers that all health workers, irrespective of their position (e.g. providers- or non-providers of medicine) should receive the same rewards and re-imbusement when participating in training.

iv) Charting

The aim of charting is to “group the ‘bits’ into meaningful entities” [209] in order to identify key themes and to map the relationship between them, thus revealing patterns, contrasts, regularities, and irregularities [209]. The process of synthesising the original data was done by placing it in a thematic matrix [177, 210]. I began by printing out the themes and sub-themes from NVivo. I then went over the material by theme. I printed out each theme and its sub-themes, which I re-read and re-analysed. This forced me to try to make data do more of the “talking,” as I felt the coding in NVivo became very mechanical at times and sometimes created sub-themes rather than “listening” to the data.

By structuring the data in rows and columns, I was able to reduce the complexity. I also added field notes, as well as the legal analysis that brought all the data together, thus helping with the comparing and contrasting of data across cases and stakeholder groups and within the individual cases. By organising the data into a framework, I could more easily visually identify patterns, recognise gaps, and detect cases that were outside of the norm (see table 5). It also made me again

review the data from the NVivo, which I felt at times became repetitive. As the data was charted, other individuals – such as supervisors and advisors – were able to provide constructive criticism, without having to be part of every stage of the data analysis or be part of the more technical aspects of the analysis[210].

v) Interpretation of the data

Although stipulated as a final stage, data interpretation occurred from the beginning of the process through the analytical memos and charting; however, at the end, a more thorough and formal analysis took place. I wrote analytical memos after each theme to help make connections between the themes and sub-themes, bring out the layers, and again question what the data were saying, such as, *Why is this being said? Who says this and why?* All this was written in my memos. When the charting and memos had been written, I began incorporating them into the chapters, which led to additional analyses and questioning of the data.

3.7 SYNTHESIS OF RESEARCH

I used triangulation to compensate for any weaknesses inherent to each particular method and to challenge any biases that might emerge by looking at the data from a single perspective. Triangulation is also recommended as a method for ensuring the quality of qualitative research [190]. In this research, three types of triangulation were used: (i) data triangulation (interviews, observation, documentation, and context meetings were used as data sources); (ii) observer triangulation (two people were observing); and (iii) theory triangulation (both human rights and public health were applied to interpret data) [187].

Although triangulation can support validity, Robson (2011) highlights that when using different methods, it can be difficult to compare and contrast between them. However, I felt that rather than generating contradictions, the use of different methods strengthened my research by allowing me to look at the same questions and issues from different perspectives. It also helped me be more open when listening and observing. Finally, using different methods was important for capturing deviant cases and helping explain potentially troublesome findings, such as why patients' rights were sometimes trumped by health workers' actions (such as with regard to patient consent and confidentiality; see chapters 6 and 7).

The next three chapters will present the results of this thesis. Chapter 4 presents the findings from the literature review (objective 1), and chapters 5 and 6 present the results from the field research (objectives 2 and 3, respectively).

CHAPTER 4: EXAMINATION OF EXISTING EVIDENCE ON THE USE OF A HUMAN RIGHTS-BASED APPROACH TO ADVANCE HEALTH

The WHO's Mental Health Action Plan for 2013–2020 underlines the need to integrate human rights legal and normative standards into public health policies, programmes, plans, and services in order to address the global burden of psychosocial disabilities[1 Art. 12(2)]. This integration is referred to by both the WHO and OHCHR as an HRBA to health[30]. An HRBA to health aims specifically at realising the right to health and health-related human rights. It should be explicitly integrated from the very beginning of a health plan, programme, strategy, or project. See chapter 1 for a more detailed explanation of the difference between human rights and an HRBA, and for the difference between an HRBA and an HRBA to health. At present, however, there does not appear to be a common definition of which right to health and/or human rights features constitute an HRBA to health generally or to mental health specifically[35].

The features of an HRBA to health are grounded in legally agreed-on global norms and standards, and their importance in the realisation of public health is generally well acknowledged. States that have ratified these treaties have agreed to their provisions and are ultimately legally bound by them. There is, however, a limited understanding of what the integration of human rights into mental health and health more broadly actually entails, how health and human rights interact, and the value of human rights to public health practice[9, 212]. This raises the question of whether evidence of the relationship between health and human rights is really necessary. However, according to Yamin and Maine (1999), although a human rights perspective is intrinsically valuable in and of itself, such arguments remain insufficient and ultimately lack force without the use of data and evidence. Yamin and Maine (1999) have argued that without a sound understanding of the epidemiology of maternal mortality, and interventions that can reduce it, talking about human rights in abstract would ultimately remain meaningless[213]. Similarly, London (2009) claims that evidence is needed to inform how an HRBA to health informs, tests, and motivates policy decisions. However, he stresses that the necessity of evidence should not detract from the fact that health is ultimately an essential right, and not only a service or economic development issue. Thus, evidence of an HRBA to health is important because it informs a better understanding of an HRBA to health and how it can most effectively be used to advance health outcomes, policies, programmes, and systems [9].

To the best of my knowledge, no narrative literature review has been conducted that examines evidence on the use of an HRBA to health. In light of this gap, this chapter looks at the literature

on HRBAs to health. The overall aim is to examine existing evidence on the use of an HRBA to advance¹⁵ health.

The chapter has the following specific objectives:

1. To describe the contexts, research methods, and health outcomes used in studies on HRBAs.
2. To describe the range of HRBAs used to advance health.
3. To explore evidence on how an HRBA may advance health.
4. To examine the strength and quality of the evidence on the use of an HRBA to advance health.

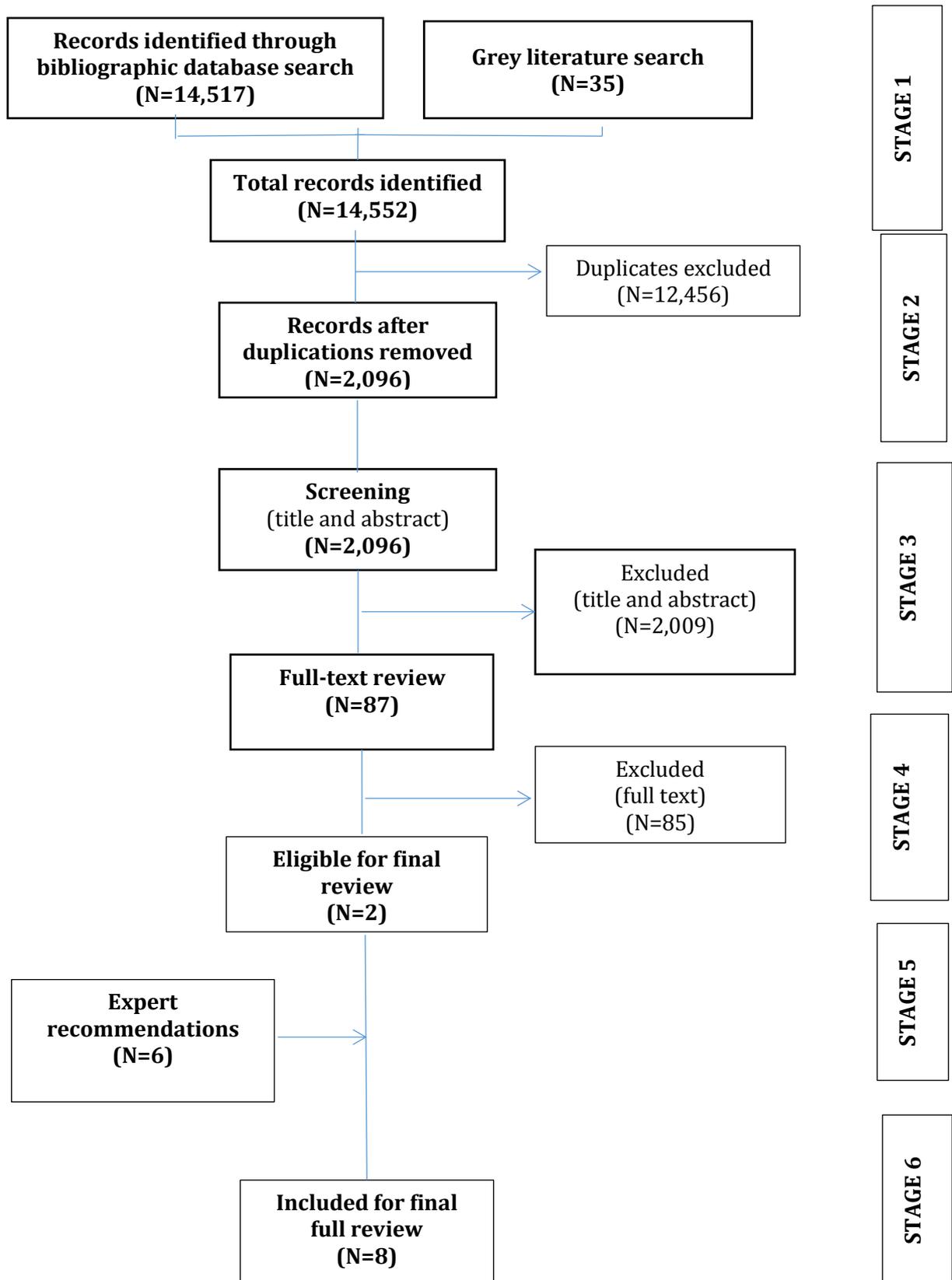
The methods for the literature review are described in chapter 3. This chapter begins by outlining the results of the study selection process, followed by a description of the context, research methods, and health outcomes. The next section then looks at the range of HRBAs for advancing health; the subsequent section looks at the range of evidence on how an HRBA may advance health. The fourth section explores the strength and quality of the evidence of the use of an HRBA to advance health. The final section discusses the findings and draws various conclusions.

The results of the study screening process are presented in figure 7. In stage 1, a total of 14,517 papers were identified through bibliographic database searches, and 34 papers were yielded through the grey literature searches. After duplicates were removed (stage 2), a total of 2,096 papers remained. The screening of titles and abstracts then excluded 2,009 studies which did not meet eligibility criteria (stage 3). The main reason for excluding these studies was because they made no specific reference to “human rights-based approach/framework,” “rights-based approach/framework,” or “right to health-based approach/framework” in their title or abstract. Thus, for stage 4, a total of 87 papers were deemed eligible for full-text review. Of these, 81 were eliminated. The main reasons for rejecting them because they were not based on primary data (e.g., literature reviews, commentaries, editorials, or summaries from other studies or case laws) or because they did not include any research methods, an explicit rights-based or HRBA framework, or evidence or influence of an HRBA to health [35, 214-223]. In addition, I was unable to access the full text for one paper, making it impossible to determine whether it would have been selected for the final review[224]. In stage 5, snowballing yielded no additional papers, and the expert consultations led to 30 papers being sent to me, of which six met the eligibility criteria. When reviewing the snowballing and the papers sent to me by experts, I excluded most of them

¹⁵ “Advance” refers to aspects that support the protection and improvement of health.

because they did not include actual research or an explicit HRBA focus (for example, [225-228]). By the end of the process, a total of eight papers met the eligibility criteria and were included in the final review (stage 6)[139, 229-235]. All of these papers were written in English.

FIGURE 7. RESULTS OF STUDY SCREENING PROCESS



4.1 STUDY CONTEXTS, METHODS, AND HEALTH OUTCOMES

Three studies were conducted in high-income countries (United Kingdom and Italy)[230, 231, 234], two in middle-high income countries (Brazil and Peru)[229, 233], and three in low-income countries (Nepal, Malawi, and Papua New Guinea)[139, 232, 235].

Of the eight studies selected, two were from published literature[231, 235] and six from expert consultations[139, 229, 230, 232-234]. All were published between 2007 and 2013 [139, 229-235]. Three studies applied qualitative methods [231, 233, 234]. The specific research methods used in these qualitative studies consisted of focus groups [231, 233, 234]; semi-structured interviews [233, 234]; in-depth interviews[233]; observations[234]; and consultations with key stakeholders/informants [139, 229, 230, 232]. Two studies used rights-based indicator survey tools[231, 235]. Two applied case studies [139, 233]. One study reviewed relevant medical records, autopsies, and other forensic medical reports and court documents[233]. All studies carried out reviews of policies, laws, and strategies. Table 7 provides an overview of the final selected studies in the literature review.

TABLE 7. FINAL SELECTED STUDIES IN THE LITERATURE REVIEW

Author and year	Aim, country, study population, and health topic	Study design	HRBA/rights-based approach	Outcome	Study results
Barros De Luca, G., Sander, G., Valonguiero, S., Leocaidio, E., Martines, J., Arajuo de Carvalho, I., Hunt, P., in Bustreo, F., Hunt, P., et al. (2013)[229]	Aim: analyse the evidence of influence of an HRBA on aspects of women's and children's health Country: Brazil Study population: women Health topic: sexual and reproductive and maternal health	Document review: policies, programmes, and laws; qualitative consultation with key informants	Availability, accessibility, acceptability, quality, participation, equality & non-discrimination, accountability (HRBA)	The mean number of children born to each woman dropped from 4.4 (1980) to 2.9 (1991) to 1.8 (2006). Women in stable relationships using contraceptives increased from 57% (1986) to 78.5% (2006–2007). Antenatal coverage increased from 74.7% (1981) to 98.7% (2006–2007). Institutional deliveries increased from 79.6% (1981) to 98.4% (2006–2007). In 1996, contraceptive use was 55.8% for the poorest quintile and 76.8% for the richest quintile; by 2006–2007, the gap had disappeared. In 1996, skilled birth attendance was 72.6% among the poorest quintile and 99.2% among the richest quintile; by 2006–2007, this gap had almost closed to 96.8% among the poorest quintile while the richest remained at similar level as 1996.	There is evidence that human rights law has explicitly changed government interventions related to women's sexual and reproductive health in Brazil and that these human rights-shaped interventions have contributed to considerable health improvements.
Longhi, S., Ricciardi, W., Meriardi, M., Benagiano, G., Bustreo, F., Hunt, P., Sander, G., in Bustreo, F., Hunt, P., et al. (2013)[230]	Aim: analyse the evidence of influence of an HRBA on aspects of women's and children's health Country: Italy Study population: women and children Health topic: women's and children's health	Document review: laws, programmes, plans, and interventions; consultation with key informants	Availability, accessibility, acceptability, quality, participation, equality & non-discrimination, accountability	Between 1989 and 2010, breast cancer mortality decreased from 38.59 per 100,000 to 23.62 per 100,000. Between 1982 and 2011, legal abortions decreased by 54.7%. Oral contraception increased by 12% between 1985 and 2000. Between 1978 and 2009, infant and neonatal mortality decreased from 16.79 and 13.30 per 1,000 live births to 3.51 and 2.47 per 1,000 live births, respectively. Vaccination coverage has improved: e.g., between 2000 and 2009, in the 0–14 age group, the incidence of measles declined by 73.42% and that of rubella by 97.8%.	There was significant improvement in key health indicators among women and children, including assistance during pregnancy, cancer screening, neonatal and infant mortality, and vaccination coverage. The use of modern contraception increased, and the number of abortions declined.

McMillian, F., Browne, N., Green, S. (2009)[231]	Aim: explore the possible significance of participation of mental health service users in policy, planning, delivery, and monitoring of services Country: Northern Ireland Study population: mental health service users Health topic: mental health (prevention of suicide)	Focus groups; indicators and benchmarks	Participation (HRBA)	Not applicable	The policy on follow-up care changed across Northern Ireland. An HRBA demanded a focus on the outcome achieved and the process of achieving it. The underlying causes of problems in service delivery remain unresolved.
Mhango, C., Mvula, L., Sander, D., Lee, JY., Hunt, P., in Bustreo, F., Hunt, P., et al. (2013)[232]	Aim: analyse the evidence of influence of an HRBA on aspects of women's and children's health Country: Malawi Study population: children Health topic: children's health	Document review: laws, policies, strategies, and programmes related children's health; consultation with key informants	Availability, accessibility, acceptability, quality, participation, equality & non-discrimination, accountability (HRBA)	In 2004, 70.7% of the children aged 12–23 months living in urban areas had received all vaccinations, compared with 63.5% of those living in rural areas. In 2010, the proportions were 75.8% and 81.8%, respectively. Between 2004 and 2010, the percentage of stunted children decreased from 53% to 47%, wasting decreased from 6% to 4%, and underweight decreased from 17% to 13%. Health facilities providing a minimum package of service for prevention of mother-to-child transmission of HIV soared from 7% to 100% between 2004 and 2009–2010.	Human rights-shaped interventions contributed positively to health improvements for children, as well as their families and communities.
Patel, A., Sharma, S., Prost, A., Sander, G.,	Aim: analyse the evidence of influence of an HRBA on aspects of	Literature review; case studies; consultation with	Availability, accessibility, acceptability, quality, participation,	Reduction in maternal mortality and under-5 mortality rate. Case study 1: a fivefold increase in met need for emergency obstetric care; increase from 3.8% to 8.3% in institutional deliveries; and	Human rights considerations contributed to the decriminalisation of abortion, as well as the implementation

Hunt, P., in Bustreo, F., Hunt, P., et al. (2013)[139]	<p>women's and children's health</p> <p>Country: Nepal</p> <p>Study population: women and children</p> <p>Health topic: maternal and child health</p>	key informants; document review	equality & non-discrimination, accountability (HRBA)	decrease from 2.7% to 0.3% in the case fatality rate. Case study 2: increase from 45% to 60% in uptake of antenatal care visits; and increase from 12.3% to 65.5% in iron tablet intake. Case study 3: 19% increase in institutional deliveries in the first 18 months of the programme. Case study 4: comprehensive abortion care services available in all of Nepal's 75 districts, with about 100,000 safe abortions carried out each year, compared to 719 safe abortions in the six months after the first service was opened. Case study 5: one district increased rates of exclusive breast feeding from 26% to 85% and increased folic acid supplementation from 6% to 60%.	of comprehensive abortion care services.
Physicians for Human Rights (2007)[233]	<p>Aim: analyse the systematic and social factors that perpetuate the injustice of maternal mortality in Peru, applying an HRBA</p> <p>Country: Peru</p> <p>Study population: pregnant women</p> <p>Health topic: maternal health (maternal mortality)</p>	In-depth interviews and semi-structured interviews; focus groups; case studies and reconstruction of cases; review of relevant documents; physical re-tracing	Non-retrogression, & adequate progress, non-discrimination & equality, participation, accountability, international assistance & cooperation (HRBA to policy)	Maternal mortality	Peru suffers from a lack of available, accessible, acceptable and quality health care, including emergency obstetric care, as well as sexual and reproductive health and rights services.
Scottish Human Rights Commission (2009)[234]	Aim: undertake an evaluation of the procedural steps and outcomes of an HRBA to facilitate	Document review; interviews; focus groups; observations;	Participation, accountability, non-discrimination & equality, empowerment of	Significant improvements were made in care and in the treatment conditions of patients. Restraint measures were "much more measured."	An HRBA contributed to a number of improvements: support for cultural change with mutual respect between staff and patients; increased work-related satisfaction

	<p>cultural change at the State Hospital</p> <p>Country: United Kingdom (Scotland)</p> <p>Study population: staff, patients, and carers in mental health at the State Hospital</p> <p>Health topic: mental health</p>	<p>survey of key indicators.</p>	<p>rights holders (HRBA)</p>		<p>among staff and increased satisfaction among patients with regard to their care and treatment; reduction in stress and anxiety among staff; reduction in “blanket” policies and increased focus on individual patients’ risks; improvements in care and treatment and the overall culture at the State Hospital (e.g., procedures to manage violence and aggression were now seen as proportionate, and seclusion was not used as punishment); greater patient engagement in decisions affecting them.</p>
<p>Williams, C., Brian, G. (2012)[235]</p>	<p>Aim: assess whether the activities considered AAAQ elements and rights obligations in Papua New Guinea was applied to the Vision 2020 plans</p> <p>Country: Papua New Guinea</p> <p>Study population: not applicable</p> <p>Health topic: eye health (prevention of blindness)</p>	<p>Indicators</p>	<p>Availability, accessibility, acceptability, quality (RBA)</p>	<p>Strengthened eye health plan (Vision 2020) by a rights-based approach, and the potential results of this.</p>	<p>None of the 36 indicators was addressed in full. Five of the twelve indicators pertaining to availability were addressed partially, as were three of ten relating to accessibility and one of six concerning human rights concepts.</p>

The health topics included two studies focusing on mental health [231, 234]; one on maternal mortality[233]; two on maternal and child health[139, 230]; one on sexual and reproductive and maternal health [229]; one on child health [232]; and one on eye health ¹⁶[235].

The studies on mental health had different outcomes of interest. The study carried out in Northern Ireland by McMillan et al. focused on mental health policies[231], while the study in Scotland by the Scottish Human Rights Commission (SHRC) focused on health services at the State Hospital (the main forensic mental health hospital for Northern Ireland and Scotland)[234].

The study on maternal mortality, which was carried out by Physicians for Human Rights (PHR), analysed the systemic and social factors that perpetuated maternal mortality in Peru, focusing on the availability, accessibility, acceptability, and quality (AAAQ) of the health system. The study also looked at how laws, policies, programmes, and plans relevant to maternal health, as well as underlying factors such as gender inequality, education, and poverty levels, may have influenced the AAAQ of maternal health services [233]. The studies on maternal and child health in Italy and Nepal explored whether and how an HRBA to maternal and child health policies and programmes could have had an influence on maternal and child health outcomes [139, 230]. The study in Brazil on sexual and reproductive and maternal health examined how laws, policies, and programmes explicitly shaped by human rights may have had an influence on sexual, reproductive, and maternal health outcomes[229]. The one study on child health, carried out in Malawi, reviewed laws, policies, and programmes related to child health that were explicitly shaped by human rights and explored whether the HRBA may have had an influence on child health[232]. The study in Papua New Guinea explored aid-funded health programmes for eye health and their possible influence on the AAAQ of health service delivery[235].

The study populations were users of mental health [231, 234], mental health service staff [234], pregnant women [233], women[229], children[232], and women and children together [139, 230].

¹⁶ Vision 2020 is a global partnership that aims to eliminate avoidable blindness by 2020. The partnership provides guidance, technical support, and resource support to countries that have formally adopted its agenda. The aim of this study was to consider whether activities considered the right to health features of availability, accessibility, acceptability, and quality, and whether the right to health obligations were applied in Papua New Guinea's Vision 2020 plan. The study focused on whether the proposed activities were in keeping with national health plans and the Papua New Guinea health system's capacity.

4.2 THE RANGE OF HRBAS AND RBAS USED

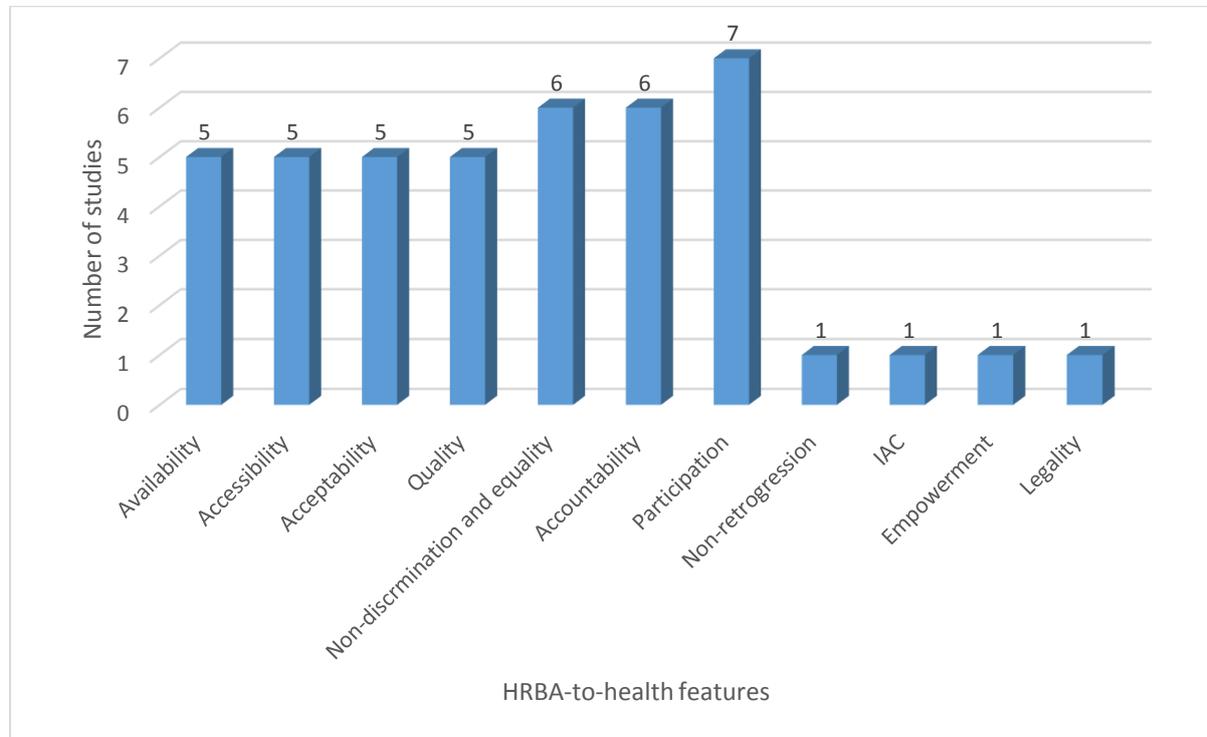
Seven studies used the term HRBA [139, 229-234], while one study used the term “rights-based approach” (RBA) [235]. Of the seven studies using the term HRBA, the human rights features varied between the studies, with four studies (the ones on maternal and child health) including exactly the same features: AAAQ, non-discrimination and equality, participation, and accountability [139, 229, 230, 232]. The PHR study on maternal mortality included three features which could be identified in five of the studies labelled HRBA: non-discrimination and equality, participation, and accountability [233]. Besides the common HRBA features, the study included two features which were not addressed by any other study: non-retrogression and adequate progress, on the one hand, and international assistance and cooperation, on the other [233]. Non-retrogression implies that the state is not permitted to worsen its realisation on the right to health unless it can demonstrate that it has made every effort to use all available resources to meet its obligations [236]. The PHR study underlines that the selected HRBA features (non-discrimination and equality, participation, accountability, non-retrogression and adequate progress, and international assistance and cooperation) are the minimum features required for HRBA on policy. The study also includes AAAQ when analysing the reasons for delay of the delivery of their case studies, which PHR refers to as the “three delays model and lack of available, accessible, acceptable and quality emergency obstetric care” [233p. 49]. However, AAAQ is not explicitly mentioned as a feature of an HRBA to maternal health and thus is not included here as a feature under PHR’s definition of an HRBA to health.

The two studies on mental health also used an HRBA but – with the exception of one feature, participation – differed in their definition of an HRBA to health. The study by McMillan et al. included one HRBA feature: participation [231]. The study by the SHRC included three features, which were also common in the studies on maternal and child health: participation, accountability, and non-discrimination and equality [234]. Participation was the one common feature across all the studies labelled HRBA. The human rights features which distinguished the studies labelled HRBA from one another were the following: appropriateness, progressive realisation, empowerment, indicators, benchmark, and legality.

The features included in the one study labelled RBA – the study by Williams and Brian, which looked at the prevention of blindness, specifically the Vision 2020 plan in Papua New Guinea – were similar to the studies labelled HRBA to health in that they included the AAAQ [235].

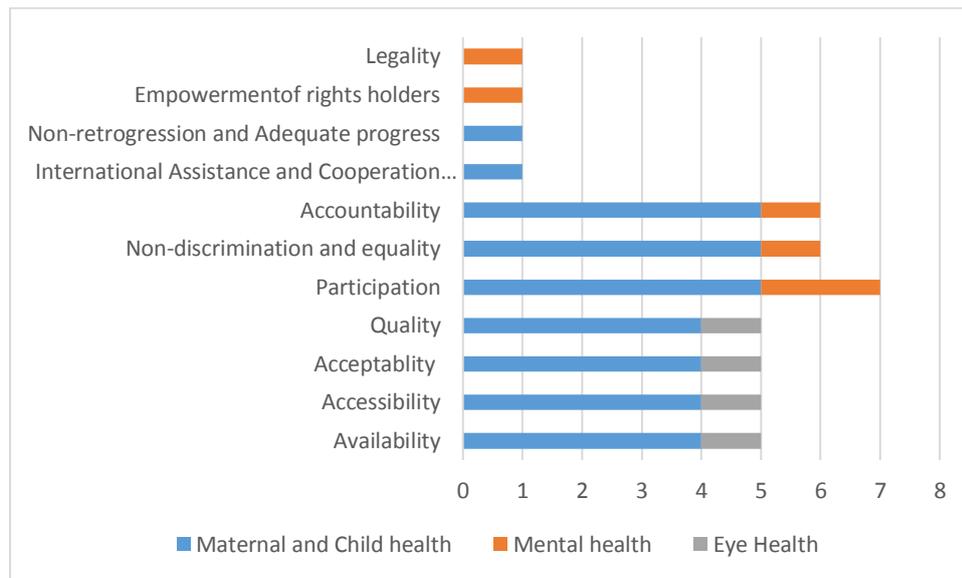
Some human rights features were shared across several of the studies, irrespective of the label of their approach. Seven studies included participation, and six studies included AAAQ, non-discrimination and equality, and accountability (see figure 8).

FIGURE 8. HUMAN RIGHTS FEATURES USED IN THE SELECTED STUDIES



When reviewing the HRBA and RBA studies based on health outcome, the four studies on maternal and child health had the same and the largest number of right to health features included in their definitions of an HRBA to health [139, 229, 230, 232]. The AAAQ features are present in the studies whose outcomes relate to eye health and maternal and child health. The most common features, irrespective of health outcome, were accountability, non-discrimination, participation, and AAAQ. These are also the features included in the WHO and OHCHR’s definition of an HRBA to health [36]. Figure 11 visualises the use of HRBA and RBA features according to health outcome.

FIGURE 9. HRBA & RBA FEATURES BY HEALTH OUTCOME



In terms of how the features were operationalised for research, three of the eight studies applied indicators [231, 234, 235]. While three studies mentioned the use of indicators, only two of them outlined the selection, application, and results of the indicators (key findings on indicators from these two studies are presented in table 2 [231, 235]). The third study, by SHRC, applied survey indicators but did not describe them in the report [234].

The study by McMillan et al. [231] developed human rights indicators identified by the user groups, focusing on four issues related to mental health services in Northern Ireland: follow-up appointments, complaints, information from general practitioners, and service users' participation. The indicators were identified through surveys and focus group discussions with other mental health service users in surrounding communities, and then linked to international human rights and local policy standards. The indicators had baseline data, and time-bound benchmarks/targets were established over six- and twelve-month periods. The proposed indicators and benchmarks were presented to an international panel of human rights and mental health experts. The panel validated the human rights benchmarks as a reasonable and necessary timeline for change in accordance with human rights standards. By setting benchmarks and specific timelines for change, the group hoped to materialise the government's obligation to progressively realise economic, social, and cultural rights [231].

The study by Williams and Brian designed a rights-based assessment tool composed of 36 indicators to assess whether the activities in the aid-funded programme considered right to

health features or AAAQ[13] and whether the rights obligations in Papua New Guinea were incorporated into the Vision 2020 plan. The tool assessed whether the programme had fully engaged with and addressed the local context and if the proposed activities were in keeping with the national health plan and the health system. The tool also assessed if the activities had been designed in the context of right to health obligations, which are binding upon Papua New Guinea and its international partners. The indicators were scored as “fully,” “partly,” or “not at all” addressed. The study’s authors assumed that if the programme had fully engaged with and addressed the local context, the programme would be well placed to ensure that the planned health services would help fulfil people’s right to health [235]. Table 8 includes details on the indicators of the studies by McMillan et al. and Williams and Brian.

TABLE 8. INDICATORS USED IN THE SELECTED STUDIES

Authors: McMillan et al. (Ireland)[231]	
HRBA features	Indicators used
Participation	Patients receiving follow-up appointment within a week of discharge
	Satisfaction with information from general practitioners about mental health issues
	Satisfaction with information from general practitioners about medication for conditions
	If unsatisfied with services, made a complaint
	If made a complaint, was offered help in making one
	Service users rating themselves as “not involved” in decisions
Authors: Williams and Brian (Papua New Guinea)[235]	
RBA features	Indicators used
Availability	What is the need for this service, and how many health workers are required to provide it?
	Does the country have the health workforce to meet the needs of this programme?
	Does the state’s health workforce plan include this service?
	Who is employing the health workers?
	How will health care workers be trained to provide the service?
	Where will the services be provided?
	Are support services in place for this service (administration, maintenance of facilities and equipment, cleaning, sterile services)?
	Are systems in place to ensure consistent availability of medicines, consumables, and other supplies?
	Will the services be available throughout the country? If not, are plans in place to increase availability?
	Does the National Health Plan include this service?
Is the service included in the state’s forecast budget?	
Accessibility	How will all people, irrespective of gender, locality, disability, ethnicity, or age, access this service?
	How will people know the services are available?

	Has a referral pathway been established from primary health centres through secondary and/or tertiary centres?
	Will patients be charged fees for this service?
	Were studies undertaken to determine willingness to pay?
	Are the medicines for these services on the essential drugs list?
	Will patients have to pay for medicines?
	What systems are in place for people who cannot afford to pay for the service or medicine?
	How is access measured and monitored?
	What data are required on access for the Ministry of Health?
Acceptability	How will the programme demonstrate acceptability by patients and the community?
	How is confidentiality of patient information being addressed?
	How is informed consent being addressed?
Quality	Is health information in place to record treatment outcomes, patient recall, and follow-up services?
	Is the patient satisfaction measured and monitored?
	How will the programme demonstrate quality service to patients and the community?
	Are health workers provided with an ongoing training programme?
	Are monitoring visits planned to each service centre?
Human rights concepts and progressive realisation*	Does the programme make reference to the country's health rights obligations and their progressive realisation?
Core obligation*	Is the service being provided one of the nation's core obligations regarding the right to health?
	Was a health system assessment undertaken as part of programme design?
	Was an impact assessment of the programme undertaken?
	Will the health ministry be advised annually of the funding provided by donors for this service?
	Is there a monitoring body for this programme that includes local people?
* These indicators are not mentioned explicitly as part of the HRBA to health but were outlined in the list of indicators they assessed.	

4.3 EVIDENCE ON HOW AN HRBA OR RBA MAY ADVANCE HEALTH

This section will look at the possible contribution to health knowledge, practice, and outcomes by the following specific HRBA or RBA features used in the papers: (i) human rights legal obligations; (ii) non-retrogression and adequate progress to the maximum extent of available resources; (iii) equality and non-discrimination; (iv) availability, accessibility, acceptability, and quality; (v) participation; (vi) empowerment; (vii) international assistance and cooperation; and (viii) accountability. After exploring these specific features, the section then highlights other findings which do not neatly fit under any of the above headings but which recurred throughout the literature.

1) Human rights legal obligations

The right to health gives rise to legally binding obligations. States that have ratified, for example, the ICESCR – which protects the right to health – are legally obliged to take all appropriate steps to implement this right. While some governments might implement the right to health, including HRBA features, without explicit reference to the right to health, many do not realise the HRBA features, and in these cases the right to health has an especially important role to play [7, 13].

The four case studies (Nepal, Brazil, Malawi, and Italy) on maternal and/or child health [139, 229, 230, 232] involved countries that had ratified key international human rights treaties regarding maternal and child health, such as the Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination against Women. The governments in these four countries had also acted on other global commitments, such as the International Conference on Population and Development, the Fourth World Conference on Women, and the Millennium Declaration. While the authors do underline that ratification in itself is unlikely to result in the realisation of an HRBA to health, their findings suggest that global commitments helped establish positive environments for women's and children's health that were shaped by human rights. For example, during its 2011 review by the UN Human Rights Council, Nepal was commended for its notable decline in maternal mortality. In addition, between 1991 and 2011, Nepal's total fertility rate declined from 5.1 to 2.6 children per woman of childbearing age; between 2001 and 2011, its skilled birth attendance rate increased from 11% to 36%; and between 1991 and 2011, its under-five mortality rate decreased from 125 to 54 per 1,000 live births [139]. The government recommitted itself to realising its human rights commitments and implementing an RBA to the development of all sectors. However, while noting Nepal's significance progress in human rights, the study found that the rule of law, upon which an HRBA depends, needed strengthening[139]. The study also includes an example from Malawi, where, in the 1990s, there were deepening concerns about human rights and governance, leading donor partners to suspend their aid. In 2012, Joyce Banda became president and replaced many of the regressive national laws; as a result, most bilateral donors lifted their aid bans[232]. Moreover, the authors of the four country case studies noted that the constitutional recognition of health-related rights helped create the conditions for human rights-framed laws, policies, and other interventions on women's and children's health. In Italy, for example, the government has recognised that, according to the Constitution, individuals are legally entitled to a minimum package of health services. In Brazil and Nepal, aspects of women's sexual and reproductive health are explicitly protected by constitutional provisions, allowing claims of violations to be brought before the courts [139, 229]. In Nepal, the case of *Prakash Mani Sharma & Others v.*

Government of Nepal was supported by an HRBA to health. In this case, the Supreme Court held that the government had violated women's constitutional right to reproductive health by failing to develop and implement policies and programmes to effectively address uterine prolapse [139].

The study by PHR, which looked at maternal mortality among rural indigenous communities in the regions of Puno and Huancavelica in Peru, found that an HRBA to health can positively contribute to Peru's present efforts to address maternal mortality [233]. The study focused primarily on Peru's obligations to protect the right to health. Peru's obligations derive from the rights enumerated in international treaties to which Peru is party, some which have also been implemented through Peru's Constitution and domestic laws. Peru also adopted the Millennium Declaration in 2000, which included a commitment to reduce maternal mortality by 75% between 1990 and 2015. The government has assumed obligations under both domestic and international law to address various factors that, according to the study's analysis of maternal mortality through an HRBA lens, have persistently led to high levels of maternal mortality[233].

In McMillan et al.'s study on Northern Ireland, the indicators related to mental health services (see table 2) were supported by local, national, and international standards regarding access to health care, including the UN's General Comment 14 (which provides scope to the right to health as outlined in the ICESCR), other UN documents, and reports by the former UN Special Rapporteur on the Right to Health Paul Hunt (2002–2008) [231].

SHRC's study on Scotland presents the results of an independent evaluation of the State Hospital which is a high-security forensic mental health hospital for Scotland and Northern Ireland that sought to adopt an HRBA [234]. The hospital's decision to conduct an examination of its human rights practice, and apply an HRBA based on the Human Rights Act, was made after the Mental Welfare Commission had presented a report year 2000 into the treatment and care of a particular patient. This inquiry was instrumental to the country's adoption of the 2003 Mental Health Care Act, which includes many of the features of an HRBA, such as non-discrimination, equality, and participation. The inquiry further noted that "the human rights of individual patients must be recognised" by the State Hospital [234 p. 16]. According to SHRC, adopting an HRBA in practice requires an explicit link to national and international human rights law; with this in mind, the SHRC examined the State Hospital's policies and practice through the lens of the Human Rights Act and other national laws which implement aspects of human rights, as well as relevant international human rights instruments.

Williams and Brian's case study on Papua New Guinea used right to health indicators, supported by international standards regarding the availability, accessibility, acceptability, and quality of health services, as outlined in General Comment 14. The study also took into consideration the international human rights conventions ratified by Papua New Guinea, with a specific focus on international human rights treaties encompassing the right to health [235].

2) Non-retrogression and adequate progress to the maximum extent of available resources

According to the obligations outlined in the ICESCR, in which the right to health is found, states must take progressive steps to realise the right. Adequate progress implies that the state establishes realistic targets, benchmarks, and timelines and that it makes appropriate effort through laws, policies, and administrative and budgetary measures. States should make adequate progress to the maximum extent of their available resources, and they will be assessed on their compliance with the realisation of the right to health in light of their resources [237]. In this way, it is understood that a state cannot retrogress in its realisation of the right to health unless it can demonstrate that it has made every effort to use all resources at its disposal to meet its obligations[13].

According to PHR, Peru retrogressed in realising the right to maternal health. For example, the study found that there had been retrogression with respect to family planning programs and the availability of contraception; health care coverage under the Social Insurance Scheme, with health care coverage declining between 2003 and 2005 for those in the lowest income quartiles; and the provision of the General Health Law relating to abortion, which required doctors to denounce acts of criminal abortion to the authorities, thereby hampering the accessibility of emergency obstetric care. Moreover, the government of Peru did not reflect health as a priority in its budget and did not use its fiscal power to collect sufficient revenues to increase the extent of its available resources, either in comparison to its neighbours or in relation to the growth of its GDP. According to PHR, this failure to devote resources to maternal health reflected a political choice and lack of will rather than absolute resource constraints. However, the study did not indicate how much of Peru's total health budget was allocated to maternal health, nor how much maternal health expenditures were cut compared to the overall health budget [233].

3) Equality and non-discrimination

Under international law, human rights, including the right to health, are to be guaranteed without discrimination of any kind. This includes discrimination on the basis of race, colour, sex, language,

religion, political or other opinion, national or social origin, property, and birth or other status[15Art. 12(2)].

The four studies on maternal and child health [139, 229, 230, 232] documented different approaches that were been applied to address equality and non-discrimination. The study in Brazil noted the introduction of a cash transfer program which helped reduce inequality and extreme poverty, thereby supporting low-income women's health [229].

PHR's case study on Peru pointed to three levels of discrimination: individual, institutional, and structural. PHR found evidence of widespread discriminatory attitudes among health care providers, including the imposition of fines for obtaining birth certificates for children who were born at home, which disproportionately affected indigenous communities. At the institutional level, PHR noted, for example, that many health establishments did not permit vertical birthing positions or other traditional practices, which reduced the accessibility of care. The study also pointed out that many of the state's indicators were not disaggregated by ethnicity, which can be problematic for tracking health equity, particularly given that, at a macro level, there were more health-related resources available in areas with smaller indigenous populations [233].

According to SHRC, many staff, patients, and carers felt that prior to their application of an HRBA, patients' rights had been "left at the door." Patients were not viewed as having rights. The study documented a perceived attitude shift among both staff and patients, in which any restrictions on patients' rights had to be justified and there was an increased focus on the rights of staff and carers. As a result, the relationship between patients and staff improved. The study also recommended regular training and ongoing assessments of policy and practice to ensure the benefits continued [234].

4) Availability, accessibility, acceptability, and quality

The right to health requires that health facilities, goods, and services be available, accessible, acceptable, and of sufficient quality. The precise application will depend on the conditions prevailing in a particular state. Accessibility encompasses four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility, and information accessibility [13]. Accessibility is a core obligation of the right to health [13 para 43].

The four case studies on maternal and child health employed the AAAQ framework to analyse their respective countries' programmes on maternal and child health; they all found that various

elements of the AAAQ had been included, applied, and respected in these countries. The authors noted that applying and respecting AAAQ contributed to health gains, such as increased emergency obstetric care in Nepal, enhanced access to modern contraception in Brazil, reduction of early childhood mortality in Malawi, and increased vaccination coverage in Italy [139, 229, 230, 232]. For example, in Italy, by respecting quality, improvements in maternal health care were realised through standardised hospital procedures, general training for health professionals in maternal care, specialised training for health professionals dealing with women victims of sexual violence, and the establishment of specialised facilities for high-risk pregnancies [229]. Although the authors of the studies on maternal and child health documented the results of AAAQ, they underline that they may not have captured all the elements of an HRBA and that more evidence may be found from a more detailed analysis [139, 229, 230, 232].

PHR's case study on Peru found that rural indigenous women and their families were often blamed for their own deaths because of their delayed decisions to seek care – a delay that was ascribed to “culture preferences.” The report, which analysed these delays through an HRBA to health lens, including AAAQ, instead highlighted how delays in these families' decisions to seek care was related to systematic inequities in Peruvian society and health care system. For example, the delays in seeking care were influenced by the limited availability and accessibility of health care facilities, goods, and services, including emergency obstetric care. Furthermore, there was a lack of culturally sensitive and acceptable care at health facilities, in terms of both traditional languages and traditional birthing customs, which contributed to delays in seeking care. The delays were also attributed to economic barriers, including the costs of transportation. In addition, when families perceived the care at the facilities to be of poor quality, they delayed the decision to seek care.

The study by Williams and Brian investigated AAAQ in Papua New Guinea's Vision 2020 plan using an indicator assessment tool (see table 8), with the aim of determining whether the programme had been designed in a way that meets health rights obligations and that would help the state make its health services available, accessible, acceptable, and of good quality. The study found that of the 36 indicators related to a RBA in the assessment tool, only 9 were addressed partially, and the remaining 27 not at all [235]. More specifically, of the 12 indicators that looked at availability, 5 were partially addressed. In addition, the authors highlighted how the Vision 2020 plan's estimate of the health workers required failed to incorporate the location of health facilities, burden of disease, overall workforce size, and availability. Other gaps included a lack of training in eye health for key health cadres, such as doctors and nurses.

In addition, the indicators measuring accessibility were only partly addressed. The authors underline that there are limitations to the response to this indicator. They pointed out that although the project had suggested that patients be charged a fee for services, the project did not address the level of payment, nor did it provide any information from studies that had determined appropriate user fees and subsidies. The authors also noted that the programme did not take into consideration key aspects required to monitor the services, nor did it take into account context specific barriers that prevent people from accessing eye care services in Papua New Guinea, such as cost, communication barriers, and gender differences. The indicators on acceptability and quality were not addressed at all by the providers [235].

5) Participation

From a human rights perspective, participation is essential component of the right to health and a core obligation. Health systems should include institutional arrangements for the active and informed participation in strategy development, policy making, implementation, and accountability by all relevant stakeholders, including disadvantaged individuals, communities, and populations[2, 13].

Participation was included in all four cases studies on maternal and child health [139, 229, 230, 232]. In all four studies, women service users had been active participants through regular meetings with medical staff, government officials, and civil society representatives in fora such as committees and village groups. In Brazil and Malawi, women had been active participants in monitoring and evaluation activities [229, 232]. The study on Malawi noted a deepened community participation in children's health issues, which contributed to reductions in child mortality [229, 232]. The four studies' authors highlight that the realisation of an HRBA to women's and children's health depended on the participation of a number of stakeholders, such as the courts and national human rights institutions, especially in Brazil and Italy[229, 230], and to a lesser degree in Nepal and Malawi [139, 232]. All four studies suggest that the participation of a well-informed, dynamic, and diverse civil society played a vital role in the application of an HRBA to maternal and child health. However, there was little evidence presented in the four studies to substantiate this claim.

PHR's study on Peru noted that although local health centres provided a potential mechanism to facilitate community participation at the local level, especially among indigenous communities, this had been systematically underfunded. The study also found that health professionals working in the health centres were frustrated because they were often not invited to participate

in decisions that affected their work, such as the allocation of ambulances, funding assigned to hospitals, and quotas for institutional deliveries that disregarded the needs of frontline health workers. If the health workers did not meet these quotas, they were left with impoverishing salaries. PHR's study also highlighted the importance of civil society participation in monitoring policy makers, noting that no consultations had been held with UN agencies, user groups, or NGOs on the design of PARSalud II (the second phase of the reform programme in health by the Ministry of Health) [233].

In Northern Ireland, participation was an important aspect in the realisation of an HRBA to mental health, as noted by the McMillan et al.'s study on the activities of a group of mental health service users, bereaved families, and carers. The study focused on one of the recommendations of this group, a "card before you leave" appointment system for mental health patients. This intervention was meant to ensure that the individuals discharged after receiving mental health treatment would receive a card with the date and time of their follow-up appointment before leaving the premises. The study reported that participation helped ensure that the involvement of service users in existing mental health structures was meaningful insofar as they were involved at every stage of the decision making process on mental health policies and programmes. The expertise of the service users was maximised through the development of the indicators and benchmarks that were based on these users' own needs and experiences (see table 8). This experience illuminates how an HRBA helped focus not only on the outcomes achieved but also, importantly, on the process used to achieve them.

SHRC's study in Scotland also noted the importance of applying a participatory approach from the onset that involves both staff and users in the realisation of an HRBA to mental health. There was consensus among staff, users, and carers that there had been a significant change and improvement in the culture at the State Hospital. For example, the staff-patient relationship – which had initially been described as a "them and us" culture with little mutual respect and trust – had improved dramatically. Patients felt they had little ability to influence, and staff worked in fear that human rights would be used against them. Although the application of an HRBA resulted in a positive change in culture and attitudes, the study noted that when the HRBA was initially introduced, it was not accepted by staff as a positive thing. Many were sceptical of what the approach would achieve and feared that it would give the patients too much power. After the application of the HRBA, the majority of staff were more positive about human rights. Furthermore, with the application of an HRBA, staff, patients, and carers had moved towards a patient-focused approach where the concept of individualised care and treatment was seen as a

consequence of an HRBA; nonetheless, the study noted that it was evident that newer staff did not always relate this specifically to the HRBA. The study also highlighted that although most staff, patients, and carers now had a positive attitude towards the HRBA and believed it had improved the hospital's culture, some staff admitted that they continued to be resistant to the need for an HRBA.

Williams and Brian's study on Vision 2020 in Papua New Guinea did not explicitly include participation as an HRBA feature. However, their assessment did incorporate indicators on acceptability, which indirectly touched on participation. Their assessment showed there was no reference to the people who would be using the services, and no information on how "acceptability" would be assessed and monitored. While some indicators assessed the participation of local people in the design of a monitoring body, Williams and Brian reported that it was only partially addressed[235].

6) Empowerment

Empowerment is not an explicit feature of human rights law. It was, however, identified by SHRC as a feature of the HRBA. SHRC defines the empowerment of rights holders thus: "everyone should know their rights and be supported to participate in decision-making, and to claim their rights where necessary"[234 p.4]. There is therefore an overlap between this feature and "participation," which SHRC defines as "everyone [having] the right to participate in decisions which affect their human rights"[234 p.4]. With respect to empowerment, SHRC reported that prior to the implementation of the HRBA, there had been low levels of overall awareness and use of advance statements¹⁷ by service users across Scotland. However, the State Hospital promoted the use of advance statements through, for example, educational sessions which were provided at Patient Partnership Meetings to promote their use. Annual patient surveys demonstrated a rise in the use of advance statements by patients from 27% in 2007 to 42% in 2009 [234]. However, it is difficult to determine on the basis of these numbers whether rights holders (e.g., users) know their rights better, or whether the results are a reflection of their increased confidence and the ability to have their voices heard.

7) International assistance and cooperation

Human rights responsibility has several components, including the duty of high-income countries to provide – and low-income countries to seek – international assistance and cooperation. States

¹⁷ An advance statement is a legal instrument that documents, during a period of capacity, a patient's preferences for treatment during a future mental health crisis or period of incapacity.

are encouraged to take joint or separate action to achieve the full realisation of the right to health. For example, the Alma-Ata Declaration (1978) proclaims that gross inequalities in the health status of populations – particularly between developed and developing countries, as well as within countries – is politically, socially, and economically unacceptable, and is therefore a common concern to all countries[13 para 38].

PHR's study found that donors affected Peru's ability to address maternal mortality and achieve other health goals. For example, the Mexico City Policy, adopted by President Bush, prohibited foreign NGOs that received USAID family planning funds from using their own, non-US funds to provide legal abortion services, lobby their own governments for abortion law reform, or even provide information, counselling, or medical referrals regarding abortion. Furthermore, the World Bank and Inter-American Development Bank included family planning in PARSalud I, the Ministry of Health's reform programme[233].

Williams and Brian looked at Papua New Guinea's and Australia's human rights obligations based on their commitments. Specifically, the study draws attention to the international jurisdiction and obligations that an NGO or donor agency has when planning an intervention in another country. The study reports that the donor made no reference to the country's health rights obligations or whether eye care was part of these obligations. As a result, the study noted that eye service was not part of Papua New Guinea's obligations under the right to health, nor was it included in the country's national health plan [235].

8) Accountability

According to human rights, including the right to health, any person or group who has been a victim of violations should have access to appropriate remedies[13]. Accountability is not about blame and punishment but about individuals' opportunity to understand how those with responsibilities have discharged their duties and about authorities' opportunity to explain what and why they have done what they have done. There are different types of accountability mechanisms, such as NGOs, the media, UN Special Rapporteurs, and judicial mechanisms, such as the courts [238].

The case studies on maternal and child health all identified different accountability mechanisms. Nepal was the only study that identified judicial accountability mechanisms, specifically the case of *Dhikta v. Government of Nepal* (2009), in which the Supreme Court ordered the government to fulfil its duties as outlined in the country's abortion law – namely, to guarantee broad access to safe and legal abortion which is accessible and affordable. The court did not, however, further

liberalise abortion in Nepal; rather, it ordered the government to take steps to ensure the effective implementation of the abortion provisions passed by Parliament.

However, the study noted that in spite of progress since the case, remote and marginalised populations still faced barriers in accessing services in terms of cost and transportation. Furthermore, in the wake of Nepal's liberalisation of abortion in 2002, human rights concerns have been raised about the potential for an increase in the number of sex-selective abortions. The study thus highlights the need for monitoring and auditing to avoid unintended consequences of the legalisation of abortion [139 p. 119,32].

PHR's study found that the accountability mechanisms in place for addressing maternal mortality in Nepal were, for the most part, focused on the errors of individuals rather than on institutional and systemic factors. Consequently, these mechanisms were inadequate for ensuring accountability in the context of maternal mortality, as defined by human rights. PHR learned, for example, that health workers who worked on a contract basis and thus did not enjoy job security frequently risked losing their jobs or being sanctioned when a maternal death occurred in their establishment, even if they themselves were not responsible for the death. As a result, the accountability created perverse incentives in the health system for workers to avoid treating women suffering from obstetric emergencies. The study further noted that there was a lack of familiarity with the human rights mechanisms among lawyers and judges [233].

Although Williams and Brian did not explicitly include accountability as an HRBA-to-health feature in their study in Papua New Guinea, they underlined the fact that accountability and transparency are two important human rights concepts. As they argue, accountability and transparency are important not only for facilitating the design of acceptable programmes but also for allowing local community health administrations and the state to monitor how donor money is spent and associated outcomes [235].

Other findings

A number of other key findings also emerged which are important for the realisation of an HRBA. For example, the four studies on maternal and child health highlighted the role of a supportive enabling environment – such as a country's ratification of key international human rights treaties, endorsement of global commitments, recognition of the right to health in its national constitution, establishment of non-judicial human rights oversight bodies, and actions taken to ensure policy coherence and effective coordination among multiple stakeholders. In addition, the continual assessment and evaluation of policy and practice was seen as an important factor for the realisation of an HRBA to health[234]. Finally, the importance of training was highlighted in the

four case studies on maternal and child health[139, 229, 230, 232], as was the need for a refresher training noted in the study by SHRC [234].

4.4 CONSTRAINTS

There is some plausible evidence in the eight studies that an HRBA to health contributed to advancing health. However, in the studies on maternal and child health in Brazil, Italy, Nepal, and Malawi[139, 229, 230, 232], the authors acknowledged that the improvements were not exclusively attributable to the use of an HRBA to health, or to a single isolated HRBA policy or programme on women's and children's health. Rather, such contributions also depended on context, political will, and proactive measures to reduce health disparities and increase investment. The studies also documented that the women's and children's initiatives were dependent on high levels of political leadership and support, which also extended to HRBA initiatives. For example, the human rights-based initiative in Brazil was dependent on the country's universal public health system[229]. In Malawi, the human rights-shaped Integrated Management of Childhood Illness policy was informed by the country's Growth and Development Strategy [232]. In Nepal, the Women's Right to Life and Health Programme was partly derived from the country's National Safe Motherhood and Newborn Health Long-Term Plan[139]. In Italy, the Consultori Familiari was grounded in the country's Servizio Sanitario Nazionale[230].

According to the authors of these four case studies, an HRBA is unlikely to be implemented comprehensively and simultaneously in all women's and children's health programmes. Governments will most likely select a few carefully chosen policies and programmes. Moreover, women's and children's health policies and programmes that are shaped by human rights are likely to be closely connected to a broader health, developmental, or other policy initiative. The experiences from these four cases studies, according to the authors, suggest that if the broader policy context is also explicitly supportive of human rights – in other words, if there is policy coherence – it will help the realisation of a specific HRBA policy or programme, such as women's and children's health[239]. The experiences from these countries do not provide a blueprint for others to follow; rather, they provide instructive illustrations of how some governments have applied an HRBA which may have had a beneficial influence on women's and children's health [36]. The case studies should be seen not as comprehensive but as works in progress. The countries still face major challenges in their work on maternal and child health: Nepal and Malawi, for example, exhibited extremely high neonatal mortality rates (33 and 31 per 1,000 live births,

respectively, during the study period) [139, 232]. In Brazil, caesarean births accounted for almost half of all deliveries [229]. In Italy, there was still a widespread disparity between the north and south of the country [230].

PHR highlighted that the seven case studies used in its report were not intended to be scientifically representative. The authors also noted limitations to drawing conclusions with respect to the social, cultural, and systematic factors underlying maternal mortality across Peru because the cases were drawn from specific regions; other regions with different circumstances might have had different experiences. Nonetheless, the authors noted that many of the issues explored in their examples were systematic in nature and therefore not necessarily limited to individual regions.

McMillan et al.'s study emphasised that although there was clear evidence that an HRBA on mental health can positively affect mental health services, it is not clear what institutional improvements are necessary to meet the human rights obligations regarding these services. Furthermore, the group did not feel that its work had significantly improved the decision making processes used for them[231]. The study recognised that the positive results generated by the group of mental health service users – which led to the countrywide adoption of the “card before you leave” scheme – were dependent on a higher-level commitment within the government. For example, a civil servant was appointed and tasked with following up with service delivery bodies and ensuring that certain tasks were accomplished and problems were addressed. Further, the then minister of health's adoption of the “card before you leave” appointment system and decision to make follow-up care for mental health patients a “priority of action” for 2009–2010 also played a significant role in the realisation of an HRBA to mental health [231]. However, the authors stressed that without addressing the non-participation of service users and the power relationships between these users and government officials, for example, many of the underlying causes of problems in services will remain unresolved[231].

SHRC's study acknowledged that although the use of an HRBA appeared to be positive for advancing mental health, “it is very difficult to attribute change to a specific initiative or approach, especially when other initiatives are occurring concurrently within a short time frame”[234 p. 28]. Moreover, not all participants attributed the positive changes to an HRBA alone. While the patients and carers could not state that the positive culture changes were the result of the application of an HRBA alone, most staff noted the coincidence in timing between the perceived shifts in the culture and the original implementation of the HRBA. Like the studies on maternal

and child health [139, 229, 230, 232] and the study by McMillan et al. [231], SHRC's study noted that a critical element for the success of the HRBA was the support of the government and high-level officials. Furthermore, the involvement of human rights experts from an early stage to support the development and tailoring of an HRBA to mental health was another aspect crucial to the successful implementation of the HRBA to mental health in Scotland[234].

4.5 STRENGTH AND QUALITY OF THE EVIDENCE ON THE USE OF AN HRBA OR RBA TO HEALTH

The four studies on maternal and child health acknowledge their methodological limitations, including their reliance on secondary data, which precludes capturing many of the distinct features of an HRBA.

I assessed the quality of the qualitative studies using the RATS guidelines[189]. A brief summary of the results of the RATS appraisal is presented in table 9. Further details of the appraisal are provided in appendix 8. A number of common methodological issues arose in the studies.

All of the eight studies used some type of qualitative method, but only four of them reported on the methods. The other four studies did not report on the qualitative methods used [139, 229, 230, 232].

PHR's study on Peru was the only study to describe how recruitment was conducted, and it also reported on those who chose not to participate and their reasons for not doing so[233]. SHRC's study stated that a research consultant was hired to carry out the research, but it did not state how the sample selection took place [234]. Only two other studies reported on who they interviewed, [231, 234] making it impossible to understand a possible selection bias in the other studies.

Data collection was only partly reported on. For example, none of the studies reported on the questions used, and only two of the studies described, even partly, the study setting[233, 234]. None of the studies discussed the role of the researcher and how this might have influenced the formulation of research questions, data collection, or data interpretation. None of the studies reported on deviant cases. Ethical clearance and informed consent were explicitly mentioned in only one study[233]; in another study, it was deemed unnecessary since the study only assessed a plan [235].

All the studies had clear frameworks for applying their HRBA or RBA [139, 229-235]. All studies used quotes, which strengthened the arguments. Only one study explicitly mentioned the term “reliability check,” [234] although all studies explicitly compared and contrasted their findings using a range of qualitative methods.

All the studies had strong discussions and interpretations, although discussion on the strengths and limitations of the studies was missing. All the manuscripts were clearly written and accessible. RATS asks if the findings presented refer to existing theoretical and empirical literature, and how they contribute to it [189]. While it was perhaps difficult for the studies to relate their findings to other studies following an HRBA given the lack of such studies, they could have referred to other relevant literature, such as studies on health outcomes of interest in the countries under exploration. The one exception is PHR’s study, which referred to a number of other studies in Peru that also used maternal mortality case studies [233].

In summary, there is a very limited quantity of high-quality studies on the impact of an HRBA to health in specific countries. As a result, it is impossible to draw firm conclusions from these studies. Substantially more research is required using a rights-based approach in a range of low-, middle-, and high-income countries and using much more rigorous research methods.

TABLE 9. APPRAISAL OF THE QUALITY OF QUALITATIVE STUDIES

Guideline/study	Barros De Luca, G., et al. (Brazil) [229]	Longhi, S., et al. (Italy)[230]	McMillan, F., et al. (N. Ireland) [231]	Mhango, C., et al. (Malawi) [232]	Patel, A., et al. (Nepal) [139]	PHR (Peru) [233]	SHRC (Scotland) [234]	Williams, C., and Brian, G. (Papua New Guinea) [235]
Relevance of the study question	✓	✓	✓	✓	✓	✓	✓	✓
Appropriateness of qualitative method	✓	✓	✓	✓	✓	✓	✓	✓
Transparency of procedure:								
Sampling	X	X	P	X	X	✓	✓	N/A
Recruitment	X	X	X	X	X	✓	P	N/A
Data Collection	X	X	P		X	✓	✓	✓
Role of researcher	X	X	X	X	X	X	X	✓
Soundness of interpretation:								
Analysis	X	X	P	X	X	✓	✓	✓
Discussion and presentation	X	X	✓	X	X	✓	✓	✓
<i>Legend</i>	<i>✓ = yes</i> <i>N/A = not applicable</i> <i>X = information is not available or not clear</i> <i>P = partly</i>							

4.6 DISCUSSION

To the best of my knowledge, this is the first narrative literature review to explore existing evidence on the use of an HRBA to health. For this current review, eight databases were searched, supplemented with an investigation of ten grey literature databases, as well as snowballing techniques and expert suggestions. Despite the diverse range of data sources and broad inclusion criteria employed, the searches yielded only eight studies.

The selected studies included a mix of health topics, with a predominance of maternal and child health and mental health. The results point to the possibly positive influence of an HRBA or RBA on the various health issues. All of the studies found that an HRBA to health had a plausibly positive association with the health issue at hand and aided the analysis of policies, projects, and plans. However, this conclusion is drawn from a very small number of studies of generally limited methodological quality (discussed further below) and should thus be treated with considerable caution.

There were very few studies which focused on an HRBA to mental health; since these were carried out in the United Kingdom, it is not possible to say whether such an approach to mental health would have a positive impact in middle- and low-income countries. There was a greater geographical distribution of maternal and child health by income levels, which could reflect the global focus and attention paid to maternal and child health through, for example, the Millennium Development Goals, when compared to mental health[240].

The findings also suggest that treaty ratification was unlikely to automatically lead to the realisation of HRBA to health. These results are in line with the findings of a study on HIV prevalence and maternal, infant, and child (<5 years) mortality in 170 countries by Palmer et al. (2009), which showed no consistent association between the ratification of human rights treaties and health or social outcomes[241]. In my review, constitutional recognition appeared to be more important than international ratification in realising an HRBA/RBA, particularly for mental health. Constitutional recognition brings rights closer to the people and strengthens national accountability, which has been shown to have a beneficial impact on health. One example is the South African legal case *Minister of Health and Others v. Treatment Action Campaign* and its success in addressing mother-to-child health transmission of HIV[242]. Although the constitutional recognition of human rights is a requirement of international human rights law, many countries are reluctant to integrate their international obligations into their national laws

or constitutions, as international accountability is often weaker than national accountability [7]. The international human rights accountability system is complex. For example, an individual complaint can be examined only if the case has not been previously determined by another international body. Moreover, the layers of protection vary from state to state, depending on the existence of a regional human rights system and each state's ratification of regional and universal human rights treaties. Further, the use of one system over another will depend not only on state membership but also on which body has produced more favourable case law, the reparations and other outcomes available at each, and practical considerations such as case processing time and backlogs[243].

In the studies on maternal and child health, civil society was highlighted as playing a very important role in the realisation of an HRBA to maternal and child health. The importance of civil society participation was highlighted by only one of the studies on mental health[234]. It is possible that the role of civil society was not highlighted to the same extent in the mental health studies because the aim of these studies was to evaluate the application of an HRBA by service users, staff, and carers [231, 234], whereas the studies on maternal and child health explored the possible influence of an HRBA on aspects of women's and children's health[36]. The study by William and Brian pointed to the need for NGOs to apply an HRBA to health[235]. Other authors have also highlighted the importance of an active and strong civil society [9, 244].

All eight studies concluded that the realisation of an HRBA, irrespective of labelling, appeared to be facilitated by an enabling environment – such as political commitments, support and resources, international human rights commitments, and the constitutional recognition of health rights – and reinforced by judicial and non-judicial human rights oversight bodies, with strong civil societies that monitor and hold those responsible to account. This conclusion resonates with those of other studies [214, 215].

There were also some common features across the studies which aligned with globally agreed-upon human rights norms and standards and which support the idea of having an HRBA to health checklist, as proposed by Gruskin et al. (2010), for participation, non-discrimination, AAAQ, accountability, and transparency [35]. However, transparency was not explicitly mentioned by any study in this review. Overall, it seems that the features presented as HRBA or RBA features are common values espoused by both the health and human rights fields; this is particularly the case with participation, which is highlighted in the public health literature as of great importance for the realisation of public health and the effective delivery of health systems [22, 245, 246].

Although the findings from this review suggest a positive impact and common features, the studies did employ a wide range of terminologies and articulations of what constitutes an HRBA to health. This ultimately makes it difficult to compare them and weakens the evidence, an observation that has been pointed out elsewhere [20, 35, 36]. However, human rights experts have claimed that different approaches are often united by a common purpose and core set of principles that provide a baseline for human rights protection, and that although varying terms may be used, they essentially mean the same thing. This might be true when discussing human rights from a legal perspective, but it does not hold true if the aim is to explore the impact of an HRBA to health, which benefits from greater levels of comparability. Furthermore, if the audience consists of health professionals, then terminologies may need to be improved and standardised in order for an HRBA to health to be systematically and meaningfully applied and researched.

The problems associated with the use of different terminologies should not be underestimated. Although progress in collaboration between health and human rights are noted, many health workers are still unsure about the exact meaning and sceptical about the added value of the right to health, and human rights in general as applied to the health sector. Collaboration with the health sector is essential for the realisation of the right to health, but the various terms used and interpretations of what constitutes an HRBA to health may lead to continued scepticism to the added value of the right to health and human rights and may discourage the health sector from applying an HRBA to health. Indeed, London's (2008) experience in South Africa led to his suggestion that inappropriate or inadequate conceptualisation of what human rights are and what an HRBA to health is may have major adverse consequences for population health[9]. The different understandings of an HRBA to health may also discourage researchers from undertaking impact evaluations and investigating the effectiveness of an HRBA to health, as methodologically it will be very challenging. Indeed, this may be another reason for the limited empirical evidence that presently exists in this area [35, 36, 247].

The review also highlighted considerable limitations with regard to the quantity and quality of the evidence base on HRBAs to advancing health. To carry out research on HRBAs requires an understanding of human rights and of research methods, which in turn requires close collaboration between the fields of health and human rights. The studies in this review highlighted the difficulties around determining, with certainty, the direct influence of an HRBA. Other authors have also highlighted that it is at times difficult to determine a direct cause-and-effect relationship of a human rights approach[248]. The WHO, in answer to its question around

what level of evidence is needed of an HRBA to maternal and child health, recommends that this depend on context and feasibility. However, it does suggest that the most suitable or “plausible” form of evidence should include a non-randomised control group, as this will provide a greater degree of confidence that the changes observed are due to interventions based on an HRBA [36]. The absence of any such studies, as identified in this review, highlights the limited evidence. However, the methodological and logistical challenges of establishing such control studies should also be acknowledged.

It is also important to recognise the limits of the role of evidence. According to London (2008), there is a tendency to focus primarily on the evidence, with the relative marginalisation of both international and constitutional legal obligations. There is thus the danger that policy makers will be relieved of their burden to respond to their international and constitutional responsibilities [9].

4.6.1 Review limitations

I was the only person screening, extracting, and appraising the data in the review, which means that the reliability of the review may be reduced compared to reviews conducted by two independent people. In addition, I applied only English-language search terms, and so studies in other languages might have been missed.

4.6.2 Conclusion

This review suggests the existence of limited evidence that improved health outcomes, including in relation to service provision, may result from the use of an HRBA to maternal, child, and mental health. This evidence, however, is based on a very small number of studies. In addition, the quality is generally extremely weak. These findings suggest that there is a need for a clear definition of what constitutes an HRBA, as well as a need for significantly more and better-quality research in all areas of health and HRBAs, particularly in low- and middle-income settings.

The next chapter will present the primary research findings with regard to objective 2, which concerns Nepali health workers’ perceptions of the right to health.

CHAPTER 5: PERSPECTIVES ON THE RIGHT TO HEALTH AMONG MENTAL HEALTH WORKERS IN NEPAL

The previous chapter looked at existing evidence on the use of HRBAs to health. The key findings demonstrate a scarcity of evidence on this topic and highlight the need for further research to better understand the strengths, weaknesses, and influence of an HRBA to health and mental health.

This chapter focuses on my field research in Nepal, specifically with regard to PRIME's project in Chitwan. The objective of this chapter is to explore perspectives on the right to health among mental health workers in Nepal. To this end, the chapter focuses on health workers' experiences and perspectives on the right to health in mental health. To capture the different perspectives of health workers – which include mental health service providers, managers, and policy makers – I used three different qualitative methods: focus groups, semi-structured interviews, and context meetings. The participants were all part of PRIME, with the exception of the participants in the context meetings (see chapter 2 for further information on the methods).

The perspectives of health workers are pivotal, as these workers are the key translators and implementers of policies and programmes. Attempting to put the right to health and other health-related rights into practice without the understanding and support of health workers, particularly health service providers, could be extremely problematic and potentially counterproductive, as different understandings and approaches could result in limited or flawed policy implementation.

This chapter begins by exploring participants' general understanding of human rights and the right to health. It then explores health workers' understanding of the rights of persons with psychosocial disabilities, as well as their perspectives on the value of the right to health in mental health. The chapter concludes by summarising the findings and highlighting some reflections.

5.1 UNDERSTANDING OF HUMAN RIGHTS AND THE RIGHT TO HEALTH

Health workers across all levels of the health system expressed awareness of human rights broadly but emphasised that their meaning was difficult to understand. As one health service provider at a PHC centre asserted, "To my knowledge, human right means getting all the things needed as human being; like getting services in proper place, proper time. Exact definition is difficult for us to say" (R1T8: PHC Centre-Service Provider).

At the district level, participants also expressed difficulties in defining human rights. As explained by two health service providers from the district hospital in Chitwan:

“Human rights, well probably even I haven’t understood properly what human rights is, what can we term as human rights” (T1: District-Service Provider).

“We are not clear what it does and doesn’t [do]” (T15: District-Service Provider-Newly trained).

Since the health workers themselves seemed uncertain of the definition of human rights, I asked them if they could describe what they thought other people – i.e., the general population – thought about human rights. Health workers at the PHC centre did not appear to feel that the general population was aware of their human rights. One of the health service providers from the “prescriber group” (participants who could prescribe medicine at the PHC centre) said, “In Nepal many people are unaware of human rights” (R4T8: PHC Centre-Service Provider). A similar belief was expressed by the “non-prescriber group” (participants who could not prescribe medicine at the PHC centre). As one of the health service providers at the PHC centre said, “I don’t think that the so-called victims at the lower level understand it ... I don’t think people have really understood what human rights is about” (R3T10: PHC Centre-Service Provider).

Some health workers at the district and national levels said that it was likely that the general population perceived human rights in broad terms – as encompassing everything they needed or wanted, all of which should be provided by the government. A health worker/coordinator based at the district level, but who also worked at the PHC centre, explained, “People understand human rights as getting what they think they need, [what] they should be allowed to do and [what the] government should provide ...” (T5: District-Manager/Coordinator).

A health manager located in Kathmandu provided an illustration of how everything becomes “human rights”:

“Because it [human rights] is connected in everywhere and every aspect, like health issues and other like poor issues and other like basic facilities, like in government level, in family level so it is quite huge, so people generally they use the word human rights, in everywhere [smiles] ... So it is quite popular and widely used term in Nepal, but it is difficult. Even the person who use this word frequently, they also, I think, don’t know exactly what is the definition of human rights, but, people use it” (T17: National-Manager/Coordinator).

The health workers also felt that urban and rural living location may influence people's perception of human rights. The PHC centres were located about one hour by motorbike from the city of Chitwan. The villages served by the PHC centres had a limited presence of civil society organisations, particularly those working on human rights. As a result, the population served by PRIME's PHC centres might not have been exposed to information on human rights. As one of the participants from a PHC centre stated, "The human rights activists ... haven't reached the lower levels yet" (R4 T10: PHC Centre-Service Provider). The health services located at the district and national levels were based in cities, which had a larger number of civil society organisations working on human rights. This was reflected by a newly trained health service provider at the district level:

"Now-days we really need to think how and what we say to the patients, as they [the users] have become aware [of their rights]. We have to give full justification for everything" (T14: District-Service Provider).

While health workers at all levels appeared to find it difficult to understand human rights, they seemed to agree that it was important for users to understand their human rights. A few participants at the district level indicated that it was also important for them as health workers to understand their human rights in order to be able to interact with users and to be more confident when talking about human rights:

"Well regarding human rights ... it has been written in the Constitution [Nepali] about human rights, so the ones who provide services they should be well informed about human rights. Like, if a patient comes to take out his tooth he should be given anaesthesia, if not I didn't do a good job. The patient should know that his tooth should be taken out without pain. I should also agree with that it is the patient's human right – I should understand [the human rights]" (T6: District-Service Provider).

Another participant, who was both a health service provider and a manager at the district level, agreed that service users have rights but also stressed the need for a clear definition of human rights, with an emphasis on equal rights between health care users and workers:

"When one right is elaborated the other's right becomes small. Like, when talking about human rights, the service providers also have rights. It might happen that we focus more on the service users' rights and forget about the service providers' rights. That is why everybody's rights should be defined ... This does not always happen" (T4: District-Service Provider).

There was a perception among a number of health managers at the national level and higher-ranking service providers at the district level that “lower-ranking” health workers did not have an understanding of human rights. As one mental health manager noted, “So health care workers [those working in the PHC centres] might not be much aware of some of the basic things of human rights principles. That is my assumption. They might not be aware of that” (T16: National-Policy Maker).

Health service providers at the PHC centres also had a similar perception. As one of them expressed when asked to define human rights, “There isn’t anything in detail regarding human rights. Human rights started from 1948 and in Nepal the educated groups of people have understood it” (R1T8: PHC Centre-Service Provider).

This person’s words reflect a perception that “higher” ranking health workers – those with greater educational levels and who work at the management and policy level in Kathmandu – have a better understanding of human rights. It may be grounded in a mix of deeply rooted hierarchical structures existing within the health sector and in the belief that people who have more years of formal education have a better understanding of human rights. When asked to define human rights, the same health service provider at the PHC centre stated, “Since we are not well trained and we haven’t received training, we may not define human rights properly. It might represent other way round” (R1T8: PHC Centre-Service Provider). The reference to “well trained” is uncertain if related to formal education or only to human rights training. Yet the belief expressed by “higher” ranking health workers that some health workers have a better understanding than others about human rights was not confirmed in this study. The findings indicate that there was no major difference between different participants’ knowledge of human rights; most participants were uncertain when talking about human rights, regardless of their job or education level. There was, however, a variance in how participants expressed their knowledge of human rights. Participants in Kathmandu and health managers at the district level seemed to be more familiar with discussing human rights, including the broader policy perspectives and human rights treaties and principles, when compared with “lower-level” service providers. For example, a few health managers/coordinators at the national level reflected on how human rights might be a Western concept. As noted by one manager/coordinator in Kathmandu, who also had close links to the PHC centres:

“It [human rights] is a western thing ... Especially when it comes with working with children. I do think, for example, the Convention of the Rights of the Child is a western product. And you notice that if you are critical about it, it is a bit of a neo-colonialist movement [smiles] in that there is a certain of a charter of rights that are of course everybody has signed up to, but they [the human rights charter] on western morale, I think” (T19: National-Manager/Coordinator).

Health service providers at the district level demonstrated confidence when expressing their views about human rights and linking human rights to the broader health system perspective, even if they had a limited formal understanding. For example, when discussing human rights through their lived experience, one service provider noted:

“The one who is facing injustice, they [the human rights activists] work for victim’s justice. But it [justice] has not happened. It [justice] has only happened to the rich and powerful. If such people [the rich and powerful] experience injustice then the [human rights] activists speak up for them. But, those who haven’t got justice, [those] who are poor, who need it – human rights haven’t been able to reach those people [R₃ agrees]” (R2: PHC Centre-Service Provider).

Some participants tried to explain why human rights were not well understood. A health manager in Kathmandu explained, “[it is] only after 12 years-long civil war and establishment of democracy system that people started to talk about rights and raise their voice ... before that it was unknown” (T17: National-Manager/Coordinator). A human rights lawyer explained in a context meeting how people had been prohibited from talking about human rights before the war. The fact that participants expressed uncertainty in their understandings of human rights may be explained by the fact that the use and application of human rights in Nepal is a recent development. Nevertheless, there was a surprising consensus among the participants in their view and understanding of human rights, even when I used different research methods. The reasons for this will be explored in chapter 7.

5.1.1. Understanding of the right to health

In contrast to the broad and uncertain ways in which health workers spoke about human rights generally, participants spoke about the right to health with much greater certainty and precision, partly as a result of the right to health being included in the Constitution of Nepal (see chapter 1, background section). The 2006 Constitution includes a focus on the right to free health services and treatments, as a noted by newly trained PHC centre health service provider:

“In Nepalese Constitution health services are defined as human right of people ... We are aware of about their [patients’] actual rights, and here the primary health care services are provided for free. The safe delivery, antenatal, post-natal and then EPI [Expanded Program for Immunization] are provided for free” (T11: PHC Centre-Service Provider-Newly Trained).

Participants from the PHC centres were quite vague when describing the right to health, but they did note how “more focus should be given to mental health” (R2: PHC Centre-Service provider). Even if the participants at the PHC centres did not elaborate on the definition of the right to health, they were aware of the right to health and its meaning. Also, at the district level, participants sometimes defined the right to health but used the term “human rights” and did not always make distinctions between the terms. One district hospital manager explained the right to health thus:

“People are demanding right and free of cost health services. And government also accept the idea of human rights, and the government has defined what is basic health services, and I think, accept this as people’s human rights. The government has defined what is basic health services and on the basis on government resources, this health serves ... it also depends on this type of health service, basic health services we should provide free of cost to all people, this is also what government is also doing, it is in line with this human right [the right to health]” (T3: District-Manager).

Two participants at the national level pointed to the fact that politicians sometimes referred to the right to health as encompassing only physical health, despite the fact that that the right to health in the Constitution encompasses both physical and mental health. One health service provider and manager at the national level described a conversation with the minister of health about the right to health:

“I am so glad you told me that every sub-health post and local place free of cost and every citizen can get free health care services, the government has made that. You told me. So, please tell me is mental health a health issue or not? If mental health is also a health issue, tell me one district hospital, one sub-health post, health post, where I can go, where I can send my people, they can get free of cost mental health services, and free of cost quality services. Show me one place, one place in Nepal. And district hospital or health post or sub-health post, I want to go there, I want to send my people. Give me one place, one place would be enough for me ... he [the minister] excused that for apology that they [the government] have done nothing for mental health” (T18: National-Manager/Coordinator).

One reason for this focus on physical health, according to a health manager for PRIME in Chitwan, is that “most of the health workers don’t know about mental health. In their medical training,

health workers only receive a few hours on mental health. That is why they don't know about mental health" (T5: District-Manager/Coordinator).

Although participants were more confident when talking about the right to health, those at the district and national levels did not think that rural populations would understand the right to health, including the fact that the right was not being realised in many rural settings. As a health manager at the national level expressed:

"In the rural areas ... [the general population] do not know ... about the right to health. Because they do not know...whose responsibility [it is] to provide health services, because the government provides free services in the primary health care centres, but you do not get anything there. If you go there you need to buy even ... paracetamol" (T17: National-Manager/Coordinator).

Another recurring theme was the perception that the right to health was being marginalised in the overall human rights discourse. The same participant noted:

"Especially after the resolution of the conflict, we are in the turning stage from monarchy, to democracy, to federalism, so now you can see, everyday demonstrations. We have more than 100 caste/ethnic group asking for their own state ... asking for different things ... No one is asking about the right to health ... We are dying without medicine, but no. It is not like it has come up on those tough issues ... [The right to health] is beyond our expectations, because the government is not ready to provide drinking water, electricity, roads, and security" (T17: National-Manager/Coordinator).

A human rights lawyer emphasised in a context meeting that most people perceived human rights thus: "They should not be killed, right to have political parties, right to participate ... Only civil and political violations are documented" (F3: National-Human Rights Lawyer). The human rights lawyer explained that the focus in Nepal had been on civil and political rights and not on the economic, social, and cultural rights in which the right to health can be found (see chapter 1).

There was also a great uniformity in participants' grasp of the right to health. It was very much a singular voice when participants talked about both human rights and the right to health, irrespective of the research method used and where in the health system the participants worked. The reasons for this uniformity are explored in chapter 7. The next section looks at participants' understanding of the rights of persons with disabilities.

5.2 UNDERSTANDING OF THE RIGHTS OF PERSONS WITH PSYCHOSOCIAL DISABILITIES

Participants' understanding of the rights of persons with psychosocial disabilities was limited. At the PHC centre level, one health service provider stated:

“In the context of human rights, every individual has different rights. People with mental illness seem to be neglected by families and society. As a result, anti-social behaviour is seen; like walking in the streets without clothes. Neither the community nor the health workers are willing to help such patients” (R2T8: PHC Centre-Service Provider).

This notion that different human rights pertain to different people was again raised in context meetings with two mental health service providers at a private hospital in Chitwan. The two providers noted that different rights pertain to people with different psychosocial disabilities, distinguishing between, for example, alcohol use, depression, and psychosis:

“There are different human rights between different patients. We have to make different rules to different mental illness, such as neurotic, psychotic, addiction and other mental disorders. People with alcohol use disorder or drug users, they are at times criminals, as they have different human rights” (F11: District-Service Provider (Private Sector)).

Another health service provider at the same hospital tried to explain this view of dissimilar rights between people with different disabilities, specifically those with alcohol use disorder: “When there is no mental health involved, and you drink and drive, you are punished. If they drink and drive, but there is mental health involved, the person goes to the hospital and is not punished” (F20: District-Service Provider (Private Sector)). This explanation confirms the limited understanding of the right to health and the consequences such as view can have. The view rather mirrors an understanding in which a person with an alcohol disorder is culpable of his or her actions; the participant seems to think that the person has intentionally driven drunk, knowing that he or she will be exonerated on account of suffering from a psychosocial disability. When this view was raised in my semi-structured interview with PRIME participants, some participants rebutted it. One participant at a PHC centre noted, “When we say rights, our rights and their rights are the same” (R3T10: PHC Centre-Service Provider). Another said, “Treatments are different, rights are the same” (R4T10: PHC Centre-Service Provider). Health service providers from the PHC centres were the ones who most strongly rebutted this distinction between rights for different disorders. The PRIME respondents did not present a hierarchical structure in which

some had more and others had fewer rights. Rather, they spoke about some of the common perceptions surrounding certain psychosocial disabilities and how these views might underpin the belief that different psychosocial disabilities deserve different rights.

PRIME participants also stressed that perceptions of the causes behind different disabilities could lead to the belief that different disabilities have different human rights. For example, with respect to depression, one of the health service providers at a PHC centre explained:

“When we talk about human rights, in depression cases ... In our society, depression is still viewed as a consequence of ghosts and evil spirits. People call such person mad. There is a kind of trend among people that they say it happens because of something is going wrong relating to Gods” (R3T10: PHC Centre-Service Provider).

This view was shared by a number of participants at the district level. However, the participants themselves disputed this explanation, as stressed by one PHC centre health service provider:

“Our thoughts on this [depression and human rights]. It is not like that. It [depression] is a mental illness. It happens because of some personal issues or social reasons or some other reasons like that, but the society doesn't think like that” (R4T10: PHC Centre-Service Provider).

Participants at the PHC centres and the district level explained how disabilities could be interrelated, as well as how they might be influenced by the Nepali context. For example, the lack of income and jobs could lead to drinking problems, particularly among the husbands, which in turn may lead to depression among, for the most part, the wife; and one or both parents got depressed if a female child was born- reflecting the widespread gender discrimination. There was also the perception that if a person committed a sin, God could punish that person, which in turn could cause them to suffer from a mental disorder such as depression. It was largely with regard to alcohol that participants distinguished between rights; perhaps this is because, as the health service providers in the context meeting explained, alcohol and alcoholics caused problems for the rest of the family in terms of causing the women to suffer from depression when their husbands cannot work and thus cannot not send their children to school.

Another perspective raised was the perception of the burden on society imposed by people with psychosocial disabilities. As explained by a health service provider/manager at the district level:

“No, it is different [rights], it is different for mentally ill people ... people think it [psychosocial disabilities] is a punishment of God or other spiritual thing. Due to that the concept here is that it [psychosocial disabilities] is a punishment for the person’s sins. Another thing is that people think it [mental disorder] can’t be treated and people think that mentally ill people are a burden of the society, burden of the family. There is this kind of thinking, that such people are a burden for us” (T4: District-Service Provider).

A manager at the national level also explained that the differentiation of rights might be related to the level of stigma attached to different disabilities:

“But [there might be] an informal picking order, I don’t know. [Perhaps] somebody with psychosis is considered much more of a mental disability than somebody with depression, or alcohol. It might also be related to the level of stigma attached to it [the disability]” (T19: National-Manager/Coordinator).

Health service providers and other health workers who had been recently trained by PRIME seemed to have a better and more nuanced understanding of the right to health. They also seemed more willing or able to reflect on their own attitudes towards people with psychosocial disabilities. One newly trained health manager at a PHC centre tried to explain how many health workers might feel in their service towards alcoholics:

“They are alcoholics, why should we bother about them? Why should we council them? Why should we look after their illness? They don’t have rights. It is also coming up in the health personnel. I think I felt like that [before the training]” (T12: PHC Centre-Service Provider (Newly Trained)).

PRIME addresses stigma and discrimination in its training, and therefore the participants might naturally object to any expressions of discrimination.

Health workers’ limited understanding of the rights of persons with psychosocial disabilities (and their related concerns with it) reflected the limited understanding of human rights more broadly, as well as an underlying frustration with human rights. For example, a health service provider at the district hospital in Chitwan noted:

“He [mental health service user] says that he has human rights, that his rights have been violated, that the doctors should be there all the time. But, he says he does not have any rights, he comes to the hospital and he is not able to see the doctor, the doctor is not on duty, and his human rights is gone. He might be right ... but he himself is not able to prioritise his problems. Whatever he thinks at the time is his problem ... But if the doctor

stays in the hospital, patients will keep coming every minute – there is no limit” (T9: District-Service Provider).

The limited understanding of the rights of persons with disabilities, as well as human rights in general, resulted in frustration among health workers, particularly health service providers at the district and national levels, when patients demanded that their human rights be met or used human rights to question health workers’ performance. In one context meeting, a health worker noted, “The human rights are not ready to accept that some things might not be possible to do now” (F20: District-Service Provider).

A health service provider at the district level also underlined:

“In the context of Nepal, which is in a transition phase, rights come up a lot. Rights and responsibility should be managed because where there are rights, there should be responsibilities. Here, it [rights] is only understood from the public perspective that there are only rights, but the public too has responsibilities” (T4: District-Service Provider).

Responsibility was associated with understanding the context in which health service providers were working:

“The public demands a lot. The government sends little resources. And, to whom does the public demand? The health worker. The public does not demand to the government, they demand to the health worker. The health worker has very little resources so she/he can provide only a little. So, that is why the situation is sort of imbalanced” (T4: District-Service Provider).

It was believed that human rights training was necessary for both health workers and the population. A mental health worker at the policy level was also critical of the training on human rights provided by the human rights community for the health sector. The worker emphasised that such training was often insufficiently tailored to the specific needs of local health service providers:

“I have attended a couple of these trainings ... sometimes I felt the training was very high level: what are human rights? What are treaty bodies? How do you report to the UN system? I mean, this is no point to provide this type of training to our health care workers, I mean, it should be related with their job” (T16: National-Policy Maker).

Health service providers at the district hospital in Chitwan had received guidelines on HIV/TB and human rights, which they found very useful. However, they felt they needed more on mental health. As a health service provider explained:

“If we can formulate some guidelines, [stating] the rights of the mentally ill: if these points are achieved he is not deprived of his rights; if these points are not achieved then his rights are violated. [If his/her rights are] deprived, then we can see what we can do to improve the rights. If we do not have the guidelines, I think it will be difficult to realize the rights of persons with psychosocial disabilities ... it will be superficial” (T9: District-Service Provider).

Participants from the PHC centre said they had not attended any human rights trainings and could therefore not express their experiences in this regard. This comment confirms the importance placed by health workers on understanding human rights (both theirs and those of users).

5.3 PERSPECTIVES ON THE VALUE OF THE INTEGRATION OF THE RIGHT TO HEALTH INTO MENTAL HEALTH SERVICES

In spite of the limited understanding with regard to the different areas of human rights (human rights, the right to health, and the rights of persons with psychosocial disabilities) and some frustrations highlighted by participants, the majority of participants still perceived the right to health and all human rights as important for improving mental health. Respondents commonly noted how human rights were “important” or commented on the “positive impact of human rights in mental health.” A health service provider at one of the PHC centres said, “Well, [if] human rights are used it will be better for the patients. It will also be better for the health workers ... because it [human rights] deals with health workers’ human rights also” (T11: PHC Centre-Service Provider (Newly Trained)). Indeed, another participant from a PHC centre noted:

“Earlier, wooden locks were put around the legs of people with psychosocial disabilities so they could not move. If people had knowledge and awareness about human rights and that people with psychosocial disabilities should be given treatment, it would be better” (R3T10: PHC Centre-Service Provider).

Participants felt that human rights should be practiced and applied in every sector – and not just the health sector – since the problems in the health sector were also related to those in the other sectors, such as a lack of housing and food. Although participants seemed to feel that they, as health service providers, should know about human rights and should apply and integrate them, in the words of one district-level service provider, “the government should be responsible for it.

If not we should fight for it [human rights]. It [human rights] is the most essential aspect” (T6: PHC Centre-Service Provider). One health manager at the national level reflected:

“This [human rights] is important and it is needed ... It is like making a nice curry, we need it in everything. If the salt is not there, then it is not tasty. It is the same in health, it is the same in the health system and its services. It [human rights] is an important component [for the mental health system]” (T17: National-Manager/Coordinator).

In light of the above comments, I asked participants to elaborate on their perspectives of the possible value of integrating the right to health into policies, plans, and programmes – in other words, applying an HRBA to health. However, since the term “HRBA” was not understood by everyone, I asked participants simply to describe the value of the application or integration of human rights or the right to health in mental health.

Although none of the PRIME participants had experience with integrating human rights into mental health, some participants – those located at the district and national levels of the health system – had previously worked on sexual and reproductive health and rights, including HIV, and had experience with HRBAs to health. As one service provider/health manager at the district hospital reflected, “More or less the HIV program has a rights based approach, and there are services for the infected and affected based on demand. More [HRBAs exist] in HIV program” (T4: District-Service Provider). The participant, although positive, was also critical of the value of an HRBA to health:

“In my view, it is not important to have big talks about the rights based approach but at least ... whatever barriers there are for reaching the services should be removed [states very assuringly] ... Actually, the rights based activists say a lot of things [states assuringly], but those things might not be practical ... In the community there should be access to services and the barriers that arise when using the services should be removed. Access to information should be there and should reach every individual, this is important” (T4: District-Service Provider).

Another health manager at the district level reflected on the impact that an HRBA had had on sexual and reproductive health and rights in Nepal:

“It [HRBA] has had a good impact in health because we didn’t have abortion services, maternal mortality was very high. Now, safe abortion services are available in the health centres. This is good. Similarly, females can give their opinion in family planning services,

which is good. I think it [HRBA] has been very good for health” (T5: District-Manager/Coordinator).

Many participants also believed that human rights and HRBAs had contributed to the reduction of maternal mortality in Nepal. As one of PRIME’s health managers at the national level explained:

“If you see the data five years back, maternal mortality was 549 per 100 000 live birth, and now it is less than 200, child, infant, maternal mortality death, so it is possible [to make change], this is possible, but it takes time” (T17: National-Manager/Coordinator).

The experience of integrating human rights into other health sectors appeared to be important for determining the value of incorporating human rights and applying an HRBA to mental health. In the words of one of PRIME’s mental health managers, “Because we have experience [in integrating human rights], we have evidence, that it [human rights] already works in other sectors” (T17: National-Manager/Coordinator).

One of the managers at the district level reflected on what the value added of applying an HRBA to mental health could be for PRIME: “An human rights based approach is always looked upon from the service-users’ point of view, which PRIME should be doing” (T5: District-Manager/Coordinator).

When asked about the value added by the right to health and human rights to mental health, one health service provider at the district level responded, “Many rights are being sought for and changes have come [as a result of human rights activists], leading to that people ask for [more] rights, which have led to changes” (T2R3: District-Service Provider).

5.4 SUMMARY OF FINDINGS

The key findings in this chapter indicate that participants were aware of human rights but had some difficulty in understanding their meaning. In contrast, participants’ understanding of the right to health was expressed with greater certainty and precision, partly attributable to the right to health being included in Nepal’s Constitution. When participants talked about human rights and the right to health, they appeared to have a very similar theoretical understanding. There was a surprising consensus among participants regarding their views on human rights and the right to health. In contrast, their understanding of the rights of persons with psychosocial disabilities was limited. For example, some of the participants – namely, the newly trained participants of

PRIME – acknowledged that health workers could have different views of users according to their disabilities. To better understand human rights, participants requested training and guidelines tailored to the specific needs of health workers.

Participants’ understanding of an HRBA to health was limited. Those from the PHC centres did not refer to it at all, while participants from the district and national levels reflected on it, drawing on their experiences from the health sectors of HIV and maternal and child health, including sexual and reproductive health and rights.

Despite revealing many challenges in participants’ perceptions of the right to health vis-à-vis mental health, the findings indicate that mental health workers were generally positive about the integration of the right to health into their work, believing it would improve the situation for people with psychosocial disabilities and for themselves.

The next chapter explores health workers’ perceptions of the actual application of an HRBA to mental health planning and service provision.

CHAPTER 6: HEALTH WORKERS' PERCEPTIONS OF THE APPLICATION OF A HUMAN RIGHTS-BASED APPROACH TO MENTAL HEALTH IN PLANNING AND SERVICE PROVISION

The previous chapter explored the perspectives of mental health workers in Nepal on the right to health. This chapter seeks to take a more focused approach. Its objective is to explore health workers' perceptions of the application of an HRBA to mental health in planning and service provision. I drafted an HRBA checklist for mental health planning and used it as a guiding tool.¹⁸ This chapter focuses on health workers' perceptions of how an HRBA to mental health could be practically applied by using this checklist. To capture the different perceptions of health workers – which include mental health service providers, managers, and policy makers – I used four qualitative data collection methods: semi-structured interviews, focus groups, observations, and context meetings. All participants were involved with PRIME, with the exception of one focus group (which included only staff from the EMERALD project) and the context meetings (which were with mental health and human rights workers who were not part of PRIME or EMERALD) (see chapter 3).

Over the last decade, there have been increasing calls for applying an HRBA to health, including to mental health to policies, plans, and programmes.[1, 41, 112, 113]. Only a limited number of studies on HRBA have been conducted (see chapter 3, literature review). There is particularly scant research on health workers' perceptions of the application of an HRBA. Yet human rights and public health scholars have emphasised the need to understand the actors involved in implementing and realising policies and plans [10, 11]. Understanding health workers' perception of an HRBA to health in planning and service provision is central to being able to realise an HRBA to health.

In this research, in HRBA to health is understood to include the seven key right to health features: availability, accessibility, acceptability, quality, non-discrimination and equality, participation, and accountability (see chapter 1)[36]. This chapter is framed around four of these features: non-

¹⁸ For the checklist itself see: https://lshtm-my.sharepoint.com/personal/lsh291090_lshtm_ac_uk/_layouts/15/guestaccess.aspx?docid=15307509e82314985a123c32c40db9aeb&authkey=AT64qqgX8NQmtphQUJUZO00 AND https://lshtm-my.sharepoint.com/personal/lsh291090_lshtm_ac_uk/_layouts/15/guestaccess.aspx?docid=15de750e7994a40cda31e3b3678414593&authkey=AYkHujKtfPnaYS0H78KB70c

Or contact Dr. Bayard Roberts, supervisor of this research, should the links not work.

discrimination, accessibility, participation, and accountability. I selected these four features because they were the ones most frequently raised by participants. In addition to these four HRBA features, the chapter also examines commonly recurring themes from the research on confidentiality, consent, and health workers' conditions. These themes do not fit neatly into the seven HRBA to health features, but were included as they were frequently raised by the participants and are pertinent to the realisation of public health and to the right to health.

This chapter will begin by looking at non-discrimination, which also includes stigma, as the participants included the two aspects together; and then discusses accessibility, which will also include confidentiality. The third section looks at participation, which includes consent. This is followed by looking at the HRBA feature of accountability, including monitoring. The final section looks at health workers' conditions, a key contextual aspect that influences the implementation of government policies and plans. The chapter concludes by summarising and briefly reflecting on the findings.

6.1. NON-DISCRIMINATION

Non-discrimination is central to all human rights, not just the right to health. It is a core obligation of the right to health, implying that it must be prioritised and that it applies to all countries irrespective of their income level or resource constraints. The human rights feature of non-discrimination is linked to equality. Equality is understood as “substantive equality” and incorporates “equality of opportunity” to address the structural inequalities in society which lead to barriers in access and empowerment. In health care, this implies guaranteeing equality of opportunity with regard to the best treatment outcomes, but it does not guarantee equality of treatment outcomes[249]. Non-discrimination and equality are related to the other HRBA features, including those mentioned in this chapter. For example, health systems must be accessible to everyone without discrimination in law or in practice, including for people with psychosocial disabilities[13]. Although the WHO and OHCHR present “non-discrimination and equality” as an HRBA feature, my discussions with participants focused on non-discrimination. Participants spoke interchangeably of stigma and discrimination, which they believed to be one of the main reasons the rights of persons with psychosocial disabilities were not realised. A health manager at the district level noted:

“We can say that there are no human rights in mental health. If someone has psychosis or other mental health issues they are paid low salary or given hard work with no pay. They

are treated with stigma and discrimination [by the family and the society]" (T5: District-Manager/Coordinator).

All participants agreed that non-discrimination was an important HRBA-to-health feature that needed to be addressed in policies, plans, laws, and health services.

The participants never defined stigma but shared how they had experienced it in their work. At the PHC centre level, one of the newly trained health service providers described how stigma affected users' decisions to seek care:

"She [the user] is having multiple pain problem, and we [the family] are not taking her to a psychiatrist, not even a counsellor, the stigma is that 'if I [the mother] take her to the psychiatrist ... oh, if the friends know that [taking the child to a psychiatrist], they will know there are psychiatric problem, all the friends will create that kind of problem for my child.' That kind of thought is coming. This is the problem here" (T12: PHC Centre-Service Provider (Newly Trained)).

When this interview was carried out, this PHC centre had yet not begun to offer mental health treatment. It was one of PRIME's future PHC centres to be included in its programme. As a result, people from this village had to travel to Chitwan or Kathmandu to receive counselling and treatment for mental health illnesses.

At the district level, participants spoke about how stigma sometimes manifested itself within the services. As one health service provider at the district level explained, "They [people with psychosocial disabilities] come to me covering their face. Like this [showing with his hands] hiding their face" (T6: District-Service Provider). The participant, however, explained that patients' fear of being recognised by others while seeking mental health care had lessened and that providers saw fewer people hiding their faces. One manager/health coordinator at the national level reflected:

"Stigma is quite high, if a person has a common mental disorder, then the family neglects that person, the community also. So when they come back [after treatment in the hospital], if the family does not support them then they have the same problem again" (T17: National-Manager/Coordinator).

Although participants at all levels of the health system spoke about stigma, the term "stigma" was used more frequently by participants at the district and national levels. At the PHC centre level, it was only the newly trained health service providers who used the word "stigma." Participants

working in PRIME's PHC centre did not speak of stigma, nor did they describe how users might hesitate to seek care in their PHC centre or in Chitwan due to stigma. Why these participants did not use the word "stigma" might be due to their use of language. At the district and national levels, a larger number of participants spoke English, while at the PHC centre they spoke Nepali, with the exception of the newly trained participants at the PHC centres. The term "stigma" was used in the verbatim translation but not in the written translation. Or it may have been that perhaps other patients at the PHC centres knew those who were coming in with psychosocial disabilities and so there was little anonymity anyway. Another reason might be that at the district and national levels, participants had witnessed more stigma because they had more experience treating people with psychosocial disabilities.

It was difficult for participants to explain why they thought stigma happened in the first place. Stigmatisation appeared to be shaped by a sequence of complex interactions between limited education on mental health, the perception of antisocial behaviours of people with psychosocial disabilities, and social, cultural, and personal beliefs about different psychosocial disabilities, as highlighted in the previous chapter. One of the newly trained health service providers at a PHC centre stressed that "[stigma] is not the problem of human rights and not the problem of the government or the constitution. The problem is caused by lack of education" (T11: PHC Centre-Service Provider (Newly Trained)). However, another health worker at the district level rebutted this and said, "Even well educated people stigmatise" (T5: District-Manager/Coordinator).

While some participants spoke only about stigma, most spoke about stigma and discrimination interchangeably. Everyone agreed that people with psychosocial disabilities face stigma and discrimination, with women being particularly vulnerable. Many participants gave marriage as an example of people's vulnerability to stigma and discrimination. Marriage in Nepali society was explained to be of great importance for men and women. But as a health manager at the national level explained, the fear and shame of being labelled with a mental illness could hinder both men and women from getting married in the first place and, as a result, from seeking care:

"People don't like to share about their problems in front of other people, due to stigma ... it is believed that if you have that sort of problem, like symptoms of psychosis, it is difficult to get married" (T17: National-Manager/Coordinator).

Women appeared to be particularly vulnerable within the marriage if they were diagnosed with a mental disorder. A health manager at the district level explained, "They [females] hesitate to disclose their problems because of social stigma – the husband may leave her due to this problem"

(T5: District-Manager/Coordinator). A health manager and service provider at the national level felt that this stigmatisation faced by women was partially attributable to the discriminatory national law:

“According to the law the husband can divorce the wife if she is mentally ill. The situation is very, very bad ... Women who are mentally ill are often forcefully thrown on the street, forcefully living on the street where they are often raped ... People don’t invest money for the [mental health] treatment of the woman” (T18: National-Manager/Service Provider).

Participants at the PHC centre confirmed that everyone who lived with or was affected by psychosocial disabilities faced stigma and discrimination. Female health workers and non-prescribers (those who could not prescribe medicine) spoke very strongly about discrimination against women in general, and particularly against women with psychosocial disabilities. They spoke powerfully and convincingly about the need to link the discrimination of women, grounded in gender discrimination, to the specific human rights of women outlined in the Convention on the Elimination of All Forms of Discrimination against Women. This further refutes the notion discussed in the previous chapter that “lower-level” providers had less understanding of human rights, especially since these providers were non-prescribers, the lowest-ranked providers at the PHC centres. All participants at all levels of the health system confirmed that women were particularly vulnerable in Nepali society. Gender equality was one of the priorities of the government and the international community, and perhaps one reason that female participants at the PHC centre were very confident when addressing stigma and discrimination against women. Another reason might be the Maoist talk about gender inequality – one of their demands was to address gender inequality (see chapter 2), and human rights have been talked about a lot after the war, according to participants (see chapter 5).

The vicious circle caused by stigma and discrimination around mental health and how it affects the realisation of the human rights of persons with psychosocial disabilities was noted by two health managers/coordinators, one at the district level and the other at the national level in Kathmandu:

“It is difficult for the service users to demand their human rights due to stigma and discrimination. As a result, the community is not aware of mental health, all this makes it difficult to realise human rights” (T5: District-Manager/Coordinator).

“The way of breaking the stigma is for people to speak out. It needs to come out that we are also human, like others ... [however] by law we [people with psychosocial disabilities]

are not allowed to register an organisation because of a personal history of mental illness” (T18: National-Manager/Coordinator).

While participants agreed on the problem of stigma and discrimination, it proved difficult to provide concrete examples of what needed to be done. Awareness and education appeared to be pivotal, and those participants who had worked on HIV issues also brought attention to the use of an HRBA to health. As one district-level health service provider noted:

“Stigma ... it is very high, both stigma and discrimination in mental health and ... mentally ill persons. In other sectors, awareness has been created with the rights based approach. But, in mental health program it is less [fewer] activities with rights based approach ... awareness, stigma and discrimination ... That’s why this [present scenario of stigma and discrimination] ... we can see more problems in mental health. Because in HIV/AIDS [stigma and discrimination are less], in leprosy also it [stigma and discrimination] has decreased; now people come up openly. There is still [stigma and discrimination] in HIV/AIDS, [but] in the case of HIV/AIDS, there are many activities running against the stigma and discrimination. There have been many activities regarding awareness for both the health worker, community service provider [in HIV and stigma and discrimination] ... but in this [mental health] it is lacking, there is a lack of such activities [awareness of mental health and of stigma and discrimination]” (T4: District Service Provider).

Another participant, a health manager/service provider at the national level, reflected on how a different approach to mental health within the health system could reduce stigma: “Integrate mental health into the health facility [health system] so it is not an isolated approach, but an integrated approach. That would reduce stigma” (T18: National-Manager/Service Provider). The solution to the problem of stigma and discrimination was known but not addressed by the government, as explained by the participants below.

When participants talked about the target group for addressing stigma and discrimination in the health sector, there appeared to be uncertainty around who faced stigma and discrimination and who carried it out.

Participants explained that it was not only those living with psychosocial disabilities who suffered stigma but also their family members. In addition, there was stigma towards health service providers themselves. As a health service provider at a PHC centre explained, “People stigmatise the psychiatric doctor, saying it is a doctor of the mad and they are looked at with hatred” (R2T8: PHC Centre-Service Provider). Although everyone was perceived as potentially engaging in stigmatising behaviour, a health manger claimed that “stigma starts from the health worker that

is what I have experienced here in Nepal” (T4-District-Service Provider). When prompted, the participant elaborated:

“Confidentiality is leaked from the health worker’s side. That should not happen ... And another thing is that in the process of providing service ... the health worker should not give priority to someone and less priority to others” (T4: District-Service Provider).

A health worker at the district level noted that “[because] of trust, belief, and/or stigma people go to the *dhamis* and *jhankris* [faith healers] rather than to the health service [for mental health treatment]” (T2R1: District-Service Provider). One of the newly trained health workers at the district level also explained that health workers stigmatise patients who might break cultural norms and traditions, such as in family planning:

“Sometimes there is stigma [in the health services] if people come to the services because they are pregnant, but they got it [pregnant] because they had extra marital affair or they are pregnant and unmarried, or sometimes people come for family planning. This is their human right, but health workers stigmatise them for coming to receive the family planning services. If pregnant and unmarried, the stigma is even higher” (T5: District-Manager/Coordinator).

This last statement reiterates the stigma and vulnerability faced by women. The comment also brings attention to the importance of involving health workers in policy and program decisions. If they are not involved, there is a risk that well-intended policies may not be realised.

6.2 ACCESSIBILITY

I selected accessibility as a theme because it was frequently raised by participants. Further, access to health services and medicine is a key HRBA feature, as well as a core obligation of the right to health. According to the right to health, accessibility is dependent on other right to health features – namely, availability, acceptability, and quality – for its realisation. Furthermore, according to the right to health, accessibility is composed of four overlapping dimensions: non-discrimination, physical accessibility, affordability, and information accessibility (addressed below under confidentiality).

Participants agreed that ensuring access to health services for everyone, including people with psychosocial disabilities, was an important goal, but some emphasised that addressing access required more than just providing services. A health service manager at the national level reflected on the different perspectives on accessibility:

“I don’t think that only putting the services in place is creating enough of sucking effect for making everyone actually come. To create a pulling effect, to actually come to the services I don’t think it [focusing solely on access to mental health services] will work at all. I don’t think the information is going to be out there, I don’t think the people have the finances to pay for transportation to be able to come to the services and there is such a high level of discrimination and stigmatization still that just providing service does not mean that people will go for it. And people, even if there are services, people don’t know even know that they are there for them because they don’t know that they have mental health problem. So I think there are a lot of obstacles in having the services in place and creating access to services” (T19: National-Manager/Coordinator).

Although the respondents acknowledged many barriers to accessing mental health services, they talked mainly about limited access due to distance, finances, and information. One participant from the district noted:

“An ordinary person can go anywhere for treatment, in every VDC [Village Development Committee] there is a health facility, but in those health facilities, there is no program for mental health” (T2R2: District-Service Provider).

The absence of provision of mental health services at the village level was commented on by a number of respondents. As explained by a health service provider at the district level who also often worked in the PHC centre:

“They [people in rural areas] have to travel for one to two days to get to the psychiatrist ... The scenario will be even worse in the mountain regions where you will have to travel for 4-5 days” (T9: District-Service Provider).

Financial barriers further limited access to mental health services. A health manager at the national level noted how accessibility was compounded by travel costs: “I don’t think the people have the finances to pay for transportation to be able to come to the services” (T19: National-Manager/Coordinator). Participants who worked at the PHC centres also raised this point, both with regard to accessing the PHC centre and with regard to being able to attend appointments at the district hospital after referral from the PHC centre.

The cost of psychotropic drugs was also raised as a financial barrier. According to the Interim Constitution of 2007, “Every citizen has the right to basic health services free of cost from the state as provided by law”[134 para 16(2)]. The Nepal Health Sector Programme Implementation Plan II (2010–2015) stipulates that “at district hospitals, outpatient, inpatient and emergency

services are free of charge to poor, vulnerable, and marginalised groups, including medicines, and 40 essential medicines are free of charge to all” [135 p.8] (see chapter 1). However, a health policy maker explained in a context meeting that “access to treatment is not possible in the rural areas” (F4). Some health service providers in Chitwan explained that the psychotropic drugs provided in the two PRIME PHC centres were free of charge, but that such medicines were not available at other PHC centres and that free psychotropic medicine was provided only at the big hospital. However, a health service provider at one of PRIME’s PHC centres explained:

“Even in district hospital people do not get the medicine for mental health free of cost. The problem is not only the distribution of medicines: Firstly, medicine should be available; secondly, it should be followed-up. If the patient requires more medicine and he can’t afford it” (T11: PHC Centre-Service Provider (Newly Trained)).

A human rights lawyer explained in a context meeting that “nearly every month there is a report in the paper about a poor family who is trying to get treatment, but can’t spend money on treatment, instead they put the person in isolation, in chains” (F16: National-Human Rights Lawyer (Context Meeting)).

A health coordinator at the national level tried to clarify in a context meeting the practice of essential medicine, which to me seemed rather confusing. The participant stated:

“There are two medicine lists in the country. One is the essential medicine list, and the second is a free medicine list. The free medicine list are drugs that are selected from the essential medicine list and are provided free of charge at the health facilities. From the free drug list, 45 drugs are supplied at the hospital level, 34 drugs are supplied at the PHC level and less than 24 drugs at the sub-health post level. There is no psychotropic drugs included on the free medicine list, only drugs for epilepsy” (F19: National-Health Coordinator at an International NGO (Context Meeting)).

The same participant elaborated on what this meant in terms of accessibility to psychotropic drugs:

“The problem with access to psychotropic drugs are that psychotropic drugs are not included on the free medicine list and the government does not want to put them there. The health workers cannot prescribe medicine at the sub-health post level as they are not trained, PRIME has a special agreement [that is why the health workers can provide medicine there] and the medicine is very expensive [if the users have to purchase], so after three to four months the patients stop taking their medicine” (F19: National-Health Coordinator at an International NGO (Context Meeting)).

Health managers at the national level confirmed that PRIME had received special treatment from the Ministry of Health to provide psychotropic drugs free of charge at the PHC centres in Chitwan. However, as explained by one of the participants, only four psychotropic drugs were included in the package, since the PRIME project was still in a trial period when this research was carried out: “If the patient comes with for example severe depression and needs three or four different types of medicines, they [the medicines] are not available in the PHCs then you have to pay yourself. You will have to go to the market and buy” (C3: National Level-Health Manager).

6.2.1 Confidentiality

Accessibility of information, according to the right to health, includes the right to seek, receive, and impart information and ideas concerning health issues[13]. A key element of access to information in the right to health also relates to confidentiality. The UN’s General Comment 14 states that “information accessibility of information should not impair the right to have personal health data treated with confidentiality” [13para12(b)]. Confidentiality was one particular feature accepted categorically by participants as important for access to, and the quality of, health services. In public health and medicine, health workers are bound by professional codes of conduct that include rules of confidentiality in order to support access to services. However, in my conversations with participants about confidentiality, it became clear that there were failures to respect the right to confidentiality. When talking to participants at the PHC centre, everyone appeared to be very aware of confidentiality and thought it was important that it be respected. Yet confidentiality was not an aspect that participants initially talked about with regard to access to services. Moreover, when I observed the health services, it became clear that confidentiality was not well respected, as documented in my field notes from my visits to the PHC centres (see box 6). Although the case shown in box 6 is from a PHC centre, I observed similar cases at both the public and private services of the district hospital.

BOX 6. FIELD NOTES FROM A PHC CENTRE ON THE ISSUE OF CONFIDENTIALITY

A man walks in. He is holding his head complaining that he is having severe headache. The woman accompanying him, which turned out to be his wife, whispers to the health service provider that he has a mental disorder. They sit down in the waiting room. A lot of other patients are around him. The man's pain increases and his wife stands up and goes to the treatment room and asks the health service provider if he can see to the patient. Nothing happens. A nurse goes to the treatment room to ask if the health service provider can see the patient as his pain has worsened, nothing happens. The man starts to cry and yell in pain, mumbling, 'everyone hates me, everyone dominates me'. The man has a seizure. The health service provider runs into the waiting room. The wife runs out with their child. Some of the patients mumble to each other and say 'he is mental.' Two men are holding the patient's hands and third patient keeps talking to him. The man calms down. The wife comes back with a lot of papers.

They stay in the waiting room and begin the consultation. The patients around are calm, but someone says 'these people are in another world.' The wife says, 'he is acting—he needs to come to his thoughts.' She also explains, holding out a bunch of papers, that they have been to another doctor and were given another medication to what PRIME gave them, but they could not complete it as they could not afford the medicine. They have not adhered to the medicine given by the PHC centres either, despite the fact that it is free of charge. She cannot explain why they have not adhered. She is told he needs another medicine, but it is not available in the PHC centres and she says they cannot afford to buy it. The health service provider in the PHC centres says they should go to Chitwan and see a psychiatrist, but they cannot afford the bus.

The patient is back the following day with scans and medicines in a green bag. His diagnosis is discussed between everyone in the waiting room, where the consultation takes place. All the health workers, including managers who are there from Chitwan are in the waiting room. They keep looking into his green plastic bag and pull out scans and papers, and share and discuss among each other. The patient is calm, but looks vulnerable and depressed. He is the observer. He sits outside the circle of discussions (O:1 010713).

When I asked health service providers at the PHC centre about what had been observed in the clinic (see box 6), they explained that they respected confidentiality better now than in the past: "before the [PRIME] training, patients were examined along with other patients" (T8R4: PHC Centre-Service Provider). Although they claimed that their respect for confidentiality had improved, a health manager at the national level explained that the incident in the waiting room had been a result of the lack of rooms:

"It is difficult to maintain confidentiality for practical reasons. We don't have separate rooms. You can easily see the consultation room, not only do you see, but you also hear [what is being said] between people, [between] the client and the service provider" (T17: National-Manager/Coordinator).

In this particular PHC centre where the incident took place, however, treating the patient in the waiting room could not be attributed solely to a lack of space, since each examination room at that clinic had walls up to the ceiling and a door which closed (see chapter 2, photo 1b). However, it is true that in the other PHC centre, counselling rooms did not have walls to the ceiling, making it possible to hear what was being said, even when the door was closed (see chapter 2, photo 1d). Although physical structures could partly explain the behaviour, it is also possible that the action was related to uncertainty. Participants in the PHC centre had expressed uncertainty with regard to more complex psychosocial disability cases besides depression and alcohol dependence, as noted in my field notes after the observation in the PHC centre:

“I am perplexed why the patient, husband, was not taken to a consultancy room the first time they notified the AUX [auxiliary health worker] that the husband was getting worse. Why did they treat him in the waiting room when all the patients were there? He did not seem to care, as he seemed to be in ‘his world’ but the wife was all over. Seemed stressed. Could it be that the health service provider, as he said yesterday, that mental health is new? Perhaps he knew what was coming with this patient and did not want to treat him on his own in the consultancy room but preferred to be in the public space, where he also received assistance from the other people?” (O: 1 010713).

The decision to treat the patient in a public space could give the health service provider some assistance and protection from being accused by the community in case the treatment was unsuccessful. Although attacks on clinics by discontented community members did not seem to be an issue in the PHC centres, providers did allude to the risks of patients’ aggressive behaviours towards staff. However, how does one explain the health workers’ decision to discuss the patient’s diagnosis in the waiting room the following day? Perhaps, given that more staff from PRIME had arrived to the clinic, it was easier to just sit in the waiting room, even though it would have been possible to go to the counselling room, located in the garden, which was larger and separated from the other patients (see chapter 2, photo 1a). The participants who did not work at the PHC centres seemed to be aware that it was rather common for health workers to not respect confidentiality.

When trying to explain this failure to respect confidentiality, a medical doctor at the district level stated:

“In my experience, those who are not psychiatrists, those who are only health workers [non-medical doctors and formally trained health professionals] they disclose their patients’ disease. Even though it is written in articles ... [the reason they disclose] may be

lack of knowledge. They don't know that they should not disclose" (T6: District-Service Provider).

A health manager in Chitwan at the district hospital reflected:

"We have usually taken these things lightly [confidentiality] ... it is important to make them [health service providers] aware of the consequences – that stigma and discrimination is prevalent, that they understand how sensitive it is [when confidentiality is broken]" (T4: District-Service Provider).

This apparent lack of respect for confidentiality in health care was exemplified during the treatment of patients at the district hospital who had come to receive their x-rays, as recorded in my field notes:

"There are queues of people waiting to get their x-rays examined. They are in the waiting room, but also in the examination room. While one patient's x-ray is being examined, the ones closest in turn hang around, listen and check-out the results given to the patient in turn. No one says anything, seems to be normal procedure. Perhaps confidentiality is understood very different in this culture to the Western concept?" (O3).

When asked about this x-ray example, a health service provider in the district hospital explained that "somebody who is having back pain has an x-ray, and bones are normal and so [confidentiality] might not matter most in our set up" (T9: District-Service Provider). But with regard to the importance of confidentiality for mental health and other diseases, the participant continued:

"HIV, STI/STD and mental health carry big social stigma. So in those cases, if we try and do our outmost in this kind of confidentiality ... But if I say you are HIV positive that might create a big confusion over here. If I say that you are a mentally ill patient that might create a big confusion over here. He is not being able to go back to his village, he is not going back to his normal life. That kind of social stigma is there. So we should be more focused on the stigma related problem of mental health when we are talking about the confidentiality, because the main confidentiality is related with the social stigma" (T9: District-Service Provider).

The lack of respect for confidentiality was believed to increase stigma and discrimination, as well as to limit access to health services, as observed by a health manager at the national level: "Because of this reason [poor confidentiality] many people do not want to come to the health facility" (T17: National-Manager/Coordinator).

When trying to propose how to address the issue of confidentiality, one health service provider at the district level recommended, in addition to improved physical space and training, that “the consumer should also be aware [about confidentiality] by forming consumer group so they can create pressure for confidentiality ... In that way they can use the rights based approach as well” (T4: District). This health manager also stressed the need to be realistic about outcomes, since changes inevitably take time.

Participants who had worked with people living with HIV/AIDS often highlighted the need to involve users. This resonates with the results from the previous chapter, which showed that participants who were more familiar with human rights – in both its definition and its application – had previous experience from work in HIV/AIDS and/or sexual and reproductive health and rights more broadly.

During my discussions with participants on accessibility and confidentiality, various participants reflected on the different perceptions that had been highlighted and what it meant to use an HRBA to health tool as a guide. There was a consensus among the participants that such a tool was positive, as was nicely captured by a health manager at the national level:

“I think it [the HRBA tool] brings up things that we might not be thinking of necessarily to, it is, we are so bogged down in getting the services on the ground and not looking at, ‘oh my God, does the patient have access to his own records?’ ‘What? We just have to make sure the person gets some treatment at all. Right?’ It does not mean you should not look at these things, it will definitely be helpful to sharpen our minds up” (C3: National-Level Manager).

6.3 PARTICIPATION

According to the right to health, participation includes participation in personal decisions about one’s own health; participation in policy making; and participation in implementation. Health systems must also include institutional arrangements for relevant stakeholders’ active and informed participation in strategy development, policy making, implementation, and accountability. Participation is a core obligation of the right to health[13].

The importance of participation was highlighted by all participants. One health manger/health service provider at the district level explained:

“Plans and activities are imposed by the central authority. Whatever the central authority does, whatever orders are given, we [health workers] have to obey. It should be bottom-up planning [from a grassroots level], bottom to top planning system [grassroots to policy maker/government level] should be there ... They should be based on the rights based approach” (T4: District-Service Provider).

Participants talked about which groups should participate. Three health service providers at the PHC centres talked about who should participate in, for example, the development of PRIME’s mental health plan. One respondent felt it should include “female community health volunteers at the VDCs [Village Development Committees], the political parties in the VDCs, Lama, Jhankrit [faith healers and traditional healers]” (R1T10: PHC Centre-Service Provider). Another respondent noted:

“Human rights activists should be there, they have an understanding of what is needed, like depression, like if depression has been caused by gender discrimination. The human rights [activists] can explain to the community and the family ... There must be a relation with the human rights activists ... Users of services usually do not participate, but it would be better [if they did]” (R3T10: PHC Centre-Service Provider). [All participants agreed by nodding and mumbling in agreement.]

A third participant from a PHC centre reiterated the importance of the participation of users: “The people who have already been cured [from psychosocial disabilities], they have the experience, if such people are involved, they can give some information” (R4T10: PHC Centre-Service Provider).

Other challenges which emerged regarding the issue of participation related to the fact that active and informed participation depends upon several factors. For example, preconditions for meaningful participation include having access to information (e.g., background information about the issues to be discussed), being able to speak openly without intimidation, and being free to organise without restriction (e.g., establishing a patients’ or nurses’ association). In addition, under Nepali law, people with a history of psychosocial disabilities may not establish NGOs. However, it appears that in practice, they can do so.

A nurse at a PHC centre described barriers to health workers’ participation on account of their rank:

“I received a similar invitation [to attend a mental health planning meeting]. When I got there, there was protest. They [higher-ranked male health workers, including public health officers and medical doctors] demanded that nursing staff should not be included

in the big program ... They [the organisers] invited me later on again, but I didn't want to attend" (R3T10: PHC centre-Service Provider).

The main participants who shed light on the complexities around participation were those from the PHC centres, as well as health managers who were closely involved with the development of PRIME's mental health plan. The fact that participants who coordinated the development of PRIME's mental health plan raised these complexities is not surprising, given that they are most likely to be struggling with turning theory into practice. The fact that participants at the PHC centre level also raised these complexities might be due to their own experiences with barriers to participating on account of being the lowest-ranking health workers, particularly in the case of women (see chapter 4).

6.3.1 Consent

According to an HRBA to health, consent is understood as a component of participation in decisions about one's own health[250]. Participants talked about the importance of consent but also the challenges in realising it. As observed in my field notes from my visits to the PHC centres:

"The issue of informed consent comes up again. In one of the clinics the health service providers do not inform the patients or ask for consent that we sit there. They inform them when they leave, not before as we had agreed, so they [the service users] have the opportunity to object to our presence! Some, or many of the patients cannot read or write, so they sign with a finger-print. The health workers seem to be telling them what is on the sheet, but I am not really sure if they are actually telling them [the patients] what it says on the consent sheet – there does not seem to be a possibility for the patients to ask, or no one seems to ask; they only agree, sign and get a copy. In the other PHC centre they do inform them [the users] before they enter the clinic, but it is only the service provider who we asked to help out in this research who informs the users, the others don't. In both of the PHC centres, the users with psychosocial disabilities do not receive any note of consent or are explained what is going on – why we are sitting there. It is easy to detect the users of psychosocial disabilities as they come with a white and blue book, their treatment plan. I need to understand this better" (O: 1 010713).

Although I had talked with service providers about the importance of getting patients' informed consent in order for me to be able to observe them in the PHC centres, the providers generally did not follow our agreement whereby patients' informed consent would be gathered upon registration at the centre. The health workers at the centre did not seem to understand why it was so important. While they agreed to change their behaviour, offering patients the option of accepting or rejecting observation by a third party, in practice nothing really changed.

There also appeared to be differences between what I observed and what was proclaimed by some health workers. One health manager, like the other participants at the PHC and district hospital, noted the importance of consent: “Consent we have to take. Immediately we have to try to get consent. Sometimes we have emergency cases, but we have then try to get consent as soon as possible” (T3: District-Manager). The participant continued by providing an example of the importance of consent:

“Consent is given priority here. Consent for certain problems. Or certain issues we have to take consent. In mental health we need consent. I will share with you a case study. The incident only happened a week ago. A leader came to the hospital complaining about headache and the doctor referred him to the mental health department. He went to the mental health department, but when he saw the sign, ‘mental health problem department’ he got so angry. He shouted, ‘I am a mental patient?’ ‘What doctor, where has the doctor sent me?’ He got very aggressive with the doctor and many, many people were there, and many people gathered together.’ I think if the doctor had sat down with the patient and explained that, ‘you have headache and I am suspecting a mental health problem. If you would like to go to a psychiatrist you can go.’ If he had describes this beforehand I do not think the patient would have been so angry” (T3: District-Manager).

Although many participants considered consent important, others saw it as difficult and impractical, and not always possible. As noted by a health manager at the national level:

“Even this consent is quite impractical, in our cases [cases of psychosocial disabilities] ... When people have disorders, it is not a question of asking about consent. Because they come to the health post for treatment and that means they have already provided consent for treatment. This is the understanding. If it is a severe case, these type of people they can’t approach themselves to the health facility, even if it is the hospital or the primary health care centre ... someone brings those type of persons, so the next person is responsible, because he brought that person ... If the person is there, it means consent, he gave consent, but it is not written, it is an understanding” (T17: National-Manager/Coordinator).

This perception of the impracticality of consent might explain providers’ failure to obtain consent in many cases. Another health service provider from one of the PHC centres confirmed this explanation but added a gender perspective to it:

“In the context of Nepal, in cases of males, it is easy to get consent, but not females; there the family is also needed ... the man makes the decision himself. If he is not capable, the family will make the decision. In the case of females, in the context of Nepal, 90% of the females cannot make a decision by themselves. About 5-10% can make their own decision ... If she needs consent, her husband or the family gives consent. If she was not able to

make a decision, because she was too ill, both the husband and the family members are required” (T13: District-Service Provider).

The participant continued to explain how the practice affected the provision of health services:

“In Nepal, instead of individual life and single decisions, people live in a joint family, in which they talk together and make decisions together. In the case of a male’s decision, it is never really 100% ... if the person is really ill it would be much easier for the health worker, from a human rights point of view, if family members or guardian could take consent” (T13: District-Service Provider).

In considering what would be required to facilitate health workers’ ability to obtain consent, the participant noted:

“Awareness and education, as we see now days, there is a big generation gap between the old generation and the new generation. For the old generation, the joint family set up is there, but for the new generation, this is less of a priority. [I think] permission should be taken from the patient. In some situation, if he [the patient] doesn’t give permission, then he/she should be convinced by the responsible person about what is going on, what will be the consequences if not acted” (T13: District-Service Provider).

While I was carrying out my research, there was a consent-related case in Kathmandu’s mental health hospital that made national headlines. A number of actors from both the health and human rights fields had been involved, including a PRIME participant. This case was raised by participants who worked with or in the issue of mental health and who also had a strong human rights focus in their work. A human rights lawyer summarised the case:

“During the armed conflict their son was killed by the Maoists. The perpetrator is a known figure, a leader of the Maoist party, and is protected. The family became so ‘angry.’ They do not want compensation, they want justice. The village where they live is Maoist. They [the family] are victims, they are IDPs [internally displaced persons]. They have fought for two years. They have been on hunger strike. They were arrested, released, detained – they were taken to the mental health hospital” (F7: National-Human Rights Lawyer).

Participants explained that the issue of consent is complex and that the lack of clear processes and practices sometimes contributes to it being used politically to silence people. As explained by a national-level service provider and manager:

“The thing was that they [the couple] could be deprived their legal capacity to go to court, or for the justice, that is why they were brought here [mental health hospital] ... if they

are tagged [diagnosed] mentally ill, what they are saying in public is that the murder who killed their son should be punished, but if labelled mentally ill their voice could be suppressed, and the government and others could say, 'oh, they are mentally ill, that is why they are saying that'" (T18: National-Manager/Coordinator).

As explained by a human rights lawyer from the National Human Rights Commission who had been involved in the case:

"I sent monitors to the hospital, the couple had been given injections. The monitors met with the director of the mental health hospital and asked for clarifications: Are they persons with mental health problems? We do not mind if you take care of them if they are staying there of free will. Or were they referred by the police or by the family? Why were they sent to the mental health hospital? What are the medications? ... NHRC [National Human Rights Commission] asked them to produce a report – the director said they had mental health problem, but the doctors had no documents, all was verbal agreement. They said there was a verbal agreement with the Chief District Officer, that he required the doctors to do it" (F7: National-Human Rights Lawyer).

The same participant confirmed the practice based on their monitoring and reports they had taken in: "a large number of people are angry with the government – many are not patients of the mental health hospital. Anyone can be taken to the mental health hospital" (F7: National-Human Rights Lawyer).

In a context meeting, I met the manager of the mental health hospital. Prior to the meeting, I had been told not to mention human rights or this particular case. However, after the manager and I sat down and talked for a while, the manager began to talk about the case, explaining it in the following way:

"The NHRC [National Human Rights Commission] took some interest in the case. We were asked to assess their [the couple's] situation, mental health and other political situation. They were discharged. They were ill [angry] against the hospital. There needs to be a mental health legislation, to have it clear, such as what it implies with involuntary treatment, the meaning of human rights. There is high time to get a legislation" (F22: National-Hospital Manager).

The importance of national laws for health workers has been outlined in previous studies (see chapter 3), and this case again reinforces the importance of having clarity on human rights and incorporating this understanding into national laws or the constitution. When the health sector does not clearly understand what is "right and wrong," it causes frustration. In this regard, there

is a need to consider whether, unless a grave violation has taken place by the health service provider, it is right to place accountability solely on health service providers and not on the overall health system structure.

6.4 ACCOUNTABILITY

From a human rights point of view, rights imply duties, and duties demand accountability. Accountability is one of the most important features of human rights – and also one of the least understood. Accountability includes the monitoring of conduct, performance, and outcomes. In the context of health systems, there must be independent, accessible, transparent, and effective accountability mechanisms in order for us to be able to understand how those with responsibilities discharge their duties. Accountability is not about blame and punishment but about learning what worked (so it can be repeated) and what did not work (so it can be revised and corrected). Human rights accountability is about ensuring that health systems are improving and that, as a result, the right to health is being realised (see chapter 1) [2, 7].

Monitoring was uncontroversial and supported by all the participants. As one health worker confirmed, “There should be the mechanism of monitoring and evaluation in each health system level” (T5). Health managers at the PHC centres, district hospital, and policy level explained the importance of both monitoring and accountability, as well as the different mechanisms that were in place. One health service manager at the district level explained:

“We have very good mechanisms [monitoring and accountability], also from the private side [private service providers] ... and from the people’s rights [civil society] there are mechanism. From the public side [government service provision] there is supervision and monitoring – our supervisors come and monitor us, and we go and monitor our health facilities if they are giving the right services or not, this is from our side, the government side. On the other hand there is the people’s society, that is NGOs, civil society and that is health organisations there and social bodies in the communities. If people are dissatisfied, discontent – whatever they have, they can express it to the social bodies” (T3: District-Manager).

A health service provider at the hospital clarified:

“If patients need anything there is a suggestion desk in places where they can raise their concerns. If a suggestion desk is not available you can go to the in-charge. If our [health workers’] voices are not heard, we can go to the higher level, like if our voices are not

heard in the health post, we can go to the district level and share our concern” (T13: District-Service Provider).

Although participants at the management level seemed familiar with the notion of accountability, there was one major difference between the health sector’s approach to accountability and the HRBA tool: under the latter, monitoring and accountability functions should be conducted by a separate, independent body from that which delivers services.

In contrast to management-level workers, participants working closer to the frontline (i.e., service delivery) were less comfortable with the concept of accountability. As one health manager expressed, “Few concepts are as difficult as ‘accountability.’ There is a need to simplify these concepts. Only educated understand these concepts” (C1-1). This statement was also confirmed by the EMERALD focus group and a health manager at the district level who had recently participated in a qualitative study with health service providers in PRIME’s PHC centres. This manager noted how health service providers “are not aware about accountability. When we did our formative research study, they [the health service providers] were somewhat really confused about this [accountability]” (T5: District-Manager/Coordinator).

Besides participants’ perceptions that accountability was difficult to understand, they still seemed aware of it and had strong views about it. The concerns expressed by participants can be divided into two broad categories: frustration around accountability and its implementation, and consequences from the lack of accountability.

One health manager who worked at the district level associated accountability negatively with the expression of human rights, explaining that “sometimes they [the patients] misuse their rights when they attack heads of the hospital or institution” (T6: District-Service Provider).

This mirrors the frustration described in the previous chapter, in which many district-level health service providers felt that human rights blamed health workers for issues beyond their control – issues related to broader systemic and structural problems.

While service providers expressed frustration with mental health service users, users also expressed frustration and vulnerability vis-à-vis the health system and the service providers and seemed to wish for accountability. On different occasions, a number of people with psychosocial disabilities commented informally (which I documented in my field notes) that they had received

electroconvulsive therapy without anaesthesia. They claimed that this was a common practice and wondered whether it was acceptable. These comments were fed back to participants at the district level, and one health service provider from a private district hospital stated in a context meeting, “The doctor should use anaesthesia, if they do not, the doctor is accountable, but the government has to ensure that anaesthesia is provided. To minimize these gaps, such as lack of anaesthesia, mental health should be integrated into the overall health system” (F12: District-Service Provider).

In terms of consequences stemming from the lack of accountability, a health worker closer to the policy level, whose role was to create a bridge between policy making management and service provision, explained that “who is accountable, who should be reported and everything is there [in the policies], but implementation is almost zero” (T17: National-Manager/Coordinator). During the context meetings, in their discussions on the consequences of weak accountability, participants brought attention to the more severe consequences of the lack of accountability. One health service provider aptly summarised what other participants had shared about the possible consequences of a lack of or weak accountability mechanism:

“There are no consequences if something has gone wrong, or done wrong. If something does go wrong, [the community] breaks the windows and doors – it becomes a political issue, not judicial. No one goes to court. They are community groups that are doing it – they want money – they ensure that the family gets compensation and themselves. That is better than if a person only dies – then they might not inherit anything. The medical staff is afraid of the political parties. They can get kidnapped. You can also bribe your way out, the hospital can pay the community groups and they [health service providers] can get clean, and you can keep working. There are no consequences if something has gone wrong, or done wrong. There was however a case with a 23 years old girl who died as a result of an incident, the violence increased and it became so bad that the court intervened” (F10: District-Service Provider).

Weak or absent accountability was also highlighted by respondents from the human rights community. During a context meeting, one human rights lawyer noted, “There is an absent rule of law. Lack of accountability is the main thing. There is no access to justice, irrespective of rights. There is no system of accountability” (F3: National-Human Rights Lawyer).

The same participant reflected on the consequences of a non-functioning accountability system: “We have had cases where someone in the detention centres have been tortured to death, if it is a high level officer or politician involved, nothing happens, while if you are poor, you are

imprisoned for life. Lack of accountability has led to that people are afraid to come forth” (F3: National-Human Rights Lawyer).

When asked to describe the problems with the implementation of accountability in the health sector, participants explained that it was a multifaceted problem, one also related to a poor or non-functioning government structure, including the health system. This complexity was exemplified one early morning when I travelled to a PHC centre, as documented in my field notes and described in box 7.

BOX 7. FIELD NOTES ON ACCOUNTABILITY

On the way with the motorbike to one of the PHC centres one morning we nearly run into, what I initially thought was a bundle of cloths or fruits, was actually a woman. She was lying in the middle of the road. Buses, cars, bikes, people, cows were passing by and no one seemed to care. I asked the person I travelled with what to do, and he thought she was drunk. I wanted to notify someone to move her out of the road. Suddenly, the complexity in the Nepali society that I had been told on different occasions, fell into place in a second of a discussion about this body, such as *“no one can claim the body besides the community; individualistic vs. community society; who is to be blamed or held to account if something were to happen to her, if the body was moved?; Who will pay, if the ambulance is sent for? And if I were to pay for that, who pays for her in the hospital? If something goes wrong in the hospital, who is to be held to account? Who can claim the body? Will the community, village mob come and claim the body or beat up the health workers if something goes wrong when treated or on the way to the hospital? And, which hospital would accept her?”* I was told that when it is “no-one’s body” it is the responsibility of the police to remove it (we went to the police, but they did not care). Suddenly on the road comes one of the health workers from one of the PHC centres. We stop him and tell him what we have seen, he *“appeared as concerned as if we had told him a pack of milk and been dropped.”* He said he guessed that it was the alcoholic woman from a village near by, she is a Dalit [lowest caste] (F23).

When asked to think about how to better address accountability, which appeared to be a problem at all levels of society, some of the participants seemed to believe that changes first had to take place at the government level. As a health manager stated:

“At the top level [the government] there is no system. So first we need to change the system and the behaviour of policy makers, and then [it will] automatically work on the ground. If there is no change at the top, there will always remain the same on the ground” (T17: National-Manager/Coordinator).

Another health manager at the national level noted the country's weak government structure but also reflected that a bottom-up approach was required: "A country where the state is not functioning, the civil society has a great role. If the government system is like it is here, then it is the civil society's role for accountability" (T18: National-Manager/Coordinator). The importance of taking into account the perspective of users was also echoed by some district-level service providers, with one provider noting how "[mental health] strategies should be made from the beneficiaries' perspectives" (T2: District-Service Provider).

In order to address the implementation of accountability, some participants at the PHC centres stressed the importance of "proper monitoring and supervision with regular feedback" (R1T8: PHC Centre-Service Provision).

Other participants at the district level thought there was a need for education and information on accountability, as well as a need for clear directives: "First, there should be mental health guidelines. The mental health guidelines should be followed. And then, recording and reporting systems should be developed and timely analysis" (T13: District-Service Provider). With regard to the question whether health workers in Nepal should follow already established guidelines, such as those issued by the WHO, the same participant reflected, "in the context of Nepal, all of WHO standards cannot be followed ... we should adjust WHO's plans and make our plans" (T13: District-Service Provider).

At the district level, a few participants agreed on the need for directives, stressing that "health workers should be accountable for his/her day to day work, [but for that] proper allocation of time ..., and for that a policy should be developed on how to perform the task" (T2: District-Service Provider).

6.5 WEAK IMPLEMENTATION OF GOVERNMENT POLICIES, PLANS, AND LAWS

Participants frequently conveyed a strong sense of concern regarding the limited government implementation of policies, plans, and human rights treaties and national laws related to mental health. A health service provider at the district level noted that the government "has already formulated a law that says we are going to incorporate mental health with the general health ... So the thing is you should get the mental health care and you should get the medicine ..." (T9: District-Service Provider). Respondents highlighted the challenge of effectively implementing

these policies and plans in order to realise people's rights. As one of PRIME's health managers explained:

"The problem is whether these [rights, policies, and plans] are feasible. What happens generally in our context, our government is taking decision and stops and holds. I give you an example, the government developed national mental health policy in 1996. And the strategies are there respecting human rights of people with mental disorder, mobilising service users, everything is there. It seems nice, but you see how difficult it is for implementation?" (T17: National-Manager/Coordinator).

A district-level health service provider further described the problems surrounding the implementation of policies and programs by the government:

"One problem is the government sector, there are frequent transfers. Some programs starts, someone is appointed to supervise it, but is then quickly transferred to another place. In order for the program to continue another person is appointed. But it takes time for that [new] person to learn the job that is the issue" (T2R3: District-Service Provider).

After a session in which participants used the HRBA tool as a guide, a health coordinator from EMERALD acknowledged the importance of understanding the link between policy and implementation: "That was a useful exercise [applying an HRBA to mental health]. Most of those who attended are implementers, and they have not been part of linking the policy-plan-implementation. Now they got to see the link" (C2: National-Coordinator).

6.5.1 Health workers' conditions

The issue of health workers' human rights was raised in the previous chapter as an important aspect of realising right to health. While human resources for health have attracted increased attention in recent years, the human rights dimensions of the issue rarely receive significant attention[2]. In this light, I asked participants to identify which conditions they saw as critical for health workers to be able to realise the right to health, and thus an HRBA to health.

Health workers play a central role in translating mental health policies, plans, and legislation into practice and in strengthening the health system at the local level. They have powerful voices that influence societies' ideas and decisions on health. Health workers' conditions are not explicitly included as a feature of HRBAs, but they are one of the WHO's health system "building blocks," are explicitly mentioned as a key feature of health systems in order for these systems to be respectful of the right to health, and are part of the WHO's checklist for what a health plan should

take into consideration. As a result, an HRBA also needs to be applied to health workers. Health workers must receive domestically competitive salaries, as well as other reasonable terms and conditions of employment. Their human rights to, for example, freedom of expression, association, and assembly must be respected. They must have the opportunity for active and informed participation in health policy making. Further, the safety of health workers, who are disproportionately exposed to health hazards, is a major human rights issue. In addition, an appropriate balance should be struck between the number of health workers at the community and/or primary level and specialists at the tertiary level. Health workers' training must include human rights, including respect for cultural diversity, as well as the importance of treating patients and others with courtesy. After qualifying, all health workers must have opportunities, without discrimination, for further professional training [2].

Participants expressed that health workers' conditions were an important requisite for realising the rights of persons with disabilities. When asked what they saw as the most critical aspects, they focused on three issues: training, salary, and safety.

In the PHC centres, health service providers had received different trainings depending on their jobs and roles, with the right to prescribe medicine being the major difference (see chapter 2). Health workers who could not prescribe medicine (non-prescribers) raised concerns about the impact this could have on patients. As stated by one of the participants:

“It is like this. Even if we [non-prescribers] aren't allowed to prescribe medicines we should at least get the knowledge about it. The [prescribers] do not come to the health post regularly. We are the ones who are always present here. We are the ones who go to the VDCs [Village Development Committee] and work in the field. People ask us. When we don't have the knowledge, we will tell them that we don't know and that is not good” (R4T10: PHC Centre-Service Provider).

Another participant in the focus group of non-prescribers at the PHC centre added:

“Let me add something. For the last two days the in-charge has not be present. A depressive patient came. Now, should we give the medicine or not? We ought to. Otherwise they would go as default cases. I had to give the medicines, breaking the rules” (R1T10: PHC Centre-Service Provider).

Equal training and remuneration for all health staff dominated the conversation among non-prescribers at the PHC centre. The aspect of remuneration was related to the per diem

participants received when they attended trainings, since the amount currently varied between prescribers and non-prescribers.

District-level health service providers did not talk about remuneration, nor did they mention the need for training on interpersonal skills between service providers and users. Instead, some of them voiced the need for training in mental health and human rights. As one of the participants stated:

“Health professionals providing mental health services should be well trained in mental health field as well as in human rights, so they can provide treatment by identifying right patient and prescribing right medicines with right dose. In addition there should be timely and regular supply of medicines and logistics etc.” (C2: District-Service Provider).

Many participants at the district level also highlighted the need for opportunities for career development after training, as expressed by one manager at the district level: “And one more thing let me add to this like ... training ... opportunity of training, opportunity for upgrading [after the training] should be provided” (T4: District-Service Provider).

Salary was another aspect highlighted by service providers at the PHC centres. As one provider noted:

“Nepal has poverty and only a small amount of salary is provided by the government – and it is not enough for them [health service providers], so they [health service providers] cheat the government, they also work in the private hospitals to get a salary. The salary from both sides is only enough for their family’s livelihood ... human rights has not been successful here” (T8R1: PHC Centre-Service Provider).

Similar observations were made by a group of district-level health service providers when talking about the provision of mental health services at the community level: “if the health service provider has enough time [with the patients], the services are free, the salary enough for livelihood, then, s/he [the health worker] will feel content and provide the services accordingly” (T2R1: District-Service Provider).

Poor working terms and conditions, which impede health workers’ practice, are not in line with the right to health and should be rectified. [17] This highlights the importance of taking into consideration health workers’ views and conditions in the realisation of the right to health.

Many participants at the district level – but none at the PHC centre level – brought attention to the need to take into account the safety of health workers. Two such participants noted:

“There needs to provision to keep the violent patient separate during the course of the treatment” (T13: District-Service Provider).

“Sometimes they [health service providers] have to work in the community, sometimes the patient threatens the health work and they need to get support from the police or the army” (T3: District-Manager).

The reason PHC centre participants did not raise the issue of safety could be that they had not yet encountered any users who were perceived as threatening to staff. The fact that participants at the district level emphasised this point may be because there is a much greater uptake of patients, including those requiring more specialised care, such as psychiatrists and secondary mental health care providers. Furthermore, prior to the PRIME project, the PHC centres in Chitwan did not offer psychosocial support – everyone had to go to the district hospital in Chitwan for treatment.

6.6 SUMMARY OF THE FINDINGS AND REFLECTION

This chapter explored mental health workers’ perceptions of the application of an HRBA to mental health planning and service provision in Nepal. This builds on the previous chapter, which explored their perspectives more broadly on the right to health in Nepal.

The key findings in this chapter indicate that participants agreed that four HRBA features – non-discrimination, accessibility, participation, and accountability – are critical to mental health planning and service provision. In addition to these HRBA features, the findings show the need to pay attention to confidentiality and consent. Although these two features were initially believed to not sit neatly within an HRBA to health, they are central to the provision of mental health services (see chapter 7). The findings indicate that confidentiality is an integral part of accessibility, and consent an important element of participation. Indeed, both confidentiality and consent appear to affect the realisation of all four HRBA features.

The findings indicate that weak implementation of government policies, plans, and laws reveals the need to understand both the health system context and the country context. It is important to involve health workers in order to understand the health system and its inner workings. Further,

the implementation of an HRBA to health requires the involvement of these workers and requires that their rights be respected, protected, and fulfilled.

The findings in the previous chapter indicated that participants were aware of human rights but had difficulty in understanding their meaning. In contrast, the understanding of the right to health more specifically was expressed with greater certainty and precision, partly because the right to health is enshrined in Nepal's Constitution. Participants' understanding of the rights of persons with psychosocial disabilities was limited, with some participants expressing that people with different psychosocial disabilities had different human rights. To better understand human rights, participants requested training and guidelines tailored to the specific needs of the health workers.

Despite many challenges in participants' perceptions and in the realisation of the right to health in mental health services, the findings indicate that mental health workers were generally positive about the integration of the right to health into their work, believing it would improve both their own situations and those of people with psychosocial disabilities. The next chapter discusses and reflects on the study's findings.

CHAPTER 7: DISCUSSION

This thesis explored the perceptions and perspectives of frontline mental health workers regarding the use of an HRBA to health, focusing on mental health. Chapter 1 provided a short introduction on the right to health, mental health, and an HRBA to health, as well as the role of health workers. It also introduced the conceptual framework. Chapter 2 introduced the case study of Nepal. Chapter 3 presented the methods for this thesis. Chapter 4 presented the findings from the literature review. Chapters 5 and 6 presented the results of my field work in Nepal.

This chapter will discuss some of the key findings from the study. It will then revisit the conceptual framework (objective 4) in light of these findings. It will conclude with a discussion on the limitations and contributions of the thesis, and some key recommendations.

7.1 EXISTING EVIDENCE ON THE USE OF HUMAN RIGHTS-BASED APPROACHES TO HEALTH

Chapter 4 explored existing evidence on the use of HRBAs to advance health, which was the first objective of this research. I achieved this objective through a narrative literature review, the results of which are discussed in chapter 4. Here, I will therefore discuss only the key findings and will draw on a special issue of Harvard's *Health and Human Rights* journal (*HHR*) titled "Making the Case: What Is the Evidence of Impact of Applying Human Rights-Based Approaches to Health?" [251], which was published in December 2015 (two years after I conducted my review). Despite the diverse range of data sources and broad inclusion criteria employed in my review, the search yielded only eight studies. The selected studies included a mix of health topics, with a predominance of maternal and child health and mental health outcomes. Notwithstanding the limited number of studies in the review, the findings provide some evidence that the application of an HRBA or RBA had a plausibly positive association with the health issue of relevance and aided the analysis of policies, projects, and plans. These findings resonate with the findings by the studies in the *HHR* special issue [252-255].

Although the findings of my review suggest plausible evidence of positive effects from an HRBA to health, they also highlight the difficulties around determining the direct influence of an HRBA to health. Similar findings were highlighted by studies in *HHR* [255-258]. For example, Lohman

et al. (2015) note how efforts to use the Universal Periodic Review¹⁹ process and UN treaty bodies to put pressure on governments “had little impact [because] ... the resulting recommendation was too vague to be meaningful, or the government did not follow-up on the recommendation”[256 p. 161].

The findings from my review highlighted the limited global distribution of studies carried out on HRBAs to health, particularly mental health. Only two studies were conducted on mental health, and these were in the United Kingdom. Therefore, it is not possible to say whether an HRBA to health could have a positive impact on mental health service provision or policies, plans, and strategies in middle- and low-income countries. A third study on mental health, carried out in England, was reviewed but was rejected on account of lacking clear methods [226]. The *HHR* issue includes a review of this case study[258]. Besides that article, no other articles in *HHR* address mental health. This reinforces the need for more studies on mental health and HRBAs to health in low- and middle-income countries.

All eight studies in my literature review concluded that the realisation of an HRBA to health, irrespective of labelling, appeared to be facilitated by an enabling environment, such as political commitments, support and resources, international human rights commitments, and constitutional recognition of health rights. Judicial and non-judicial human rights oversight bodies, with strong civil society organisations that monitor and hold those responsible to account, reinforced this. This conclusion resonates with observations in the studies published in *HHR* [252, 254, 256, 259, 260].

Some of the studies in my review and in *HHR* – including an interview with Francisco Songane (2015), Mozambique’s former minister of health (2000–2004) – seem to indicate that the realisation of an HRBA to health was made possible by a combination of civil society organisations and intensive human rights education [139, 229, 230, 232, 234, 255, 260]. According to Songane, human rights education was one of the two “agents of change” required for the implementation of an HRBA to health. The other agent of change was the health workers who implement the programs and work directly with users. He stresses that health workers have a particularly important role, since they need to be able to confirm that these individuals’ unmet health needs are a denial of their human rights. He clarifies that this is what raises people’s awareness of the

¹⁹ Universal Periodic Review is a mechanism of the UN Human Rights Council that emerged from the 2005 UN reform process.

fact that the non-availability of services reflects a deeper, more profound denial of rights. He also maintains that civil society organisations can be important partners in the process of addressing inequalities in the steps towards their realisation of an HRBA to health [260]. In this way, civil society can play a number of roles, from actors who monitor and hold to account, to providers of technical support (such as human rights training)[261].

The literature review demonstrated that a number of methods were needed to capture the plausible evidence of impact of an HRBA and/or RBA to health, including both qualitative and quantitative methods, but that qualitative studies dominated. The findings are similar to the results by the studies in *HHR*. Polet et al. (2015) point out that quantitative evaluations and their measurable outputs can show which activities were undertaken and which changes were made. But it might be insufficient for showing *how* the results were obtained. Unnithan (2015) argues that in order to be able to evaluate the effects of an HRBA or RBA to health, certain qualitative studies, such as ethnographic studies, lend themselves easily, as they can be carried out in everyday settings and can pay particular attention to contextual features of interactions[259]. Thomas et al. (2015) suggest that the impact of an HRBA to health “is best measured across a spectrum of change – at the individual, programmatic, structural and societal levels” [262 p. 11].

The results of the review show that the studies employed a wide range of terminologies and articulations of what constitutes an HRBA or RBA to health. In the discussion section of chapter 4, I noted how this is problematic for evaluating the influence of an HRBA to health. The studies in the *HHR* series include additional variations of what constitutes an HRBA to health, demonstrating the very broad understanding of what forms an HRBA or RBA to health. Thomas et al. (2015) reinforce the point I made in chapter 1 – that when the UN adopted the common understanding of an HRBA to health in 2003, it left open to interpretation the exact formula for designating an approach an HRBA or RBA to health[262]. The same authors note that today, most health policy makers and researchers would be able to identify some elements that constitute an HRBA to health, such as participation, non-discrimination, and accountability[262]. However, Songane (2015) notes how “the main issue is that an HRBA to health is a new discipline that is still being established. There are very few people acquainted with HRBAs or how to apply them”[260 p. 40]. This reflects the findings from my study on the importance of health workers’ understanding of an HRBA to health in order for an HRBA to health and mental health to be realised.

The review reveals that the most common features used and studied in HRBAs and RBAs were participation, non-discrimination and equality, and AAAQ (see chapter 4, figure 3), which are the same features that I have used as the definition of an HRBA to health. However, the studies in *HHR* have additional “combinations” of what constitutes an HRBA to health. For example, “accountability and transparency” were defined to constitute an HRBA to health by the project “My Health, My Voice” [257]. Silberhorn (2015), however, defines an HRBA to health as “non-discrimination and equality of opportunity; participation; empowerment; and accountability and transparency”[253], while Escobar et al. (2015) define an HRBA to health as constituting “participation, accountability, non-discrimination, transparency, human dignity, (citizen) empowerment, and rule of law”[263].

HHR also includes a number of studies in which it was difficult to determine how an HRBA to health was defined, such as the study by MacNaughton et al. (2015) which states that “the Vermont Workers’ Centre’s human rights-based approach ... , including intensive grassroots organizing coupled with human rights education and human-rights based policy advocacy”[255 p. 84]. Furthermore, the study by Davis (2015), which looks at the Global Fund’s realisation of an HRBA to health, refers to a “country dialogue approach,” explaining that while the Global Fund does not explicitly use an “HRBA, [the country dialogue approach] is generally in line with what is described by the UN Common Understanding”[257 p. 102]. Frenk and Gomez-Dantes (2015) explain that ethical values and human rights were the foundation of the comprehensive reform in Mexico, but only mention the ethical values of the Mexican health reform, which are “social inclusion, equal opportunity, financial justice, individual autonomy and social responsibility” [254]. In contrast, studies with no explicit HRBA or RBA to health were excluded in my review.

Ten years ago, Gruskin (2006) wrote that having a number of definitions of an HRBA to health leads to confusion between those of us who consider ourselves part of the health and human rights community [264]. The quest for clarity about health and human rights in order to make the realisation of an HRBA to health more effective and to be able to present clear and persuasive arguments[264], as well as comparative results, requires a common definition and a common voice. This quest is still urgently needed, as human rights integration is today required by many[9], including by the WHO for improving the mental health response[1]. Hunt et al. (2015) comment that one of the issues that clearly emerges in the *HHR* series is the lack of a common definition of what constitutes an HRBA to health, highlighting that “the gulf between the human rights community and the health community still exists and requires work”[251 p. 8]. As such, it is important that a definition of the core elements of HRBAs is agreed upon as soon as possible,

even if it might change in the future as more studies on an HRBA/RBA to health evolve as experience is gained.

Even if, a common definition is adopted, the responsibility that the burden of proof of respecting, protecting and fulfilling the right to health produces better health outcomes than when rights are neglected and violated is the responsibility of everyone at the national level, from policy makers, government ministries such as finance, health, education, housing, migration, transport and gender; as well as civil society, health service providers, academia and donors. The realisation of an HRBA health and mental health again confirms what was stressed in 1994 in the Vienna Declaration, the universality, indivisibility and interdependence and inter-relation of all human rights.

The review also showed that there is significant room for improvement in the quality of the research methods applied. Even if more studies are carried out evaluating an HRBA to health, they must be of good quality. Without this, there is a risk that even positive results might be questioned and overlooked by the health sector, or denied by those who are not yet fully convinced of the benefit of systematically applying an HRBA to health.

The next section will discuss the findings from chapter 5, which explored health workers' perspectives on the right to health and health-related human rights.

7.2 PERSPECTIVES ON THE RIGHT TO HEALTH AMONG MENTAL HEALTH WORKERS IN NEPAL

The previous section discussed the existing evidence of the use of an HRBA to health, providing a global perspective. This section discusses the findings of chapter 5, which explored mental health workers' perspectives on the right to health in Nepal. It begins by discussing health workers' perspectives on human rights in general and then examines their understanding of the right to health and the rights of persons with psychosocial disabilities. It then explores health workers' understanding of an HRBA to health.

7.2.1 Human rights and the right to health

The findings indicated consensus among participants in that they appeared to embrace human rights. However, participants also emphasised difficulties in understanding their meaning and how to articulate it, irrespective of which level of the health system they were working in, which sector (public or private) they belonged to, whether they were male or female, and their level of education. There were no major differences in attitude among participants, despite my using

different qualitative methods. The reasons for this consensus might be partly attributed to human rights being frequently discussed in Nepal after the war. During my research, it emerged that higher-ranking health workers thought that lower-ranking ones (those based at the PHC centres) would not understand human rights. However, the findings demonstrated that this was not the case. Health workers at the PHC centres – particularly women – were very aware of human rights and even referenced the Convention on the Elimination of All Forms of Discrimination against Women.

There was also a large degree of consensus among participants regarding their understanding of the right to health. Participants' perspectives on the right to health were expressed with greater certainty and precision than when they talked about human rights more generally. That health workers thought it was easier to describe the right to health might not be so surprising given that they work in health. Furthermore, narrowing the discussion from human rights to, for example, health and human rights, or to health and education, can make it more concrete and easier to understand. In addition, the right to health is included in Nepal's Constitution, which many participants referenced. Moreover, as described in chapter 2, the Maoists in Nepal had historically demanded free health care, which was another issue that many participants referred to when describing how they thought people would understand the right to health. Although the state's provision of free health care is not required by the right to health, the full right to health includes numerous entitlements, such as the availability of good-quality health facilities and access to essential medicines, which require positive outlays by the state[13]. As a result, the right to health is contingent upon the availability of adequate, equitable, and sustainable financing for health, at both the domestic and the international level[265], and it is the state that decides how to organise its finances, which should ensure that everyone has access to facilities, goods, and services without discrimination. What is interesting to note here is the importance of national (as opposed to international) recognition of the right to health. Health workers did not refer to the international treaties to which Nepal is party (see chapter 2 for further details) but rather to national laws – most likely due to the inclusion of the right to health into national law through Nepal's Constitution.

Although national recognition appears to have aided health workers' understanding of the right to health and to have guided them in understanding what was expected of them, it did not automatically translate into accurate perceptions of the law as it is written. For example, the Nepali Constitution stipulates that the right to health encompasses physical and mental health, but the majority of health service providers vocalised it as including only physical health[134].

This is likely a reflection of the broader marginalisation of mental health in Nepal and around the world – indeed, Paul Hunt, the first UN Special Rapporteur on the Right to Health (2002–2008) has described mental health as among the most grossly neglected elements of the right to health[74]. Evidence from South and Southern Africa has also shown how different conceptions of human rights substantially affect states’ willingness and ability to meet constitutional obligations with regard to the right to health[9].

A 2008 study looked at the relationship between countries’ ratification of relevant human rights treaties, and national human rights recognition, finding that less than two-thirds of countries’ ratifications had translated into national constitutions or other laws[7]. One reason for this reluctance might be the risk of increased litigation, as national accountability is often stronger than international accountability[7], an issue alluded to in chapter 1. A study by Hogerzeil and colleagues (2006) demonstrated that national legal recognition of the right to health has generated significant case law[266]. They analysed 71 court cases from 12 countries and concluded that in 59 cases, access to essential medicine was enforced through the courts as part of the right to health[228]. However, according to Bell (2005), the ICESCR is complex and states have therefore been reluctant to accord the economic, social, and cultural rights the same constitutional recognition as civil and political rights. As a result, socioeconomic rights such as the right to health tend to be found scattered throughout a variety of legislation, and be supported with less resources, making enforceability problematic[267]. Lang et al. (2010) note that while many developing countries have very progressive disability policies and explicit constitutional mention of disability rights, these rights are often honoured in the breach – in other words, a state ratifies a treaty or incorporates this ratification into national laws or the constitution but does not implement these laws or even violates them[268]. There is thus an “implementation gap” between policy formulation and implementation, which was also highlighted by some of the participants in this research.

One of the participants at the national level noted that there was a difference between the ICCPR and the ICESCR. The participant explained that the right to health did not seem to have the same value as, for example the right to freedom of religion, a right found under article 18 of the ICCPR[269]. In the context meetings, the human rights participants also acknowledged that their focus on human rights in Nepal was on civil and political rights, not economic, social, and cultural rights. These findings resonate with findings in my literature review, highlighting that the realisation of the right to health, like all other rights, depends not only on legislation but also on political, social, economic, scientific, and cultural actions and on social monitoring. More must be

done to raise the profile of the right to health and of the rights of persons with disabilities, including psychosocial disabilities. These rights should have the same value as civil and political rights.

7.2.2 The rights of persons with psychosocial disabilities

Although there was general consensus among participants in terms of their perspectives on human rights and the right to health, the same consensus was not found among participants when talking about the rights of persons with psychosocial disabilities. Their understanding of the rights of persons with psychosocial disabilities was limited in that they found it difficult to describe what rights such persons have under human rights law. One reason for this might be, as raised in chapter 5, that health workers tended to describe what they saw or experienced in their work and in everyday practice in society.

All participants agreed that people with psychosocial disabilities faced stigma and discrimination in society and had no rights in practice. One issue that emerged during the context meetings was that some participants from the private sector at the district level referred to different human rights as pertaining to people with different psychosocial disabilities, most notably denying rights to those with alcohol dependency.

These views might be the product of cultural norms, as it was common for respondents to express that people dependent on alcohol ruined families and were unruly and rude. In Nepal, alcohol consumption has also been thought of as sinful among the upper-caste Paribatiya Hindus, though normal among Newars and other Tibeto-Burman hill groups [124]. It should, however, be recognised that alcohol dependency (along with drug dependency and schizophrenia) is commonly viewed more negatively than other mental disorders in a range of cultural settings globally [270].

This view of differential rights is inconsistent with the right to health, and all human rights. Although in practice many people do not enjoy all their human rights equally, in theory, all human beings have the same rights, which they hold equally and inalienably and which can never be taken away [23, 37, 271]. According to Kinderman and Butler (2006), the message people receive about human rights is often confusing and in some cases creates a feeling of hostility. As a result, people create mental models of how human rights relate to themselves by reaching for the meaning that is most available to them, at times based on possibly adverse and absurd reports in the press[272]. This also confirms the subtle-realist position – the epistemological basis of this

research (discussed in chapter 3) – which underlines that knowledge is mediated by pre-existing ideas and values. In addition, this issue highlights the importance of understanding the attitudes and perspectives of frontline workers. According Lipsky (2010), service bureaucracies consistently favour some clients over others, despite official policies designed to treat everyone alike; sometimes street-level bureaucrats act contrary to their own rules and goals. As a result, it is important to understand how the rules are experienced by workers within an organisation, what latitude workers have in acting on their preferences, and what other pressures they experience [11].

Another point that emerged was the way in which patients demanded their rights be met from their health service providers, which resulted in frustrations among health workers, particularly service providers at the district level. I initially interpreted this as limited respect for people with psychosocial disabilities but soon came to realise that what the health workers were expressing might rather be a reflection of the frustration some participants had expressed over the sole focus on users' human rights, rather than a joint focus on both users' and health workers' rights. This highlights the need for discussions with health service users around the fact that rights also come with responsibilities. It also highlights the need to recognise, particularly within the human rights community, that health workers are often unable to change their practices due to systematic and structural constraints beyond their control. Lipsky (2010) notes how in some circumstances, service users can effectively demand their rights, but these strategies appear useful only in certain circumstances, and usually not for long. He argues that the relationship is determined primarily by the priorities and preferences of street-level bureaucrats (health workers), but the character and terms of the relationship are substantially affected by the limits of the job[11].

7.2.3 HRBA to health

There was generally a low level of understanding about HRBAs to health among PHC-level participants. Initially, I asked the participants to describe an HRBA to health, but this question was soon removed, as I quickly realised that they could not describe it and that the question caused confusion. Instead, I asked participants if they had ever heard of it and, if so, what they thought of it in general. This resonates with Songane's (2015) observation that few health workers know what an HRBA to health is [260].

The participants who had heard of an HRBA to health had no practical experience or evidence of its impact in mental health planning or service provision. Instead, they referred to evidence in

other health sectors where they felt an HRBA to health had worked, such as HIV/AIDS and sexual and reproductive health and rights.

To improve their understanding of human rights, respondents requested training and guidelines tailored to the specific needs of health workers. This emphasis on human rights training echoes the finding in the literature review presented in chapter 4 and in the discussion in section 7.1 of this chapter. According to the first UN Special Rapporteur on the Right to Health, “human rights education is an essential starting point for equipping health professionals with the knowledge and tools to empower them to promote and protect human rights. As well as enabling them to define the rights of their patients, human rights education also has an important role to play in assisting health professionals to defend their own rights”[12]. Indeed, the importance of human rights training for health workers was reinforced in 2011, when the UN Declaration on Human Rights Education and Training was adopted [273].

Few participants appeared to have participated in any human rights training, but those who had pointed out that the training had to be tailored to their needs, instead of focusing just on laws and treaties. According to Kinderman and Butler (2006), human rights training that largely focuses on legal questions suggests to non-lawyers that it is not relevant to them. Instead, the training should be interactive so participants can share how they can apply human rights in practice, which will encourage people to adapt their existing “mental models” to make more sense of human rights. The authors also underline the importance of ensuring that human rights training does not seek to change people’s belief systems, as this might cause resistance. Instead, training should suggest how human rights can be complementary to the work that is already being carried out[272]. These comments resonate with the findings from a control trial exploring the impact of an intervention to change health workers’ attitudes towards and knowledge of HIV/AIDS in Nigeria. This study found that when the intervention applied methods suited to the health workers, including discussions of discrimination and human rights, a positive change was noted in their perception of risk groups and behaviours, perceived skills in treatment and counselling, reduced fears and increased concern for people with HIV disease, and improved treatment and prevention of HIV, when compared with a control group in another state in Nigeria [274].

Just as health professionals need to “translate” and use lay persons’ language when speaking to a patient, there is a need for the human rights community to better understand how to talk about the right to health with lay people. This research has demonstrated that health workers do know about human rights and are willing to learn more and apply it on the ground, if given the tools to

translate legal rights into daily practice. However, change is rarely easy if the innovation requires complex changes in clinical practice, better collaboration between disciplines, or changes in the organisation of care. As a result, time is required for lasting changes to be observed [260]. Although there are a number of challenges to implementing an HRBA to health, it is worth also acknowledging opportunities. For example, in this research, participants explained that it was only recently, after the peace agreement, that human rights began to be discussed – and this creates a window of opportunity to integrate human rights. Silberhorn (2015) reports that in Nepal, the German Agency for International Cooperation applied an HRBA to health with a focus on social audits, which led to increased citizen participation, social inclusion, and mutual accountability. In addition, the audits helped fill vacant positions through temporary contracts, improved the conduct of health workers, made facilities more responsive to patients' needs, and helped re-energise health facility management[253].

The next section explores health workers' perceptions of the application of an HRBA to health on mental health planning and service provision, and the difference between the theoretical knowledge of participants and actual practice.

7.3 HEALTH WORKERS' PERCEPTIONS OF THE APPLICATION OF A HUMAN RIGHTS-BASED APPROACH TO MENTAL HEALTH PLANNING AND SERVICE PROVISION

Chapter 6 explored mental health workers' perceptions of the application of an HRBA to health in mental health planning and service provision in Nepal. It sought to capture the practical reflections on the application of HRBAs to health in mental health planning and service provision. District- and national-level participants believed that the adoption of an HRBA to health would improve the situation for people with psychosocial disabilities and for themselves as health workers, as such an approach had aided other health sectors, such as HIV and sexual and reproductive health and rights.

A checklist (see chapter 3) was used to realise objective 3. The checklist seemed to help concretise the discussions. Participants agreed that the HRBA-to-health features of non-discrimination, accessibility, participation, accountability, and quality were critical to mental health planning and service provision. These were also the most common features identified in the literature review (chapter 4) of what constitutes an HRBA to health. They all identified obstacles in implementing the abovementioned features, but their arguments mirrored their own practical experiences and thus varied accordingly.

I used observation as an additional qualitative method for chapter 6. My observations were used as qualitative vignettes, as stimuli to extend the discussions and an aid to try to identify differences between how participants believed the right to health should be realised (chapter 5) and their practice (chapter 6). Confidentiality and consent were two features which all participants agreed were important in public health and for the realisation of the right to health. However, through my observations, it surfaced that in practice they did not necessarily respect confidentiality and consent. Here, I will focus on the issue of consent because it has attracted considerable debate, particularly since it is quite “new” in human rights in the sense that through the adoption of CRPD, states are now legally bound to respect, protect, and fulfil consent.

The participants in this study explained that consent was important but complex. They brought attention to the way in which consent was sometimes difficult and impractical to obtain, and in other circumstances even impossible to obtain, such as when a person was very ill and could be a danger to himself/herself or others. According to participants, the difficulties in obtaining consent were also related to the Nepali cultural context in which men and other family members give consent for women. In addition, in Nepal, decisions are often made in groups rather than by individuals. The lack of clear processes on human rights and practices was a third explanation provided by participants regarding the complexity in obtaining consent.

Although people agreed that consent was important, no one referenced how and when consent should be obtained; instead, it appeared to be up to the practitioner if and when to seek consent. None of the participants referred to any processes or guidelines on when and how consent should be obtained. However, in a context meeting, a mental health manager from the national mental health hospital in Kathmandu recommended the development and adoption of mental health legislation outlining when consent should be obtained and what constitutes involuntary treatment. The participants working in human rights and in civil society organisations underlined that a consequence of the lack of clear processes for obtaining consent appeared to, at times, be used politically to silence people.

Three examples from my research demonstrate different understandings of when consent should be sought and how that translated into different practices. The first example was the perspective of a medical doctor at the district hospital in Chitwan who explained that consent should always be obtained, irrespective of the case’s severity. If it was not possible to obtain consent immediately upon the person’s arrival, consent should be obtained as soon as possible thereafter.

The second example was the perspective of a health manager at the national level who worked primarily at a PHC centre. He explained that when a person comes to the PHC centre for treatment, it means that the person has already given consent for treatment and so there is no need to obtain consent. Furthermore, if a severe case arrives to the health centre, someone most likely brought the person there, and it is that accompanying person who becomes responsible. In this event, the user's consent is not needed since, by agreeing to come to the health centre, the user has already given consent to the person(s) who brought him or her.

In the third example, a couple whose son had been killed by a famous Maoist leader during the war had been admitted to the mental health hospital in Kathmandu because of a verbal agreement between the chief district officer and the hospital. Therefore, the couple never gave their consent and were involuntary treated. According to my context meetings with the National Human Rights Commission (see chapter 6), the couple wanted justice, not compensation. To obtain justice, they went on a hunger strike. They were then arrested, released, and, during my research, detained again. According to the people I spoke with from the commission, as well as others who had actively participated in bringing attention to this case, the couple's admission to the mental health hospital could have been a political attempt to silence them. Furthermore, according to one of the participants, by admitting the couple to the hospital and diagnosing them with a mental disorder, they would be denied legal capacity according to the Nepali legal system (see chapter 2). This reflects numerous examples from other settings globally and historically, where legal capacity has been prejudicially denied to certain individuals [275]. According to the director of this hospital, there was a need for clarity regarding involuntary treatment and guidelines on the meaning of consent and of human rights laws.

These mixed findings resonate with the conclusions of Weller (2012), who reports that other studies have shown that clinicians reported not obtaining consent because of a lack of time, resources, knowledge, and training, as well as confusion about what is required by the law [276]. The CRPD includes a reference to "free and informed consent" in article 25(d), which protects the right to health[37]. This is the first time, to my knowledge, that informed consent is referred to in a binding international instrument. Prior to the CRPD, the general recommendations and general comments issued by UN treaty bodies referred to "fully informed consent"[19 para 20,22], "informed choices"[13 para 37(3)], and "informed consent"[277 para 32], but these documents are not legally binding upon states.

Today, there is also guidance regarding involuntary treatment, as the director of the hospital requested at the time of my research. A report by the UN Special Rapporteur on Torture states:

“criteria that determine the grounds upon which treatment can be administered in the absence of free and informed consent should be clarified in the law, and no distinction between persons with or without disabilities should be made. Only in a life-threatening emergency in which there is no disagreement regarding absence of legal capacity may a health-care provider proceed without informed consent to perform a life-saving procedure”[278 para 66].

In May 2014, about one year after carrying out my data collection in Nepal, the Committee on the Rights of Persons with Disabilities adopted General Comment 1 on article 12 (equal recognition before the law) of the CRPD[275]. This general comment was adopted because of the committee’s observations of “the general failure to understand the human rights-based model of disability, [which] implies a shift from the substitute decision making paradigm to one that is based on supported decision making”[275]. General Comment 1 explains that health professionals, including psychiatrists, are required to obtain the free and informed consent of persons with disabilities prior to any treatment. It also states that substitute decision makers are not permitted. The document further explains that “all health and medical personnel should ensure appropriate constitution that directly engages the person with disabilities. They should also ensure, to their ability, that assistance or support persons do not substitute or have under influence over the decisions of persons with disabilities”[275 para 41].

In September 2015, the Committee on the Rights of Persons with Disabilities adopted guidelines on article 14 (the right to liberty and security of persons with disabilities) of the CRPD. These guidelines explain that the freedom to make one’s own choices includes the freedom to take risks and make mistakes on an equal basis with others. In this way, the deprivation of liberty on the basis of actual or perceived impairment or health conditions in mental health amounts to a violation of article 12 of the convention[279 para 15]. Furthermore, article 14 of the convention protects the right to be free from involuntary detention in a mental health facility and not to be forced to undergo mental health treatment [275 para 31].

The guidelines note:

“it is a contrary to article 14 [of the CRPD] to allow for the detention of person with disabilities based on the perceived danger of persons to themselves or others. The involuntary detention of persons with disabilities based on risk or dangerousness, alleged need of care or treatment or other reasons tied to impairment to health diagnosis is

contrary to the right to liberty, and amounts to arbitrary deprivation of liberty”[279 para 13].

The guidelines explain that all persons have a duty to do no harm. Legal systems based on the rule of law often have criminal and other laws in place to deal with the breach of this obligation[279]. However, according to the guidelines, persons with disabilities are often denied equal protection under these laws and are diverted to a separate track of law, including mental health laws. These laws have often lower standards in terms of human rights protection, particularly with respect to due process and fair trial[279].

Although the committee’s guidelines and General Comment 1 might help, they need to be known and implemented, and in Nepal, accountability appears to be one of the weakest aspects according to both the lawyers and the health workers who participated in this research. Although, at the time of my research, the civil society movement on mental health appeared to be growing and mental health was one of the priorities of the National Human Rights Commission, the Committee on the Rights of Persons with Disabilities was not a strong accountability body.

The study results indicate that weak implementation of government policies, plans, and laws reveals the need to understand both the health system context and the country context. It is important to involve health workers in order to understand the health system and its inner workings. Further, the implementation of an HRBA to health requires the involvement of these workers and requires that their rights be respected, protected, and fulfilled. In addition, time is required, as highlighted in Songane’s (2015) interview with *HHR*: “Adopting HRBAs to program design and implementation is not easy and requires time. HRBAs introduce complex concepts that can require health workers and policy makers to adopt a new vision of health care. The people involved must have commitment and enthusiasm so they can encourage co-workers to adopt the same approach...but they require support from management”[260]. The implementation of an HRBA to health spans the disciplines of law, medicine, and public health, a challenge also confirmed by Hunt et al. (2015) [251]. The difficulties of translating human rights law into practice, including an HRBA to health and mental health has been highlighted throughout this thesis. This raises a number of fundamental questions. For example, whether the construct of HRBA to health, which appears (based on the thesis’ findings) not well understood or apparently implemented, is flawed? Can it not lend it itself to implementation and evaluation in the way that assessments of impacts of human rights-violations can? I would argue that despite the limitations with an HRBA, the understanding and application of this concept is increasing

based upon the findings of the narrative review in this thesis and broader literature. Further, limited documentation of its implementation does not automatically imply an HRBA is not implemented. Rather it might be that adequate documentation and research of this implementation is not taking place. To 'give up' on HRBA and only rely on evidence of violations would reject the objective of applying an HRBA / RBA of preventing violations from happening in the first place. Ultimately, documentations of violations and HRBA to research are complementary and both very important.

The next section looks at the conceptual framework for this research and evaluates it by analysing and synthesising the findings from this research.

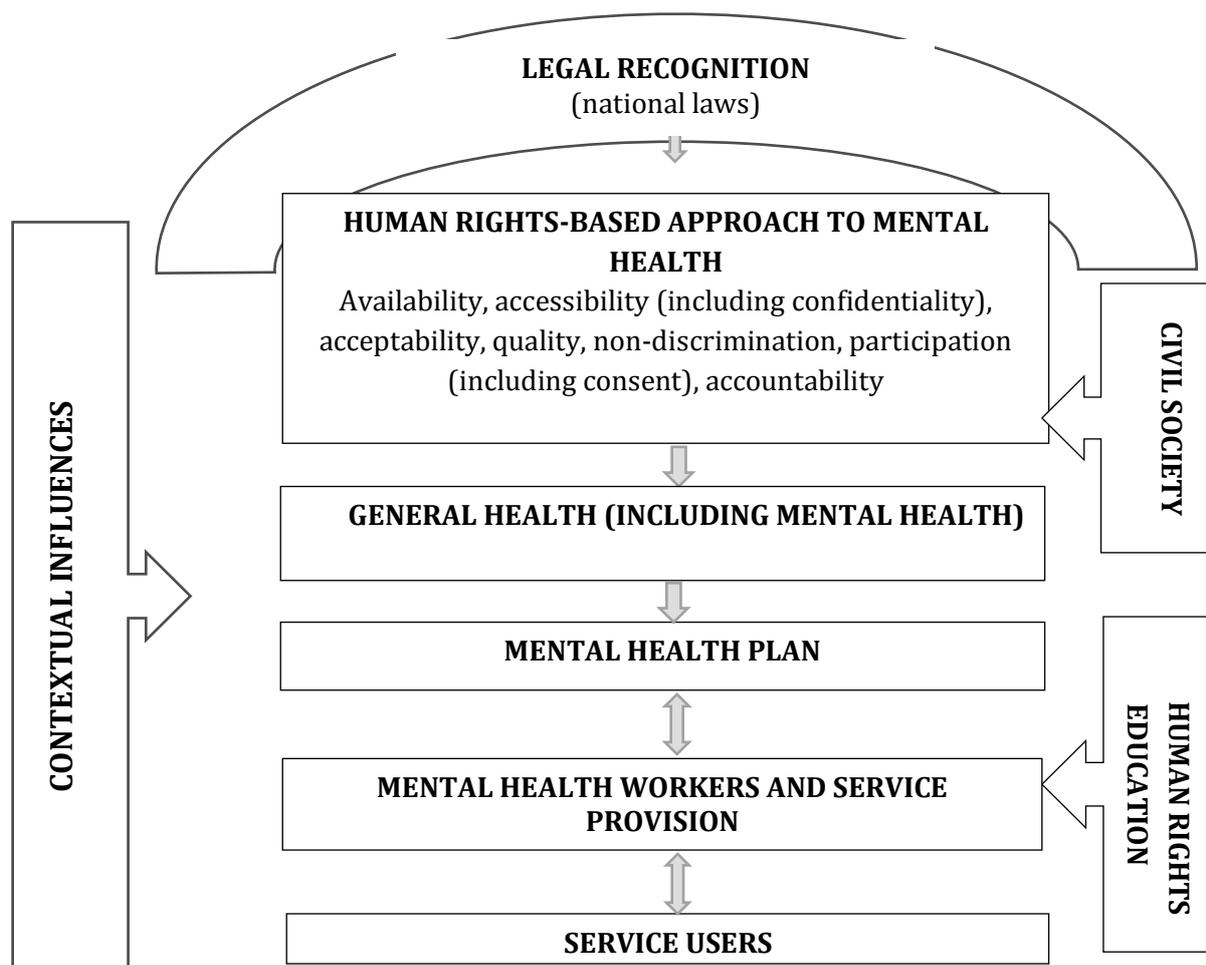
7.4 THE COMPLETION OF THE CONCEPTUAL FRAMEWORK ON A HUMAN RIGHTS-BASED APPROACH TO MENTAL HEALTH

This section corresponds to the completion of objective 4, the development of a conceptual framework. In chapter 1, I presented and explained the conceptual framework. In this section, I develop the conceptual framework by analysing and synthesising the findings from this research. Figure 10 presents the updated framework, and the subsequent text describes its individual components.

The original conceptual framework (see chapter 1) included the following elements: legal recognition, human rights-based approach, general health (including mental health), mental health plan, mental health workers, and service provision. Based on my findings from the literature review and primary research, I then added the following elements: national laws, contextual influences, service users, civil society, and human rights education.

Below the conceptual framework, an agenda for further research and actions is presented in Table 10. Table 10 includes the following headings: research needs, structural changes, capacity building, advocacy needs and expected outcomes.

FIGURE 10. REVISED HRBA TO MENTAL HEALTH



National laws

Many of the national laws in Nepal were reviewed and adjusted to respect human rights during the conflict (please see Chapter 2). The review (and some of the studies in the *HHR* special issue) emphasised the importance of national laws (including the constitution) for supporting the realisation of an HRBA to health. Nepali health workers saw the recognition of the right to health in Nepal’s Constitution as important for better understanding the meaning of the right to health. However, even if constitutional recognition did improve their understanding, health workers adopted their own interpretations of what constitutes the right to health.

However, as discussed in chapter 5, one participant also highlighted the importance of clarity in the national law to understand what is permitted by the law and by human rights. Some health workers thought that the Nepali discriminatory national law, such as the law which permits the

husband to divorce his wife if mentally ill, might partially be attributed to the stigmatisation faced by women with mental health. As such, this research indicates the translation of enactment of human rights laws would play an important role in guiding the health workers in better understanding and changing health workers' beliefs, attitudes and practice in Nepal.

Although it is acknowledged that national laws and a country's constitution do not automatically translate into practice at the service level, they are important in various ways, such as by supporting civil society organisations in their advocacy efforts, monitoring of the realisation of the right to health and an HRBA to health and mental health and at times as service providers. Further, as mentioned in the literature review, and by the health workers in Nepal translating *de jure* rights into substantial *de facto* rights also requires political capacity and support of the civil society organisations.

Contextual influences

The contextual influence in this conceptual framework is broadly understood to include history; the social, economic, and political environment; religion; and culture. I added contextual influences to the framework given that a number of studies in the literature review (and in *HHR*) highlighted that the success or failure of an HRBA to health is dependent on the context. For example, in the studies on maternal and child health in Brazil, Italy, Nepal, and Malawi, the authors acknowledged that the improvements of the application of an HRBA are not exclusively attributable to the use of an HRBA to health, or to a single isolated HRBA policy or programme on women's and children's health. Rather, such contributions also depend on the context, political will, and proactive measures to reduce health disparities and increase investment [139, 229, 230, 232]. The importance of political leadership was also mentioned by some of the participants who emphasised that realising an HRBA had to start with political leadership and that the rest would follow.

References to Nepali history, politics, culture, and beliefs were also made by health workers when explaining how the right to health and all human rights, including the rights of persons with disabilities, were perceived. For example, participants explained that before the war they could not talk about human rights and that consent was influenced by culture, including women's position and role in society, and that if changes were to take place they had to start with politicians and policy makers. Reference to the cultural context was also made when discussing consent and confidentiality. In the case of this thesis, this involves understanding how the country context may influence health workers' perspectives and perceptions of the right to health and

health-related human rights, including the application of an HRBA on mental health planning and service provision.

According to Porter (2012), examining health workers' behaviour requires an understanding of the economic, social, political, cultural, and historical contexts in which they work[280]. Studies in public health also emphasise the importance of considering the context for the implementation of policies and programmes[281, 282]. Dahlgren and Whitehead (1991) describe a social ecological theory of health and the interrelationship between the individual, his or her environment, and the disease in question. At the centre is the individual, whose health is influenced by the lifestyle factors, which in turn are influenced by social and community networks, which in turn are influenced by general socioeconomic, cultural, and environmental conditions [282].

In human rights literature, country contexts are often referred to as underlying determinants – as aspects which are claimed to be important for the realisation of the right to health but might not explicitly be included in a particular treaty on the right to health, such as level of education, gender, freedom of association, water, and sanitation [13]. Landman (2005) notes that the realisation of civil and political rights is influenced by domestic factors, such as the level of democracy, wealth, and embeddedness of international government organisations[283]. Risse, Ropp, and Sikkink (2004), who also focus on civil and political rights, argue that the implementation of human rights norms requires some measure of political transformation and domestic structural change[244]. Cole (2012) highlights that the implementation of women's rights, for example, is influenced by the cultural context[284].

Service users

Service users were added to the framework. In the literature review, users had an important role in the realisation of an HRBA to health. This was the case, for example, in the study on Northern Ireland [231]. Some of the studies in the *HHR* special issue also underline the importance of involving users in the realisation of an HRBA to health. Further, the adoption of the CRPD and subsequent UN general comments and guidelines reinforces the active participation of persons with disabilities – a paradigm shift from earlier human rights law, which was rather paternalist towards persons with disabilities[37(Art. 3, 29,30)]. The involvement of service users is not only good practice but also beneficial from a psychological perspective in that the interaction between different groups of people – in this case, service users and providers – has been documented to

reduce stigma and “social distance.” Closer engagement enhances empathy, which is critical for the realisation of an HRBA to health[272].

Not all of the health workers in this study embraced the idea of service users demanding their rights. Some health workers expressed frustration with users who demanded goods and services from them, which the health personnel seemed to feel they could not provide due to system failures. Nevertheless, many health workers underlined the importance of realising users’ human rights, particularly the rights of the most vulnerable, who they felt were not aware of their human rights. Songane (2015) notes how health workers also have an important role in helping users understand their right to health, and that not receiving health care is also a violation of human rights[260]. London (2008) emphasises the importance of users, civil society, and health workers working together to address system failures[9].

Civil society

In addition, I added civil society to the conceptual framework. Civil society is broadly understood to include any civil society group, including user groups, human rights groups, and the health sector. The role of civil society organisations was highlighted in the literature review as important in the realisation of an HRBA to health. Some studies in the *HHR* special issue also acknowledge the important role of civil society. Participants in my research did not address the role of the civil society explicitly, other than noting that the civil society should hold to account and could provide human rights education. Perhaps this was because some of the participants represented NGOs and were supportive of the role of civil society organisations.

The CRPD underlines the importance of civil society involvement for the realisation of the rights of persons with disabilities[37 (Art. 33.3)].

Human rights education

I also added education to the conceptual framework, as it was identified in the review and by some of the studies in *HHR*, as well as by the health workers, as being of great importance in understanding the right to health and mental health and an HRBA to health and mental health. Many actors, including civil society organisations and academia, can carry out educational efforts.

TABLE 10. AGENDA FOR FURTHER RESEARCH AND ACTION

Action Point		Expected Outcomes
1. Research needs		
1.1	Include the users of the health services, in this case users of the mental health services. The right to health highlights the importance of active participation of people affected by policies and programmes. The ICRPD specifically stipulates the active participation of people with disabilities, including people with psychosocial disabilities.	Better understanding of the needs of those using the mental health services, be it people living with psychosocial disabilities or, for example, care providers.
1.2	Consider including service providers, including non-formal (traditional) health care workers.	Better understanding of their perceptions and perspectives of human rights, the right to health and an HRBA to health.
1.3	Consider involving human rights workers as collaboration between the health and human rights sectors is pivotal for an HRBA/RBA to be fully implemented.	Better understanding of the right to health by both human rights workers and health professionals, including challenges in the implementation of the right to health and an HRBA to health in the health system. This could lead to improved collaboration between the health and human rights sectors.
1.4	Consider involving donors, as they determine what to fund, and how project and programs should be formulated and prioritised.	Better donor understanding of the perceptions and perspectives of human rights and an HRBA to health in policy development, legislation, priority setting and practice, which could support greater donor engagement and influence on HRBA to health.
1.5	Strengthen research evidence on the application and implementation of an HRBA to health by increasing the quantity and quality of studies on the topic. These studies should seek to address different health topics, such as mental health, maternal, adolescent, child and sexual and reproductive health, treatment of chronic conditions, non- communicable diseases and infectious diseases.	Strengthened evidence base of an HRBA to health. Greater understanding and arguments for why or why not an HRBA to health should be applied for those yet not convinced that the application of human rights to health is relevant and achieving better outcomes with respect to both. This could support evidence informing practice and policies.
1.6	Promote and support research specifically in low- and middle income countries on the application and implementation of an HRBA to health, including mental health.	Stronger evidence and ability to compare and contrast research results, which in turn would strengthen policy and research arguments for why or why not human rights and/or HRBA to health should be applied. Additionally, it would result in improving research

		methods and the robustness of their outcome.
1.7	Strengthen research collaboration between health and human rights researchers.	Improved research results, and understanding of health and human rights; hopefully greater dissemination of results to a greater number of audience, in a manner both groups understand.
1.8	Include key actors to help determine research priorities for HRBAs to health, such as people living with psychosocial disabilities/mental health users, health workers, and governmental, inter-governmental, non-governmental and donor agencies.	New areas of research will most likely be identified and participatory processes in research stimulated.
1.9	Pay attention to possible gender and age differences in the attitude and practice of health workers and users of the health services in future research.	Possible identification of difference in attitudes between sex and age of the health workers to human rights and / HRBA to health. Promotion of gender equality and equity in human rights and health terms.
1.10	Promote and support research on health workers' perceptions and perspectives on mental health and extension to enhancing the ability of the community to provide care and support, in favourable environment, to community members living with psychosocial disabilities.	Better understanding of health workers' perceptions and perspectives on the community to provide care and support. The results should inform policy makers how to structure the support to the community to ensure it receives support by the community, the users and the health workers.
1.11	Explore health workers' concerns about violent expressions of psychosocial disabilities, their experience and possible capacity they have or need for dealing appropriately with such cases.	Better understanding experience and capacity to possibly deal with violent expressions of psychosocial disabilities in health care, institutional and community settings.
2. Structural changes		
2.1	Consent and confidentiality should be included in the definition of an HRBA to mental health as part of a clear description of the specific elements that constitute accessibility, use of services and participation.	Explicit monitoring by civil society that HRBA is respected, protected and fulfilled.
2.2	Obtain consensus on the definition of the core elements of an HRBA to health and HRBA to mental health, as well as consistent use of terminology among those working in the application of an HRBA, including human rights workers, policy makers, NGOs, and academics.	Clear definitions may help improve understanding of HRBA/RBA and support more objectives research, monitoring and evaluation on HRBA/RBA activities. Core elements would be included by default in all HRBAs and complemented, as the case may be, by additional elements best suited to demands, needs, capacities and institutional agendas.
2.3	Translate international human rights ratifications into national laws.	Better translation of human rights into national and local laws, regulations

		and practice. Achieving these outcomes will require accompanying civil society and political actors and securing financial support.
3. Capacity building		
3.1	Develop and provide regular human rights training tailored to the needs of health workers at all levels of the health system and for all cadres of health workers. And, provide public health training to human rights workers, including civil society on the centrality of health systems in realising the right to health and public health.	Increase awareness of a larger group of people who might not usually apply critical thinking, including people who are already or are being trained to engage in professional lives. Better understanding of the health system, and health workers' centrality in this. Improved collaboration between various actors, including the human rights civil society and the health workers in addressing systemic problems in the system.
3.2	Provide human rights training and education to health and human rights researchers.	To increase researchers' understanding and interest in carrying out research on human rights and HRBAs to health more specifically.
3.3	Establish UN guidelines on HRBAs to mental health, similar to the UN technical guidelines on the application of a human rights-based approach to the implementation of policies and programmes to reduce preventable maternal morbidity and mortality, developed in 2012[285].	Provide practical methods and tools on how to apply an HRBA to mental health.
4. Advocacy needs		
4.1	Publish research studies in peer-reviewed journals on HRBA to health and mental health.	Awareness of quality research results across health, human rights and other connected disciplines. Better translation of research outcome into policy and practice.
4.2	Dissemination of key research outcomes through public (e.g. radio) and social media targeted at wider audience beyond researchers.	Increased awareness and understanding of health, human rights and other connected disciplines. Better translation of research outcome into policy and practice, and if human rights is not respected that the people at different levels of the society demand that human rights is applied, i.e. respected, protected and fulfilled.
4.3	Hold seminars, workshops and conferences on the right to health, health and human rights and the application of an HRBA to health. Where possible include actors from different sectors and areas of responsibility, including policy makers, donors, practitioners and users	Better understanding of the topic, increased collaboration across sectors and fields, information sharing of possible methods and tools available, and hopefully increased application.

	including people with psychosocial disabilities.	
4.4	Access policy makers and ministries and share research evidence.	Information sharing and awareness, which hopefully leads to, if required, change in policy work channeling of research funding.
4.5	Awareness raising about best practices regarding mental health, including role of HRBA in supporting best practice for mental health care.	Improved care, quality and outcome of mental health services.
4.6	Involve civil society to carry advocacy work, to raise awareness of, and hold to account key actors engaged in the application of the right to health and HRBA to health.	More awareness and accountability in the spheres of public of health and human rights and HRBA to health.

7.5 LIMITATIONS

The first method used in this thesis was a narrative literature review; the limitations of that method are discussed in chapter 4 and will not be repeated here.

Limitations regarding the qualitative research include the fact that the case study approach limits the transferability of study findings to other settings. In addition, the qualitative research design, which focused on capturing health workers' experiences through a relatively small purposively driven sample, did not aim to produce findings which would necessarily be representative of the broader health worker population in Nepal.

There is an inevitable limitation in that the research methods capture what participants say, but this does not necessarily reflect what they do. This is why my research focused on respondents' perceptions and perspectives rather than claiming to reflect the reality of their actions. An exploration of the actual practical application of an HRBA to health and mental health would be a valuable future contribution to this field of work.

The limitations of the use of translation were discussed in detail in chapter 3 and will not be repeated here. However, one aspect which was not talked about in chapter 3 was the practical consequences of me not speaking the local language and how this could also create a feeling of distance, as highlighted in my field notes during my observations in one of the PHC centres:

“the older patients expressed that they were very keen to see foreigner in the PHC and they were wondering how they could talk to me. An older woman came up to the research associate and asked: ‘does she understand our language? As we can’t understand her and she can’t understand us, if we wish to talk to her we are unable to” (O1-2 010713).

This made me feel like an outsider and distant to the people and the society. I think it is desirable that the researcher speak at least a little bit of the language of the group and country one is researching, and not just the greeting phrases that I was able to speak and understand. Even though my translator tried to translate as soon as possible after something was said, a lot was also required of the translator during the observations, since a number of conversations often took place simultaneously. Inevitably, nuances might have been missed.

While I felt my presence was necessary in the focus groups and interviews, as neither the translator nor research associate had worked explicitly in the field of the right to health, this also resulted in some limitations. For example, the researcher’s values and perspectives influence his or her research, and therefore the research cannot be value free [170]. My background and belief in the importance and usefulness of human rights and the right to health may have influenced the participants and offset their ability to be openly critical of human rights and the right to health. However, this did not seem to be the case, and criticisms were made (see chapters 5 and 6).

It could also have been interesting to include other actors in the research. For example, female health volunteers could have provided useful insight, but they were not part of PRIME’s health workers. It could have been beneficial to include users of the mental health services, particularly people living with psychosocial disabilities, but this would have increased the complexity and ethical challenges of my research. Similarly, gaining donor perspectives could have been useful and human rights actors. The principal reason for not including these other actors was that the focus of this study was on health workers, and I wanted to ensure an in-depth knowledge of their perspectives and perceptions of the right to health, rather than risk spreading the research too thinly by including too many actors. Certainly, involving these other actors, particularly users, would be valuable in future studies.

The focus of this study was on one right – the right to health – and on one aspect of the right to health – the right to mental health. As explained in chapter 1, I chose this in order to ensure focus in the study. I readily acknowledge that the right to health is dependent on other human rights for its realisation [13]. However, even focusing on one right was a challenge, and I am aware that I have not managed to address all the features included in the realisation of the right to health,

such as the underlying determinants. But this is a common challenge when working on the implementation of rights.

7.6 CONTRIBUTION OF THE RESEARCH

I believe this research has contributed empirically, methodologically, and conceptually – as well as through a potential policy influence – to help better understand the perceptions and perspectives of health workers regarding the realisation of an HRBA to mental health.

Empirically, the narrative literature review was the first of its kind, with a focus on primary data, and thus it provides an important global synthesis on an HRBA to health. This review suggests that there is some evidence that improved health outcomes, including in relation to service provision, may result from the use of an HRBA on maternal, child, and mental health. It also suggests that there is a need for a clear definition of what constitutes an HRBA to health. But overall, the evidence is weak in both quantity and quality.

To the best of my knowledge, this is also the first research effort to explore an HRBA to health in mental health planning and service provision in a low-income country. This research contributes to a better understanding and empirical knowledge of health workers' perceptions and perspectives on human rights, the right to health, and the rights of persons with psychosocial disabilities, particularly with respect to alcohol, depression, and psychosis. The research also contributes to increased understanding of health workers' views on an HRBA to health in mental health planning and service provision.

Methodologically, the review also evaluated the quality of the methods used in the studies, thereby highlighting methodological areas for improvement in future empirical research on this topic. One strength of this study was its mix of qualitative methods. I tried to capture views on the right to health and an HRBA to mental health among different levels of workers through different qualitative methods and to then compare and contrast my findings. The observational portion also allowed me to take into account the specific interactions between health workers and users.

I developed and refined a conceptual framework, which could guide the future application of HRBAs to mental health planning and service provision. This framework includes the key features of non-discrimination, availability, accessibility, acceptability, quality, participation and

accountability. In addition to these HRBA features, the findings show the need to pay attention to confidentiality and consent. Indeed, it appears that both confidentiality and consent affect the realisation of all the mentioned HRBA features, but in particularly non-discrimination, accessibility, quality and participation.

The conceptual framework recognises how the implementation of an HRBA to health, including to mental health, requires the need to understand both the health system context and the broader country context. It is also important to involve health workers in order to understand the health system and its inner workings. Further, the implementation of an HRBA to health requires the involvement of these workers and requires that their rights respected, protected, and fulfilled. To be able to better be involved in and to better understand an HRBA to health, workers require training and education in human rights, tailored to their specific needs. In addition, users need to be involved in the realisation of an HRBA to health, which also includes involving civil society organisations.

From a policy perspective, this research contributes to the next report by the UN Special Rapporteur on the Right to Health (which is on mental health). The findings from this research have also been presented to the Swedish Ministry of Foreign Affairs and Sida, to health, human rights and research departments.

I have also communicated my research through presentations on the methods and results at Karolinska University in Sweden, as well as I have used this research as part of an evaluation team of the donor health fund, 3MDGs in Myanmar. Finally, part of this research will be included in a book on international relations, in a chapter that focuses on the ICESCR and the right to health and mental health (to be published in 2018 by Palgrave Macmillan).

7.7 CONCLUSION

The overall aim of this thesis was to explore the perceptions and perspectives of mental health workers in Nepal on the use of a human rights-based approach to mental health. This research makes empirical, methodological, conceptual, and policy-related contributions.

The narrative literature review highlighted the limited empirical work on HRBAs to health. My qualitative research highlighted that participants, irrespective of where they worked in the health

system, were aware of human rights but faced difficulty in understanding their meaning and application. In contrast, their understanding of the right to health was expressed with greater certainty and precision, partly attributable to the right to health being included in Nepal's Constitution. Participants' understanding of the rights of persons with psychosocial disabilities was limited. Their understanding of an HRBA to health was also generally limited, with more familiarity among participants from the district and national levels who had previously worked with HIV; sexual and reproductive health and rights; or research, policy, or the international community. Participants at the PHC centres did not use the term HRBA to health but saw potential value for it.

According to participants, the HRBA-to-health features of non-discrimination, accessibility, participation, accountability, and quality were believed to be critical to mental health planning and service provision. In addition, confidentiality and consent were highlighted as critical elements of an HRBA to health.

The findings further indicate that the implementation of an HRBA to health and related plans requires understanding both the health system context and the country context. It is important to involve health workers in order to understand the health system and its inner workings. Further, the implementation of an HRBA to health requires their rights need to be respected, protected and fulfilled. This also requires training in human rights, tailored to their needs. In addition, users – need to be involved in the realisation of an HRBA, which also includes civil society organisations working on mental health and user organisations. A conceptual framework was developed and refined, which will could guide the application of an HRBA to health in mental health planning and service provision. A number of key research areas and actions are also given to support future work on HRBA covering four key themes –research needs, structural changes, advocacy needs, capacity building and expected outcome- strengthening the implementation of an HRBA to health.

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APPENDIX 1. *THE LANCET* ARTICLE “HEALTH SYSTEMS AND THE RIGHT TO HEALTH: AN ASSESSMENT OF 194 COUNTRIES”

Health systems and the right to health: an assessment of 194 countries



Gunilla Backman, Paul Hunt, Rajat Khosla, Camila Jaramillo-Strouss, Belachew Mekuria Fikre, Caroline Rumble, David Pevalin, David Acurio Páez, Mónica Armijos Pineda, Ariel Frisancho, Duniska Tarca, Mitra Motlagh, Dana Farcasanu, Cristian Vladescu

60 years ago, the Universal Declaration of Human Rights laid the foundations for the right to the highest attainable standard of health. This right is central to the creation of equitable health systems. We identify some of the right-to-health features of health systems, such as a comprehensive national health plan, and propose 72 indicators that reflect some of these features. We collect globally processed data on these indicators for 194 countries and national data for Ecuador, Mozambique, Peru, Romania, and Sweden. Globally processed data were not available for 18 indicators for any country, suggesting that organisations that obtain such data give insufficient attention to the right-to-health features of health systems. Where they are available, the indicators show where health systems need to be improved to better realise the right to health. We provide recommendations for governments, international bodies, civil-society organisations, and other institutions and suggest that these indicators and data, although not perfect, provide a basis for the monitoring of health systems and the progressive realisation of the right to health. Right-to-health features are not just good management, justice, or humanitarianism, they are obligations under human-rights law.

Introduction

December, 2008, marks the 60th anniversary of the Universal Declaration of Human Rights.¹ The declaration provides the foundation for the international code of human rights.² This code gives an internationally agreed set of standards to guide and assess the conduct of governments across a wide range of sectors and has a direct, close bearing on medicine, public health, and the strengthening of health systems.³

The international code of human rights consists of legally binding international components. Among the most important of these components for health systems are the International Covenant on Economic, Social, and Cultural Rights (ICESCR)⁴ and the Convention on the Rights of the Child (CRC).⁵ Both these human-rights treaties are legally binding for those countries that have ratified them. Most states have ratified the ICESCR, and all but two (Somalia and the USA) have ratified the CRC. The right of everyone to enjoy the highest attainable standard of physical and mental health—sometimes known as the right to the highest attainable standard of health or the right to health—is an integral part of both of these international treaties. All countries have ratified one or more binding treaty that includes the right to health, such as the International Convention on the Elimination of All Forms of Racial Discrimination.⁶ Also, many countries include this right in their national constitutions.⁷ The Constitution of WHO,⁸ the Declaration of Alma-Ata,⁹ the Ottawa Charter for Health Promotion,¹⁰ the Bangkok Charter for Health Promotion in a Globalized World,¹¹ and other important documents agreed by the health community also recognise this fundamental human right.

In recent years, national and international policy makers, courts, non-governmental organisations, and other stakeholders have adopted and applied features of the right to the highest attainable standard of health. Uganda's review of its health policy expressly uses a right-to-health analysis¹² as does WHO in, for example, its publication on

human rights, health, and poverty reduction.¹³ Courts, too, are explicitly relying on the right to health in their decisions, most recently in a landmark judgment of the Colombian Constitutional Court.^{14,15} On the basis of a detailed understanding of the right to health, this court effectively ordered a phased restructuring of the country's health system by way of a participatory and transparent process based on current epidemiological information.¹⁶ Civil-society guides to the right to health are increasing in number, and many civil-society organisations use these in their work.^{17,18} Both the UN General Assembly and Human Rights Council have discussed numerous reports on the right to health, covering a wide range of issues, such as neglected diseases,¹⁹ sexual and reproductive health,²⁰ maternal mortality,²¹ mental disability,²² the Millennium Development Goals (MDGs),²³ medicines,²⁴ and water and sanitation.²⁵

Recognition that a strong health system is an essential element of a healthy and equitable society is growing. However, according to a recent WHO publication, health systems in many countries are failing and collapsing.²⁶ Too many health systems are inequitable, regressive, and unsafe.²⁷ WHO also confirms that sustainable development, including achievement of the MDGs, depends on effective health systems.²⁸

As with a fair court system, an effective health system is a core social institution and, for this reason, crucially, both systems are protected by human rights.^{29,30} Although many human rights are important to a well-functioning court system, the key one is the right to a fair trial.³¹ Through human-rights treaties, national laws and policies, judicial decisions, and so on, the right to a fair trial has helped to identify the key features of a fair court system, such as an independent judiciary and trials without undue delay. The right to a fair trial has not only identified unfair judicial processes but also led to welcome reforms in many countries.

By analogy, the right to the highest attainable standard of health can help to establish health systems that are

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APPENDIX 2. DETAILED TOPIC GUIDE: SEMI-STRUCTURED INTERVIEWS

Guidelines

Welcome and introduction

Greetings

Thank participants for agreeing to participate

Explain the research (including what the right is in this research)

Explain the rationale for the interview

Through these questions, I would like to explore the challenges and opportunities in developing and applying a mental health plan that is respectful of the right to health, using Nepal as a case study

Key area of investigation	Rationale	Themes	Example questions	Explanatory notes
General understanding of mental health	Introductory questions to encourage them to discuss and contextualise the situation they are working in and to better understand what their issues of concerns are.	<ul style="list-style-type: none"> • Structure of provision of services • Areas of priority 	<p>How long have you worked in the area of mental health?</p> <p>Can you please tell me a bit about your work?</p> <p>To provide good mental health service, what are some of the most important things that are needed? What should be prioritised for a) alcohol use disorder, b) depression and c) psychosis?</p>	<i>Deliberate not to start with the right to health. I would like to get a general understanding of mental health and their work.</i>
LINK AND EXPLANATION TO THE NEXT AREA THAT WILL BE TALKED ABOUT:				
<i>I will now turn to the topic of human rights. I am very interested to learn how you view human rights, as it is a topic of discussion at the international level. I am interested in both positive and negative experiences, so I can learn.</i>				
Human rights	As these informants are asked to implement what the government has committed to, I would like to see what their understanding is to human rights and how it actually impacts their work, positive or negative.		<p>How do you think human rights is understood in Nepal? How is it talked about in Nepal?</p> <p>What do you think the right to health means in Nepal?</p> <p>How is “human rights” explained in Nepali? How would you explain the “right to health” in Nepali? (Is there a specific word in Nepali for the two human rights with the same meaning?)</p> <p>Has human rights been used/applied in the area of health, even if not in mental health?</p>	<p><i>In Nepal it appears that the human rights movement is not so strong in health. It has its first litigation case on abortion 2012.</i></p> <p><i>The right to health stands for the right to the enjoyment of the highest attainable standard of physical and mental health.</i></p>

			<p>How has it [human rights] impacted the health sector?</p> <p>How has human rights impacted your job? What do you feel?</p> <p>What do you think other people think the rights are of people with mental disability?</p> <p>Do you think other people think there are different human rights dependent on the person's mental disorder, e.g., alcohol, depression and/or psychosis?</p>
<p>LINK AND EXPLANATION TO THE NEXT AREA THAT WILL BE TALKED ABOUT: <i>I will now turn to talk about PRIME's mental health care plan. I would very much like if you could tell me a bit about it, so I better understand the overall project here in Chitwan, Nepal.</i></p>			
<p>Development of PRIME's mental health care plan</p>	<p>Would like to learn how the PRIME plan was developed. This question can inform the focus groups.</p>	<ul style="list-style-type: none"> • Process, including participation of users? Health workers? • Non-discrimination • Prioritisation • Access to everyone • Linked health system plan/health system? • Costing? • Multisectoral collaboration 	<p>Can you tell me about the process in developing PRIME's mental health care plan? How was it?</p> <p>The government of Nepal has committed to mental disability and to human rights, the right to health. How does that affect your job? How did that affect the development of the plan?</p> <p>Collaboration with human rights groups?</p>

LINK AND EXPLANATION TO THE NEXT AREA THAT WILL BE TALKED ABOUT:

I will now turn to the case study in exploring the integration of a human rights based approach (HRBA) to health. The concept and application of this approach is rather new, or yet not settled, so your comments and views are very important to shape the approach. Only to explain, I have focused on the right to health as it is narrowing my research, and through that I have selected a couple of features to be included in an HRBA to mental health.

<p>Integration of an HRBA on PRIME's mental health care plan</p>	<p>Integration of an HRBA on PRIME's mental health care plan</p>	<ul style="list-style-type: none"> • Understanding of the meaning of the right to health features. 	<p>Human rights often use terms, but then they might not be well explained, are all the terms clear in the right to health/human rights to you? If not, could you please tell me which ones are not clear? How do you understand them?</p>
<p>Human rights and health-collaboration</p>	<p>Presently there is a gap between theory and practice in health and human rights, in many countries. The understanding of human rights and the right to health is still on non-discrimination and "naming and shaming." In other countries the focus might be solely on civil and political rights (e.g., freedom from torture, the right to life). To move human rights from theory to practice and integrate it into the health services, it needs to be presented in a manner that the health workers understand and can apply it.</p>	<ul style="list-style-type: none"> • Particular interest in the right to health core obligations (e.g., essential medicines, non-discrimination) • Health workers' condition (Inc. training of health workers) • Access (information, \$, physical) • Participation • Accountability, monitoring & redress • Quality • Confidentiality • Prioritisation • Essential medicine • Referral • Progressive realisation 	<p>If you were to prioritise, of all the competing needs in the health services, to improve the services for people with mental disability, specifically alcohol use disorders, depression, or psychosis?</p> <p>Would you say that the priorities are the same for someone who suffers from alcohol use disorder, or depression or psychosis? If not, could you please explain what would be the most important to focus on for the different disorders, and explain why the prioritise are different?</p> <p>Do you think it is possible to integrate HR?</p> <p>If so, why is it important?</p>

What would be the challenge to integrate it?

- Health system structure
- Transparency
- International Assistance and Cooperation
- Comparative core obligations: **sexual and reproductive rights**, appropriate training for health personnel, including education on health and human rights
- Multisectoral collaboration.

What has been your experience of using an HRBA? Could it be used again? What do you think could be the benefits and what do you think could be the obstacles?

APPENDIX 3. DETAILED TOPIC GUIDE: FOCUS GROUP DISCUSSIONS

Guidelines

Welcome and introduction

Greetings

Thank participants for agreeing to participate

Explain the research (including what the right is in this research)

Explain the rationale for the interview

Through these questions, I would like to explore the challenges and opportunities in developing and applying a mental health care plan that is respectful of the right to health, using Nepal as a case study.

Key area of investigation	Rationale	Themes	Example questions	Explanatory notes
Dynamics in the clinic/challenges	Introductory questions to encourage discussions and contextualise the situation for the patients they care for, and their own situation. The questions touch upon human rights issues without labelling it human rights. Their response will give an indication how the mental health context is seen from the health workers' perspective. It will help phrase the subsequent questions.	<ul style="list-style-type: none"> • Availability • Accessibility • Acceptability • Quality 	<p>How long have you worked with people with mental disabilities?</p> <p>Can you please tell me what a typical day would look like?</p> <p>What do you think is needed to provide good care in mental health? To provide good care for people with alcohol use disorder, depression and/or psychosis- what do you think is needed?</p>	<i>Deliberate not to start with the right to health. I would like to get a general understanding of mental health and their work.</i>
LINK AND EXPLANATION TO THE NEXT AREA THAT WILL BE TALKED ABOUT:				
<i>I will now turn to the topic of human rights. I am very interested to learn how you view human rights, as it is a topic of discussion at the international level. I am interested in both positive and negative experiences, so I can learn.</i>				
Human rights	<p>As these informants are asked to implement what the government has committed to, I would like to see what their understanding is of human rights and how it actually impacts their work, be it positive or negative.</p> <p>With the HIV movement it was recognised that if people's human rights were respected infected and affected could better cope with HIV People generally recognise that everyone's human rights should be respected, in practice, however, people's people views might differ.</p>		<p>How do you think human rights is understood in Nepal? How is it talked about in Nepal?</p> <p>What do you think "the right to health" means in Nepal?</p> <p>How is "human rights" explained in Nepali? How would you explain the "right to health" in Nepali? (Is there a specific word in Nepali with the same meaning for human rights vs. the right to health?)</p> <p>Has human rights been used/applied in other areas of health? If, how has it impacted the health sector?</p>	<p><i>In Nepal it appears that the human rights movement is not so strong in health. It has its first litigation case on abortion 2012.</i></p> <p><i>The right to health stands for the right to the enjoyment of the highest attainable standard of physical and mental health.</i></p>

It is well known that people with mental disorders are often discriminated against, and many of their human rights violated. They are not only poorly treated, but the overall health system is not structured to provide care for people with mental disorders. As a result, health workers are not provided with the means to give the care they might want, such as provide the users with essential medicine. However, human rights might be understood as “naming and shaming” – something that will criticise the health sector for not providing the care that they ideally would like to.

At times, there might be a view that people with mental disorder have no rights, or that they [health workers] would like to respect their rights, but it is difficult with limited resources.

There is also the misconception that human rights, and perhaps more so ESCR can only be realised in rich countries; and that human rights cannot and will not assist if it is applied in developing or fragile settings. That human rights are

What do you think other people think of the rights of people with mental disabilities?

Someone told me that people with alcohol use disorder, depression and psychosis have different rights, why do people say that? Could you please help me understand? It is an interesting view. I have not thought of it like that.

unrealistic, too expensive to apply.				
LINK AND EXPLANATION TO THE NEXT AREA THAT WILL BE TALKED ABOUT:				
<i>I will now turn to talk about PRIME's mental health care plan. I would very much like if you could tell me a bit about it, so I better understand the overall project here in Chitwan, Nepal.</i>				
PRIME's mental health care plan	I would like to learn how the PRIME plan was developed, and about the implementation of it. We would like to hear from those who are implementing the plan what they think of it, and how they were involved in developing it.	<ul style="list-style-type: none"> • Participation in development of the plan [process] • The implementation of the plan • Monitoring, accountability and redress • Transparency 	<p>Can you tell me about the process in developing PRIME's mental health care plan? How was it?</p> <p>How is it to implement it?</p> <p>Who monitors that the plan is being implemented?</p> <p>Who knows about the plan? Who can access it?</p>	
LINK AND EXPLANATION TO THE NEXT AREA THAT WILL BE TALKED ABOUT:				
<i>I will now turn to the case study in exploring the integration of a human rights based approach. The concept and application of this approach is rather new, or yet not settled, so your comments and views are very important to shape the approach. Only to explain, I have focused on the right to health as it is narrowing my research, and through that I have selected of a couple of features included in an HRBA, and some which are critical for the realisation of the right to health.</i>				
Integration of an HRBA on PRIME's mental health care plan	There are every limited studies of the impact of a RTHBA/HRBA on mental health. Those that have been carried out are anyhow positive, but mainly from high income countries. There is no universal agreement of what right to health features should be included for a plan to be fully respectful of a RTHBA/HRBA in health/mental health, so we have	<ul style="list-style-type: none"> • Understanding of the meaning of the right to health features. • Particular interest in the right to health core obligations (e.g., essential medicines, non-discrimination) • Health workers' condition (Inc. training of health 	<p>Human rights often use terms, but then they might not be well explained, are all the terms clear in the right to health/human rights to you? If not, could you please tell me which ones are not clear? How do you understand them?</p> <p>Will look at a couple of features, and I would like to know how you feel about the relevance of these</p>	<p>Features of the checklist will be mentioned, verbally-briefly explaining the right to health. The health workers will then be asked what they think about the feature, what they think is needed to translate it into practice – if they think it is relevant, if they agree with the feature or not.</p> <p>We want to understand what needs to be altered, if anything, in respect to language, attitudes.</p>

here an opportunity to influence what it means.

Presently there is a gap between theory and practice in health and human rights, in many countries. The understanding of human rights and the right to health is still to a great extent on non-discrimination and “naming and shaming.” In other countries the focus might be on civil and political rights (e.g., freedom from torture, the right to life). To move human rights (specifically the right to health) from theory to practice and integrate it into the health sector, it needs to be presented in a manner the health workers understand how to apply it. How can we do it?

workers)

- **Access**
- **Participation**
- **Accountability, monitoring & redress**
- **Quality**
- **Confidentiality**
- **Consent**
- Referral
- **Gender**
- Essential medicine
- Prioritisation
- Progressive realisation
- Training for the health workers
- Health system structure
- Transparency
- International Assistance and Cooperation
- Comparative core obligations: sexual and reproductive rights, appropriate training for health personnel,

features. If you think these are important, why? If not, why not? Which are more important?

If you were to prioritise, of all the competing needs in the health services, to improve the services for people with mental disability, specifically alcohol use disorders, depression, or psychosis?

Would you say that the priorities are the same for someone who suffers from alcohol use disorder, or depression or psychosis? If not, could you please explain what would be most important for the different disorders and why the priorities are different.

What do you think should be included in developing a plan?

What has been your experience of using a HRBA checklist? Could it be used again? What do you think could be the benefits and what do you think could be the obstacles?

including education on
health and human rights

APPENDIX 4. ETHICAL APPROVALS

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Observational / Interventions Research Ethics Committee

Gunilla Backman
PhD Research Student
HRSP / PHP
LSHTM

24 April 2013

Dear Ms. Backman,

Study Title: Exploring the integration of a Right to health based approach on PRIME's mental health care plan: A case study of Nepal and South Africa
LSHTM ethics ref: 6395

Thank you for your letter of 23 April 2013, responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
LSHTM ethics application	n/a	
Protocol		
Proposed Topic Guide for focus groups with PRIME's PHC health workers		
Information Sheet & Consent Form - Focus Groups		23/04/2013
Information Sheet & Consent Form - In-depth Semi-structured Interviews		23/04/2013

After ethical review

Any subsequent changes to the application must be submitted to the Committee via an E2 amendment form. All studies are also required to notify the ethics committee of any serious adverse events which occur during the project via form E4. At the end of the study, please notify the committee via form E5.

Yours sincerely,



Professor John DH Porter
Chair

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Nepal Health Research Council

Estd. 1991



NHRC

Ref. No. 1327

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National Planning Commission

Ministry of Health & Population

Chief, Research Committee, IOM

Chairman, Nepal Medical Council

13 May 2013

Mr. Nagendra Prasad Luitel

Principal Investigator

Transcultural Psychosocial Organization (TPO) Nepal
Baluwatar, Kathmandu

Ref: **Approval of Research Proposal** entitled **Community and Health Facility Survey on Mental Health in Chitwan District**

Dear Mr. Luitel,

It is my pleasure to inform you that the above-mentioned proposal submitted on 30 January 2013 (**Reg. no. 10/2013** please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on 10 May 2013 (2070-01-27).

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol.

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal and submit progress report and full or summary report upon completion.

As per your research proposal, your total research amount is USD. 8,931.00 and NHRC processing fee is NRs. 8,650.00.

If you have any questions, please contact the research section of NHRC.

Thanking you.

.....
Dr. Shanker Pratap Singh
Member Secretary

APPENDIX 5. INFORMATION SHEET AND INFORMED CONSENT FORM: SEMI-STRUCTURED INTERVIEWS AND FOCUS GROUPS

Informed consent form and survey participant information sheet for SEMI-STRUCTURED interviews

In case of any questions, please contact:

- 1) Nepal affiliation to be added here, Programme for Improving Mental health care (PRIME)
Tel.#####. E-mail #####
- 2) Gunilla Backman, London School of Hygiene and Tropical Medicine
Tel: +44 7774 261 457. E-mail:gunilla.backman@lshtm.ac.uk

Participant Consent Form for In-Depth, Semi-Structured Interviews

Study title: “EXPLORING THE INTEGRATION OF A RIGHT TO HEALTH BASED APPROACH ON PRIME’S MENTAL HEALTH CARE PLAN: A CASE STUDY OF NEPAL”

I have read and understood the attached sheet giving details of the study (or understand the verbal explanation) and I have a copy of it for me to keep. I have had the opportunity to ask the researcher any questions that I had about the project and my involvement in it.

My decision to consent is entirely voluntarily. I understand that I am free to withdraw at any time without giving a reason, and if do withdraw there will be no effect, good or bad, on me.

My questions concerning this study have been answered by:.....
[Name of interviewer]

I agree to take part in this study

Signature of participant:..... Date:.....
(dd/mm/yyyy)
Participant’s name (CAPITALS):.....

I agree that my interview can be recorded

Signature of participant:..... Date:.....
(dd/mm/yyyy)
Participant’s name (CAPITALS):.....

I agree that anonymous quotes may be used from my interview

Researcher’s signature:..... Date:.....
(dd/mm/yyyy)

In case of any questions, please contact:

- 1) Nepal/South African affiliation to be added here, Programme for Improving Mental health care (PRIME)
Tel.#####. E-mail #####
- 2) Gunilla Backman, London School of Hygiene and Tropical Medicine
Tel: +44 7774 261 457. E-mail:gunilla.backman@lshtm.ac.uk

Participant Information Sheet for In-Depth, Semi-Structured Interviews

Study title: "EXPLORING THE INTEGRATION OF A RIGHT TO HEALTH BASED APPROACH ON PRIME'S MENTAL HEALTH CARE PLAN: A CASE STUDY OF NEPAL"

This sheet provides the information which you have been asked to participate in.

The purpose of this study is to understand the health workers' views and opinions in using and applying human rights, in particular the human right that specifically focuses on health (the right to health). We are particularly interested in understanding what you think, both the positive and negative aspects, of including the right to health in a mental health care plan; and to hear your views about the possibility of implementing a mental health care plan that includes the right to health, at the primary health care level.

We are from the London School of Hygiene and Tropical Medicine in the United Kingdom. We are doing this project in partnership with, *The Programme for Improving Mental health care* (PRIME). The study is carried out in Nepal. The research is funded by the Swedish International Development Cooperation Agency (Sida). This study received approval from the Governments of Nepal. We are interviewing health workers, broadly defined, who has been part in developing PRIME's mental health care plan. The interviews will last about 45 minutes to 1 hour, and will be recorded.

Your participation is completely voluntarily so you should feel free to withdraw at any time without giving a reason, or not answer questions you do not feel comfortable with. If you withdraw there will be no effect, positive or negative, on you or your family. The study does not give any benefits for you or other people in the family.

The interview will be held in a private space, and all answers are anonymous and confidential. We will not write down any names on the forms or anywhere else, so no answers can be connected to individual persons. If you agree, we would like to record the interviews, to ensure we have captured what you state correctly. The tapes will not be shared with anyone besides the researcher and will be destroyed once written up. If you do not agree, we will not record. We will not say your name on the recording of the interview. No one will be able to tell what any person said during the interview. We will keep all the tapes and forms securely stored and they will not be shared with anyone outside the research team.

If you have any questions or comments, please ask us now. It is important you understand the study and what your role is. If you have any questions or comments after this session or would like further information, please contact us on the information on the top of the sheet. Thank you for your kind help.

Informed consent form and survey participant information sheet for FOCUS GROUP DISCUSSIONS

In case of any questions, please contact:

- 1) Nepal affiliation to be added here, Programme for Improving Mental Health Care (PRIME)
Tel.#####. E-mail #####
- 2) Gunilla Backman, London School of Hygiene and Tropical Medicine
Tel: +44 7774 261 457. E-mail:gunilla.backman@lshtm.ac.uk

Participant Consent Form for Focus Group

Study title: “EXPLORING THE INTEGRATION OF A RIGHT TO HEALTH BASED APPROACH ON PRIME’S MENTAL HEALTH CARE PLAN: A CASE STUDY OF NEPAL ”

I have read and understood the attached sheet giving details of the study (or understand the verbal explanation) and I have a copy of it for me to keep. I have had the opportunity to ask the researcher any questions that I had about the project and my involvement in it.

My decision to consent is entirely voluntarily. I understand that I am free to withdraw at any time without giving a reason, and if do withdraw there will be no effect, good or bad, on me.

My questions concerning this study have been answered by:.....
[name of interviewer]

I agree to take part in this study

Signature of participant:..... Date:.....
(dd/mm/yyyy)

Participant’s name (CAPITALS):.....

I agree that my interview can be recorded

Signature of participant:..... Date:.....
(dd/mm/yyyy)

Participant’s name (CAPITALS):.....

I agree that anonymous quotes may be used from my interview

Researcher’s signature:..... Date:.....
(dd/mm/yyyy)

In case of any questions, please contact:

- 1) Nepalaffiliation to be added here, Programme for Improving Mental Health Care (PRIME)
Tel.#####. E-mail #####
- 2) Gunilla Backman, London School of Hygiene and Tropical Medicine
Tel: +44 7774 261 457. E-mail:gunilla.backman@lshtm.ac.uk

Participant Information Sheet for Focus Group

Study title: "EXPLORING THE INTEGRATION OF A RIGHT TO HEALTH BASED APPROACH ON PRIME'S MENTAL HEALTH CARE PLAN: A CASE STUDY OF NEPAL"

This sheet provides the information which you have been asked to participate in.

The purpose of this study is to understand the health workers' views and opinions in using and applying human rights, in particular the human right that specifically focuses on health (the right to health). We are particularly interested in understanding what you think, both the positive and negative aspects, when including the right to health in a mental health care plan; and to hear your views about the possibility of implementing a mental health care plan that includes the right to health, at the primary health care level.

We are from the London School of Hygiene and Tropical Medicine in the United Kingdom. We are doing this project in partnership with *The Programme for Improving Mental health care* (PRIME). The study is carried out in Nepal. The research is funded by the Swedish International Development Cooperation Agency (Sida). This study received approval from the Governments of Nepal. We are carrying out focus groups with health workers working in PRIME's primary health care clinics for people with mental disability, specifically alcohol use disorders, depression and/or psychosis (such as schizophrenia). The focus groups will last about two hours, and will be recorded. You might be contacted again after one or two weeks by the research team for a separate interview to discuss further interesting issues that were raised in the focus group.

Your participation is completely voluntarily so you should feel free to withdraw at any time without giving a reason, or not answer questions you do not feel comfortable with. If you withdraw there will be no effect, positive or negative, on you or your family. The study does not give any benefits for you or other people in the family.

The interview will be held in a private space, and all answers are anonymous and confidential. What we talk about in here in the focus groups should be treated as private and confidential and should not be shared beyond the focus group. We will not write down any names on the forms or anywhere else, so no answers can be connected to individual persons. If you agree, we would like to record the interviews, to ensure we have captured what you say correctly. The tapes will not be shared with anyone besides the researcher and will be destroyed once written-up. If you do not agree, we will not record. We will not say your name on the recording of the interview. No one will be able to tell what any person said during the interview. We will keep all the tapes and forms securely stored and they will not be shared with anyone outside the research team.

If you have any questions or comments, please ask us now. It is important you understand the study and what your role is. If you have any questions or comments after this session or would like further information, please contact us on the information on the top of the sheet. Thank you for your kind help.

APPENDIX 6. INFORMATION SHEET AND CONSENT FORM: OBSERVED PARTICIPATION

Informed consent form and information sheet for OBSERVED PARTICIPATION

In case of any questions, please contact:

- 1) Nepal affiliation to be added here, Programme for Improving Mental Health Care (PRIME)
Tel.#####. E-mail #####
- 2) Gunilla Backman, London School of Hygiene and Tropical Medicine
Tel: +44 7774 261 457. E-mail:gunilla.backman@lshtm.ac.uk

Consent Form for Observed Participants (Service Users)

Study title: "EXPLORING THE INTEGRATION OF A RIGHT TO HEALTH BASED APPROACH ON PRIME'S MENTAL HEALTH CARE PLAN: A CASE STUDY OF NEPAL"

I have read and understood the attached sheet giving details of the study (or understand the verbal explanation) and I have a copy of it for me to keep. I have had the opportunity to ask the researcher any questions that I had about the project and my involvement in it.

My decision to consent is entirely voluntarily. I understand that I am free to ask them to interrupt the observation without giving a reason, and if I do there will be no effect, good or bad, on me or my family.

My questions concerning this study have been answered by:.....
[name of person]

I agree to take part in this observational study.

Signature of participant:..... Date:.....
(dd/mm/yyyy)
Participant's name (CAPITALS):.....

I agree that notes will be taken on the observations made in the clinic

Signature of participant:..... Date:.....
(dd/mm/yyyy)
Participant's name (CAPITALS):.....

APPENDIX 7. INFORMATION SHEET AND CONSENT FORM: SERVICE USERS

In case of any questions, please contact:

- 1) Nepal affiliation to be added here, Programme for Improving Mental Health Care (PRIME)
Tel.#####. E-mail #####
- 2) Gunilla Backman, London School of Hygiene and Tropical Medicine
Tel: +44 7774 261 457. E-mail:gunilla.backman@lshtm.ac.uk

Information Sheet for Observed Participants (Service Users)

Study title: "EXPLORING THE INTEGRATION OF A RIGHT TO HEALTH BASED APPROACH ON PRIME'S MENTAL HEALTH CARE PLAN: A CASE STUDY OF NEPAL"

This sheet provides the information about an observational study which is ongoing in the clinic. The purpose of our work here is to observe health workers here in the health clinic. Sitting in the clinic will allow me to appreciate the everyday running of the clinic. As I am not familiar with the local languages I use a translator to assist me in better understanding the daily activities in the clinic. This research is part of a bigger study exploring PRIME's mental health care services.

We are from the London School of Hygiene and Tropical Medicine in the United Kingdom. We are doing this project in partnership with *The Programme for Improving Mental health care (PRIME)*. The study is carried out in Nepal. The research is funded by the Swedish International Development Cooperation Agency (Sida). This study received approval from the Governments of Nepal.

I will use written notes to record my observations. The notes will not relate to any specific individuals and no names will be taken and so the notes will be completely anonymous.

My focus and interest is on the everyday running of the clinic and the health workers. But if you as user of the service do not want me to sit and observe in the clinic you should feel free to tell me so and I will withdraw, without giving a reason and there will be no effect, positive or negative, on you or your family. The study does not give any benefits to you or other people in the family, or the health workers.

If you have any questions or comments, please feel free to ask. If you have any questions or comments once you have left the clinic or would like further information, please contact us on the information on the top of the sheet.

Thank you for your kind help.

APPENDIX 8. DETAILED RESULTS OF RATS QUALITY ASSESSMENT

ASKED OF THE MANUSCRIPT	Consider if the following is included in the manuscript	Barros De Luca, G., et al. (Brazil)	Longhi, S., et al. (Italy)	McMillan, F., et al. (Northern Ireland)	Mhango, C., et al. (Malawi)	Patel, A., et al. (Nepal)	PHR (Peru)	SHRC (Scotland)	Williams, C., and Brian, G., (Papua New Guinea)
Relevance of the study question	Research question explicitly stated.	✓	✓	✓	✓	✓	✓	✓	✓
Is the research question interesting (relevant)?	Research question justified and linked to the knowledge base, theory, practice?	✓	✓	✓	✓	✓	✓	✓	✓
Is the research question relevant to clinical practice, public health, or policy?		✓	✓	✓	✓	✓	✓	✓	✓
Appropriateness of qualitative method	Study design described and justified e.g., why was a particular method chosen?	Yes. But a large part of the study was based on review of documents	Yes. But a large part of the study was based on review of documents	Yes. No justification for why one method was chosen	Yes. But a large part of the study was based on review of	Yes. But a large part of the study was based on review of documents	Yes. No justification for why one method was chosen	The study methods were described: to fulfil a specific objective. But there was no justification	✓

				over another.	documents.		over another.	for why one method was chosen over another.	
Interviews						✓	✓		
Focus groups			✓	✓		✓	✓	✓	N/A
Ethnography						✓			
Textual analysis		✓	✓	✓	✓	✓	✓	✓	✓
Transparency of procedures									
<i>SAMPLING</i>									
Criteria for selecting the study sample justified and explained.		X	X	X	X	X	✓	✓	N/A
Are the participants selected the most appropriate to provide access to type of knowledge sought of the study?		X	X	X	✓	X	✓	✓	N/A
Is the sampling strategy appropriate?		X	X	X	X	X	✓	✓	N/A
<i>RECRUITMENT</i>									
Was recruitment conducted using appropriate methods?	Details of how recruitment was conducted and by whom.	X	X	X	X	X	✓	X	N/A
Could there be selection bias?	Details of who chose not to	X	X	X	X	X	✓	X	N/A

	participate and why.								
<i>DATA COLLECTION</i>									
Was collection of data systematic and comprehensive?	Methods outlined and examples given (e.g., interview questions).	Methods outlined, but questions to consultants not mentioned	Methods outlined, but questions to consultants not mentioned	No. The methods are described, but cannot tell if systematically applied-although, appears to be comprehensive. The indicators are clear, but the focus group questions are not given.	Methods outlined, but questions to consultants not mentioned.	Methods outlined, but questions to consultants not mentioned	Yes. Methods outlined, but the questions are not included besides the themes used when asking questions	Yes, But the questions are not attached. However, the framework from where the questions were drawn to create the different methods is included.	Yes. Indicators.
Are characteristic and study setting clearly described?		X	X	X	X	X	Partly.	Partly.	N/A
Why and when data collection stopped, and is this reasonable?	End of data collection justified and described?	Yes, in respect to lit. review, but not justified.	Not clear. Also not explicit. States "roughly."	Yes.	X	Yes, in respect to the lit review, but	Yes.	To some extent. Explained when it was	Yes.

						not justified.		stopped, but not justified.	
<i>ROLE OF RESEARCHER</i>									
Is the researcher(s) appropriate? How might they bias (good and bad) the conduct of the study and results?	Do the researchers occupy dual roles (clinician and researcher)? Are the ethics of this discussed? Do the researcher(s) critically examine their own influence on the formulation of the research question, data collection, and interpretation?	X	X	X	X	X	Partly.	X	✓
<i>ETHICS</i>									
Was informed consent sought and granted?	Informed consent process explicitly and clearly detailed.	X	X	X	X	X	✓	X	N/A

Were participants' anonymity and confidentiality ensured?	Anonymity and confidentiality discussed.	X	X	X	X	X	✓	X	N/A
Was approval from an appropriate ethics committee received?	Ethics approval cited.	X	X	X	X	X	✓	Partly. Approval from THS research committee. No ethical committee mentioned explicitly.	N/A
Soundness of interpretative approach									
<i>ANALYSIS</i>									
Is the type of analysis appropriate for the type of study?	Analytic approach described in depth and justified.	X	X	✓ Partly.	X	X	✓	X	✓
<i>Thematic:</i> exploratory, descriptive, hypothesis generating	Indicator quality: Description of how themes were derived from the data (inductive or deductive).	X	X	✓	✓	✓	Yes and No. Following an HRBA when analysing the data.	✓	✓
<i>Framework:</i> e.g., policy	Evidence of alternative	✓	✓	✓	✓	✓	Yes and No.	✓	✓

	explanations being sought.								
<i>Constant comparison/grounded theory: theory generating, analytical</i>	Analysis and presentation of negative or deviant cases.	X	X	X	X	X	X	X	N/A
Are the interpretations clearly presented and adequately supported by the evidence?		✓	✓	✓	✓	✓	✓	✓	✓
Are quotes used and are these appropriate and effective?	Description of the basis on which quotes were chosen. Semi-quantification when appropriate. Illumination of context and/or meaning, richly detailed.	X	X	✓	X	N/A	✓	✓	N/A
Was trustworthiness/reliability of the data and the interpretations checked?	Method of reliability check described and justified – e.g., was an audit trial, triangulation,	X	X	Yes. Independent analysis. Not sure about contesting themes, not sure	X	X	X	Yes. Triangulations. An interim report was presented to national and internal experts who	N/A

	or member checking employed? Did an independent analyst review data and contest themes? How were disagreements resolved?			how disagreements were resolved.				advised SHRC throughout the implementation of the project, highlighting what further information was required to be collected.	
<i>DISCUSSION AND INTERPRETATION</i>									
Are findings sufficiently grounded in a theoretical or conceptual framework?	Findings presented with reference to existing theoretical and empirical literature, and how they contribute?	✓	✓	✓	✓	✓	✓	✓	✓
Is adequate account taken of previous knowledge and how the findings add?		✓	✓	No.	✓	✓	✓	✓	✓
Are the limitations thoughtfully considered?	Strengths and limitations explicitly described and discussed.	✓	✓	Of the findings, but not of the methods.	No and yes.	No and yes.	✓	✓	Partly.

Is the manuscript well written and accessible?	Evidence of the following guidelines (format, word count). Detail of methods or additional quotes contained in appendix. Written for health sciences audience.	✓	✓	✓	✓	✓	✓	✓	✓
Are red flags present? These are common features of ill-conceived or poorly executed qualitative studies, are a cause for concern, and must be viewed critically. They might be fatal flaws, or they may result from lack of detail or clarity.	<i>Grounded theory</i> : not a simple content analysis but a complex, sociological, theory generating approach. <i>Jargon</i> : descriptions that are trite, pat or jargon filled should be viewed sceptically. <i>Over interpretation</i> : interpretation must be	✓	✓	✓	✓	✓	✓	✓	N/A

	<p>grounded in “accounts” and semi-quantified if possible or appropriate. <i>Seems anecdotal, self-evident:</i> may be a superficial analysis, not rooted in conceptual framework or linked to previous knowledge, and lacking depth. <i>Consent process thinly discussed:</i> may not have met ethics requirements. <i>Doctor-researcher:</i> consider the ethical implications for patients and the bias in data collection and interpretation.</p>								
--	--	--	--	--	--	--	--	--	--

