# WORKING PAPER

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## THE RIGHT TO HEALTH & UNIVERSAL HEALTH COVERAGE IN INDIA RTH-UHC Working Paper 1

## C-FIELP | CENTRE FOR HEALTH EQUITY, LAW & POLICY



#### RTH-UHC Working Paper 1 The Right to Health and Universal Health Coverage in India June 2023

The Centre for Health Equity, Law & Policy of the Indian Law Society Pune, is a research, knowledge production and advocacy forum, which works on law & policy issues related to health, embedding its work in the right to health as envisaged within India's constitutional framework and her international commitments.

#### Authorship and acknowledgement

In 2022, C-HELP was commissioned by the Governance Workstream of the Lancet Citizens' Commission on Reimagining India's Health System to conduct research into the critical intersections of rights, health and law. This research is being updated, edited and published by C-HELP in a series of working papers on the Right to Health and Universal Health Coverage in India.

This Paper is built on the shared knowledge and experience of C-HELP. It was written by Kajal Bhardwaj, Vivek Divan and Shivangi Rai, with contributions from Gargi Mishra and Disha Verma. The content emerged from extensive research mapping on health-related laws and policies in India conducted by Kajal Bhardwaj, Vivek Divan, Shefali Malhotra, Gargi Misra, Harshit Pande, Shivangi Rai, Suraj Sanap and Disha Verma.

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#### BACKGROUND

In December 2020, the Lancet Citizens' Commission on Reimagining India's Health System was set up and tasked to develop a roadmap for achieving Universal Health Coverage (UHC) in India in the next 10 years. A commentary published by the co-chairs of the Commission noted that, "underpinning the Commission's work is a normative commitment to strengthening India's public health system in all its dimensions, including promotive, preventive, and curative care."<sup>i</sup> Some of the key questions identified for the Commission's work include, "negotiating the intersections and complementarities between public and private health provision and the design of a regulatory structure that holds each component of the health system accountable; addressing the role of traditional systems of medicine; negotiating the federal dimensions and associated heterogeneity of health systems' capacity across India's states to articulate the distinctive roles and responsibilities of the central, state, and local governments in delivering and regulating health care; and building health system capacity for enabling and regulating the use of technology in a way that supports and strengthens health delivery while protecting citizens' rights."<sup>i</sup>

The Commission recognises that its work requires consultative and participatory engagement. Its many workstreams represent this attempt at multisectoral collaboration, with its Governance workstream seeking to *"articulate pathways for building a robust and accountable governance framework…to achieve a vision of universal health coverage which is equitable, affordable, and accessible to all."*<sup>ii</sup> In particular, this workstream focuses on health sector regulation, accountability, and governance systems linked with federalism that impact health delivery. All the workstreams mention the key issues of accessibility, availability, affordability, equity and citizen's engagement.

Critical to the key questions identified by the Commission is a well-rounded understanding of how legal frameworks and policy impact health – positively and negatively. Indeed, inherent to the features of equity, affordability and accessibility that the different workstreams seek to address, is the issue of rights. Experience has shown that rights-based approaches to health challenges, reflected in law, policy and practice play a vital role in positive health outcomes. The World Health Organisation (WHO) has categorically stated that, "UHC is firmly based on the 1948 WHO Constitution, which declares health a fundamental human right and commits to ensuring the highest attainable level of health for all."<sup>iii</sup> While the co-chairs' commentary suggests that theCommission's work may, "serve as the foundation for propelling a citizens' movement to demand the practical realisation of the aspiration of health as a fundamental right"<sup>ii</sup> it may be noted that the right to health is already well-recognised and articulated in Indian jurisprudence and law. The commentary also notes that the Commissionwould focus only on the "architecture of India's Health System."<sup>ii</sup> However, the links between the right to health and UHC may require the Commission to also take into account the social determinants of health.

In this background, an examination of health-related law/ policy frameworks and developments in the context of rights becomes essential to informing the Commission's findings and recommendations on UHC. C-HELP was commissioned by the Governance workstream of the Lancet Commission to conduct research in this regard. The outcomes of that research are being updated, edited and published by C-HELP in four working papers on the Right to Health and UHC in India:

- Working Paper 1 provides a framework of analysis to apply the right to health to UHC, articulating linkages between the two and accounting for contemporary debates and critiques of UHC.
- Working Paper 2 presents an overview of judicial pronouncements on health, the roles of central and state governments in health and regulation of the private health sector.
- Working Paper 3 examines the implementation of the right to health through laws and policies in India while also exploring lessons from the implementation of rights-based social sector laws.
- Working Paper 4 explores legal-ethical issues that arise in the use of digital technologies in health.

i. Patel, V., Mazumdar-Shaw, K., Kang, G., Das, P., & Khanna, T. (2021). Reimagining India's health system: A Lancet citizens' commission. The Lancet, 397(10283), 1427–1430. Available at: <a href="https://doi.org/10.1016/s0140-6736(20)32174-7">https://doi.org/10.1016/s0140-6736(20)32174-7</a>. ii. Workstreams - Reimagining India's Health System – Citizens health. Available at: <a href="https://www.citizenshealth.in/workstreams/">https://www.citizenshealth.in/workstreams/</a> iii. Workstreams - Reimagining India's Health System – Citizens health. Available at: <a href="https://www.citizenshealth.in/workstreams/">https://www.citizenshealth.in/workstreams/</a> iii. World Health Organisation. (2022, December 12). Universal Health Coverage. Factsheet. Available at: <a href="https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc]">https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc)</a>

#### 1. INTRODUCTION

Over the past decade, universal health coverage (UHC) has dominated health-related discussions and debates at the international level. Despite multiple international declarations and resolutions affirming the international community's comitment to implementing UHC nationally and a broad understanding that this entails ensuring that financial barriers do not prevent access to healthcare, a consensus on the definition of UHC remains elusive. Conceptions of UHC have been the subject of much debate and range from a form of health insurance to comprehensive health programmes delivered by the public sector. The role of human rights and the right to health in particular have been central to these debates on UHC. Scholars and advocates calling for the right to health to be integral to conceptions of UHC have contributed significantly to more progressive and better understandings of how countries should design and implement UHC programmes. The centrality of human rights in government responses to health needs is well established by the experience with HIV and has been reinforced during the COVID-19 pandemic. While this paper does not set out to provide a definition of UHC for the Indian context, it seeks to build on existing scholarship on health and rights to argue that any roadmap for UHC in India must be built on the right to health, which contrary to common misconceptions is a well-recognised and enforceable fundamental right in India. During the COVID-19 pandemic, the Supreme Court and various High Courts of India were particularly active in interpreting and enforcing this right. Focussing on the pratical ways in which the right to health can assist law and policy makers, this paper highlights a framework of analysis for the application of the right to health in relation to UHC in India, traversing and articulating linkages between the two, while accounting for contemporary debates and critiques of UHC.

This paper is divided into six sections. Section 1 provides the introduction. Section 2 analyses the right to health in India and highlights the linkages between the right to health and UHC playing particular attention to various myths surrounding rights-based frameworks. Section 3 illustrates through multiple examples the many real and practical ways in which law and policy intersects with the right to health in India, including on the social determinants of health, all of which have relevance to UHC. This section unpacks the right to health and UHC in the context of Indian law and policy using two key analytical frameworks offered by the right to health. The first is the availability, accessibility, acceptability and quality or the AAAQ framework which is applied to various judicial, legal and policy interventions on health in India. The second is the Respect-Protect-Fulfil paradigm which is applied to focus on the key issues of discrimination, the regulation of the private sector and the role of the public sector. In highlighting key examples, this section pays particular attention to law and policy developments during the COVID-19 pandemic. Section 4 provides a case study of the successes of the HIV programme in India to demonstrate the powerful and at times, unexpected, role that rights play in the design and implementation of health interventions. Section 5 seeks to highlight the practical implications of the right to health for UHC in India including the importance of legal and policy frameworks including brief examples from other countries with a particular focus on mechanisms for ensuring community participation, the potential of rights-based indicators and benchmarks for UHC programmes and the necessity for grievance redressal and accountability measures. Finally, Section 6 offers conclusions and key messages emerging from this paper.

#### 2. RIGHT TO HEALTH AND UHC

#### 2.1 The Right to Health is well-recognised in international and Indian law

The right to health is well recognized and established in international law. Its clearest and most important articulation is in the International Covenant on Economic, Social and Cultural Rights<sup>1</sup>

<sup>&</sup>lt;sup>1</sup> International Covenant on Economic, Social and Cultural Rights. (1966, December 16). Available at <u>https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights</u>

("ICESCR"), Article 12 of which states, "State Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."<sup>2</sup> In 2000, the Committee on Economic, Social and Cultural Rights ("Committee") which is charged with the interpretation and implementation of the ICESCR issued General Comment 14 on the right to the highest attainable standard of health ("General Comment 14" or "Comment"),<sup>3</sup> "with a view to assisting States parties' implementation of the Covenant and the fulfilment of their reporting obligations."<sup>4</sup> The Comment focuses on the normative content of Article 12, States parties' obligations and implementation at the national level, and also addresses the obligations of actors other than States parties.

General Comment 14 describes health as "a fundamental human right indispensable for the exercise of other human rights" <sup>6</sup> and that "the right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of *health.*"<sup>7</sup> The right to health includes health care and the underlying determinants of health: clean water, adequate food, safe housing and sanitation, healthy workplaces and environments, and access to health information and education.

While the Comment acknowledges that implementation at the national level will differ from one State to another and also calls for the The normative framework of the right to health as described in General Comment 14 includes the following key elements<sup>5</sup>:

- Inclusive right (underlying determinants of health)
- Freedoms and Entitlements
- Non-discrimination
- Availability, Accessibility, Acceptability, Quality (AAAQ)
- Progressive Realisation/Taking Steps
- Core Minimum Obligations
- Obligation to Respect, Protect, Fulfil
- Participation
- Accountability
- International Co-operation

discretion of the State to adopt the most effective measures, it clearly recognises the duty imposed by the ICESCR on States "to ensure that everyone has access to health facilities, goods and services so that they can enjoy, as soon as possible, the highest attainable standard of physical and mental health."<sup>8</sup> According to the Comment, the four essential elements of the right to health are availability, accessibility, acceptability and quality (AAAQ). The obligations on States in terms of the right to health are to be realised progressively and there is a recognition of resource constraints. However, as discussed below, certain core obligations must be met by the State immediately. The State must fulfil the right to health without discrimination, with the participation of affected communities, ensuring access to health information and accountability.

At the national level, there is a common misconception that there is no Constitutional mandate for the right to health in India.<sup>9</sup> The Indian Constitution, in Article 21, recognises the right to life and liberty of every individual. This right has been interpreted by the Supreme Court to include the right to

<sup>&</sup>lt;sup>2</sup> Ibid.

<sup>&</sup>lt;sup>3</sup> Committee on Economic, Social and Cultural Rights. (2000). General Comment 14. (Twenty-second session, 2000), U.N. Doc. E/C.12/2000/4 (2000). Available at <u>https://www.refworld.org/pdfid/4538838d0.pdf</u>.

<sup>&</sup>lt;sup>4</sup> Ibid, para 6.

<sup>&</sup>lt;sup>5</sup> The Office of the High Commissioner for Human Rights (OHCHR). (n.d.) Factsheet No. 31. Available at: <u>https://www.ohchr.org/sites/default/files/Documents/Publications/Factsheet31.pdf</u>

<sup>&</sup>lt;sup>6</sup> Id. at 3, para 1.

<sup>&</sup>lt;sup>7</sup> Id. at 3, para 9.

<sup>&</sup>lt;sup>8</sup> Id. at 3, para 53.

<sup>&</sup>lt;sup>9</sup> For a discussion on the right to health in India, see Bhardwaj, K., Johari, V. and Divan, V. (2018) "The right to health," *Equity and Access*, pp. 360–391. Available at: <u>https://doi.org/10.1093/oso/9780199482160.003.0018</u>.

health.<sup>10</sup> The Constitution also casts upon the State the duty of improving public health.<sup>11</sup> The Supreme Court has held that maintenance and improvement of public health have to rank high amongst State obligations, as these are indispensable to the very physical existence of the community.<sup>12</sup> It has further held that providing adequate medical facilities for the people is an essential part of the obligation undertaken by the government in a welfare State, and the State cannot deny this obligation.<sup>13</sup>

India's obligations on the right to health also stem from international covenants like the ICESCR that India is signatory to. Treaty obligations are enforceable in India either through an Act of Parliament<sup>14</sup> or where there is no domestic law, through court decisions. <sup>15</sup> The reliance on the ICESCR and other international instruments to give meaning to the content of the right to health has to be seen from two aspects. Firstly, the *Protection of Human Rights Act, 1993* specifically provides for the protection of human rights, including those enumerated in the ICESCR.

Secondly, the Supreme Court has time and again taken recourse to covenants and international conventions to give meaning to the fundamental rights guaranteed by the Constitution. The Supreme Court has held that the provisions of an international convention or covenant, which elucidate and effectuate Fundamental Rights guaranteed by the Indian Constitution, can be relied on by courts as facets of those Fundamental Rights and are hence enforceable as such.<sup>16</sup> They have also been read as part of domestic law, as long as there is no inconsistency between international and domestic law.<sup>17</sup> While nonbinding international instruments such as UN resolutions and political declarations at UN High Level Meetings such as the one on UHC in 2019, cannot be equated with the binding obligations of the ICESCR<sup>18</sup>, these too would have persuasive and interpretative value when determining the scope of the right to health under the Indian Constitution.<sup>19</sup>

<sup>&</sup>lt;sup>10</sup> Vincent Panikurlangara v Union of India (1987) 2 SCC 165; Paramanand Katara v Union of India and Others (1989) 4 SCC 286; Surjit Singh v State of Punjab (1996) 2 SCC 336; Dr. Ashok v. Union of India (1997) 5 SCC 10; State of Punjab v Ram Lubhaya Bhagga (1998) 4 SCC 117. See also Suo Moto v State of Rajasthan, RLW 2005(2) Raj 1385: MANU/RH/0097/2005 where the Rajasthan High Court held, "International Human Rights Law requires the States to adopt effective measures for the prevention, investigation, prosecution and punishment of sexual violence to ensure its citizens the highest attainable standard of health and to provide reparations to victims of serious human rights violations". <sup>11</sup> Art. 47, Constitution of India; see also J. P. Unnikrishnan v State of A.P., (1993) 1 SCC 645.

<sup>&</sup>lt;sup>12</sup> Vincent Panikurlangara v Union of India. (1987) 2 SCC 165

<sup>&</sup>lt;sup>13</sup> Paschim Banga Khet Mazdoor Samity v State of W.B., (1996) 4 SCC 37, pp. 43-44; State of Punjab v. Ram Lubhaya Bagga

<sup>&</sup>lt;sup>14</sup> See Article 253, Constitution of India.

<sup>&</sup>lt;sup>15</sup> See Vishaka v State of Rajasthan (1997)6 SCC 241

<sup>&</sup>lt;sup>16</sup>People's Union for Civil Liberties (PUCL) v Union of India, (1997) 3 SCC 43.

<sup>&</sup>lt;sup>17</sup>Vishaka v. State of Rajasthan, (1997) 6 SCC 241; Sheela Barse v Secretary, Children's Aid Society, MANU/SC/0118/1986; People's Union for Civil Liberties (PUCL) v Union of India, (1997) 1 SCC 301; see also Chairman, Railway Board and Ors. v Mrs. Chandrima Das and Ors., MANU/SC/0046/2000; Gramophone Company of India Ltd. v Birendra Bahadur Pandey and Ors., AIR 1984 SC 667.

<sup>&</sup>lt;sup>18</sup> *PUCL v Union of India* (2005) 5 SCC 363 where the Supreme Court held that a UN General Assembly Resolution cannot be exalted to the status of a covenant under International law and no legal obligation exists merely because India is a party.

<sup>&</sup>lt;sup>19</sup> See *Apparel Export Promotion Council v A.K. Chopra* (1999) 1 SCC 759 where the Supreme Court while discussing the need to eliminate sexual harassment at the workplace held that international instruments like the Convention on the Elimination of all forms of Discrimination against Women, the Beijing Declaration and the ICESCR "cast an obligation on the Indian State to gender sensitise its laws. The courts in India are under an obligation to see that the message of the international instruments is not allowed to be drowned." Also see *John Vallanattam v Union of India* (2003) 6 SCC 611 where the Supreme Court while determining the validity of S. 118 of the Succession Act noted that India is a signatory to the Declaration on the Right to Development by the World Conference on Human Rights and the International Covenant on Civil and Political Rights and that the impugned section must be judged having regard to these treaties and covenants. The Supreme Court struck down S.118 as arbitrary, discriminatory and violative of Article 14 keeping in view international law. See also *Samatha v State of Andhra Pradesh* (1997) 8 SCC 191 and PUCL v. Union of India (1997) 1 SCC 301.

#### 2.2 Universal Health Coverage is anchored in the Right to Health

Of the seventeen Sustainable Development Goals (SDGs) agreed between UN member States in 2015, to "ensure healthy lives and promote well-being..."<sup>20</sup> is the third goal focused on health. Within it one of the targets is to "achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all."<sup>21</sup>

In September 2019, the UN convened a high-level meeting (HLM) on UHC. In the Political Declaration adopted at the HLM, countries recognised that, "universal health coverage implies that all people have access, without discrimination, to nationally determined sets of the needed promotive, preventive, curative, rehabilitative and palliative essential health services, and essential, safe, affordable, effective and quality medicines and vaccines, while ensuring that the use of these services does not expose the users to financial hardship, with a special emphasis on the poor, vulnerable and marginalized segments of the population."<sup>22</sup>

In the UHC Political Declaration, UN member States, first and foremost state that they, "[*r*]*eaffirm the right of every human being, without distinction of any kind, to the enjoyment of the highest attainable standard of physical and mental health.*"<sup>23</sup> Indeed, UHC as it has been recognised and articulated in multiple UN resolutions over nearly two decades has been consistently grounded in human rights and the right to health in particular. Scholars note that notions underlying UHC have long been reflected in the international obligations related to the right to health. For instance, Article 12.2 of the ICESCR provides that the steps that a State party to the convention must take to achieve the full realisation of this right, "*shall include those necessary for ... the creation of conditions which would ensure to all medical services and medical attention in the event of sickness.*"<sup>24</sup> General Comment 14 requires States "to ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups."<sup>25</sup>

The recognition of the centrality of the right to health in UHC programmes assists policy makers in understanding the various dimensions of health while designing UHC programmes. This is crucial as, *"not all potential paths to a universal health system are consistent with human rights requirements."*<sup>26</sup> As discussed below while examining the AAAQ framework, the right to health helps policy makers identify not just what health services need to be delivered but also how they should be delivered.

Most debates on UHC tend to focus on financial risk protection and healthcare financing. Even in India, discussions around UHC have focussed on government programmes like the Rashtriya Swasthya Bima Yojana (RSBY) and Pradhan Mantri Jan Arogaya Yojana (PM-JAY) and older schemes that have covered government employees like the Central Government Health Scheme (CGHS). More recently the Niti Aayog has presented a document pushing for a health insurance product that covers the middle

https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A\_RES\_7 0\_1\_E.pdf

<sup>&</sup>lt;sup>20</sup> United Nations General Assembly. (2015). *Transforming our world: the 2030 Agenda for Sustainable Development*. A/RES/70/1. Available at

<sup>&</sup>lt;sup>21</sup> United Nations General Assembly. (2015). *Transforming our world: the 2030 Agenda for Sustainable Development*. A/RES/70/1. Available at

https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A RES 7 0 1 E.pdf

<sup>&</sup>lt;sup>22</sup> United Nations General Assembly. (2019). *Political Declaration of the High-level Meeting on Universal Health Coverage*. Para 8. Available at: <u>https://www.un.org/pga/73/wp-content/uploads/sites/53/2019/07/FINAL-draft-UHC-Political-Declaration.pdf</u>

<sup>&</sup>lt;sup>23</sup> Ibid, para 1.

<sup>&</sup>lt;sup>24</sup> Id. at 1, Article 12.2.

<sup>&</sup>lt;sup>25</sup> Id. at 3, para 43(a).

<sup>&</sup>lt;sup>26</sup> Chapman, A. R. (2016). The Contributions of Human Rights to Universal Health Coverage. *Health and Human Rights*, *18*(2), 1–6.

classes.<sup>27</sup> This narrow approach to UHC is often linked to the term "coverage." Breaking down the three terms making up the UHC acronym, one scholar notes that "universal" means all-inclusive as seen in the Universal Declaration of Human Rights, "health" is defined in the WHO's constitution and the term "coverage" as opposed to insurance, is closer to the human rights concept of "protection."<sup>28</sup> Thus, she notes, that the Committee on Economic, Social and Cultural Rights has interpreted "coverage" to mean that "all persons are covered by the social security system, especially individuals belonging to the most disadvantaged and marginalized groups without discrimination" and has noted that non-contributory schemes are necessary to ensure "universal coverage."<sup>29</sup> As this paper covers below, people can be and often are excluded from systems for reasons other than their ability to pay. These exclusions can be based on class, ethnicity, caste, gender, sexual orientation, gender identity, occupation and others. Not accounting for such exclusions would fail the requirement of universality.

While UHC is clearly anchored in the right to health, this also raises the question of the link between UHC and the social determinants of health. There is little disagreement among scholars that UHC can be considered to be the practical expression of the right to healthcare. However, the right to health also extends to the social determinants of health. There have been two broad approaches to this question. For some scholars, there is no difficulty in limiting the understanding of UHC to the right to healthcare. However, they note that this approach may be problematic, "*if the authorities who are in charge of realizing UHC consider that this is not their job, while the authorities of other sectors think that UHC includes all of these issues, in the end nobody is taking responsibility...so health sector policy-makers should, at a minimum, assume responsibility for advocacy aimed at other sectors that impact on health, including education, sanitation and nutrition."<sup>30</sup>* 

Others have argued that UHC must encompass the social determinants of health. This was also the approach taken by a High-Level Expert Group (HLEG) in its 2011 report on UHC in India. In 2010, the HLEG was established by the Planning Commission to develop a framework for providing easily accessible and affordable healthcare to all Indians; reflecting most UHC debates, the principal objective was initially on financial protection. The HLEG report released in 2011 dealt with multiple aspects including the availability of adequate healthcare infrastructure, skilled health workforce, access to affordable drugs and technologies, efficient management systems, active engagement of empowered communities and the social determinants of health. The HLEG noted in their report that their primary approach was to take a rights-based approach to UHC. In including the social determinants of health within UHC in India, the HLEG argued, "it will be difficult, if not impossible, to achieve and sustain UHC without addressing the social determinants of health. Urgent and concrete actions addressing the social determinants of health are needed to move towards greater health equity, bridge gaps and reduce differentials in health by class, caste, gender and region across the country. In other words, UHC can be achieved only when sufficient and simultaneous attention is paid to at least the following health-related areas: nutrition and food security, water and sanitation, social inclusion to address concerns of gender, caste, religious and tribal minorities, decent housing, a clean environment, employment and work security, occupational safety and disaster management."<sup>31</sup>

Notably, in its indicators for measuring UHC, the WHO includes adequate sanitation, as well as tobacco control.<sup>32</sup> Certainly, promotive and preventive needs related to communicable and non-

<sup>31</sup> *High Level Expert Group Report on Universal Health Coverage for India*. (2011). p. 4. Available at <u>https://nhm.gov.in/images/pdf/publication/Planning Commission/rep\_uhc0812.pdf</u>

<sup>&</sup>lt;sup>27</sup> Kumar, A. and Sarwal, R. (2021). Health Insurance for India's Missing Middle. Niti Ayog. Available at: <u>https://www.niti.gov.in/sites/default/files/2021-11/HealthInsuranceforIndia%E2%80%99sMissingMiddle\_01-11-2021\_digital%20pub.pdf</u>

 <sup>&</sup>lt;sup>28</sup> Nygren-Krug, H. (2019). The Right(s) Road to Universal Health Coverage. *Health and Human Rights*, 21(2), 215–228.
 <sup>29</sup> Ibid.

<sup>&</sup>lt;sup>30</sup> World Health Organization (2015), *Anchoring universal health coverage in the right to health: What difference would it make?* p. 3. Available at <u>https://apps.who.int/iris/bitstream/handle/10665/199548/9789241509770\_eng.pdf</u>

<sup>&</sup>lt;sup>32</sup> World Health Organisation (WHO) and The World Bank (2021). *Tracking Universal Health Coverage; 2021 Global Monitoring Report.* p.64 Available at <u>https://cdn.who.int/media/docs/default-source/world-health-data-</u>

communicable diseases are linked to several social determinants of health. Distinguishing the right to healthcare as separate from the social determinants of health for the purposes of UHC, then, may not offer as neat a demarcation.

Another key concern that has arisen in the context of UHC and the right to health is **the role of the private sector** in UHC programmes. Particularly, in the context of the privatisation of healthcare in India, the notion of UHC itself has been critiqued by some scholars as a departure from the Alma Ata call for "health for all." They argue that that the slogans "Health for All" and "Universal Access to Health Care" (the latter replacing the former in the context of UHC) while appearing to be similar are fundamentally different; the former slogan is based on the Alma Ata Declaration of 1978 which recommended that governments deliver healthcare through comprehensive national health systems. UHC on the other hand allows much greater space for the private sector and disconnects the funding of health services from their delivery. This shift, they argue, "from promoting public health systems (public financing/public provisioning) as the main approach to providing universal access to health care to seeing the private sector as a major player and, indeed, a collaborator funded by public monies (public financing/private provisioning)," is problematic.<sup>33</sup>

The normative framework for the right to health internationally, on the face of it, may appear to be agnostic in this debate. General Comment 14 while recognising the obligation of the State to protect people from violations of the right to health by the private sector, focuses more on the regulation of the private sector. While it is abundantly clear that the State is ultimately the duty holder in fulfilling the right to health, whether there is an obligation to achieve this only through a public health system is not as clear. At the same time, there is increasing evidence that violations of the right to health continue to plague the private sector, providing greater impetus to the argument for public provisioning to meet obligations under the right to health. The issue of the regulation of the private sector and the obligation for a robust public health sector is discussed in greater detail below.

#### 2.3 Myths about the RTH in the context of UHC

Law and policy makers can often view the right to health as impractical or merely aspirational. For some, the right implies immediate access to the most expensive of healthcare technologies. Some of these myths about the right to health framework are explored in this section.

In reality the ICESCR itself takes a practical approach by providing for the "**progressive realisation**" of the economic, social and cultural rights enumerated in the Covenant including the right to health. Article 2 of the ICESCR provides that governments are obligated to "[...] take steps, individually and through international assistance and co-operation, [...] to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant [...], without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status." <sup>34</sup> The reference to availability of resources implies that there is a "recognition that States have resource constraints and that it necessarily takes time to implement the treaty provisions"<sup>35</sup> and as a result some components of the right to health are deemed "subject to progressive realization."<sup>36</sup>

platform/events/tracking-universal-health-coverage-2021-global-monitoring-report\_uhcday.pdf?sfvrsn=fd5c65c6\_5&download=true

<sup>&</sup>lt;sup>33</sup> Sengupta, A. & Prasad, V. (2011). *Developing a Truly Universal Indian Health System: The Problem of Replacing "Health for All' with "Universal Access to Health Care"* Social Medicine. p. 69 – 72. Available at <u>https://www.academia.edu/82428685/Developing a Truly Universal Indian Health System The Problem of Replacing Health for All with Universal Access to Health Care ?f ri=4441</u>

<sup>&</sup>lt;sup>34</sup> Id. at 1, Article 2

<sup>&</sup>lt;sup>35</sup> Id. at 5

<sup>&</sup>lt;sup>36</sup> OHCHR, Factsheet No. 33, page 13. Available at:

https://www.ohchr.org/sites/default/files/documents/publications/factsheet33en.pdf

However, this does not mean that a country can postpone indefinitely its obligations to put in place policies, programmes and actions to realise right to health, on the ground of unavailability of resources. In this regard General Comment 14 clarifies that "the progressive realization of the right to health over a period of time, however, should not be interpreted as depriving State parties' obligations of all meaningful content. Rather, progressive realization means that States parties have a binding, specific and continuing obligation to move as expeditiously and effectively as possible towards the full realization of the right to health ."<sup>37</sup> Taking necessary budgetary, legislative, policy and programmatic measures towards the progressive realisation of the right to health definitely and must be "implemented, measured and monitored."<sup>38</sup>

Further guidance is provided by the Office of the High Commissioner for Human Rights (OHCHR), which clarifies: "States must demonstrate that they are making every effort to improve the enjoyment of economic, social and cultural rights, even when resources are scarce. For example, irrespective of the resources available to it, a State should, as a matter of priority, seek to ensure that everyone has access to, at the very least, minimum levels of rights, with particular focus on programmes to protect the poor, the marginalized and the disadvantaged."<sup>39</sup> Even when faced with severe resource constraints, States must adopt targeted programmes to protect vulnerable members of society.<sup>40</sup>

In addition, certain obligations arising from the right to health require immediate compliance in every country, regardless of its level of development or availability of resources. These immediate obligations can be considered to be the bottom line of what governments can do, cannot do, and must do. In the case of the right to health, minimum core obligations include the provision of minimum essential standards of health care and of the underlying/social determinants of health. The fact that economic conditions may make it impossible for a government to fulfil its core obligations immediately does not mean that it is entitled to do nothing about them. The state still has the obligation to take immediate, deliberate, concrete and targeted steps towards fully realizing the right to health, and must start immediately and in a systematic manner to create the conditions necessary to fulfil its core obligations.

Crucially, this obligation has also been recognised by the Supreme Court of India.

In Paschim Banga Khet Mazdoor Samity v State of Bengal,<sup>41</sup> the Supreme Court held that, "It is no doubt true that financial resources are needed for providing these facilities. But at the same time it cannot be ignored that it is the constitutional obligation of the State to provide adequate medical services to the people. Whatever is necessary for this purpose has to be done. In the context of the constitutional obligation to provide free legal aid to a poor accused, this Court has held that the State cannot avoid its constitutional obligation in that regard on account of financial constraints."<sup>42</sup>

Apart from taking **steps** towards the progressive realization of the right to health, other core obligations of the State include preventing, avoiding or halting **discrimination**, refraining from taking any measures that **infringe** upon (or interfere with), directly or indirectly, the enjoyment of the right to health, **refraining from retrogressive measures** (take-backs such as introducing user fees for a

<sup>37</sup> Id. at 3

41 (1996) 4 SCC 37

<sup>&</sup>lt;sup>38</sup> Judith Asher (2004). The Right to health: A Resource Manual for NGOs. Available at: <u>https://www.aaas.org/sites/default/files/s3fs-public/RT\_Health.pdf</u>

<sup>&</sup>lt;sup>39</sup> Id. at 36, p. 14

<sup>&</sup>lt;sup>40</sup> Committee on Economic, Social and Cultural Rights, General Comment 3, The Nature of States Parties' Obligations (Fifth session, 1990), U.N. Doc. t E/1991/23 (1999), para 12. Available at

https://www.refworld.org/pdfid/4538838e10.pdf

<sup>&</sup>lt;sup>42</sup> Ibid, at para. 16

previously free health service) and ensuring that people can **participate** in decision-making processes which may affect their health, well-being and development.

A concern often expressed by policy makers is whether the right to health entails obligations on the government to provide the best and most **expensive** treatments available. General Comment 14 specifies that the nature of health goods and services are dependent on the developmental level of a country. However, it also states that there is a core obligation that governments must immediately meet i.e., to provide access to essential medicines as defined by the WHO from time to time.

In response to a request by the 1975 World Health Assembly, the first WHO Model List of Essential Medicines (EML) was released in 1977; in 1978, the provision of essential medicines was identified as a key element of the provision of primary healthcare in the Alma Atta Declaration on Health for All.<sup>43</sup> According to the WHO, essential medicines are those that, *"satisfy the priority health care needs of the population"* and are selected taking into account, *"disease prevalence and public health relevance, evidence of clinical efficacy and safety, and comparative costs and cost-effectiveness."<sup>44</sup>* 

As can be seen the concept of 'essentiality' brings in cost-effectiveness and rational use while determining the obligations of the State. It is important to note that the commitment to fulfilling UHC in the SDGs is framed around 'essential' medical services and 'essential" medicines.' High-cost medicines or treatments, particularly for rare diseases and conditions may not make it to these lists of essential services or medicines that the government must provide as part of health UHC programmes, but this does not mean that the obligation of the State ends there. Some high-cost treatments may be critical to the life and health of an individual. Indeed, as discussed below in the section on 'Availability', courts in India have recognized the responsibility of the State to provide such medicines.

As noted earlier, the existence of financial constraints must be taken into account when determining whether the highest attainable standard of health has been adequately achieved. However, the **'inability'** of a State must be distinguished from its **'unwillingness'** to fulfil the right to health. According to General Comment 14, if resource constraints render it impossible for a State to comply fully with its Covenant obligations, *"it has the burden of justifying that every effort has nevertheless been made to use all available resources at its disposal in order to satisfy, as a matter of priority, the obligations outlined above."*<sup>45</sup> As noted above, the State is required to take *"deliberate, concrete and targeted steps towards the full realisation of the right to health"*<sup>46</sup> and *"adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures."*<sup>47</sup>

Another area of concern for law and policy makers is the limits of various aspects of the right to health. A recurring arena of tension in the human rights field is the perceived clash between public health imperatives and the right to health, particularly in the context of emergencies as has been seen in the COVID-19 pandemic. Mandatory testing, breaches of confidentiality, mandatory isolation and quarantine, vaccine mandates apart from even harsher measures like total or partial lockdowns are all being tested against human rights standards in courts across the world. These tensions have preceded the current pandemic and are well recognised within the human rights framework as are the guiding principles by which States should decide the imposition of such limitations.

<sup>&</sup>lt;sup>43</sup> Laing, R et al. (2003). 25 years of the WHO essential medicines lists: progress and challenges. The Lancet. Available at <u>https://core.ac.uk/reader/9416867?utm\_source=linkout</u>

<sup>&</sup>lt;sup>44</sup> WHO. (2021). *WHO model list of essential medicines - 22nd list, 2021*. Available at <u>https://www.who.int/publications/i/item/WHO-MHP-HPS-EML-2021.02</u>

<sup>&</sup>lt;sup>45</sup> Id. at 3.

<sup>&</sup>lt;sup>46</sup> Ibid.

<sup>&</sup>lt;sup>47</sup> Ibid.

General Comment 14 notes that such restrictions, "must be in accordance with the law, including international human rights standards, compatible with the nature of the rights protected by the Covenant, in the interest of legitimate aims pursued, and strictly necessary for the promotion of the general welfare in a democratic society...such limitations must be proportional, i.e., the least restrictive alternative must be adopted where several types of limitations are available. Even where such limitations on grounds of protecting public health are basically permitted, they should be of limited duration and subject to review."<sup>48</sup>

This is not to say that States may not exceptionally restrict individual rights. What is required though, is that restrictions are justified on evidence, and are not unfettered. The Siracusa Principles are often cited as a framework that assesses the conditions for deployment of State power, and came about in the context of laying out how rights in the International Covenant on Civil and Political Rights (ICCPR) may be limited by the State. Similar to the aforementioned quotation of General Comment 14, they prescribe that such limitations can occur when they are: "(1) provided for and carried out in accordance with the law; (2) directed towards a legitimate objective of general interest; (3) strictly necessary in a democratic society; (4) the least intrusive and restrictive in severity and duration to achieve the objective; and (5) based on scientific evidence and neither drafted nor imposed arbitrarily nor in a discriminatory manner."<sup>49</sup>

#### 3. UNPACKING THE RIGHT TO HEALTH AND UHC IN CONTEXT OF INDIAN LAW AND POLICY

The preceding section elucidated that UHC must be interpreted as part of and is anchored in the right to health. It is important then to understand the many real and practical ways in which law and policy intersects with the right to health. This section illustrates (not exhaustively) many of these intersections between law, policy and the right to health, all of which have relevance to UHC. In doing so, the paper amplifies the manner in which the right to health is embedded in India's law and policy framework, and therefore intrinsic to any conception of UHC.

This section uses two key analytical frameworks to describe these linkages and reiterate the extant relationship between health and rights, and consequently the inextricable link between rights and UHC. These frameworks are what has come to be known as **AAAQ** and the **Respect-Protect-Fulfil** paradigm.

#### 3.1 Applying the AAAQ framework

One of the most important conceptual frameworks identified in General Comment 14 is the AAAQ framework that identifies four essential elements of the right to health: Availability, Accessibility, Acceptability and Quality.

#### The AAAQ Framework

"According to the General Comment, the right to health contains four elements:

- Availability. Functioning public health and health care facilities, goods and services, as well as programmes in sufficient quantity.
- Accessibility. Health facilities, goods and services accessible to everyone, within the jurisdiction of the State party. Accessibility has four overlapping dimensions:
   ✓ non-discrimination

<sup>&</sup>lt;sup>48</sup> Ibid.

<sup>&</sup>lt;sup>49</sup> UN Commission on Human Rights, *The Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights*, 28 September 1984, E/CN.4/1985/4, available at: <u>https://www.refworld.org/docid/4672bc122.html</u>

- ✓ physical accessibility
- ✓ economical accessibility (affordability)
- ✓ information accessibility
- Acceptability. All health facilities, goods and services must be respectful of medical ethics and culturally appropriate as well as sensitive to gender and life-cycle requirements.
- Quality. Health facilities, goods and services must be scientifically and medically appropriate and of good quality."<sup>50</sup>

#### 3.1.1 Availability

The contents of 'availability' in relation to the right to health and UHC may be understood through various examples. As General Comment 14 notes, availability envisages health-related "facilities, goods and services... available in sufficient quantity" including "the underlying determinants of health, such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs...".<sup>51</sup> Indeed, it not only includes human resources being available at the point of delivery of healthcare, but also circumstances that are conducive to these human resources being able to function optimally. For the right to health to be realized, all of these aspects need to be provided in unison. A health clinic without nurses or vice versa, physicians without medical technologies (depending on their location within primary, secondary or tertiary health) and medicines, and an X-ray machine without a room fail the requirement of 'availability'.

This was most vividly evident in 2021 during the surge of the COVID-19 Delta strain throughout urban India, where large-scale failure by hospitals to provide oxygen led to unnecessary deaths.<sup>52</sup> As has been well-documented, this was not confined to cities, with underserved districts feeling the brunt during exigencies of the pandemic.<sup>53</sup> While this traumatic time was a stark example of the failure of the State to deliver on the right to health, unavailability of this kind manifests in more insidious and less publicized ways, all contributing to a failure to deliver on the right to health.

The availability of medicines is a self-evident aspect of the right to health, and one that is repeatedly emphasized as core to the achievement of UHC in the UN Political Declaration of the High-Level Meeting on Universal Health Coverage, 2019.<sup>54</sup> It is an aspect that India is committed to ensuring, deriving from a multitude of international agreements and treaties that it has signed. Domestic law and policy too recognizes the need for medicines to be available – through the *Essential Commodities Act, 1955*<sup>55</sup> and its *Drugs (Prices Control) Order (DPCO), 2013*<sup>56</sup> – and mechanisms to complain about lack of availability, such as the Pharma Jan Samadhan of the National Pharmaceutical Pricing Authority (NPPA).<sup>57</sup> Availability of medicines is also affected by intellectual property rights such as patents that

<sup>&</sup>lt;sup>50</sup> WHO and OHCHR. (Undated). Factsheet: Right to Health. Available at:

https://www.ohchr.org/sites/default/files/Documents/Issues/ESCR/Health/RightToHealthWHOFS2.pdf <sup>51</sup> Ibid.

<sup>&</sup>lt;sup>52</sup> Chatterjee, R., [@MasalaBai]. (2021, May 3). For those who don't know anything about internal struggles of procuring oxygen, hope this grim thread helps. Hospitals have put onus of arranging oxygen on patients. Critical patients are on 24 hour O2 support. A 40-50 litre cylinder will last the night. But refill is a nightmare. Twitter. Available at: https://twitter.com/MasalaBai/status/1389112478462746625 (and others)

<sup>&</sup>lt;sup>53</sup> Angad, A. (2021, May 11). Jharkhand district battles second wave: 'Could my son have been saved if we got oxygen on time?' *The Indian Express*. Available at: <u>https://indianexpress.com/article/india/jharkhand-district-dhanbad-battles-second-wave-could-my-son-have-been-saved-if-we-got-oxygen-on-time-7310141/</u>

<sup>&</sup>lt;sup>54</sup> Id. at 22, paras 9, 24, 39, 49-53.
<sup>55</sup> The *Essential Commodities Act, 1955*. Available at

https://www.indiacode.nic.in/bitstream/123456789/7053/1/essential commodities act 1955.pdf <sup>56</sup> The Drugs (Prices Control) Order (DPCO), 2013. Available at https://www.nppaindia.nic.in/wpcontent/uploads/2018/12/DPC02013\_03082016.pdf

<sup>&</sup>lt;sup>57</sup> National Pharmaceutical Pricing Authority, Pharma Jan Samadhan. Available at: <u>https://nppaipdms.gov.in/NPPA/PharmaJanSamadhan/registration</u>

allow exclusive rights to vest in pharmaceutical manufacturers, empowering them to determine how, where and at what price life-saving medicines will be available. Recognising this, several provisions in India's *Patents Act, 1970* are aimed at protecting the availability and affordability of medicines. One such provision, Section 3(d) which prevents the granting of minor or frivolous patents on medicines, was famously challenged by multinational company Novartis over the denial of its patent application on the crucial cancer medicine, imatinib mesylate. While Novartis sold the medicine at a global price of USD 2500 per person per month, Indian generic companies were selling it at one-tenth the price. The Supreme Court of India in its decision in *Novartis AG v Union of India and others*<sup>58</sup> upheld the strict application of the provision noting in its judgment that the provision emerged from Parliamentary concerns over the availability of affordable medicines.

Courts have also intervened to ensure availability of expensive medicines for rare diseases to those in need. In *Baby Devananda D. v Employees State Insurance Corporation*,<sup>59</sup> two children with rare genetic disorders were denied insurance coverage for the cost of life-saving medicines and treatment through their parents under the Employee State Insurance Scheme. The Delhi High Court decided the case based on Article 21 of the Constitution, holding that life-saving medicines must be made available as a component of the fundamental right to health. It stated:

"Although obligations under Article 21 are generally understood to be progressively realizable depending on maximum available resources, yet certain obligations are considered core and non-derogable irrespective of resource constraints. Providing access to essential medicines at affordable prices is one such core obligation."

In keeping with several principles of the right to health, Indian courts in cases relating to high priced medicines for rare diseases have pushed the government to evolve a policy and explore mechanisms not only to provide these treatments but also to bring down their costs. These cases are discussed in greater detail in Working Paper 2 in this series.

Availability of sanitation facilities has also been the subject matter of court cases. In *Milun Saryajani* & Ors. v Pune Municipal Commissioner & others,<sup>60</sup> a public interest litigation by women's rights groups seeking relief in terms of availability of public toilets and sanitation facilities for women in public spaces, the Bombay High Court noted that the right to health included underlying determinants of health, such as those sought by the petitioners. It held that a fundamental duty of the State was to improve public health by providing public toilets for women in hygienic conditions, in public spaces, and issued several directions to municipal corporations across Maharashtra with respect to upgrading existing facilities as well as ensuring availability through construction and maintenance of new public toilets and sanitation facilities.

COVID-19 also laid bare another critical component of 'availability' in relation to personnel who provide health services – the abject lack of occupational safety in the workplace. For a significant time during the early phase of the pandemic a large number of nurses had to function without essential safety requirements, including the inadequate provision of personal protective equipment (PPE).<sup>61</sup> In this context the National Human Rights Commission issued an advisory on human rights protection

<sup>&</sup>lt;sup>58</sup> Civil Appeal Nos. 2706-2716 of 2013

<sup>&</sup>lt;sup>59</sup> 2017 SCC Online Del 12779

<sup>60 2015</sup> SCC Online Bom

<sup>&</sup>lt;sup>61</sup> Marathe, S. and Yakkundi D. (2021). *The Impact of COVID-19 on Fundamental Rights of Nurses.* Centre for Health Equity, Law & Policy, ILS Pune. Available at <a href="https://covid-19-constitution.in/analyses/the-impact-of-covid-19-on-fundamental-rights-of-nurses#\_ednref6=">https://covid-19-constitution.in/analyses/the-impact-of-covid-19-on-fundamental-rights-of-nurses#\_ednref6=</a>. See also, Sharma, B. (2020, April 2). Meet The Nurses Risking Their Lives at The Coronavirus Frontline In India. *Huffington Post.* Available at: <a href="https://www.huffpost.com/entry/indian-nurses-coronavirus n\_5e84f217c5b60bbd734e769d?ri18n=true/">https://www.huffpost.com/entry/indian-nurses-coronavirus n\_5e84f217c5b60bbd734e769d?ri18n=true/</a>. While availability of PPE and other prophylaxis is discussed here, healthcare workers' protection entails many more aspects including issues of workload, granting of leave, denial of or deduction in pay that all came to the fore during the COVID-19 pandemic, as discussed in the cited paper.

for healthcare workers, including on actions to assure protection from infection, medical care, and humane working conditions.<sup>62</sup> Occupational unsafety has also been the experience of ASHA workers during the pandemic.<sup>63</sup> While the *Occupational Safety, Health and Working Conditions Code, 2020* is the legal framework which governs health and working conditions of those employed in various establishments, it fails to cater to the specific needs of healthcare workers. The *HIV/AIDS (Prevention & Control) Act* (HIV Act) is the only legislation that requires the provision of a safe working environment by establishments "where there is a significant risk of occupational exposure to HIV."<sup>64</sup>

#### 3.1.2 Accessibility

The component of 'accessibility' of the right to health includes several aspects – apart from the assurance of non-discrimination, it requires fulfilment of physical, economic and information accessibility. Healthcare systems, services, goods and infrastructure need to be easily understood, reached, affordable, and non-exclusionary. Indeed, accessibility is essential for universal health coverage to be 'universal'. A clinic that is too far away or cannot be accessed by a person with disabilities, medicines that are unaffordable, or a hospital that provides a particular quality of care to a privileged class while denying the same to marginalized communities based on the ability to pay or based on social status, all fail on the measure of accessibility.

Here too, COVID-19 demonstrably revealed the inequity in access that many had to deal with. Cases abound of those denied admission and healthcare in hospitals for COVID-19 treatment.<sup>65</sup> The adoption of information technology in the form of CoWin revealed the digital divide and lack of internet penetration in India that left vast numbers of persons behind in their ability to access vaccines. The technological solution offered erroneously assumed much from the public, including the abilities to navigate an English portal (as it was in the first few months), to set aside time to obtain a vaccination slot as and when it became randomly available, and the digital literacy to comprehend various online processes such as registration – all to the detriment of access.<sup>66</sup> Indeed, CoWin accentuated another aspect of lack of access – the role of gender disparity in vaccine uptake, caused by structural inequality and embedded patriarchy that restrict the ability of women to access and utilise it.<sup>67</sup>

<sup>&</sup>lt;sup>62</sup> National Human Rights Commission. (2020, September). *Advisory on Right to Health in Context of COVID-19* [Press release]. Available at:

https://nhrc.nic.in/sites/default/files/NHRC%20Advisory%20on%20Right%20to%20Health%20in%20context%20 of%20covid-19.pdf

<sup>&</sup>lt;sup>63</sup> Jain, D. (2021). ASHA Worker's Rights Violations in the Time of Covid-19. Centre for Health Equity, Law & Policy, ILS Pune. Available at <u>https://covid-19-constitution.in/analyses/asha-workers-rights-violations-in-the-time-of-covid-19-a-critical-reflection</u>

<sup>&</sup>lt;sup>64</sup> Section 19, Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act, 2017 (HIV Act)

<sup>&</sup>lt;sup>65</sup> BBC News. (2020, July 4). India coronavirus: Questions over death of man "turned away by 18 hospitals." *BBC News*. Available at: <u>https://www.bbc.com/news/world-asia-india-53275315</u>, The Quint. (2020, June 9). Chasing Hospitals for 13 Hrs, Pregnant UP Woman Dies in Ambulance. Available at:

https://www.thequint.com/news/india/denied-admission-in-hospitals-pregnant-woman-dies-in-ambulance#readmore, NewsBytes. (2020, May 8). Delhi: Turned away by two hospitals, constable dies of coronavirus. Available at: https://www.newsbytesapp.com/news/india/delhi-constable-turned-away-by-hospitals-dies/story, Times of India. (2020, April 29). Boys, 12 & 7, die after many hospitals turn them away. Available at: https://timesofindia.indiatimes.com/city/arra/turned-away-by-covid-scared-hospitals-2-minors-

https://timesofindia.indiatimes.com/city/agra/turned-away-by-covid-scared-hospitals-2-minorssuccumb/articleshow/75440257.cms

<sup>&</sup>lt;sup>66</sup> de Souza, SP. and Chacko, A. (2021). *CoWin and the emergence of divides, dependence and theatres.* Centre for Health Equity, Law & Policy, ILS Pune. Available at <u>https://covid-19-constitution.in/analyses/cowin-and-the-emergence-of-divides-dependence-and-theatres#\_edn7</u>

<sup>&</sup>lt;sup>67</sup> Madan, A. (2021, July 21). *Gender disparity in the vaccination drive and its underlying causes*. Observer Research Foundation. Available at: <u>https://www.orfonline.org/expert-speak/gender-disparity-in-the-vaccination-drive-and-its-underlying-causes/</u>. Guha, N. (2021, June 28). India's Covid gender gap: women left behind in vaccination drive. *The Guardian*. Available at: <u>https://www.theguardian.com/global-development/2021/jun/28/india-covid-gender-gap-women-left-behind-in-vaccination-drive</u>

The judiciary has emphatically articulated access in other aspects of health as part of the rights to health and life too. In *Kali Bai v Union of India*<sup>68</sup> where the petitioner lost her daughter due to poor health facilities and mismanagement of her treatment at the Community Health Centre (CHC) in Bilaspur, Chhattisgarh the Supreme Court held that the right to health included the right to access public health facilities and the right to minimum standards of treatment and care through such facilities. It directed the state government to ensure that the CHC and other healthcare facilities be made effective in terms of equipment, personnel, medicines, and blood supply within a stipulated period, and that healthcare facilities are run without any deficit in healthcare personnel, or interruption in supplies of health products.

In *Meenakshi Balasubramanian v Union of India*<sup>69</sup> the Madras High Court held that persons with disabilities should be given priority in COVID-19 vaccination and the state should enable vaccination as expeditiously as possible to protect the lives of persons with disabilities. It further directed that vaccination centres be made accessible to persons with disabilities by constructing ramps or other measures in accordance with the *Rights of Persons with Disabilities Act, 2016*.

Again, in relation to the crisis of COVID-19 in a suo motu petition the Madhya Pradesh High Court directed the state government to ensure access in public and private hospitals, "including about the treatment of poor patients under Ayushman Bharat Yojana reserving 20% beds for Ayushman Bharat Yojana beneficiaries and increase the empanelment of more private hospitals under the said scheme. The State Government should ensure regular and continuous supply of Oxygen not only to the Government Hospitals but also to private hospitals, which are generally denying treatment to Covid-19 patients due to non-availability of Oxygen."<sup>70</sup>

Recognising the fact that differential access to the health system plays out in many forms, some legislations contain provisions meant to counter discrimination. The *West Bengal Clinical Establishments (Registration, Regulation & Transparency) Act, 2017* does so in two ways, recognising both economic and structural inequality. It requires all clinical establishments that receive land or other facilities from the government to provide free treatment to 20 percent of out-patients and 10 percent of in-patients. It also stipulates that no person shall be discriminated by the clinical establishment *"in access to facilities, goods, care and services including admission"* on the basis of *"nationality, sex, physical or mental disability, occupation, religion, sect, language, caste, political or other opinion, actual or perceived health status and disease condition… or such other arbitrary grounds."*<sup>71</sup>

Other laws have also legislated access and non-discrimination. The *Mental Healthcare Act, 2017* is holistic in its articulation of the right to health, fully following the AAAQ framework. It provides that, *"the right to access mental healthcare and treatment shall mean mental health services of affordable cost, of good quality, available in sufficient quantity, accessible geographically, without discrimination on the basis of gender, sex, sexual orientation, religion, culture, caste, social or political beliefs, class, disability or any other basis and provided in a manner that is acceptable to persons with mental illness and their families and caregivers."<sup>72</sup> It further reiterates that persons with mental illness shall be treated equally to people with physical illnesses in the provision of all healthcare, and this includes no discrimination on any basis including caste, class, culture, disability, gender, religion, sex, sexual orientation, social or political beliefs.<sup>73</sup> Further, the Act recognises informational accessibility, providing that all persons with mental illness and their nominated representatives shall have the right* 

<sup>&</sup>lt;sup>68</sup> AIR 2018 (NOC 695) 242

<sup>&</sup>lt;sup>69</sup> Writ Petition No. 2951/2021

<sup>&</sup>lt;sup>70</sup> Sushil Kumar Patel v Union of India, W.P. No.8914/2020

<sup>&</sup>lt;sup>71</sup> Section 7, West Bengal Clinical Establishments (Registration, Regulation & Transparency) Act, 2017

<sup>&</sup>lt;sup>72</sup> Section 18, *Mental Healthcare Act, 2017* 

<sup>73</sup> Section 21, Mental Healthcare Act, 2017

to information of the provisions of the Act under which they are being admitted to a healthcare institution, of the ability to apply for a review of the admission, and of the nature of the mental illness and the proposed treatment plan.<sup>74</sup>

With regard to physical accessibility, section 25 of the *Rights of Persons with Disabilities Act 2016* requires the government and local authorities to ensure that persons with disabilities are provided free healthcare in their vicinity, particularly in rural areas, and barrier-free access in all public and private hospitals and other healthcare institutions, with priority given to them in being attended to and treated.

Accessibility to social determinants of health is also seen as vital to the fulfilment of public health imperatives. Section 3(2) of the *Assam Public Health Act, 2010* requires the health ministry to coordinate with other departments and ensure access to food security, safe drinking water, sanitation services and housing, with state and district Public Health Boards mandated to formulate and implement action plans related to food, water, sanitation and housing.<sup>75</sup>

And accessibility in the context of effective health delivery institutions has also been acknowledged in policy. For instance, Health Ministry guidelines note that district hospitals across the country need urgent strengthening to address accessibility of services, hitherto largely limited only to clinical service delivery and without many basic specialties due to shortage of human resources. Rectification is emphasised through mandatory provision of basic specialty services.<sup>76</sup> Yet, while the National Programme for Palliative Care under the National Health Mission articulates "availability and accessibility of rational, quality pain relief and palliative care to the needy, as an integral part of healthcare", there is no separate allocation of resources for this.<sup>77</sup>

#### 3.1.3 Acceptability

The notion of 'acceptability' requires that "health facilities, goods and services be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned."<sup>78</sup> Informed consent to health procedures and confidentiality of health status and other private information imparted in the context of seeking or obtaining healthcare are cornerstones not just of medical ethics but also the law. Privacy (also a Fundamental Right) and confidentiality features in the Hippocratic Oath, which requires that a physician "will respect the privacy of my patients, for their problems are not disclosed to me that the world may know."<sup>79</sup> The Indian Medical Council (Professional conduct, etiquette and Ethics) Regulations, 2002, (which continue to be in force through the National Medical Commission Act, 2019) which govern medical practice in India state that a doctor shall not disclose confidential information of the patient except if required by law, or when the doctor believes that a "duty to society requires"

<sup>&</sup>lt;sup>74</sup> Section 22, *Mental Healthcare Act, 2017* 

<sup>&</sup>lt;sup>75</sup> Sections 3, 14 and 16, Assam Public Health Act, 2010

<sup>&</sup>lt;sup>76</sup> Ministry of Health & Family Welfare, *Strengthening the District Hospital for Multi-speciality care and as a Site for Training*, 2017,

https://nhm.gov.in/New Updates 2018/NHM Components/Health System Stregthening/DHS/Guideline District H ospital Strengthening.pdf

<sup>&</sup>lt;sup>77</sup> National Health Mission, National Programme for Palliative Care. Available at:

<sup>&</sup>lt;u>https://www.nhm.gov.in/index1.php?lang=1&level=2&sublinkid=1047&lid=609</u>. State governments also have palliative care policies. See for eg.: Government of Kerala. (2019). Kerala Palliative Care Policy, 2019. Available at: <u>https://palliumindia.org/2020/04/kerala-state-palliative-care-policy-2019</u>. Kerala envisages a public-private partnership (PPP) model of financing.

<sup>&</sup>lt;sup>78</sup> Id. at 3.

<sup>&</sup>lt;sup>79</sup> Hajar R. The Physician's Oath: Historical Perspectives. *Heart Views*. 2017;18(4):154-159. doi: 10.4103/HEARTVIEWS.HEARTVIEWS\_131\_17. Available at <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5755201/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5755201/</a>

him to employ knowledge, obtained through confidence as a physician, to protect a healthy person against a communicable disease to which he is about to be exposed. In such instance, the physician should act as he would wish another to act toward one of his own family in like circumstances."<sup>80</sup>

The National AIDS Control Programme, pursuant to the *HIV Act* recognising the crucial nature of privacy and confidentiality of health and related data, issued data protection guidelines in 2018. These guidelines require all establishments that store HIV-related information to adopt data protection measures including procedures for protecting information from disclosure, for accessing information, putting in place security systems to protect information stored in any form, and mechanisms to ensure accountability and liability of persons in cases of breach.<sup>81</sup>

Like the *HIV Act*, the *Mental Healthcare Act 2017* also lays down robust standards for informed consent, one of its guiding principles being of autonomy whereby all persons have the capacity to take decisions regarding matters related their life, including their mental healthcare and treatment, for which supported decision-making is integral. The law covers consent in relation to appointment and revocation of nominated representatives,<sup>82</sup> release of information to the media,<sup>83</sup> receiving treatment in a mental health establishment,<sup>84</sup> for psychosurgery,<sup>85</sup> or research.<sup>86</sup>

The Supreme Court of India has also recognised the central role of informed consent in relation to healthcare. In Samira Kohli v Prabha Manchanda & Another,<sup>87</sup> relating to a gynaecological case, the court held that "a doctor has to seek and secure the consent of the patient before commencing a 'treatment' (the term 'treatment' includes surgery also). The consent so obtained should be real and valid, which means that: the patient should have the capacity and competence to consent; his consent should be voluntary; and his consent should be on the basis of adequate information concerning the nature of the treatment procedure, so that he knows what is consenting to."

Yet, issues of acceptability gain greater significance at a time when digital health technologies are being deployed with much eagerness. The implications on informed consent, privacy and confidentiality are of great significance in a context where this deployment is taking place in the absence of any legislative framework. For instance, the Indian government launched its National Digital Health Mission (NDHM) in 2020 and issued a policy document to guide its implementation, the Health Data Management Policy (HDMP). Among other things, the HDMP seeks to allow a range of entities – private and public – to collect personal health data of persons. However, it fails to fulfil a critical test laid down by the Supreme Court while declaring privacy to be a Fundamental Right – that an action which implicates the right to privacy must be based in law.<sup>88</sup> In seeking to digitize health records of patients via Electronic Health Records (EHRs) – longitudinal electronic versions of patients' demographic details and complete medical history linked to a Unique Health Identity – sensitive health information will be kept at a single location, easily shared between various healthcare providers and private and public entities. This is of grave concern and even more so given that such policy is effectively a non-statuory executive instruction that governs a vital aspect of the right to health without basis in law.<sup>89</sup>

 <sup>&</sup>lt;sup>80</sup> Clause 2.2, Indian Medical Council (Professional conduct, etiquette and Ethics) Regulations, 2002
 <sup>81</sup> HIV/AIDS: Data protection guidelines of the NACP (2018)

http://naco.gov.in/sites/default/files/Data%20Protection%20Guideline%20of%20National%20AIDS%20Control% 20Programme.pdf

<sup>&</sup>lt;sup>82</sup> Section 14, *Mental Healthcare Act, 2017* 

<sup>&</sup>lt;sup>83</sup> Section 24, *Mental Healthcare Act, 2017* 

<sup>&</sup>lt;sup>84</sup> Section 86, *Mental Healthcare Act, 2017* 

<sup>&</sup>lt;sup>85</sup> Section 96, Mental Healthcare Act, 2017

<sup>&</sup>lt;sup>86</sup> Section 99, Mental Healthcare Act, 2017

<sup>&</sup>lt;sup>87</sup> (2008) 2 SCC 1

<sup>&</sup>lt;sup>88</sup> Justice K. S. Puttaswamy (Retd) v Union of India (2017) 10 SCC 1

<sup>&</sup>lt;sup>89</sup> Centre for Health Equity, Law & Policy & Internet Freedom Foundation, Working Paper: Analysing the NDHM Health Data Management Policy, 2021, <u>https://www.c-help.org/wp-analysing-the-ndhm-hlth-data-mgmt-p</u>

#### 3.1.4 Quality

The aspect of 'quality' requires that health facilities, goods and services be scientifically and medically appropriate and of good quality, comprising "skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation."<sup>90</sup>

Statutory law deals with the issue of quality as it concerns many of these areas. For instance, the Drugs & Cosmetics Act, 1940 prohibits manufacture and sale of medicines and medical devices that are spurious or not of standard quality.<sup>91</sup> This law also lays down good manufacturing practices<sup>92</sup> and contains many provisions on misbranded, adulterated and spurious drugs.<sup>93</sup> The Drugs and Magical Remedies (Objectionable Advertisements) Act, 1954 prohibits advertising drugs and remedies claiming magical properties, while the Indian Penal Code levies fines and punishment for adulteration of drugs. Laws such as the National Commission for Homeopathy Act, 2020 govern homoeopathy and medical education in that regard, seeking to improve access to high quality homoeopathy medical professionals. The Clinical Establishments (Registration and Regulation) Act, 2010 (CEA) a model central law adopted by only a few states since then and the *Rules* issued under it, have as their main thrust a focus on quality control of a variety of healthcare establishments and personnel, from rules that stipulate minimum standards for pathology laboratories<sup>94</sup> to those which lay down minimum qualifications for technicians to head laboratories.<sup>95</sup> Consumer protection law has been used to hold physicians or healthcare institutions accountable in cases of medical negligence. It is of note that the Supreme Court has recently clarified that healthcare services continue to be covered by the recently enacted Consumer Protection Act, 2019, which replaced the previous Act and aims to protect consumers from defects in products or deficiency of services.<sup>96</sup>

An important dimension of quality requires that treatment must be medically appropriate. This issue came up in *Dr. Raman Kakar v Union of India and Anr*<sup>97</sup>, a public interest litigation (PIL) filed before the Supreme Court in 2016, where the petitioner sought directions to the government to switch from intermittent tuberculosis (TB) treatment to daily treatment, based on a list of 5,300 patients who had relapses after completing treatment, sometimes on multiple occasions.<sup>98</sup> In response, the Health Ministry stated that it was preparing to procure drug formulations for implementing the daily regimen and that the transition which required not just procurement but also staff training would take 9 to 12 months. The court disposed Dr. Kakar's petition ordering that the drugs for daily treatment be administered to all new patients after the expiry of a period of nine months.<sup>99</sup>

When there has been dereliction in the guarantee and maintenance of quality healthcare courts have intervened to direct governments. In *Rajesh Kumar Srivastava v AP Verma & Others*, <sup>100</sup> which related

90 Id. at 3.

<sup>&</sup>lt;sup>91</sup>Section 18, Drugs & Cosmetics Act 1940

<sup>&</sup>lt;sup>92</sup> Schedule M, Drugs & Cosmetics Act 1940

<sup>&</sup>lt;sup>93</sup> Sections 16 -17B, *Drugs & Cosmetics Act 1940* 

<sup>94</sup> Clinical Establishments (Central Government) Amendment Rules, 2018, available at:

http://clinicalestablishments.gov.in/WriteReadData/4161.pdf

<sup>&</sup>lt;sup>95</sup> *Clinical Establishments (Central Government) Amendment Rules, 2020,* available at: <u>http://clinicalestablishments.gov.in/WriteReadData/5511.pdf</u>

<sup>&</sup>lt;sup>96</sup> Press Trust of India. (2022, April 29). Healthcare Services Covered Under Consumer Protection Law: Supreme Court. *NDTV.Com*. Available at: <u>https://www.ndtv.com/india-news/healthcare-services-covered-under-consumer-protection-law-supreme-court-2932555</u>.

 <sup>&</sup>lt;sup>97</sup> Writ Petition (Civil) No.604 Of 2016, Supreme Court of India, order dated 23 January 2017
 <sup>98</sup> Anand, U. (2016, November 21). Doctor's tenacity nudges government to overhaul TB programme. *The Indian Express* Available at: <a href="http://indianexpress.com/article/india/india-news-india/doctors-tenacity-nudges-government-to-overhaul-tb-programme-tuberculosis-4388704/">http://indianexpress.com/article/india/india-news-india/doctors-tenacity-nudges-government-to-overhaul-tb-programme-tuberculosis-4388704/</a>

<sup>&</sup>lt;sup>99</sup> Dr. Raman Kakar v Union of India And Anr., Writ Petition (Civil) No.604 Of 2016, Supreme Court of India, order dated 23 January 2017

<sup>&</sup>lt;sup>100</sup> MANU/UP/0021/2004

to the appalling condition of public health in Uttar Pradesh and the inability of the state government to control the proliferation of unqualified and unregistered medical practitioners, the Allahabad High Court issued strict directions for compliance by various entities as a means to impose quality checks. It required all hospitals, nursing homes, maternity homes, medical clinics, private practitioners practicing medicine and offering medical and health care services, pathology laboratories, and diagnostic clinics to register themselves with the Chief Medical Officer of the district where they are situated, and provide full details of the medical facilities offered, and names of practitioners with their qualifications and proof of their registration.

In Poonam Verma v Ashwin Patel,<sup>101</sup> the Supreme Court held that "a person who does not have knowledge of a particular system of medicine but practices in that system is a quack and a mere pretender to medical knowledge or skill."

And, recognising that structural determinants of health are as vital as the health system itself, the Supreme Court in *Bandhua Mukti Morcha v Union of India*<sup>102</sup> held that the right to clean water is part of the right to live with human dignity as enshrined in Article 21 of the Constitution. In *A.P. Pollution Control Board II v Prof. M.V. Nayudu*<sup>103</sup> it held that the right to access to drinking water is fundamental to life and there is a duty on the State under Article 21 to provide the same. This broader perspective in grappling with health issues is also reflected in the National Health Policy of 2017,<sup>104</sup> wherein reducing indoor and outdoor air pollution is identified as one of the seven priority areas for improving the environment for health, <sup>105</sup> and a focus area of urban health policy is to seek convergence with the wider determinants of health, including air pollution, solid waste management and water quality.<sup>106</sup>

Health-focused policy also speaks to the issue of quality in healthcare. The National Guidelines for Infection Prevention & Control in Healthcare Facilities 2020<sup>107</sup> significantly detail issues related to infection prevention and control in healthcare facilities including roles and responsibilities of various personnel/ departments, development of manuals, regular training, building maintenance, risk assessment and management, planning and monitoring, occupational safety protocols, air and ventilation, cleaning and sanitation, safe water and food, biowaste, and specialised care settings. Similarly, the Operational Guidelines for Ayushman Bharat – Comprehensive Primary Health Care through Health and Wellness Centers<sup>108</sup> lay out minimum standards for health infrastructure at the primary health level. The Health Ministry's 'Kayakalp' scheme promotes cleanliness, hygiene and infection control practices in public healthcare facilities through awards, and it has also issued National Guidelines for Clean Hospitals including emphasis on the availability of basic sanitation infrastructure, and health and safety of sanitation staff.<sup>109</sup>

https://www.nhm.gov.in/New\_Updates\_2018/NHM\_Components/Health\_System\_Stregthening/Comprehensive\_pri mary\_health\_care/letter/Operational\_Guidelines\_For\_CPHC.pdf

<sup>101 (1996) 4</sup> SCC 332

<sup>&</sup>lt;sup>102</sup> AIR 1984 SC 802

<sup>&</sup>lt;sup>103</sup> (2001) 2 SCC 62

<sup>&</sup>lt;sup>104</sup> Ministry of Health and Family Welfare, Government of India, 2017, National Health Policy. Available at: <u>https://www.nhp.gov.in/nhpfiles/national health policy 2017.pdf</u>

<sup>&</sup>lt;sup>105</sup> Ibid. Para 3.2.

<sup>&</sup>lt;sup>106</sup> Ibid. Para 3.3.5.

<sup>&</sup>lt;sup>107</sup> National Centre for Disease Control, Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India. (2020). National Guidelines for Infection Prevention and Control in Healthcare Facilities. Available at: <u>https://www.mohfw.gov.in/pdf/National%20Guidelines%20for%20IPC%20in%20HCF%20-%20final(1).pdf</u>

<sup>&</sup>lt;sup>108</sup> Ministry of Health and Family Welfare, Government of India & National Health Systems Resource Centre. (2018). *Ayushman Bharat Comprehensive Primary Health Care through Health and Wellness Centers: Operational Guidelines* Available at:

<sup>&</sup>lt;sup>109</sup> See Ministry of Health and Family Welfare, Government of India. (2015). *Guidelines for Implementation of 'KAYAKALP' Initiative*. Available at <u>https://nhm.gov.in/images/pdf/in-</u>

<sup>&</sup>lt;u>focus/Implementation Guidebook for Kayakalp.pdf</u>; and see Ministry of Health and Family Welfare, Government of India. (2015). *National Guidelines for Clean Hospitals: Tertiary Care Hospitals, Hospitals associated with Medical* 

From a gender perspective, the *Pradhan Mantri Surakshit Matritva Abhiyan*<sup>110</sup> aims to ensure quality antenatal care and high-risk pregnancy detection in women on the ninth of every month. To further accelerate decline in maternal mortality ratio the Health Ministry launched the *LaQshya programme* (*Labour room Quality improvement Initiative*),<sup>111</sup> focused on strengthening key processes in labour rooms and maternity operation theatres to improve quality of care around birth and ensuring respectful maternity care.

### **3.2** Respect, Protect, Fulfil: Understanding Obligations and Violations under the Right to Health

#### The Respect-Protect-Fulfil Paradigm

"The right to health, like all human rights, imposes on States Parties three types of obligations:

- **Respect:** This means simply not to interfere with the enjoyment of the right to health.
- **Protect:** This means ensuring that third parties (non-state actors) do not infringe upon the enjoyment of the right to health.
- Fulfil: This means taking positive steps to realize the right to health."<sup>112</sup>

As discussed above, States have a general legal obligation towards the progressive realization of the right to health even as some core obligations, particularly, non-discrimination, must be met immediately. Some practical steps that governments can take in this regard are discussed in the subsequent section on Practical Implications of the Right to Health. But apart from general legal obligations, there are three specific legal obligations on States i.e., to respect, protect and fulfil the right to health.<sup>113</sup> The implications of these specific legal obligations in the context of UHC and key issues in Indian law and policy are discussed below.

#### 3.2.1 Duty to Respect: Focus on Discrimination

The duty to respect the right to health, requires States "to refrain from interfering directly or indirectly with the enjoyment of the right to health."<sup>114</sup> There is no justification for a State, at any level of development to fail to comply with obligations to respect the right to health.<sup>115</sup> As per General Comment 14, among other things, the duty to respect entails actions that a government must not do, including refraining from "introducing laws, policies, or actions that have the effect of denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and palliative health services and enforcing discriminatory practices as a State policy;"<sup>116</sup>

This duty is largely understood as a negative right. However, negative rights can also impose obligations on the State to take positive measures that could be legislative or programmatic.<sup>117</sup> For instance, for the government to not interfere with the right of prisoners to access medical facilities, it

https://main.mohfw.gov.in/sites/default/files/7660257301436254417\_0.pdf

Colleges & Super-specialty Hospitals. Available at:

<sup>&</sup>lt;sup>110</sup> Pradhan Mantri Surakshit Matritva Abhiyan. (2020, August 31). PMSMA. Available at: <u>https://pmsma.nhp.gov.in/</u> <sup>111</sup> 'LaQshya' programme (Labour Room Quality Improvement Initiative). (2018, October 24). The National Institute of Health and Family Welfare. Available at: <u>https://www.nhp.gov.in/%E2%80%98laqshya%E2%80%99-programme-</u> [labour-room-quality-improvement-initiative]. pg

<sup>&</sup>lt;sup>112</sup> Id. at 50.

<sup>&</sup>lt;sup>113</sup> Id. at 3. <sup>114</sup> Id. at 3.

<sup>&</sup>lt;sup>114</sup> Id. at 3. <sup>115</sup> Id. at 3.

<sup>&</sup>lt;sup>116</sup> Id. at 3.

<sup>&</sup>lt;sup>117</sup> United Nations Office on Drugs and Crime. Positive and Negative Obligations of the State. Module 2. E4J University Module Series: Trafficking in Persons & Smuggling of Migrants. Available at: <u>https://www.unodc.org/e4j/zh/tip-and-som/module-2/key-issues/positive-and-negative-obligations-of-the-state.html</u>

must at a minimum, put in place the infrastructure and systems required to facilitate the prisoners' access to medical facilities and services. Failure to do so would constitute violation of the duty to respect their right to health. Similarly, the negative duty to refrain from preventing people's participation in health matters, places an obligation on the government to put in place processes, mechanisms and platforms to enable people's engagement and participation.<sup>118</sup>

A key issue in the context of UHC in India relates to discrimination. As noted above, the overwhelming focus of UHC discussions on financial exclusion often ignores the myriad other bases for exclusions from healthcare. Discrimination in access to health care services, goods and facilities or the underlying determinants of health, constitutes failure of the duty to respect the right to health as highlighted through the examples below.

#### **3.2.1.1** Discrimination on socio-structural factors, health and other status

Although discrimination is prohibited by the Indian Constitution (Articles 14-16), instances of discrimination in healthcare settings abound. Discrimination in healthcare settings may act as a barrier to appropriate healthcare for people that are socially marginalised due to religion, caste, gender, sexual orientation, citizenship, immigration, health status or other status.<sup>119</sup>

Instances of acts of discrimination encompass denial of admission, treatment or disrespectful attitudes towards people living with HIV,<sup>120</sup> sex workers,<sup>121</sup> COVID-19 patients,<sup>122</sup> vulnerable internal migrants,<sup>123</sup> transgender persons,<sup>124</sup> and refugees or asylum seekers.<sup>125</sup> In a survey conducted by Oxfam India in 2021, 30 percent of all respondents, over 20 percent of Dalit and Adivasi respondents, and a third of Muslim respondents said they had experienced discrimination at a hospital or from a medical professional because of their race, religion, or caste; the study noted that the COVID-19

https://www.forbesindia.com/article/new-year-special-2022/discrimination-against-transpersons-plagues-indiashealth-care-system-its-time-to-overhaul-it-aqsa-shaikh-harikeerthan-raghuram/72791/1

<sup>118</sup> Id. at 3.

<sup>&</sup>lt;sup>120</sup> Nair, M., et al (2019). Refused and referred-persistent stigma and discrimination against people living with HIV/AIDS in Bihar: a qualitative study from India. *BMJ Open*, *9*(11), e033790. Available at: https://bmjopen.bmj.com/content/9/11/e033790

<sup>&</sup>lt;sup>121</sup> Purandare, V. (2016, December 1). Mumbai hospital deny medical treatment to HIV positive sex worker. *The Asian Age*. Available at: <u>https://www.asianage.com/metros/mumbai/011216/nair-hospital-doctors-deny-medical-treatment-to-hiv-positive-sex-worker.html</u>

<sup>&</sup>lt;sup>122</sup> Sharma, M. (2020, June 4). Delhi: Private hospital reverses stance after refusing to treat pregnant coronavirus patient. *India Today*. Available at: <u>https://www.indiatoday.in/india/story/delhi-private-hospital-reverses-stance-after-refusing-to-treat-pregnant-coronavirus-patient-1685642-2020-06-04</u>

<sup>&</sup>lt;sup>123</sup> Vijayaraghavan, H. (2020, September 30). *Gaps in India's Treatment of Refugees and Vulnerable Internal.* migrationpolicy.org. Available at: <u>https://www.migrationpolicy.org/article/gaps-india-refugees-vulnerable-internal-migrants-pandemic.</u>; Santalahti, M., et al. (2020). Barriers to accessing health care services: a qualitative study of migrant construction workers in a southwestern Indian city. *BMC Health Services Research, 20*(1). Available at: <u>https://doi.org/10.1186/s12913-020-05482-1</u>; Colney, K. (2021, June). How India and the UNHCR failed to provide healthcare and vaccination for Chin refugees. *The Caravan.* Available at:

https://caravanmagazine.in/health/how-india-and-the-unhrc-failed-to-provide-healthcare-and-vaccination-for-chinrefugees

<sup>&</sup>lt;sup>124</sup> Shaikh, A. H. R. (2022, January 7). Discrimination against transpersons plagues India's health care system. It's time to overhaul it: Aqsa Shaikh, Harikeerthan Raghuram. *Forbes India*. Available at:

<sup>&</sup>lt;sup>125</sup> Shanker, R., & Raghavan, P. (2020). The Invisible Crisis: Refugees and COVID-19 in India. *International Journal of Refugee Law*, *32*(4), 680–684. Available at: <u>https://doi.org/10.1093/ijrl/eeab011</u>; Id. at 124 Colney.

pandemic deepened existing structural inequalities in health settings finding that "one in four Indians faced discrimination while accessing health services due to their caste and religion;"<sup>126</sup>

International human rights law requires that positive measures of protection are particularly necessary when certain groups of persons have been continuously discriminated against by States parties or private actors.<sup>127</sup> General Comment 14 categorically states that there is no justification for the lack of protection of vulnerable members of society from health-related discrimination, be it in law or in fact.<sup>128</sup>

#### 3.2.1.2 Exclusions due to lack of official identity, residence proof and other documents

Over the past few years, increasing digitisation of the health programmes and insistence on formal address and residence proofs, including insistence on Aadhaar cards, for access to healthcare goods, services and facilities, has resulted in exclusion of already marginalised persons like the poor or the homeless who probably need government healthcare services the most.<sup>129</sup>

The courts have intervened in this regard (although the requirements for identity documents to access health is an ever-increasing barrier). In a case concerning systemic failure of public health institutions which resulted in denial of benefits to two mothers below the poverty line (BPL), the Delhi High Court held that documentary evidence to prove BPL status should not be allowed to become a barrier to accessing health services for a mother. The court said that the approach of the government should be to ensure that as many people as possible get 'covered' by the scheme and are not 'denied' its benefits, and that insisting on documentation to prove socio-economic status is an onerous burden and constitutes a major barrier to availing services.<sup>130</sup>

#### 3.2.1.3 Digitalisation and exclusions

While technology has often been stated to be a solution to access, this may not be the case in digitally divided India. Given this and the large exclusion from accessing healthcare services it could perpetuate, digital health tools should be introduced to complement existing health service delivery and not to replace it. The divide became apparent when the government made registration on the CoWin platform mandatory to access COVID-19 vaccination, resulting in large numbers of people being left out.

This was noted by the Supreme Court in a May 2021 order: "A vaccination policy exclusively relying on a digital portal for vaccinating a significant population of this country between the ages of 18-44 years would be unable to meet its target of universal immunisation owing to such a digital divide. It is the marginalized sections of the society who would bear the brunt of this accessibility barrier".<sup>131</sup>

<sup>&</sup>lt;sup>126</sup> Press Trust of India. (2021, November 23). "1 in 4 Indians face discrimination due to caste, religion in healthcare." *Business Standard*. Available at: <u>https://www.business-standard.com/article/current-affairs/1-in-4-indians-face-discrimination-due-to-caste-religion-in-healthcare-121112300943 1.html</u>

 <sup>&</sup>lt;sup>127</sup> Id. at 3.
 <sup>128</sup> Id. at 3.

<sup>&</sup>lt;sup>129</sup> The Wire. (2017, November 1). *Activists Slam Mandatory Linking of Aadhaar to Health Services After Woman Denied Abortion*. Available at: <u>https://thewire.in/government/activists-slam-mandatory-linking-aadhaar-health-services-woman-denied-abortion</u>; Economic Times (2021, May 15). "No one should be denied medicine, hospital or vaccine for want of aadhaar: UIDAI". Available at: <u>https://economictimes.indiatimes.com/tech/tech-bytes/no-one-should-be-denied-medicine-hospital-or-vaccine-for-want-of-aadhaar-uidai/articleshow/82661364.cms. <sup>130</sup> Laxmi Mandal and Ors v Deen Dayal Harinagar Hospital 172 (2010) DLT 9)</u>

<sup>&</sup>lt;sup>131</sup> In Re Distribution of Essential Supplies and Services During Pandemic, Suo Motu Writ Petition (Civil) 3 of 2021.

#### 3.2.1.4 Exclusion of non-citizens: refugees and asylum seekers

The ICESCR as well as the Constitution of India guarantee the right to health to all persons living in a country, not only to citizens. However, refugees and asylum seekers face immense barriers in accessing welfare services including healthcare services, due to their tenuous legal status and consequent lack of government documentation.<sup>132</sup> Insistence on Aadhaar adds another layer of exclusion, as they are rarely granted this document owing to the uncertain status of their residency. This has been noted in the context of COVID-19 where refugees have faced several barriers in getting vaccinated<sup>133</sup> and in generating vaccination certificates. Similarly migrant workers from neighbouring countries also report difficulty in accessing healthcare in India. A study of migrants who worked in 15 of India's 29 states identified key barriers such as *"lack of insurance, low wages, not having an Indian identification card tied to individual biometrics so called: Aadhaar card… unsupportive employers, discrimination at healthcare facilities and limited information about the locations of healthcare services."*<sup>134</sup>

#### 3.2.1.5 Discrimination embedded in the legal framework

The duty to respect places an obligation on the government to review, suitably amend or abrogate laws that undermine the right to health and equity.<sup>135</sup> Laws that stigmatise or discriminate against vulnerable groups are known to worsen health disparities as well as health outcomes.<sup>136</sup>

The recently enacted *Assisted Reproductive Technologies (ART) Act, 2021* is a patently discriminatory law that violates the constitutional guarantee of equality and non-discrimination, in permitting only married couples and (possibly) unmarried women from using ARTs to have children. It effectively excludes single men, transgender and intersex individuals, couples in live-in relationships, and couples in same-sex relationships. An inherent component of the right to health – reproductive rights – are also violated.<sup>137</sup>

Another recent legislation, the *Surrogacy (Regulation) Act 2020* has been criticised on similar grounds. Among other things, it excludes single, divorced or widowed persons, unmarried couples and homosexual couples from pursuing surrogacy to have children. India's jurisprudence recognises the reproductive autonomy of single persons, the rights of persons in live-in-relationships and rights of transgender persons, which the law overtly ignores.<sup>138</sup>

<sup>&</sup>lt;sup>132</sup> National Human Rights Commission. (2022, January 20). Minutes of the Open-House Discussion on Protection of the Basic Human Rights of Refugees and Asylum Seekers in India. Available at:

https://nhrc.nic.in/sites/default/files/Minutes%20of%20the%20Meeting%20on%20Protection%20of%20the%20B asic%20Human%20Rights%20of%20Refugees%20and%20Asylum%20Seekers%20in%20India 20thJan2022.pdf <sup>133</sup> Colney, K. (2021, June). How India and the UNHCR failed to provide healthcare and vaccination for Chin refugees. *The Caravan*. Available at:

https://caravanmagazine.in/health/how-india-and-the-unhrc-failed-to-provide-healthcare-and-vaccination-for-chinrefugees

 <sup>&</sup>lt;sup>134</sup> Adhikary, P, et al. (2020). Accessing health services in India: experiences of seasonal migrants returning to Nepal.
 *BMC Health Services Research*, 20(1). Available at: <u>https://doi.org/10.1186/s12913-020-05846-7</u>.
 <sup>135</sup> Id. at 3.

<sup>&</sup>lt;sup>136</sup> Gostin, L. O., et al. (2019). The legal determinants of health: harnessing the power of law for global health and sustainable development. *The Lancet*, *393*(10183), 1857–1910. Available at: <u>https://doi.org/10.1016/s0140-6736(19)30233-8</u>.

<sup>&</sup>lt;sup>137</sup> Centre for Health Equity, Law & Policy, ILS Pune, 2020. Submissions to the Department Related Parliamentary Standing Committee on Health and Family Welfare on the Assisted Reproductive Technology (Regulation) Bill, 2020 [On file with the authors]

<sup>&</sup>lt;sup>138</sup> Mishra, G. (2022, October 27). With the Surrogacy Act, the judiciary has the chance to expand scope of reproductive rights. *The Indian Express*. Available at: <u>https://indianexpress.com/article/opinion/columns/with-the-surrogacy-act-the-judiciary-has-the-chance-to-expand-scope-of-reproductive-rights-8232007/</u>.

The Protection of Children from Sexual Offences Act, 2012 (POCSO) has been debated over provisions that criminalise consensual sexual acts between minors. As per the National Crime Record Bureau (NCRB) 2015, 4114 cases registered were against adolescents aged 16-18 years of the 8833 cases.<sup>139</sup> While typically it is the family of the minor girl that files a criminal complaint against the minor boy, several courts have been granting bail to the accused if the consensual nature of the relationship is easily established.<sup>140</sup> Reflecting the need to balance the objectives of the law in such cases, the Delhi High Court while ganting bail in one such case opined that *"the intention of POCSO was to protect children below the age of 18 years from sexual exploitation. It was never meant to criminalize consensual romantic relationships between young adults. However, this has to be seen from facts and circumstances of each case. There might be cases where the survivor of sexual offence, may under pressure or trauma be forced to settle."<sup>141</sup>* 

This criminalisation under POCSO has a rippling effect on broader reproductive and sexual rights of adolescents including "lack of access to comprehensive sexuality education and to essential sexual and reproductive health services" (contraception, abortion, maternal health care).<sup>142</sup> As a result, "one in four adolescents has an unmet need for contraception and seven million adolescents give birth each year."<sup>143</sup> Early pregnancy and childbearing, in turn, pose significant risks to adolescent health and wellbeing.<sup>144</sup>

In India, abortion has been allowed in limited circumstances only. The Medical Termination of Pregnancy (MTP) Act, 1971 was passed, creating an exception to abortion, which is otherwise an offence under the Indian Penal Code, 1860 (IPC).<sup>145</sup> Lacking a rights-based perspective, the law's primary purpose was population control and family planning,<sup>146</sup> which violates reproductive rights of women – stripping pregnant persons of their right to bodily and decisional autonomy by vesting the decision to abort with the doctor. Amendments made to the MTP Act in 2021 expanded access to abortion for unmarried women, but it still limited the time limit for abortion to 20 weeks of pregnancy. The law also continues to predicate the right to an abortion based on a doctor's opinion rather than at the request or will of the woman, thereby still not recognising the reproductive autonomy of women.<sup>147</sup> In a significant judgement in September 2022, the Supreme Court ruled that all women, regardless of their marital status, were entitled to safe and legal abortion till 24 weeks. Any distinction between a married and an unmarried woman was held to be discriminatory and constitutionally unsustainable.148 The SC had further ruled that the term 'woman' will include persons other than 'cis-gender woman' who may want to terminate their pregnancies, thus paving way for members of the transgender community to also get abortions. Additionally, to facilitate the rights of minors to access abortion services, the court said that for the purposes of termination of pregnancy, a medical

<sup>147</sup> Center for Reproductive Rights. (n.d.) The world's Abortion Laws: The definitive record of the legal status of abortion in countries across the globe updated in real-time. Available at: <u>https://reproductiverights.org/maps/worlds-abortion-laws/</u>

 <sup>&</sup>lt;sup>139</sup> Joshi, A. (2021). POCSO Act and Sexual Rights of Adolescents: a gap in legal framework. *The Daily Guardian*.
 Available at: <a href="https://thedailyguardian.com/pocso-act-and-sexual-rights-of-adolescents-a-gap-in-legal-framework/">https://thedailyguardian.com/pocso-act-and-sexual-rights-of-adolescents-a-gap-in-legal-framework/</a>
 <sup>140</sup> The Wire Staff (2022, November 14). 'POCSO Should Protect Minors From Sexual Abuse, Not Criminalise
 Consensual Relationships': Delhi HC. The Wire. Available at: <a href="https://thewire.in/law/delhi-hc-grants-bail-to-pocso-accused">https://thewire.in/law/delhi-hc-grants-bail-to-pocso-accused</a>

 <sup>&</sup>lt;sup>141</sup> XXXXX v State Govt of NCT of Delhi. BAIL APPLN. 2729/2022. Delhi High Court. Order dt. 21.10.22
 <sup>142</sup> Center for Reproductive Rights. (2022, September 21). Adolescent Sexual and Reproductive Health and Rights. Available at: <u>https://reproductiverights.org/our-issues/adolescent-sexual-and-reproductive-health-and-rights/</u>; Thanawala, S. (2022). The need for revising the age of consent under the POCSO Act. The Leaflet. Available at: <u>https://theleaflet.in/the-need-for-revising-the-age-of-consent-under-the-pocso-act/</u>

 <sup>&</sup>lt;sup>143</sup> Center for Reproductive Rights. (2022, September 21). Adolescent Sexual and Reproductive Health and Rights.
 Available at: <u>https://reproductiverights.org/our-issues/adolescent-sexual-and-reproductive-health-and-rights/</u>
 <sup>144</sup> Ibid.

<sup>&</sup>lt;sup>145</sup> Mishra, G. and Srivastava, S. Medical Termination of Pregnancy Act 1971: An Explainer. Centre for Health Equity, Law & Policy. Available at: <u>https://www.c-help.org/explainer-med-termination-of-pregnancy</u>

<sup>&</sup>lt;sup>146</sup> Barua, A. et al. (2020). The MTP 2020 Amendment Bill: anti-rights subjectivity. *Sexual and Reproductive Health Matters*, *28*(1), 1795447. Available at: <u>https://doi.org/10.1080/26410397.2020.1795447</u>.

<sup>&</sup>lt;sup>148</sup> X v. Health and Family Welfare Department 2022 SCC OnLine SC 1321

practitioner need not inform authorities if the minor and their guardian so request. The MTP Act needs to be amended to reflect the reproductive rights jurisprudence developed by the Supreme Court as these expanded rights are still not being fully implemented at the ground due to lack of clarity and training.<sup>149</sup>

Indirect discrimination occurs when a law or policy applies to all persons, but has a worse effect on some people more than others because of who they are. For instance, in the case of *Madhu and Anr. v Northern Railways & Ors.*,<sup>150</sup> the Delhi High Court examined the validity of a practice where medical insurance to family members of employees, including spouses and unmarried daughters, was provided by the Northern Railways based on a declaration by the employee. When this same method was used by an employee to ensure that no medical insurance was provided to his spouse and daughter with whom there was a dispute, the court noted that, "*a facially neutral decision*" of using the declaration as the basis of provision of insurance, "*can have disproportionate impact on a constitutionally protected class.*"<sup>151</sup> The court struck down the order of the Northern Railways, finding that the practice of Northern Railways which resulted in denying healthcare goods, services and facilities was in effect violating the right to health under Article 21 as well as the guarantee of non-discrimination as per Article 15 by discriminating against the constitutionally protected class of women.

Another example of indirect discrimination was Section 377 IPC which criminalised consensual same sex sexual acts between adults. The Delhi High Court decision in *Naz Foundation v Union of India*<sup>152</sup> struck down section 377 on several grounds, one of which was indirect discrimination against homosexuals. The court averred that though the provision, "*is facially neutral and it apparently targets not identities but acts, but in its operation it does end up unfairly targeting a particular community. The fact is that these sexual acts which are criminalised are associated more closely with one class of persons, namely, the homosexuals as a class. Section 377 IPC has the effect of viewing all gay men as criminals... The inevitable conclusion is that the discrimination caused to MSM and gay community is unfair and unreasonable and, therefore, in breach of Article 14 of the Constitution of India."<sup>153</sup>* 

#### 3.2.2 Duty to Protect: Regulation of the Private Sector

Protecting the right to health obliges governments to make efforts to minimise risks to health and its determinants, and to take all necessary measures to safeguard the population from infringements of the right to health by third parties. States are responsible for taking measures to ensure that private bodies (including multinational corporations, pharmaceutical companies, health insurance companies, biomedical research institutions, and private healthcare providers) refrain from violating the right to health of individuals and communities.

This includes taking legislative and other measures to regulate the conduct of individuals and groups working in the private sector with the objective of ensuring non-discrimination in access to health facilities, goods and services, and to ensure quality. Indeed, this obligation of the government extends beyond healthcare goods, facilities and services and applies to underlying determinants of health as well.

<sup>&</sup>lt;sup>149</sup> Porecha, M. (2023, January 9). Why the Supreme Court order on abortion is not helping women. The Hindu. Available at: <u>https://www.thehindu.com/news/national/despite-supreme-court-judgment-abortion-for-unmarried-women-after-20-weeks-a-catch-22/article66354052.ece</u>

<sup>&</sup>lt;sup>150</sup> (2018) SCC Online Del 6660

 <sup>&</sup>lt;sup>151</sup> Ibid. For a more detailed discussion on indirect discrimination, see Gandhi, D. (2020). Locating Indirect Discrimination in India: A Case for Rigorous Review Under Article 14. NUJS Law Review. 13 NUJS L. Rev. 4.
 <sup>152</sup> 160 DLT 277 (2009)

Over the years several such legislations have been passed, covering a host of subject matters: manufacturing of food as per safety standards;<sup>154</sup> prevention of food adulteration;<sup>155</sup> import, manufacture, distribution and sale of drugs and cosmetics;<sup>156</sup> removal and transplantation of human organs and tissues;<sup>157</sup> infant milk substitutes to protect breastfeeding and promote health of infants;<sup>158</sup> medical professionals ethical standards to ensure consent, autonomy, confidentiality and privacy of patients;<sup>159</sup> and prohibition of discrimination on the ground of HIV status,<sup>160</sup> mental health conditions,<sup>161</sup> and disabilities.<sup>162</sup>

Several laws have also been enacted pertaining to underlying determinants of health, including on gender equality and non-discrimination;<sup>163</sup> protection of the environment from degradation;<sup>164</sup> and occupational health and safety in different work settings.<sup>165</sup>

#### 3.2.2.1 States are obligated to regulate the private sector to protect the right to health

As noted above, the right to health recognises that it is the primary responsibility of states to design health systems and implement health laws, policies and programmes in conformity with human rights obligations. *"However, in the contemporary health landscape, health services are increasingly delivered through private health sector institutions, and governments often lack direct and effective control over some or many components of the health system."*<sup>166</sup>

In principle, international human rights law appears to be agnostic as to how healthcare services should be delivered, as long as healthcare provision is consistent with human rights requirements. General Comment 14 specifically states that the obligation to protect requires that *"whether privately or publicly provided, health care services must be affordable to all, including socially disadvantaged and poorer households."*<sup>167</sup> It states that the duty to protect enjoins upon states to ensure that *"privatisation of the health sector does not constitute a threat to the availability, acceptability, and quality of health facilities, goods and services"*.<sup>168</sup> It further directs that *"State parties should take appropriate steps to ensure that members of the private business sector… are aware of and consider the importance of the right to health in pursuing their activities."*<sup>169</sup>

It is therefore imperative to use a right to health lens coupled with the obligation of the State as the ultimate guarantor of rights, through which to evaluate private sector health services provision and the privatisation of healthcare. In the opinion of Paul Hunt, former United Nations Special Rapporteur on the Right to Health, "the adoption of any national policy, including privatisation, should be preceded by an independent, objective, and publicly available assessment of the impact, especially on the right

<sup>&</sup>lt;sup>154</sup> Food Safety and Standards Act, 2006

<sup>&</sup>lt;sup>155</sup> Prevention of Food Adulteration Act, 1954

<sup>&</sup>lt;sup>156</sup> Drugs and Cosmetics Act, 1940

<sup>&</sup>lt;sup>157</sup> Transplantation of Human Organs and Tissues Act, 1994

<sup>&</sup>lt;sup>158</sup> Infant Milk Substitutes, Feeding Bottles and Infant Foods (Regulation of Production, Supply and Distribution) Act, 1992

<sup>&</sup>lt;sup>159</sup> The Indian Medical Council Act, 1956 (Professional Conduct & Ethics) Regulations, 2002

<sup>&</sup>lt;sup>160</sup> Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act, 2017 (HIV Act)

<sup>&</sup>lt;sup>161</sup> Mental Healthcare Act 2017

<sup>&</sup>lt;sup>162</sup> Rights of Persons with Disabilities Act, 2016

<sup>&</sup>lt;sup>163</sup> Protection of Women from Domestic Violence Act, 2005; Protection of Women from Sexual Harassment Act 2013; Pre-Natal Diagnostic Techniques (Regulation and Prevention Of Misuse) Act, 1994; Maternity Benefit Act

<sup>&</sup>lt;sup>164</sup> Environment Protection Act, 1986; Air Act, 1981, Water (Prevention and Control of Pollution) Act, 1974, BMW Disposal Rules etc.

<sup>&</sup>lt;sup>165</sup> Factories Act 1948, Mines Act 1952, Child and Adolescent Labour (Prohibition and Regulation) Act, 1986

<sup>&</sup>lt;sup>166</sup> Chapman, A. R. (2014). The impact of reliance on private sector health services on the right to health. *Health and Human Rights*, *16*(1), 122–133.

<sup>&</sup>lt;sup>167</sup> Id. at 3, para 12

<sup>&</sup>lt;sup>168</sup> Id. at 3, para 35

<sup>&</sup>lt;sup>169</sup> Id. at 3, para 55.

to health of the poor."<sup>170</sup> According to Hunt, "private sector delivery should involve explicit respect for national and international human rights law at all stages, including policy formulation, monitoring, and accountability arrangements."<sup>171</sup>

Pertinent to the trajectory that programmes such as Ayushman Bharat/ PM-JAY appear to be taking, or the increasing public private partnerships (PPP) in operationalising primary health centres, and the recently proposed handing over of district hospitals and medical colleges to corporate hospitals – is General Comment No. 24 to the ICESCR, which expands on the obligations of State parties in the context of business activities. It raises concern over the privatisation of goods and services necessary for the enjoyment of economic, social and cultural rights, and states that "the increased role and impact of private actors in traditionally public sectors, such as the health or education sector, pose new challenges for States parties in complying with their obligations under the Covenant." <sup>172</sup> It further recommends that although privatisation is not per se prohibited by ICESCR, due to evidence-based critique and failure of privatisation in ensuring better quality and access to essential public services like water, sanitation, healthcare and education, private providers should be "subject to strict regulations that impose 'public service obligations'."<sup>173</sup> It further adds that privatisation should not result in the enjoyment of Convention rights being "conditional on the ability to pay which would create new forms of socioeconomic segregation."<sup>174</sup> Because of the lack of accountability that results from privatisation, General Comment No. 24 further recommends that States ensure the right of people to participate in decisions involving the provision of such goods and services.<sup>175</sup>

General Comment 24 defines the obligation to protect as requiring States to take a series of different measures to regulate these actors and provide victims of corporate human rights abuses with effective justice and remedies. It lists a number of measures, which States should take under this obligation: imposing criminal and administrative sanctions against businesses which abuse rights in the ICESCR (e.g., to withdraw business licences or subsidies), enabling civil suits against businesses for affected communities and individuals to claim reparations (para 15). States also have a *"positive duty to adopt a legal framework requiring business entities to exercise human rights due diligence."*<sup>176</sup>

Reiterating the obligation of the State to regulate private sector entities to ensure compliance with right to health requirements, the General Recommendation on Health from the Committee on the Elimination of Discrimination Against Women (CEDAW) specifies that "*States parties cannot absolve themselves of responsibility in the areas of women's ill-health by delegating or transferring these powers to private sector agencies.*"<sup>177</sup> Based on this test, CEDAW rendered a ruling in the *Alyne da Silva Pimentel v. Brazil*, <sup>178</sup> a landmark judgement on maternal mortality, in 2011. The case pertained to a woman who, as a result of subpar care in a private healthcare institution, passed away from pregnancy-related issues. The Committee determined that Brazil was directly at fault for failing to oversee private institutions when medical services were contracted out to them under international

<sup>&</sup>lt;sup>170</sup> Committee on the Rights of the Child, Day of General Discussion, Summary Record (Partial) of the 813th Meeting, (2002), U.N. Doc. CRC/C/SR.813, paras. 10-18; Id. at 168.

<sup>171</sup> Ibid

<sup>&</sup>lt;sup>172</sup> CESCR, 2017. General Comment No. 24 on State Obligations Under the International Covenant on Economic, Social and Cultural Rights in the Context Of Business Activities. Para 21.

<sup>&</sup>lt;sup>173</sup> Ibid. para. 24

<sup>174</sup> Ibid. para 22

<sup>&</sup>lt;sup>175</sup> FIAN International, Analysis of General Comment No. 24 on State Obligations Under the International Covenant on Economic, Social and Cultural Rights in the Context Of Business Activities, 2018. Available at

https://www.fian.org/fileadmin/media/publications 2018/Reports and guidelines/analysis GC no24 2018 EN.pdf <sup>176</sup> Id. at 172. para 16.

<sup>&</sup>lt;sup>177</sup> Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW) General Recommendation No. 24: Women and health (Article 12), (1999), para 17.

<sup>&</sup>lt;sup>178</sup> Views. Communication No. 17/2008. Committee on the Elimination of Discrimination against Women, forty-ninth session, 11 to 29 July 2011. New York: CEDAW; 2011. c.f. J. Bueno de Mesquita and E. Kismödi (2012). "Maternal mortality and human rights: landmark decision by United Nations human rights body," *Bulletin of the World Health Organization* 90: 79-79A. Available at <u>https://doi.org/10.2471/blt.11.101410</u>; Id. at 161

human rights law. The ruling emphasised that States parties must make sure that private healthcare institutions abide by national and international norms for reproductive health care.

It is established that States are primarily responsible for complying with human rights obligations in delivering health services. In the event they outsource it to private entities, they are still responsible for ensuring that the private entities comply with human rights related standards.

## **3.2.2.2** Challenges in Regulation of the private sector, impact on rights (AAAQ) and equity and impact on public health systems

Privatisation of health services does not alter the role of the State as the ultimate guarantor of the right to health obligations, it however, makes implementing its responsibilities more difficult.<sup>179</sup> It has been contended that challenges to proper regulation of private sector arise for the following reasons:

- The fragmentation of the health system makes it more difficult to monitor and advance a rightsbased perspective on health;<sup>180</sup>
- "Segmentation coupled with a poorly functioning public sector catering primarily to the poor and better quality private health institutions catering to the more affluent, tends to undermine support for investing in improvements in institutions for the public provision and financing of health care and likely erodes commitment to the right to health as well;"<sup>181</sup>
- the objectives and ambitions of commercial healthcare organisations frequently diverge from the principles and standards of the human rights paradigm;<sup>182</sup>
- Working successfully with and through private sector providers also demands comprehensive health information systems and oversight expertise, both of which many governments, especially those in low- and middle-income nations, sometimes lack.<sup>183</sup>

A review of recent empirical evidence on privatisation in developing countries, with particular focus on distributional impacts of privatisation, concludes that privatisation must be preceded by creation of regulatory and institutional capacity and attention to poverty and societal impacts. However, these conditions are difficult to achieve in developing countries.<sup>184</sup>

While on the one hand several reports highlight the difficulties in regulating the private sector and the lack of institutional capacities for its robust regulation in developing countries, on the other, evidence has been emerging on the deleterious impact of privatisation on the right to health. Further, privatisation has been justified on several grounds, such as cost and efficiency. However, as discussed below there is a striking disconnect between this narrative and the findings contained in many of the theoretical and empirical studies on the subject.

The UN Special Rapporteur on poverty evaluates the empirical studies on impact of privatization on health, dignity and poverty, in both developed and developing countries, and submits that "privatization often involves the systematic elimination of human rights protections and further marginalization of the interests of low-income earners and those living in poverty," <sup>185</sup> and that such

<sup>179</sup> Id. at 166

<sup>&</sup>lt;sup>180</sup> Id. at 166

<sup>&</sup>lt;sup>181</sup> Id. at 166

<sup>&</sup>lt;sup>182</sup> Id. at 166

<sup>&</sup>lt;sup>183</sup> Id. at 166: Lister (2013). *Health policy reform: Global health versus private profit* (Farington: Libri Publishing). p. 188.

<sup>&</sup>lt;sup>184</sup> Saul E. and Pelletier, A. (2018). Privatisation in Developing Countries: What Are the Lessons of Recent Experience?, *The World Bank Research Observer*, Volume 33, Issue 1, Pages 65–102. Available at <a href="https://doi.org/10.1093/wbro/lkx007">https://doi.org/10.1093/wbro/lkx007</a>

<sup>&</sup>lt;sup>185</sup> United Nations Special Rapporteur on Poverty. (2019). Extreme Poverty and Human Rights, A/73/396. Available at: <u>https://www.ohchr.org/en/documents/thematic-reports/a73396-report-special-rapporteur-extreme-poverty-and-human-rights</u>

privatised care is "also especially susceptible to racial and other forms of discrimination."<sup>186</sup> Referring to findings from Latin American countries, he submits that "privatization of social protection often results in the poor being relegated to a new even more underfunded public sector."<sup>187</sup>

There is an underlying difference in the values underpinning the public (public service) and the private sector (profit motive), which makes privatisation inherently incompatible with the right to health. "*The model of training social workers to recognize the inherent fragility of the human condition and identify the specific social, psychological, economic and even structural challenges faced by individuals is replaced by a model that is driven by economic efficiency concerns and is aimed at minimising the time spent per client, closing cases earlier, maximising outputs in formal but not human terms, generating fees wherever possible and thus catering especially to the better-off, and minimising reporting and follow-up."<sup>188</sup>* 

Evidence from developing countries increasingly reveals that privatisation negatively impacts the right to health and equity, resulting in further underfunding and weakening of public health systems, while failing to be more efficient than public health systems. These findings erode the justifications for outsourcing in the first place. Economists such as Joseph Stiglitz, former chief economist of the World Bank, have argued that the "case for privatization is, at best, weak or non-existent."<sup>189</sup>

- Studies on the impact of neoliberal reforms in Colombia document that on one hand public health programmes have declined; and on the other, privatization has increased health expenditures while failing to enhance efficiency and equity. The *"increase in public expense has predominantly benefited the wealthy, who have seen their co-payments reduced,"*<sup>190</sup> while the poor face access barriers due to high co-payments. The study found that *"the lowest quintile were paying more than those in the fourth and third quintiles, a trend that questions the equity of the reform."*<sup>191</sup> The study concludes *"that neoliberal reforms do not improve quality of care, equity, and efficiency."*<sup>192</sup>
- According to a study that examined outcomes before and after fast privatisation, healthcare
  performance post-privatisation had declined. For instance, the commercialisation of fertility
  control services in Brazil resulted in higher rates of abortion and sterilisation; this was
  associated with higher death rates in younger women. Privatisation also increased
  discrepancies in healthcare coverage, increased, inequities in the distribution system and led to
  insufficient disease reporting in the private sector made it difficult for the public sector to
  respond to or address communicable diseases.<sup>193</sup>
- A systematic review of comparative analysis of private and public healthcare sectors in low and middle-income countries found strengths and weaknesses in both.<sup>194</sup> While, the private

https://link.springer.com/content/pdf/10.1007%2Fs10615-015-0546-1.pdf

<sup>&</sup>lt;sup>186</sup> Ibid. para 35, p. 13

<sup>&</sup>lt;sup>187</sup> Noy, S (2017). Banking on Health: The World Bank and Health Sector Reform in Latin America (Cham, Switzerland, Springer Nature. pp. 18–19

<sup>&</sup>lt;sup>188</sup> Abramovitz, M and Zelnick, J, (2015). "Privatisation in the human services: implications for direct practice", *Clinical Social Work Journal*, vol. 43, No. 3, p. 283. Available at:

<sup>&</sup>lt;sup>189</sup> Stiglitz, Joseph E., Foreword, in Gérard Roland, ed. (2008). Privatisation: Successes and Failures. Columbia University Press. New York. p. xii.

<sup>&</sup>lt;sup>190</sup> Homedes, N and Ugalde, A. (2005). *"Why neoliberal health reforms have failed in Latin America,"* Health Policy 71. pp. 83-96. Available at:

http://www.proexcel.fiocruz.br/inalteraveis/Sistemas%20de%20Saude/4.why%20politica%20neolib%20falhou%2 0na%20amer%20latin.pdf

<sup>&</sup>lt;sup>191</sup> Ibid.

<sup>&</sup>lt;sup>192</sup> Ibid

<sup>&</sup>lt;sup>193</sup> Rehman, S. (2012, June 22). Rapid privatisation has worsened health care services in poor and middle-income nations: study. *Down to Earth*. Available at: <u>https://www.downtoearth.org.in/news/rapid-privatisation-has-worsened-health-care-services-in-poor-and-middleincome-nations-study-38504</u>

<sup>&</sup>lt;sup>194</sup> Basu S, et al. (2012) Comparative performance of private and public healthcare systems in low- and middleincome countries: A Systematic Review. *PLoS Medicine.* 

healthcare sector reportedly, typically lacked published data by which to assess their performance, had greater risk of low-quality care, and served higher socio-economic groups; the public sector frequently lacked access to supplies and tended to be less patient-responsive. However, contrary to popular belief, the private sector appeared to be less effective than the public sector due to higher drug costs, an unfavourable incentive for pointless testing and treatment and higher risks of complications.<sup>195</sup> The study concluded that *"studies evaluated in this systematic review do not support the claim that the private sector is usually more efficient, accountable, or medically effective than the public sector."* 

 Similar findings emerged from a review of public-private partnerships in health and education in Africa, Asia and Latin America that pointed to high public costs, and onerous ongoing administrative burdens for the public sector.<sup>197</sup>

Evidence has also emerged from the UK<sup>198</sup> and Europe<sup>199</sup> that challenge the assumption that privatisation or PPP models in essential public services score better on costs and efficiency. In context of COVID-19, a report by Corporate Europe Observatory, a research and campaign group, states "from hospitals to care homes, the evidence is mounting that outsourcing and private provision of healthcare accompanied by health budget cuts has significantly degraded EU member states' capacity to deal effectively with Covid-19 and actually costs governments more than public healthcare. The EU must reverse course on the kind of economic governance which has accelerated healthcare liberalisation, instead putting public provision at the centre of its strategy. If it doesn't more lives will be at stake."<sup>200</sup>

A cross-country analysis by the United Nations Development Programme looking at the effect of healthcare privatisation on COVID-19 found that a "10% increase in private health expenditure relates to a 4.3% increase in COVID-19 cases and a 4.9% increase in COVID-19 related mortality".<sup>201</sup> In other words, greater privatisation of healthcare significantly raises the rates of COVID-19 prevalence and mortality across countries. The research concluded that policies which privatise healthcare systems in order to "boost efficiency" in the short term, "reduce countries' long-term preparedness for dealing with pandemics."<sup>202</sup>

Six UN Special Rapporteurs recently testified "*Covid-19 has exposed the catastrophic impact of privatising vital public goods and services.*"<sup>203</sup> They submit that the pandemic has revealed that "*there are goods and services that must be placed outside the laws of the market.*"<sup>204</sup> They go on to contend that "*human rights can help articulate the public goods and services we want – participatory, transparent, sustainable, accountable, non-discriminatory and serving the common good.*"<sup>205</sup>

<sup>&</sup>lt;sup>195</sup> Ibid.

<sup>&</sup>lt;sup>196</sup> Ibid.

<sup>&</sup>lt;sup>197</sup> Languille, S. (2017). Public Private partnerships in education and health in the global South: a literature review. *Journal of International and Comparative Social Policy*, *33*(2), 142–165. Available at: <u>https://doi.org/10.1080/21699763.2017.1307779</u>.

<sup>&</sup>lt;sup>198</sup> Comptroller and Auditor General. (2018). *PF1 AND PF2*. National Audit Office. Available at:

https://www.nao.org.uk/wp-content/uploads/2018/01/PFI-and-PF2.pdf

<sup>&</sup>lt;sup>199</sup> Id. at 166.

<sup>&</sup>lt;sup>200</sup> When the market becomes deadly. (2021, January 26). *Corporate Europe Observatory*. Available at: <u>https://corporateeurope.org/en/2021/01/when-market-becomes-deadly</u>

<sup>&</sup>lt;sup>201</sup> Assa, J., & Calderon, C. (2020). Privatization and Pandemic: A Cross-Country Analysis of COVID-19 Rates and Health-Care Financing Structures. *Research Papers in Economics*. Available at: <u>https://econpapers.repec.org/RePEc:new:wpaper:2008</u>.

<sup>&</sup>lt;sup>202</sup> Ibid.

<sup>&</sup>lt;sup>203</sup> Farha, L., Schutter, O. de, & Carmona, M. S. (2022, October 19). Covid-19 has exposed the catastrophic impact of privatising vital services. *The Guardian*. Available at: <u>https://www.theguardian.com/society/2020/oct/19/covid-19-exposed-catastrophic-impact-privatising-vital-services</u>.

<sup>&</sup>lt;sup>204</sup> Ibid.

<sup>&</sup>lt;sup>205</sup> Ibid.

As evidenced by the studies and reports discussed above, unbridled privatisation or PPPs undermine realisation of the right to health and other human rights, negatively impact equity and push people into poverty, while having little benefit with respect to cost or efficiency. Moreover, the lack of institutional capacity in developing countries results in failure to effectively regulate the private sector or public-private arrangements, and hold them accountable to human rights standards or violations. This constitutes a failure of the State to protect the right to health.

#### 3.2.2.3 Regulation of private health sector in India

Joseph Stiglitz has been critical of privatisation as advocated by the International Monetary Fund and World Bank, stating that "the IMF argues that it is far more important to privatise quickly; one can deal with the issues of competition and regulation later. But the danger here is that once a vested interest has been created, it has an incentive, and the money, to maintain its monopoly position, squelching regulation and competition, and distorting the political process along the way."<sup>206</sup> On the impact of privatisation, he says "whether the privatised monopolies were more efficient in production than government, they were often more efficient in exploiting their monopoly position; consumers suffered as a result."<sup>207</sup>

This is certainly true for India, which has extremely weak institutional and regulatory capacity to regulate the private sector. Private medicine has burgeoned and flourished in India because of a weak regulatory climate with no standards to monitor quality, ethics or costs.<sup>208</sup> As a result the private sector remains largely unregulated, unaccountable and non-transparent and resists any efforts at regulation. Problems range from inadequate and inappropriate treatment, excessive use of higher and more expensive technologies, and wasting of scarce resources to problems of medical malpractice and negligence.<sup>209</sup> The regulatory and accountability mechanisms in terms of policies and legislations in India are inadequate and unresponsive to ensure that healthcare services are affordable, acceptable and of quality; or to prevent malpractice, negligence and corrupt practices that are plaguing India's health system.<sup>210</sup> Indeed, the right to health is greatly diminished in such an environment.

A comprehensive Working Paper on analysing the regulation of the private sector discusses some disturbing trends that are increasing Out-of-Pocket-Expenditure (OOPE) in accessing the private sector and causing impoverishment.<sup>211</sup> An analysis of bills from four reputed private hospitals in the Delhi and National Capital Region region by the National Pharmaceutical Pricing Authority (NPPA) revealed that profit margins from the sale of drugs, consumables and diagnostics ranged from 100 percent to 1,737 percent and that these three components accounted for about 46 percent of a patient's bill.<sup>212</sup>

<sup>&</sup>lt;sup>206</sup> Stiglitz, J. (2002). *Globalization and Its Discontents*. Penguin.

<sup>&</sup>lt;sup>207</sup> Ibid.

<sup>&</sup>lt;sup>208</sup> Jain, A. et al. (2014). Corruption: medicine's dirty open secret. *BMJ*, *348*(jun 25 9), g4184–g4184. Available at: https://doi.org/10.1136/bmj.g4184.

<sup>&</sup>lt;sup>209</sup> Clinical Establishments (Registration and Regulation) Act, 2010, Preamble.

<sup>&</sup>lt;sup>210</sup> Nandraj, S. (2018, October 12). *Regulating Healthcare Establishments: The Case of the Clinical Establishment Act, 2010.* Available at:

https://www.academia.edu/37572301/Regulating Healthcare Establishments The Case of the Clinical Establishm ent Act 2010.

<sup>&</sup>lt;sup>211</sup> Shukla, A. et al. (2020). *Analysing Regulation of Private Healthcare in India*. Oxfam India. Available at: <u>https://dlns4ht6ytuzzo.cloudfront.net/oxfamdata/oxfamdatapublic/2021-</u>

<sup>&</sup>lt;u>03/Private%20Healthcare%20in%20India%20Working%20Paper%20%282%29.pdf?PE1gbRdFxZROyh7pXtecVgI4</u> <u>Y2ecBs8N</u>.

<sup>&</sup>lt;sup>212</sup> Nagarajan, R. (2018, February 21). Private hospitals making profits of up to 1,737% on drugs, consumables and diagnostics: Study. *The Times of India*. Available at: <u>https://timesofindia.indiatimes.com/india/private-hospitals-making-over-1700-profit-on-drugs-consumables-and-diagnostics-study/articleshow/62997879.cms</u>.

Women are affected disproportionately due to the lack of regulation of private healthcare, including lack of standard treatment protocols.<sup>213</sup> In 2019, there were reports<sup>214</sup> of large-scale unwarranted hysterectomies (surgical removal of the uterus) in women working as sugarcane cutters in Beed, Maharashtra. Further, research has shown that caesarean section births are nearly three times more in the private sector as compared to the public sector in India.<sup>215</sup> In 2015-16, 17 percent of all institutional deliveries were conducted through caesarean section, crossing the WHO threshold of 15 percent.<sup>216</sup>

The issues that arise out of poor regulation of the private healthcare sector, also plague PPP arrangements, such as PM-JAY. Studies report unscrupulous and corrupt practices by empanelled private providers, which include pushing patients towards more expensive procedures; Outpatient Department (OPD) cases deliberately and unnecessarily being made into inpatient care cases; double billing that involves submitting an insurance claim while also illegally charging a co-payment, or asking patients to purchase drugs, diagnostics and consumables from outside.<sup>217</sup>

As noted in the section on Quality above, the CEA is a central legislation providing for the registration and regulation of clinical establishments with the objective to prescribe minimum standards of facilities and services. The *Clinical Establishments (Central Government) Rules, 2012* issued under the CEA, added, inter alia, provisions pertaining to standard treatment guidelines, display of rates charged for each type of service, and the range of rates for each type of procedure and services to be determined by Central government in consultation with the state governments.

However, the CEA has been adopted by only 11 states. In these states the implementation has been rather poor,<sup>218</sup> primarily due to stiff resistance from the private healthcare sector and professional bodies.<sup>219</sup> There are also several limitations in the CEA – failing to lay down rights of patients, provide for a grievance redress mechanism or for clinical and social audits. These are missed opportunities to augment accountability of the private sector towards right to health compliance.

## **3.2.2.4** Judicial interventions regulate the private sector on social determinants of health; less so the private health services sector

Perhaps the strongest judicial interventions in the context of health and the private sector in India have come in the context of a key social determinant of health i.e., safe and healthy working conditions. Invoking the principles of social justice related to obligations of a welfare State, the Supreme Court in *Consumer Education and Research Centre v Union of India*,<sup>220</sup> concluded that *"the right to health, and medical aid to protect the health and vigour of a worker while in service or post-retirement is a fundamental right in keeping with the dignity of the person"*. It emphasised that social justice was the crux of the Constitution, which ensured life to be meaningful and liveable with human dignity, and a device to mitigate sufferings of the poor, weak, and marginalised and to enable their

<sup>&</sup>lt;sup>213</sup> Id. at 211

<sup>&</sup>lt;sup>214</sup> Chatterjee, P. (2019). Hysterectomies in Beed district raise questions for India. *The Lancet, 394*(10194), 202. Available at: <u>https://doi.org/10.1016/s0140-6736(19)31669-1</u>.

<sup>&</sup>lt;sup>215</sup> Singh, P. et al.(2018). "High prevalence of caesarean section births in private sector health facilities- analysis of district level household survey-4 (DLHS-4) of India." *BMC public health* vol. 18,1 613. Available at: <u>https://doi:10.1186/s12889-018-5533-3</u>.

<sup>&</sup>lt;sup>216</sup> Guilmoto CZ and Dumont A. (2019). Trends, Regional Variations, and Socioeconomic Disparities in Cesarean Births in India, 2010-2016. *JAMA Netw Open*..Available at: <u>https://doi:10.1001/jamanetworkopen.2019.0526</u>.

 <sup>&</sup>lt;sup>217</sup> Risky Insurance: The Pradhan Mantri Jan Arogya Yojana in Jharkhand. (2020, December 9). *Economic and Political Weekly*. Available at: <a href="https://www.epw.in/engage/article/risky-insurance-pradhan-mantri-jan-arogya-yojana">https://www.epw.in/engage/article/risky-insurance-pradhan-mantri-jan-arogya-yojana</a>; Vitsupakorn, S. et al. (2021). *Early experiences of Pradhan Mantri Jan Arogya Yojana (PM-JAY) in India: a narrative review*. Available at: <a href="https://centerforpolicyimpact.org/wp-content/uploads/sites/18/2021/02/PMJAY\_FINAL.pdf">https://centerforpolicyimpact.org/wp-content/uploads/sites/18/2021/02/PMJAY\_FINAL.pdf</a>.
 <sup>218</sup> Ministry of Health & Family Welfare, Government of India. (2016). *13th Common Review Mission*. Available at: <a href="https://nhsrcindia.org/sites/default/files/2021-04/13th">https://nhsrcindia.org/sites/default/files/2021-04/13th</a> common review mission-Report 2019 Revise.pdf.
 <sup>219</sup> Id. at 210.

<sup>220</sup> AIR 1995 SC 923

equality. Here, the court ordered the implementation of asbestos safety guidelines published by the International Labour Organization in all industries.

Similarly, In *Bandhua Mukti Morcha v Union of India*,<sup>221</sup> the Supreme Court held that Article 21 must be interpreted in light of the Directive Principles of State Policy and include protection of health and strength of workers. It held that in a welfare state, the State was obliged to create and sustain conditions favourable to promote good health.

During the COVID-19 pandemic the Supreme Court issued orders to hospitals, including private hospitals, to provide personal protective equipment to all healthcare workers *"actively attending to, and treating patients suffering from COVID-19."*<sup>222</sup>

Judicial interventions have also recognised the strong connections between the environment and public health, particularly the obligation of the government to regulate the private sector in this regard. In *MC Mehta v Union of India*, <sup>223</sup> the Supreme Court held that "*Articles 39(e), 47 and 48 A by themselves and collectively, cast a duty on the state to secure the health of the people, improve public health and protect and improve the environment.*" In *Municipal Council, Ratlam v Shri Vardhichand*,<sup>224</sup> it held that industries cannot make profit at the expense of public health, and directed the municipal council, state government and sub-divisional magistrate to take immediate action to stop the effluents from an alcohol plant flowing into the street. In *Rural Litigation and Entitlement Kendra v State of U.P*,<sup>225</sup> the court held that the right to employment of mining lessees cannot supersede the right of the people to live in a healthy environment with minimal disturbance of ecological balance, and without avoidable hazards to them and to their cattle, homes and agricultural land and undue affectation of air, water and environment.

In *MC Mehta v Union of India*,<sup>226</sup> the Supreme Court held that *"where regulatory authorities connive or act negligently by not taking prompt action to prevent, avoid or control damage to the environment, natural resources and peoples' life, health and property, the principles of accountability for restoration and compensation have to be applied."* 

However, in relation to the private sector that delivers health services, judicial interventions present a mixed bag. While these judicial decisions are discussed and analysed in greater detail in a forthcoming C-HELP publication, it is worth noting that in terms of the obligations of the private health services sector, the strongest judicial interventions have come in the context of access to emergency care. The Supreme Court has held that it is the professional obligation of every physician, whether government or private, to extend medical aid to the injured immediately, to preserve life without waiting for formalities to be complied with under the *Code of Criminal Procedure 1973* (CrPC).<sup>227</sup> It has also issued detailed directives to private hospitals to provide treatment to acid attack victims<sup>228</sup> and reinforced Section 357C of the CrPC, which requires all private hospitals to provide first aid or medical treatment free of cost to victims of sexual violence.<sup>229</sup>

In terms of accountability of the medical profession, the Supreme Court's decision in *Jacob Mathew v State of Punjab and Anr*<sup>230</sup>, laid down guidelines restricting the prosecution of medical professionals

<sup>&</sup>lt;sup>221</sup> [1984] 2 S.C.R. 67

<sup>&</sup>lt;sup>222</sup> In Jerryl Banait v Union of India, Supreme Court Order dated 8th April 2020.

<sup>223</sup> JT 2002(3) SC 527

<sup>&</sup>lt;sup>224</sup> AIR 1980 SC 1622

<sup>&</sup>lt;sup>225</sup> AIR 1985 SC 652

<sup>&</sup>lt;sup>226</sup> AIR 2004 SC 4016

<sup>&</sup>lt;sup>227</sup> Parmanand Katara v Union of India AIR 1989 SC 2039

<sup>&</sup>lt;sup>228</sup> Laxmi vs Union Of India & Ors on 10 April, 2015

<sup>&</sup>lt;sup>229</sup> In Re: Indian Woman says gang-raped on orders of Village Court published in Business & Financial News dated 23.01.2014, Suo Motu Writ Petition (Criminal) No. 24 of 2014

<sup>&</sup>lt;sup>230</sup> (2005) 6 SCC 1

for negligence, including requirements that a complainant produce a credible opinion given by another competent doctor and the investigating officer also obtain an independent and competent medical opinion. Arguably these requirements make it highly unlikely to pursue criminal cases related to medical negligence. Patients have turned to the consumer protection law which is applicable when payments have been made for medical services. There have been many cases where significant compensation has been awarded. For instance, in *B. Suvarama Phani v Miot Hospitals*,<sup>231</sup> the complainant's husband had TB, and died after appropriate tests were not conducted and his condition was misdiagnosed. The hospital report revealed that the wrong procedure was undertaken. The Tamil Nadu State Consumer Disputes Redressal Commission found the doctors negligent, and granted INR 35 lakhs as compensation, and INR 5 lakhs for mental agony. Yet, negligence is often hard to prove and cases such as these take years to reach a conclusion.

#### 3.2.2.5 The COVID-19 pandemic: Failure of the State to protect the right to health?

The effect of an unregulated and unaccountable private healthcare sector was laid bare during the COVID-19 pandemic. There was widespread reporting of private sector hospitals initially refusing services to COVID-19 patients and later grossly overcharging them. A compendium comprising 23 testimonies illustrates patients' traumatic experiences seeking treatment in private hospitals during the first wave of the pandemic in Maharashtra. These powerful testimonies highlight the rights violations as well as gross overcharging by private hospitals during the pandemic and highlights the serious consequences of failure to regulate the private sector during the crisis. It also initiates a discussion of possible ways to regulate and socialise the private healthcare sector in India.<sup>232</sup>

Responding to growing anguish over the high cost of COVID-19 treatment, most states capped charges. However, nearly 75 percent of COVID-19 patients who were treated at private hospitals in the state were overcharged despite a price cap set by the Maharashtra government.<sup>233</sup> As per a report despite the price cap, "over 80% of families would be financially crippled by just 1 member undergoing treatment. Even at capped costs, bills for even 10 days of treatment work out to several times their monthly expenditure. The lowest priced isolation bed in a non-accredited Delhi hospital would cost Rs 80,000 for 10 days. This is more than three times the monthly spending of 80% of the population. For a patient with severe Covid in ICU care with ventilator support, the bill could be several lakhs."<sup>234</sup> A more recent report revealed that COVID-19 had pushed millions of Indians into poverty.<sup>235</sup>

The Department-Related Parliamentary Standing Committee on Health and Family Welfare, Rajya Sabha, in its Report also agreed that "the cost of health service delivery increased due to absence of specific guidelines for Covid treatment in private hospitals as a result of which patients were charged exorbitant fees." <sup>236</sup> This report mentions that "India's Government Health Expenditure (GHE) as percent of the Current Health Expenditure (CHE) is only 27.1%. In India, Out of Pocket Expenditure in

<sup>231</sup> IV (2012) CPJ50(RE)

<sup>&</sup>lt;sup>232</sup> SATHI. (2022). Patients' voices during the Pandemic: Stories and analysis of rights violations and overcharging by private hospitals. Available at:

https://www.researchgate.net/publication/359451423 Patients voices during pandemic SATHI.

<sup>&</sup>lt;sup>233</sup> Shelar, J. (2021, September 29). 75% Covid patients overcharged by private hospitals in Maharashtra despite price cap: Survey. *Hindustan Times*. Available at: <u>https://www.hindustantimes.com/cities/mumbai-news/75-covid-patients-overcharged-by-private-hospitals-in-maharashtra-despite-price-cap-survey-101632923241696.html</u>.

 <sup>&</sup>lt;sup>234</sup> Covid treatment can cripple 80% families even at capped costs: Report. (2020, October 12). *The Times of India*.
 Available at: <a href="https://timesofindia.indiatimes.com/videos/in-depth/covid-treatment-can-cripple-80-families-even-at-capped-costs-report/videoshow/78613152.cms">https://timesofindia.indiatimes.com/videos/in-depth/covid-treatment-can-cripple-80-families-even-at-capped-costs-report/videoshow/78613152.cms</a>

<sup>&</sup>lt;sup>235</sup> The Economist. (2022, January 12). The covid-19 pandemic pushed millions of Indians into poverty. *The Economist*. Available at: <u>https://www.economist.com/graphic-detail/2022/01/12/the-covid-19-pandemic-pushed-millions-of-indians-into-poverty</u>.

<sup>&</sup>lt;sup>236</sup> Ministry of Health and Family Welfare & Ministry of AYUSH. (2020). *One Hundred Twenty Third Report on The Outbreak of Pandemic Covid-19 And Its Management*. Available at: <u>https://raiyasabha.nic.in/rsnew/Committee\_site/Committee\_File/ReportFile/14/142/123\_2020\_11\_15.pdf</u>.

*Health is 62.4% and India ranks 15 out of 186 countries in OOPE as % of CHE.*<sup>237</sup> The Committee opined that "*amidst the pandemic and the uncertainty in the treatment protocol, this OOPE may have further driven many families to below poverty line.*<sup>238</sup> It was of the view that arriving at a sustainable pricing model to treat COVID-19 patients could have averted many deaths.

As the pandemic raged on, in *In Re the Proper Treatment of Covid 19 Patients and Dignified Handling* of Dead Bodies in the Hospitals Etc.,<sup>239</sup> the Supreme Court averred that the right to health was a fundamental right guaranteed under Article 21 of the Constitution, which included affordable treatment. The court observed that, "it cannot be disputed that for whatever reasons the treatment has become costlier and costlier and it is not affordable to the common people at all. Even if one survives from Covid-19, many times financially and economically he is finished. Therefore, either more and more provisions are to be made by the State Government and the local administration or there shall be cap on the fees charged by the private hospitals, which can be in exercise of the powers under the Disaster Management Act, 2005."<sup>240</sup>

*In Re: Suo Moto v Union of India and others*<sup>241</sup> a suo motu writ petition was taken up by the Madhya Pradesh High Court on the basis of a letter regarding an incident where an elderly COVID-19 patient was chained to a bed in a private Bhopal hospital, allegedly because of the failure to pay fees for his treatment. The court directed the State Government to ensure strict compliance of all directions including about the treatment of poor patients under Ayushman Bharat Yojana reserving 20 percent beds for Ayushman Bharat Yojana beneficiaries and increase the empanelment of more private hospitals under the said scheme and that *"the State Government should ensure regular and continuous supply of Oxygen not only to the Government Hospitals but also to private hospitals, which are generally denying treatment to Covid-19 patients due to non-availability of Oxygen."<sup>242</sup>* 

As discussed above, there is lack of evidence justifying privatisation on the basis of cost and efficiency. In fact, evidence has emerged of the deleterious impact of privatisation on the right to health and on equity, and further underfunding and weakening of public health systems. In this context, the duty to protect should make the State revisit the move towards accelerated privatisation or excessive PPP arrangements due to its incompatibility with right to health obligations. At the very least, an evaluation of evidence and undertaking of a human rights impact assessment of privatisation in health in partnership with civil society and community groups is warranted. Meanwhile, there is an urgent need to develop the government's regulatory and institutional capacity for governance of private sector and PPP arrangements; set norms and principles to satisfy justifications for PPP arrangements laws to monitor the private sector; contracts with the private sector that include human rights indicators with penalties for violations; effective and systematic monitoring, including community-based monitoring of facilities in PPP mode; routine assessment of impact of PPP models on public health systems.

### 3.2.3 Duty to Fulfil: Ensuring a robust public health sector

The duty to fulfil in the context of the right to health requires States to adopt a whole range of *"appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realization of the right to health."*<sup>243</sup> This means taking immediate steps to meet core

<sup>&</sup>lt;sup>237</sup> Ibid.

<sup>&</sup>lt;sup>238</sup> Ibid.

<sup>&</sup>lt;sup>239</sup> In Suo Motu Writ Petition (Civil) No.7/2020

<sup>&</sup>lt;sup>240</sup> Ibid.

<sup>&</sup>lt;sup>241</sup> Writ Petition No. 8914/2020, Madhya Pradesh High Court, order dt. 19.04.2021

<sup>&</sup>lt;sup>242</sup> Ibid

<sup>&</sup>lt;sup>243</sup> Id. at 3.

obligations as well as concrete, targeted steps towards progressive realisation as discussed above.<sup>244</sup> Effective and integrated health systems, encompassing healthcare and the underlying determinants of health are also key to ensuring the right to the highest attainable standard of health.<sup>245</sup>

### 3.2.3.1 Duty to Fulfil the right to health and the Judiciary

Constitutional courts have consistently called upon the government to make good on its obligation to fulfil the right to health based on international human rights obligations read with the fundamental rights to health, life, equality and non-discrimination and the Directive Principle of State Policy in the Indian constitution that obligate the State to take steps to promote public health.

In Vincent Panikurlangara v Union of India,<sup>246</sup> the Supreme Court read Articles 21 and 47 together and observed, "...maintenance and improvement of public health have to rank high as these are indispensable to the very physical existence of the community and on the betterment of these depends the building of the society of which the Constitution makers envisaged. Attending to public health, in our opinion, therefore, is of high priority-perhaps the one of the top."

In Paschim Banga Khet Mazdoor Samity<sup>247</sup>, the Supreme Court noted that, "... it is the Constitutional obligation of the State to provide adequate medical services to the people. Whatever is necessary for this purpose has to be done."

With respect to rural and tribal health, in *Dr. Rajendra Sadanand Burma & Ors. v State of Maharashtra*,<sup>248</sup> the Bombay High Court directed the government to appoint gynaecologists and paediatricians in rural and tribal districts which experience shortfalls in such personnel and services; provide hot cooked meals to tribal women, children and improve access to food security; appoint at least one ASHA to provide home-based new born and child care in order to reduce infant mortality; provide adequate supply of antibiotics for treatment of newborns and children with pneumonia; and ensure better working conditions of ASHA and strengthen the programme.

In *Rinzing Chewang Kazi v State of Sikkim*,<sup>249</sup> a petition was filed claiming violation of Articles 14, 15 and 21 of the Constitution, for failure of the state to provide reproductive and child health services and elderly care in rural villages. The Sikkim High Court issued a slew of directions to the government, including to effectively implement National Rural Health Mission (NRHM) programmes like Janani Suraksha Yojana and Janani-Shishu Suraksha Karyakram; ensure availability of life-saving drugs; and regularly conduct Maternal Death Reviews and Community-Based Monitoring to be uploaded on the National Health Mission website.

in *Snehalata Singh v State of Uttar Pradesh*,<sup>250</sup> a petition was filed seeking directions to be issued to the government on the plea of unavailability of medicines, inadequately trained paramedical staff and medical officers, and non-implementation of NRHM programmes with respect to antenatal, delivery and postnatal care across all levels of healthcare institutions in the state. The Allahabad High Court directed the government to fill existing vacancies, ensure supply to essential medicines and constitute special committees with citizen's participation to monitor status of public health infrastructure on the

<sup>&</sup>lt;sup>244</sup> Id. at 3.

<sup>&</sup>lt;sup>245</sup> Hunt, P. and Backman, G. (2008). Health systems and the right to the highest attainable standard of health. *Health and Human Rights Journal.* Available at: <u>https://www.hhrjournal.org/2013/09/health-systems-and-the-right-to-the-highest-attainable-standard-of-health/</u>

<sup>&</sup>lt;sup>246</sup> (1987) 2 SCC 165

<sup>&</sup>lt;sup>247</sup> (1996) 4 SCC 37

 $<sup>^{\</sup>rm 248}$  PIL No. 133/2007, Bombay High Court, order dated 17.07.2015

<sup>&</sup>lt;sup>249</sup> 2016 SCC Online Sikk 38

<sup>&</sup>lt;sup>250</sup> Snehalata Singh v State of Uttar Pradesh, PIL No. 14588 of 2009, order dt. 09.03.2018. Allahabad High Court

basis of the obligation of the government to fulfil the right to health under Article 21 and right to nondiscrimination under Article 15.

## **3.2.3.2** Duty to Fulfil the right to health is predicated on a strong, responsive and accountable public health system

India's Constitution enjoins the State to secure a welfare state. Under specific provisions,<sup>251</sup> the State is duty bound to strive towards 'social justice' by securing the interests of weaker sections of society, protecting them from discrimination and inequalities. Article 47 of the Constitution obligates the State to, inter alia, *"improve public health."* The provision of health services and improvement of public health is primarily the responsibility of the State. This holds particularly true in societies where there are significant socio-economic disparities and inequalities. Indeed, 'health services' are a 'public good' fulfilling core human need, and not a 'commodity' to be left at the mercy of market forces.

In order to attain universal and equitable healthcare, a rising corpus of worldwide research supports the pertinence and centrality of publicly financed healthcare. An Oxfam study evaluates data from 44 middle- and low-income countries that shows a negative relationship between access to care and the extent of private sector involvement in basic healthcare..<sup>252</sup> The study also noted that *"no low- or middle-income country in Asia has achieved universal or near-universal access to health care without relying solely or predominantly on tax-funded public delivery."*<sup>253</sup> The WHO Commission Report of 2008 on the Social Determinants of Health similarly underscores the centrality of the public health sector for achieving universal health care.<sup>254</sup>

As per a recent report published by SATHI, "lack of access to quality care in public health facilities forces people to turn to the private health sector and the resultant out of pocket (OOP) expenditure on health has resulted in impoverishment for vast numbers of people." <sup>255</sup> It highlights the findings of a study quantifying the financial burden of households from 1986-2004, which revealed that the number of hospitalisation episodes in which an ailing population had to pay out of pocket, had risen dramatically from about 41 percent to 72 percent. This increased OOPE resulted in "people falling below state specific official poverty lines, and the percentage of households falling below the poverty line increased from 4.19% in 1993–1994 to 4.48% in 2011–2012. This translated to 55 million persons in 2011–2012."<sup>256</sup> India has one of the most highly privatised and commercialised healthcare sectors in the world, along with an underfunded public health system. This combination reinforces and perpetuates socio-economic inequities, and "often has ruinous consequences for majority of its people, especially women, marginalised and vulnerable sections of society."<sup>257</sup>

<sup>254</sup> Commission on the Social Determinants of Health. (2010). Closing the gap in a generation. In *Health Equity Through Action on the Social Determinants of Health*. World Health Organisation. Available at:

https://apps.who.int/iris/bitstream/handle/10665/43943/9789241563703\_eng.pdf?sequence=1. <sup>255</sup> Marathe, S. et al (2022). Patients' Voices During the Pandemic: Stories and analysis of rights violations and overcharging by private hospitals. Sathi. Available at: <u>https://sathicehat.org/wp-</u>

<sup>&</sup>lt;sup>251</sup> Art 38 (1). The State shall strive to promote the welfare of people by securing and protecting as effectively as it may, a social order in which justice, social, economic and political, shall inform all institutions of national life. Art 38(2). The State shall, in particular, strive to minimise the inequalities in income ...eliminate inequalities in status, facilities and opportunities. Art. 39 (1) The State shall...direct its policy towards securing ... (b) that the ownership and control of the material resources of the community are so distributed as best to subserve the common good.
<sup>252</sup> Blind Optimism: Challenging the myths about private health care in poor countries. (2020, October 29). Oxfam Policy & Practice. Available at: <a href="https://policy-practice.oxfam.org/resources/blind-optimism-challenging-the-myths-about-private-health-care-in-poor-countrie-114093/">https://policy-practice.oxfam.org/resources/blind-optimism-challenging-the-myths-about-private-health-care-in-poor-countrie-114093/</a>.

<sup>&</sup>lt;sup>253</sup> Ibid. p. 2

content/uploads/2022/04/Compendium-Patients-voices-during-the-pandemic email.pdf

 <sup>&</sup>lt;sup>256</sup> Ibid.; Selvaraj, S. (2018). Quantifying the financial burden of households' out-of-pocket payments on medicines in India: a repeated cross-sectional analysis of National Sample Survey data, 1994–2014. *BMJ Open. 2018; 8(5): e018020.* doi: <u>10.1136/bmjopen-2017-018020</u>

On the other hand, empirical evidence on the impact of tax-funded public healthcare provisioning reveals that high public provisioning of healthcare facilities significantly contributes to reducing the share of health payments in households' total consumption expenditure, share of health payments in households' non-food expenditure and in reducing the catastrophic burden of health payments (measured if OOPE exceeded 10 percent of the households' consumption expenditure). These factors play a huge role in protecting people from falling below the poverty line because of health payments.<sup>258</sup>

The presence of a strong and reliable public health system serves to put a check on the unregulated growth of the private sector and helps in preventing unethical practices in the private sector. The availability of high-quality public hospitals is associated with lower OOPE by patients who seek care at private hospitals, suggesting that high-quality public hospitals are able to put competitive pressure on private hospitals to maintain care standards while reducing prices. For example, a one-standard-deviation increase in the perceived quality of public hospitals in certain states is associated with a decrease of 21 percent in the OOPE of private hospitalisation.<sup>259</sup> In the absence of a properly functioning public health system, efforts at regulation of the private sector in terms of costs and quality are not likely to succeed, as there would be no alternative available to the people.

Jean Drèze and Amartya Sen point out that there are different implications to introducing private health services in a health system with pre-existing strong foundations of universal healthcare provided by the State, as compared with relying on private healthcare where the state provides very few health facilities. In the event of the former, such as in Kerala, private healthcare can provide additional options without harming the public health system. In the latter case, such as in northern states, *"poor people are reliant on poor quality and expensive private care because of the low allocation of funds to and the resulting inadequacies of public healthcare."*<sup>260</sup>

Further, where healthcare is provided by the public sector, it enables citizens to hold the government accountable. Though there are inadequacies and shortfalls in the public health system, owing partly to consistent underfunding, it is important to reiterate that the success stories of health systems are in fact the successes of public health systems around the world, including Cuba, Thailand, Costa Rica, Sri Lanka, Brazil, apart from developed countries.<sup>261</sup> It is worth pointing out that despite the huge expansion of the private sector and inadequacies of the public health system in India, an estimated 40-50 percent still rely on the public sector for in-patient care.<sup>262</sup>

Hence, the pursuit of constructing a universal, effective, efficient and accountable public health system which fulfils the requirements of the AAAQ framework is the pressing need. Care provided in the public healthcare facility must be seen as a social protection measure, where payment has been collected as part of general taxation and free service is provided by the facility. In one assessment the endeavour should be that over 80 percent of all in-patient and out-patient care needs are part of assured services available within a publicly provisioned district health system, with a focus on comprehensive primary healthcare including preventive, promotive, curative, palliative and rehabilitative health; convergent action on social determinants of health; and robust community engagement and monitoring for building accountability and trust.<sup>263</sup>

<sup>262</sup> Ibid.

<sup>&</sup>lt;sup>258</sup> Kumar, S. (2016). *Health in the Era of Neoliberalism: Journey from State Provisioning to Financialization*. Available at: <u>https://isid.org.in/wp-content/uploads/2022/09/WP196.pdf</u>.

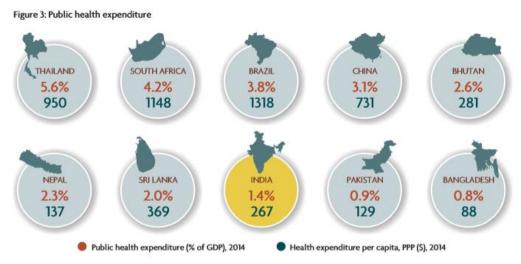
<sup>&</sup>lt;sup>259</sup> Almeida, R., et al. (2017). The Role of Government in the Indian Hospital System. Available at: <u>https://spia.princeton.edu/sites/default/files/content/docs/India%20Workshop%20Report 2017.05.10%20FINAL.pdf</u>.

 <sup>&</sup>lt;sup>260</sup> Drèze, J., & Sen, A. (2013). *An Uncertain Glory: India and Its Contradictions*. Amsterdam University Press.
 <sup>261</sup> Jan Swasthiya Abhiyan. (2012). *Universalising Health Care for All*. Available at: <u>http://phmindia.org/wp-content/uploads/2015/09/universalising-health-care-for-all.pdf</u>.

<sup>&</sup>lt;sup>263</sup> Ibid.

### 3.2.3.3 Budgetary allocations and the Duty to Fulfil

Progressive realisation of the right to health is predicated on adequate, effective and equitable budget allocation. A Lancet Review of UHC in 111 countries concludes that strong UHC performance is correlated with the share of a country's health budget.<sup>264</sup> However, public spending on health in India is among the lowest in the world – approximately 4.5 percent of GDP, which is less than half the global average of 10 percent.<sup>265</sup> In the year 2020-2021, the government allocated only 1.28 percent of its GDP towards health, significantly lower than the global average of 6 percent.<sup>266</sup> The 'Commitment to Reducing Inequality Index 2020' by Oxfam points out that India spent less than 4 percent of its budget on health and ranked 155<sup>th</sup> on the health spending index, its budget being the fourth lowest in the world.<sup>267</sup> Fellow BRICS governments in South Africa, Brazil and China spent at least double, and Thailand spent triple the amount.<sup>268</sup> (See figure below).



Source: Financing Universal Health Coverage in India, Global Health Strategies, 2017

A WHO Report on Health System Review, 2022 states "despite numerous policy pronouncements prioritizing health, the governments in India at the Centre and state levels have historically underfunded the public health sector, resulting in poor health outcomes and rising inequity in access to health care." It adds "India's overall health spending (public and private) is currently estimated to be 3.8% of its GDP, lower than the LMIC average of health spending share of GDP of around 5.2%."<sup>269</sup>

<sup>&</sup>lt;sup>264</sup> Wagstaff, A, and Neelsen, S, Lancet Glob Health 2020; A comprehensive assessment of universal health coverage in 111 countries: a retrospective observational study. Available at: <u>https://doi.org/10.1016/S2214-109X(19)30463-2</u>.

<sup>&</sup>lt;sup>265</sup> World Health Organization Global Health Expenditure database, Health expenditure, total (% of GDP) . Available at: <u>https://apps.who.int/nha/database/country\_profile/Index/en</u>

<sup>&</sup>lt;sup>266</sup> Ibid.; Ghosh, P. (2023, March 21). *Opportunities of Health Financing in India: With a focus on achieving the SDG 3 targets*. Available at: <u>https://www.linkedin.com/pulse/challenges-opportunities-health-financing-india-focus-pujan-ghosh/</u>

<sup>&</sup>lt;sup>267</sup> Banerjee, C. (2020, October 11). India's health budget fourth lowest in world: Oxfam. *The Times of India*. Available at: <u>https://timesofindia.indiatimes.com/india/indias-health-budget-fourth-lowest-in-world-oxfam/articleshow/78597933.cms</u>.

<sup>&</sup>lt;sup>268</sup> Global Health Strategies, International Vaccine Access Center, Johns Hopkins Bloomberg School of Public Health, & IKP Trust. (2015). *Financing Universal Health Coverage in India*. Available at: <u>http://globalhealthstrategies.com/wp-content/uploads/2017/11/Financing-UHC-in-India-GHS-Nov-2017.pdf</u>.

<sup>&</sup>lt;sup>269</sup> WHO (2022). India Health System Review. Asia Pacific Observatory on Health Systems and Policy. Available at: <u>https://apo.who.int/publications/i/item/india-health-system-review;</u> Deol, T. (2022, September 22). India's persistently high out-of-pocket health expenditure continues to push people into poverty. *Down to Earth.* Available at: https://www.downtoearth.org.in/news/health/india-s-persistently-high-out-of-pocket-health-expenditurecontinues-to-push-people-into-poverty-85070.

While the proportion of OOPE as percentage of total health expenditure has declined from 64.2 percent (in 2004-05) to 48.2 percent (in 2018-2019);<sup>270</sup> it still remains much higher than the global average of 18 percent as of 2019.<sup>271</sup> OOPE on health services (mostly for outpatient care and medicines) has important implications for poverty levels in India. The WHO report noted "existing literature for India shows that OOP payments not only impoverish a large number of households, but also deepen poverty among already poor households."<sup>272</sup> The report further notes that "high OOPE on health is impoverishing some 55 million Indians annually, with over 17 per cent households incurring catastrophic levels of health expenditures every year."<sup>273</sup>

According to another analysis, *"insufficient allocation for the health sector pushes 7% of Indians below the poverty line and about 23% of the sick cannot afford healthcare."*<sup>274</sup> The National Sample Survey Office (NSSO) revealed that outstanding loans for health reasons doubled between 2002 and 2012.<sup>275</sup> A matter that requires greater attention from policy makers and public health professionals is also the high rates of suicide ascribed to *"illness"* in the National Crime Records Bureau; nearly 18 percent of suicides were put down to *"illness"* in 2020.<sup>276</sup>

Pointing to the huge variation in utilisation of public health services and OOPE across states in India, a 2019 study concludes that "the poor people in the poorer states in India pay significantly more to avail hospitalization in public health centers than those in the developed states."<sup>277</sup> It adds "states with high levels of poverty make higher use of the public health centers and yet incur high OOPE."<sup>278</sup> The study finds that "among the poor using public health centers, the share of direct cost account 24% in Tamil Nadu compared to over 80% in Bihar, Odisha and other poorer states."<sup>279</sup> The authors contended that "low public health investment, poor public health infrastructures, non-availability of medicines and diagnosis tests and user fees are the main reasons for the high inter-state variations of OOPE in India."<sup>280</sup>

Several reports have established the need to increase public spending on health for India to provide universal health care/coverage to its citizens, which currently hovers around 2 percent of the GDP.<sup>281</sup> For example, the HLEG on UHC recommended that public health expenditure be increased to 3 percent of GDP by 2022.<sup>282</sup> Similarly, a study conducted by Ernst & Young had estimated that government expenditure on health should have accounted for 3.75 percent - 4.5 percent of GDP by 2022.<sup>283</sup> The National Health Policy 2017, commits to increasing public health expenditure to 2.5

<sup>&</sup>lt;sup>270</sup> Press Information Bureau. National Health Estimates (2018-19). Available at:

https://pib.gov.in/PressReleasePage.aspx?PRID=1858770.

<sup>&</sup>lt;sup>271</sup> WHO. Regional Office for South-East Asia. (2017, December 12). *Health financing profile 2017: India*. Available at: <u>https://apps.who.int/iris/handle/10665/259642</u>.

<sup>&</sup>lt;sup>272</sup> Id. at 269, p. 105

<sup>&</sup>lt;sup>273</sup> Id. at 269, pp. 1 and 79

<sup>&</sup>lt;sup>274</sup> Down to Earth. (n.d.). India's Health Crisis: Insufficient allocation for the health sector pushing 7% of Indians below the poverty line and about 23% of the sick cannot afford healthcare. Available at: <u>https://www.downtoearth.org.in/dte-infographics/india\_s\_health\_crisis/index.html;</u>

<sup>&</sup>lt;sup>275</sup> Ibid.

<sup>&</sup>lt;sup>276</sup> National Crime Records Bureau, Ministry of Home Affairs. (2022). *Accidental Deaths & Suicides in India 2020*. Available at: <u>https://ncrb.gov.in/sites/default/files/adsi2020 Chapter-2-Suicides.pdf</u>

<sup>&</sup>lt;sup>277</sup> Dash A. and Mohanty. SK. (2019). Do poor people in the poorer states pay more for healthcare in India?. *BMC Public health Open Access* 

<sup>&</sup>lt;sup>278</sup> Ibid.

<sup>&</sup>lt;sup>279</sup> Ibid.

<sup>&</sup>lt;sup>280</sup> Ibid.

<sup>&</sup>lt;sup>281</sup> Live mint. Health expenditure at 2.1% of GDP in FY23: Economic Survey. Jan 21, 2023. Available at: https://www.livemint.com/news/india/health-expenditure-at-2-1-of-gdp-in-fy23-economic-survey-11675160463795.html

 <sup>&</sup>lt;sup>282</sup> Planning Commission of India. (2011). *High level Expert Group Report on Universal Health Coverage in India*. Available at: <a href="https://nhm.gov.in/images/pdf/publication/Planning\_Commission/rep\_uhc0812.pdf">https://nhm.gov.in/images/pdf/publication/Planning\_Commission/rep\_uhc0812.pdf</a>.
 <sup>283</sup> Global Health Strategies. (2016). Financing Universal Health Coverage in India. Available at: <a href="http://globalhealthstrategies.com/wp-content/uploads/2017/11/Financing-UHC-in-India-GHS-Nov-2017.pdf">http://globalhealthstrategies.com/wp-content/uploads/2017/11/Financing-UHC-in-India-GHS-Nov-2017.pdf</a>

percent of GDP by 2025. However, current spending levels fall far short of these targets and put India behind several other developing countries in terms of health investments.

This consistent underfunding has been one of the reasons for a weakened public health system and an expanded private health sector, the disastrous consequences of which were laid bare during the COVID-19 pandemic. The Economic Survey 2020-21 stated that the pandemic underscored the importance of the healthcare sector and its linkages with other sectors.<sup>284</sup> The survey demonstrated how a health crisis transformed into an economic and social crisis and noted that the National Health Mission (NHM) played a critical role in mitigating inequality, a salutary reminder that health bureaucracies play a vital role in not only addressing narrow definitions of healthcare, but also structural aspects that contribute to poor health outcomes. It further advocated for an increase in public healthcare spending from 1 to 2.5-3 percent of the GDP as it can decrease the OOPE from 65 percent to 35 percent of overall healthcare spending.

The devastating experience of COVID-19 has made the need to increase budgetary allocation for strengthening the public health system incontrovertibly clear. In this backdrop the continued poor allocation of resources to public health in the budgets that followed (FYs 2021-22 and 2022-23) has been inexplicable and heavily criticised for wilful neglect of public health, despite clear lessons to the contrary presented by the pandemic.<sup>285</sup>

Expressing serious disappointment over the 2022 budget, Sujatha K Rao, former Secretary of Health and Family Welfare, wrote that "*Rs. 70,000 crore have been spent by the people out-of-pocket for medical treatment that the government ought to have provided. Spending at a time when earnings were down, pushed millions below the poverty line and hunger has emerged as a major issue placing India low on the malnutrition and hunger index rankings.*" She further noted, "*Covid resulted in an over 30 per cent shortfall of coverage under all these programmes giving rise to fears of drug-resistant HIV and tuberculosis and left lakhs of children unprotected from vaccine-preventable diseases. These programmes required a much bigger boost alongside strategies to ensure they are insulated from another viral outbreak.*" Rao also criticised the budget for not being equitable, prioritising digitisation over building a resilient public health system, strengthening primary healthcare, improving infrastructure such as laboratories and human resources, public health surveillance systems and epidemic preparedness and resilience.<sup>286</sup>

The observations in the report of the Department-Related Parliamentary Standing Committee of Health and Family Welfare, Rajya Sabha on the outbreak and management of the pandemic are telling:

"The Committee reiterates its considered view that the healthcare spending in India is abysmally low for an emerging economy with a population of 1.3 billion. Lack of desired level of investment in the health infrastructure has so far resulted into fragility of the Indian health ecosystem which posed a big hurdle in generating an effective response against the pandemic. The Committee has time and again recommended the Ministry for increasing its spending in the health sector for ensuring better health infrastructure and health services to the needy common masses. The Committee expresses its serious displeasure over the Government's reluctance to act upon the Committee's recommendations in letter and spirit. The Committee is assured that the serious impact of the pandemic could have been minimized

<sup>&</sup>lt;sup>284</sup> Ministry of Finance. (2021, January 29). *Key Highlights of Economic Survey 2020-21* [Press release]. Available at: <u>https://www.pib.gov.in/PressReleasePage.aspx?PRID=1693231</u>

<sup>&</sup>lt;sup>285</sup> Connection, G. (2022, February 2). Health Budget 2022 "falls flat", share of health in total budget drops to 2.26%: Jan Swasthya Abhiyan. *Gaonconnection | Your Connection With Rural India*. Available at:

https://en.gaonconnection.com/health-budget-2022-jan-swasthya-abhiyan-nirmala-sitharaman-covid-vaccination-mental-health-ayushman-bharat-digital-mission/.

<sup>&</sup>lt;sup>286</sup> Rao, S. K. (2022, February 2). Budget's missed healthcare opportunity. *The Indian Express*. Available at: <u>https://indianexpress.com/article/opinion/columns/the-missing-focus-on-health-union-budget-7752130/</u>.

had the Government over the years increased its investment in the healthcare system. The Committee is pained to note the trauma and distress the public had to undergo due to absence of a dedicated healthcare system. The Committee, therefore, strongly recommends the Government to increase its investments in the public healthcare system and make consistent efforts to achieve the National Health Policy targets of expenditure upto 2.5% of GDP within two years as the set timeframe of year 2025 is far away and the public health cannot be jeopardized till that time schedule."<sup>287</sup>

"The Committee is of the view that pandemic Covid-19 offers a window to revisit the country's health policy with the purpose of strengthening the health sector, and thus necessitates a higher investment in creating permanent basic health infrastructure. The Committee also believes that a higher budgetary allocation will also boost the healthcare industry and shift the focus to Indian manufacturers and domestic supply chain of products. The Committee believes that it is the opportune time to boost India's healthcare infrastructure and push for greater technology deepening in the healthcare sector."<sup>288</sup>

The consistent underfunding of public health in India has been a matter of concern since before the COVID-19 pandemic. WHO research from 2019 shows that countries must increase spending on primary healthcare by at least 1 percent of their GDP if the world is to close glaring coverage gaps and meet the health targets agreed under the SDGs.<sup>289</sup> The pandemic has made the need to increase budgetary allocation and direct it to strengthen public health systems, undeniable and urgent.

### 4. CASE STUDY: RIGHTS AS CRITICAL TO THE SUCCESS OF HEALTH INTERVENTIONS

The previous section traversed the many ways which various facets of the right to health are inextricably linked with the health system in India, featuring in legislation, judicial decisions, policy and practice, their centrality also manifest in instances where there has been a failure to deliver on the right to health, exemplified by the COVID-19 pandemic. Many of these illustrations have a strong link with UHC, involving as they do a panoply of issues from medicine supply to health institution governance, and human resources for health to disease-specific concerns.

It would be useful to further substantiate the practical ways in which the right to health plays out in programmatic efforts, and the role law and policy has played in aiding their elevation as part of what comprises the right to health. The HIV response is apposite in this context.

A virus that morphed into an epidemic in the early 1980s, and took hold in the global south by the early 1990s, HIV was first seen as afflicting and most visibly present in sexually active gay men in North American and European cities. It is crucial to recall this, since this prevalence led to a particular government and public health policy response – of phobia and apathy. People at the margins, who became sick because of their marginal contexts, continued to be ignored. It took an exceptional activism by many for their concerns to be heard – a bottom-up pressure, at the heart of which was a clamour for justice and the building of community alliances. This had a salutary effect on how HIV would be engaged with in other democratic contexts – in a manner that demanded transparency, understood marginalisation, involved communities affected, and recognised the linkage between a human rights and public health challenge, social determinants of health and the need for holistic solutions.

<sup>&</sup>lt;sup>287</sup> Id. at 236, p. 100, paras. 8.10-8:11.

<sup>&</sup>lt;sup>288</sup> Id. at 236, p. 100, para. 8.12

<sup>&</sup>lt;sup>289</sup> WHO, Data Analytics & Delivery (2019, September 9). *Primary health care on the road to universal health coverage:* 2019 monitoring report. Available at: <u>https://www.who.int/publications/i/item/9789240029040</u>

Yet, this took some time. On the realisation that HIV and AIDS were as destructive within heterosexual contexts as they were in homosexual ones, greater attention began to be paid by public health and policy experts. That attention gave emphasis to means that were coercive and punitive in controlling HIV spread – forced testing, breaching confidentiality of health status, often isolation of the HIV-positive person, and unchecked discrimination in access to institutions and services. In India, this manifested first in Goa's amended *Public Health Act* in 1987.<sup>290</sup>

But over time, understandings of how to tackle HIV changed, including the knowledge that isolationist approaches needed to be jettisoned as they were not serving public health goals. Indeed, by then it was clear that HIV was spreading in groups of people who were the most socially and economically unempowered.<sup>291</sup> In India, this vulnerability manifested most starkly in communities of sex workers, people who use drugs, men who had sex with men and transgender women. HIV was anchoring itself in contexts of violence, gender inequality, criminalisation, human rights violations, discrimination and oppression. It was these contexts that were making people vulnerable, as much if not more than any particular behaviours. Empowerment and rights recognition were a critical way to lessen this defencelessness.<sup>292</sup> Imposing punishment through law and policy that condemned would not serve public health priorities of coaxing people towards health-seeking behaviour. Instead, it would push them away and heighten the stigma that these communities already lived with. At the heart of this empowerment were aspects of availability, accessibility, acceptability, quality, the necessity of respecting, protecting and fulfilling their rights, and addressing social determinants of health such as gender, inequality and criminalisation.

Much of this understanding of the centrality of rights and empowerment came from an extraordinary public health intervention in the brothels of Kolkata. The context of sex work was an early concern in relation to HIV among public health experts in India, the Sonagachi brothel of Kolkata proving to be an outstanding example of how despite criminalization, when access and availability of health education, information, commodities and services was extended to sex worker communities, a critical impact was made in curbing the spread of HIV. While sex work is effectively criminalized under overarching anti-trafficking legislation, rights-based efforts to empower sex workers were implemented through a health intervention project related to sexually transmitted infections (STI), HIV and AIDS in the brothel in 1992. This included provision of STI treatment, information and education on sexual health and HIV, and condom promotion through a strategic participatory, peeroriented & rights-based approach. Very positive results were witnessed over time through the efforts of the sex worker collective, Durbar Mahila Samanway Committee (DMSC)<sup>293</sup> and its associated Usha Cooperative.<sup>294</sup> Condom use showed sharp increases, along with significant reductions in STIs and HIV.<sup>295</sup> Self-regulatory boards (SRB) that were set up reduced minors in sex work from 25 percent to 2 percent, while the median age of women in sex work increased from 22 to 28 years.<sup>296</sup> The SRBs constituted by and of sex workers set up a system of screening women and girls, and assistance was provided to unwilling women and girls with counselling and reintegration to non-hostile family contexts or government or private homes. Other women who were screened and chose to continue in sex work were supported with various measures to reduce their vulnerability to health and socioeconomic challenges, including counselling and healthcare services, and savings schemes.<sup>297</sup>

<sup>297</sup> Ibid. See also, Rao, K. Sujatha. (2017). Do We Care? India's Health System, OUP.

<sup>&</sup>lt;sup>290</sup> Goa Public Health (Amendment) Act, 1987

<sup>&</sup>lt;sup>291</sup> Marks, Stephen. (2001). Jonathan Mann's Legacy to the 21st Century: The Human Rights Imperative for Public Health. Journal of Law, Medicine & Ethics. No. 29. pp 131-138

<sup>&</sup>lt;sup>292</sup> Fee, E., Parry, M. Jonathan Mann, HIV/AIDS, and Human Rights. *J Public Health Pol* 29, 54–71 (2008). https://doi.org/10.1057/palgrave.jphp.3200160

<sup>&</sup>lt;sup>293</sup> Durbar Mahila Samanway Committee. (n.d.). History. Available at: <u>https://durbar.org/history-2/</u>

<sup>&</sup>lt;sup>294</sup> Durbar Mahila Samanway Committee. (n.d.). Cooperative. Available at: <u>https://durbar.org/cooperative/</u>

<sup>&</sup>lt;sup>295</sup> UNAIDS. (2005). AIDS Epidemic Update December 2005. Available at: <u>http://data.unaids.org/Publications/IRC-pub06/epi update2005 en.pdf</u>

<sup>&</sup>lt;sup>296</sup> Jana S, et al, Combating human trafficking in the sex trade: can sex workers do it better? *J Public Health* (2014) 36
(4): 622-628. <u>http://jpubhealth.oxfordjournals.org/content/36/4/622.long</u>

The realisation of the centrality of rights began to be reflected in Indian policy through the National AIDS Control Programme (NACP) launched in 1992 at the central level and over time increasingly decentralized, establishing state level bureaucracies and concertedly involving communities affected including people living with HIV and NGOs in determining priorities and informing implementation.<sup>298</sup> The rights-based approach became apparent in a National AIDS Prevention and Control Policy in 2002<sup>299</sup> that centred principles of testing linked with informed consent and counselling, confidentiality of health status, non-discrimination, the involvement of people living with HIV and other affected communities, and eventually the launch of a national programme ensuring access to antiretroviral treatment (ART).<sup>300</sup>

It is important to highlight the dimension of **acceptability** reflected in standards of informed consent and confidentiality of health status that were central to rights-based approaches to HIV, recognising the importance of autonomy, bodily integrity and privacy, which flow from rights guarantees of life and personal liberty. While mandatory HIV testing featured prominently in early responses to the epidemic, the importance of voluntary and confidential testing began to be understood as vital in contributing to reducing stigma and discrimination related to HIV, while encouraging people to access the health system.<sup>301</sup> Indeed, informed consent was robustly supported by pre- and post-test counselling services, which were crucial in imparting vital health, safety and behaviour change information that contributed to controlling HIV spread. Much of this was done in a legal vacuum, but reinforced by policy – the aforementioned National AIDS Prevention and Control Policy 2002.

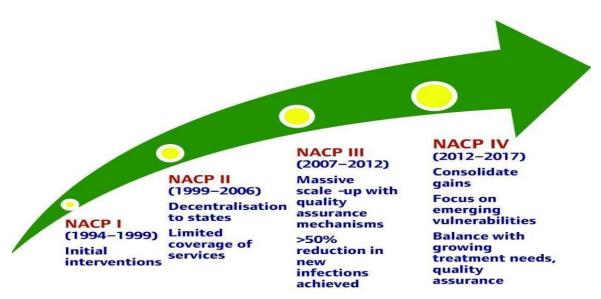
The NACP is also a prime example of **progressive realisation**. Over the last three decades, "it has evolved and expanded to provide HIV prevention, testing and treatment services countrywide. Scaling up has been uniform across all strategic components and has not only halted, but also reversed, the spread of the epidemic and ensured a major reduction in the number of AIDS-related annual deaths."<sup>302</sup> Four phases of the NACP have been implemented, each with a duration of 5 years. The focus in each phase has been on improving coverage of comprehensive HIV prevention, care and treatment services nationwide (See Figure 1). The fifth phase (2017-2024) aims to eliminate HIV/AIDS from India by 2035.<sup>303</sup>

 <sup>&</sup>lt;sup>298</sup> National AIDS Control Organisation, National AIDS Control Programme. Available at: <a href="http://naco.gov.in/nacp">http://naco.gov.in/nacp</a>
 <sup>299</sup> National AIDS Control Programme, National AIDS Prevention and Control Policy. Available at: <a href="http://www.naco.gov.in/sites/default/files/NationalAIDSContyrol%26PreventionPolicy2002.pdf">http://naco.gov.in/nacp</a>
 <sup>300</sup> Ibid.

<sup>&</sup>lt;sup>301</sup> WHO and UNAIDS, "Statement on HIV testing and counselling: WHO, UNAIDS re-affirm opposition to mandatory HIV testing," 28 November 2012.

<sup>&</sup>lt;sup>302</sup> Tanwar, S., at al. (2016). India's HIV programme: successes and challenges. *Journal of Virus Eradication*, *2*, 15–19. Available at: <u>https://doi.org/10.1016/s2055-6640(20)31094-3</u>.

<sup>&</sup>lt;sup>303</sup> National AIDS Control Organisation. National Strategic Plan for HIV/AIDS and STI (2017-2024): "Paving Way for an AIDS Free India". Available at: <u>http://naco.gov.in/national-strategic-plan-hivaids-and-sti-2017-24</u>



*Figure 3 Source: Tanwar S, Rewari BB, Rao CD, Seguy N. India's HIV programme: successes and challenges. J Virus Erad. 2016 Nov 28;2(Suppl 4):15-19. PMID: 28275445; PMCID: PMC5337408.* 

The judiciary, civil society and community groups have played a leading role in ensuring timely scale up of the anti-retroviral (ARV) rollout programme in the country. A PIL was filed before the Supreme Court, *Sankalp Rehabilitation Trust & Anr. v UOI<sup>304</sup>* praying for a right to health-based HIV programme and for universal access to HIV counselling, diagnostics and treatment. For over a decade the Supreme Court assumed oversight of the rollout programme and issued a slew of orders pertaining to rapid and time bound scale up in counselling, testing and first-line and later second-line ARVs; nondiscrimination against persons living with HIV in access to healthcare services and facilities; adherence to protocols of informed consent, confidentiality and privacy; adherence to standard treatment guidelines by the private sector for rational treatment; availability of local grievance redress systems; PPE for healthcare workers, and training and sensitization of general healthcare personnel with protocols.<sup>305</sup>

The orders of the Supreme Court and the resultant implementation of the programme showed that some obligations are immediately applicable, such as:

- Ensuring non-discrimination in access to services;
- Discontinuing drugs (Stavudine) established to be harmful to patients;
- Providing universal precautions and post-exposure prophylaxis (PEP) to healthcare workers;
- Although the objective of ensuring universal access to second-line ART was considered to be
  progressive, it required, as an immediate obligation, the drawing up a plan of action, with time
  bound targets and benchmarks, indicators, monitoring and submission of status reports, with
  robust engagement of civil society and community groups;<sup>306</sup>
- Need to support the programme with adequate budgetary allocations;
- Involvement of civil society and community groups in planning, implementation and monitoring Instituting of grievance redress mechanisms.

A key phenomenon that has been pervasive in relation to HIV also speaks to the structural determinants that influence health outcomes. As mentioned above, HIV is often found to reside in parts of society that are the most marginalized or have been traditionally shunned – people who use drugs, sex workers, transgender women, and men who have sex with men. India's epidemic continues

<sup>&</sup>lt;sup>304</sup> Writ Petition (Civil) No. 512/1999

<sup>&</sup>lt;sup>305</sup> Sankalp Rehabilitation Trust v Union of India, WP (C) No. 512/1999, Orders dt. 01.10.2008, 16.12.2010, 11.12.2012 and 02.12.2013

<sup>&</sup>lt;sup>306</sup> Sankalp Rehabilitation Trust v Union of India, WP (C) No. 512/1999, Order dt. 16.12.2010

to fester in these communities. Much of their marginalization has been cemented in the social fabric over several generations, creating virulent stigma. Combined with behaviours this stigma has fuelled the epidemic. But another crucial aspect that has done so is law: these communities have been oppressed by criminalization (only recently same-sex sex having been decriminalised) through laws. Such laws have played their part in discouraging people from accessing the health system, receiving vital health information, and legitimised stigma and discrimination. Indeed, in this manner the law itself has been and is a determinant of health. As has been noted, *"law exerts a powerful influence on health by structuring, perpetuating, and mediating the risk factors and underlying conditions known as the social determinants of health: education, food, housing, income, employment, sanitation, and health care... As such, law can be a powerful tool for securing and advancing health and equity. It can be used to set and defend the norms and standards of good health, to establish and strengthen resilient health systems, and to hold actors and institutions accountable."<sup>307</sup>* 

Many of the efforts in infusing the HIV programme with rights-based strategies came from the extraordinary activism of communities living with and affected by HIV that asserted their right to health through protest, contestation and litigation. Nearly every aspect of the right to health in the context of HIV was litigated in India: discrimination in employment, schooling and healthcare, the importance and limits of confidentiality, the criminalisation and marginalisation of vulnerable groups like sex workers, gay men, people who use drugs, trans people, treatment access, right to treatment in prison settings, property and matrimonial cases and so on. Internationally and nationally one of the most far-reaching consequences of this activism and litigation was in the field of access to treatment; in particular challenges to the monopoly rights claimed by pharmaceutical companies, which prevent millions from accessing life-saving ARTs because of patent protections. Even today people living with HIV continue to challenge patents and patent applications on critical HIV-related treatment.

It is not surprising then that several of the efforts in relation to HIV have come to be reflected in the law – the *HIV Act* (the drafting of which itself was a remarkable participatory process of empowerment). This law addresses the many aspects of the AAAQ framework. A unique provision guarantees protection from non-discrimination based on HIV status. This is a pioneering section in the law, because it is first of its kind (along with the *Mental Healthcare Act, 2017*) that prohibits discrimination even in the private sector, critical in a context where that sector is playing an increasing but largely unregulated role in healthcare.<sup>308</sup>

As a critical factor in strengthening health governance for UHC, Working Paper 3 in this series further examines the implementation of participation mechanisms in key health-related laws and policies in India. As much as essential amenities are required to deliver health – the institutional presence, and the availability of health products, services, and personnel – so too is there a need to make available a system of accountability (including in the form of grievance redress) when the right to health is violated. For a patient in or user of the health system (or their next of kin) this means instituting mechanisms by law that inquire into complaints, provide opportunities for complaints to be fairly heard, and the quick, equitable and efficient resolution of grievances. This becomes even more essential in the backdrop of a justice system that is overburdened, intimidating and remote.

While the Act provides substantive rights (informed consent and counselling for testing and treatment, confidentiality guarantees, and treatment access among others) it also lays out a clear pathway for grievance redress in case rights are violated. The law localizes grievance redress, requiring it to be available institutionally for establishments comprising more than 100 persons, and for healthcare establishments of more than 20 persons through appointment of a Complaints Officer who

<sup>&</sup>lt;sup>307</sup> Gostin L. et al. (2019, April 30). The legal determinants of health: harnessing the power of law for global health and sustainable development. The Lancet. Available at:

https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(19)30233-8/fulltext <sup>308</sup> Section 3, HIV *Act* 

is expected to rapidly resolve complaints.<sup>309</sup> Moreover, the Complaints Officer is to be trained by the establishment on the substance of the law and the issues implicated in relation to HIV including information on prevention, care, support and treatment related to HIV, human sexuality, sexual orientation and gender identity, drug use, sex work, stigma and discrimination.<sup>310</sup> Furthermore, the Act also provides for pre-court dispute resolution through a state-appointed Ombudsperson who is to investigate grievances related to discrimination and provision of health services including issues of informed consent, confidentiality, and a safe working environment, and resolve appeals from decisions of Complaints Officers.<sup>311</sup> Here too, dispute resolution is to be done in a time-bound manner.

In this context it is instructive to juxtapose the experience of the TB control response in India. TB tests are largely routine, not requiring special consent from the patient. And due to a lack of focus on this issue even in the National TB Elimination Programme, counselling for TB has also been given less attention.<sup>312</sup> Consent and counselling are particularly important in relation to TB treatment for two vital reasons – to ensure adherence to regimens, and to fully inform patients of the toxicity and potential side effects of many TB medications so that they can take an informed decision about their health – acceptability in its most literal sense.

Counselling is considered particularly important as part of the continuum of services related to TB in order to inculcate trust in the health system by the patient, reduce stigma and encourage TB treatment and nutrition adherence.<sup>313</sup> Indeed, practice has shown that investing in robust counselling for TB treatment can bear immense benefits, including significant reduction in treatment dropouts.<sup>314</sup>

While some policy documents do recognise the importance of consent in relation to drug resistant TB (DR-TB),<sup>315</sup> prioritising counselling for TB is a rare occurrence. As has been observed by those involved in both HIV and TB treatment delivery, often a treating physician would follow consent protocols for HIV, but not implement the same for other conditions. But in instances where TB treatment is linked to HIV treatment (for people living with HIV who also have TB and are accessing ART or ART centres), counselling services are seen to be robust, having been rooted in HIV-related health delivery for some time. TB counselling is also well-provided where TB survivors and patients' groups (including networks of people living with HIV) have rendered it as peer counsellors.<sup>316</sup> Yet, an increasing recognition of this important component of acceptability is evident in efforts such as the development of manuals and protocols for DR-TB that include consent and counselling requirements.<sup>317</sup> What becomes clear here is that where rights-based imperatives are bypassed (TB) due to gaps in law, policy or practice, there are gaps in delivering effective health interventions. But where they are actualised (HIV) there are positive health outcomes.

Another notable aspect in relation to TB mentioned above is that of nutrition and the necessity to recognise it as intrinsic to better health; therefore, for a person with TB very much at the heart of their right to health. Wholesome nutrition is critical for people with TB who are on medication and in

<sup>309</sup> Section 21, HIV Act

<sup>&</sup>lt;sup>310</sup> Rule 9, Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Rules, 2018

<sup>&</sup>lt;sup>311</sup> Chapter X, *HIV Act* 

<sup>&</sup>lt;sup>312</sup> REACH. (2018). Legal Environment Assessment of TB in India. Available at:

https://img1.wsimg.com/blobby/go/52cad3d5-1167-465b-8f13-e419aeaee141/downloads/REACH-CRG-LEA-2018-Full-Version.pdf?ver=1637742004164

<sup>&</sup>lt;sup>313</sup> Ibid.

<sup>&</sup>lt;sup>314</sup> Ibid.

 <sup>&</sup>lt;sup>315</sup> Guidelines for Programmatic Management of Drug-resistant TB (PMDT) in India 2017
 <sup>316</sup> Id. at 312.

<sup>&</sup>lt;sup>317</sup> Central TB Division, Ministry of Health & Family Welfare. (2017). Annual TB Report 2017. Available at: <u>https://www.tbcindia.gov.in/WriteReadData/TB%20India%202017.pdf</u>

recovery.<sup>318</sup> Indeed, good nutrition strengthens one's ability to improve immunity and keep debilitating TB at bay.<sup>319</sup> Having much to do with a person's socio-economic standing, and while not usually understood as part of 'healthcare', nutrition is a structural determinant of health that must be factored in while considering programmes such as UHC that seek to improve societal health.

In relation to access to treatment too, there is an important resonance with TB, for which the policy environment hinders accessibility in fundamental ways. Regarding pricing and affordability of newer multidrug-resistant TB (MDR-TB) drugs – bedaquiline and delamanid – patent law is a hurdle, prioritising, as it does, private profit interests over patients' health. Not only have the main compounds for bedaquiline and delamanid been patented, some evergreening or new form and new use patents have also been granted. Such patents extend the period of exclusivity that patent holders enjoy over these vital medicines and further delay generic competition that could ease affordability and availability. With both medicines under patent, access to them has been dependent on 'compassionate use' programmes, the donation programmes or the tiered prices set by the patent holders. Given India's high burden of TB and the avowed goal of the Indian government to eradicate TB by 2025, the inability to effectively access bedaquiline and delamanid to cope with worrying MDR-TB prevalence in India fundamentally impinges on the right to health.<sup>320</sup>

Of late, the TB programme in India has taken note of the successes of the HIV programme and rights language has found its way into policy documents. The recognition of vulnerability of certain populations has also been recognised, as has the importance of community participation.

### 5. PRACTICAL IMPLICATIONS OF THE RTH IN UHC

### 5.1 Role of law and policy

While General Comment 14 recognises that measures to implement the right to health are likely to vary, it notes that the core obligation for States to take the necessary steps towards the achievement of the right, require at a minimum a national strategy. The ideal approach according to General Comment 14 would be a legal framework. Studies to determine the extent to which a country has adopted or achieved UHC have often examined if there is a legally binding commitment to implement UHC.

A review of laws adopted in some countries to this end indicates a range of approaches with some laws establishing national health insurance that may be mandatory or voluntary or laws that enshrine the right to healthcare and the government's obligation to implement UHC (Table 1). The package of services including in-patient and out-patient, the coverage (citizens only or all residents including refugees and migrants), co-payments and several other features differ across countries (Table 2).

<sup>318</sup> Central TB Division, Ministry of Health & Family Welfare. (2017). Guidance Document on Nutritional Care and Support for patients with Tuberculosis in India. Available at:

https://tbcindia.gov.in/index1.php?sublinkid=4731&level=3&lid=3277&lang=1 <sup>319</sup> Id. at 312.

<sup>&</sup>lt;sup>320</sup> Id. at 312.

### TABLE 1

Ghana	Tanzania	Thailand	Uruguay
National Health Insurance Act 2012 <sup>321</sup> establishes the National Health Insurance Fund, National Health Insurance Authority	National Social Security Fund Act 1997 (NSSF) <sup>322</sup> - includes health insurance benefit National Health Insurance Fund Act 1999 (NHIF) <sup>323</sup> established the National Health Insurance Fund. Administered by Ministry of Health, Community Development, Gender, Elderly, and Children. Community Health Fund Act 2001 (CHIF) <sup>324</sup> established the Community Health Fund + Tiba Twa Kadi.	National Health Act 2007 <sup>325</sup> - to promote RTH and SDHsNational Health Security Act 2002 <sup>326</sup> - governing act for UHCHealth Promotion Fund Act 2001 <sup>327</sup> - sin tax on alcohol and tobacco for Non- Communicable Disease controlSocial Security Act 1990 <sup>328</sup> - contributory social security for formal sector employeesRoyal Decree on CSMBS 1980/89 <sup>329</sup> - civil servants	Law 18.211 of 2007 <sup>330</sup> - creating the National Integrated Health System and National Health Insurance Law 19.353 of 2015 <sup>331</sup> - creating National Integrated Care System for dependants Decree 444/016 <sup>332</sup> - establishing "care committee"

<sup>&</sup>lt;sup>321</sup> National Health Insurance Act 2012, National Health Insurance Authority, Ghana. (2012). Available at: <u>https://www.nhis.gov.gh/files/ACT852.pdf</u>

<sup>327</sup> Health Promotion Foundation Act 2001, ILO Natlex. (2001). Available at:

https://www.ilo.org/dyn/travail/docs/1017/Social%20Security%20Act%20BE%202533%201990.pdf <sup>329</sup> Royal Decree on CSMBS 1980 and 2015 amendment thereto, ILO. (2015). Available at:

https://extranet.who.int/mindbank/download\_file/3279/61b93a13352cd8f84c63cbbd4a4fa89f5302ea96 <sup>331</sup> Law 19.353 of 2015, Normativa y Avisos Legales del Uruguay. (2016). Available at:

https://www.impo.com.uy/bases/leyes/19353-2015

<sup>&</sup>lt;sup>322</sup> National Social Security Fund Act 1997, ILO Natlex. (1997). Available at:

https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/86532/97750/F1545649803/TZA86532.pdf <sup>323</sup> National Health Insurance Fund Act 1999, ILO Natlex. (1999). Available at:

https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/67038/97748/F505096058/TZA67038.pdf <sup>324</sup> Community Health Fund Act 2001, ILO Natlex. (2001). Available at:

https://www.ilo.org/dyn/travail/docs/2243/Community%20Health%20Fund%20Act%202001.pdf <sup>325</sup> National Health Act 2007 (Unofficial English Translation), ILO Natlex. (2007). Available at: http://thailaws.com/law/t\_laws/tlaw0368.pdf

<sup>&</sup>lt;sup>326</sup> National Health Security Act 2002, NHSO, Thailand. (2002). Available at:

https://eng.nhso.go.th/assets/portals/1/files/NHS%20ACT book revised%20Apr5.pdf

https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/62433/102611/F1235579305/THA62433.pdf <sup>328</sup> Social Security Act 1990, ILO Natlex. (1990). Available at:

https://www.ilo.org/dyn/natlex/natlex4.detail?p lang=en&p isn=53174&p country=THA&p count=441 <sup>330</sup> Law 18.211 of 2007 (Spanish), WHO. (2007). Available at:

<sup>&</sup>lt;sup>332</sup> Decree 444/016, Normativa y Avisos Legales del Uruguay. (2015). Available at: <u>https://www.impo.com.uy/bases/decretos/444-2016</u>

### TABLE 2

	Ghana	Tanzania	Thailand	Uruguay
Covered groups	All residents	Government employees Private sector employees Self-employed Rural residents Urban poor	Government employees and dependents Private sector employees Remaining population (informal workers) Addl VHC for families	Active formal workers and their dependents (dependent children under 18 years of age and of legal age with disabilities); Spouse or common-law partner; Retired people
Enrolment	Voluntary	Mandatory + voluntary	Mandatory + Automatic + Voluntary	Voluntary
Inpatient/ outpatient care	Both are covered	Both are covered	Only inpatient	Both are covered

A review of UHC-related laws and policies of other countries also reveal interesting and creative approaches to ensuring peoples participation. The National Health Commission of Thailand convenes the National Health Assembly (NHA) periodically, under the community monitoring provisions of the *National Health Act, 2007*<sup>333</sup> that bring together government officials, CSOs and academics/ health experts. Consensus-based resolutions of the NHA are submitted to the National Health Commission and further to the Cabinet for policy reform. Area-based health assemblies for decentralised dialogues and issue-based health assemblies are also convened. In Brazil, Health Councils have been set up at the municipal, state and federal levels, with the mandate of civil society participation in health system monitoring and resource allocation.<sup>334</sup> Under Tanzania's *Community Health Fund Act 2001*,<sup>335</sup> community members have powers of administering and monitoring the community health funds through participation in the Council Health Services Board.

These efforts to ensure peoples' **participation** are of critical importance. It is worth reiterating that the right to health extends to the full participation of the population in all health-related decisions like implementation of programmes or framing of legislation at the community, national and international

<sup>&</sup>lt;sup>333</sup> Id. at 325

 <sup>&</sup>lt;sup>334</sup> Health Organic Law/Law 8.080 and Law 8.142; See also Martinez, M.G., Kohler, J.C. (2016). Civil society participation in the health system: the case of Brazil's Health Councils. *Global Health* 12, 64 Available at: <a href="https://doi.org/10.1186/s12992-016-0197-1">https://doi.org/10.1186/s12992-016-0197-1</a>
 <sup>335</sup> Id. at 324

levels. As stated in General Comment 14, "the right of individuals and groups to participate in decisionmaking processes, which may affect their development, must be an integral component of any policy, programme or strategy developed to discharge governmental obligations under article 12. Promoting health must involve effective community action in setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health. Effective provision of health services can only be assured if people's participation is secured by States."<sup>336</sup>

Community participation is not only a basic right but by viewing people as active participants and not passive beneficiaries, it contributes to making development processes equitable.<sup>337</sup> In a review of health systems around the world, participation was considered critical to improving health outcomes, reducing information asymmetries and strengthening social capital and deepening democratic processes.<sup>338</sup> The importance of participation in health-related laws and policies is also well recognised at the national level. The HIV response described in the case study above, for instance, highlights various facets of community participation. As a critical factor in strengthening health governance for UHC, Working Paper 3 in this series further examines the implementation of participation mechanisms in key health-related laws and policies in India.

The question of whether UHC in India should have a legal framework is complicated by the fact that health is a State subject under the Indian Constitution. That said, there are three rights-based health laws that have been passed by Parliament in the past decade – the *HIV Act*, the *Mental Healthcare Act, 2017* and the *Rights of Persons with Disabilities Act 2016*. India's international obligations which fall under the Central list of Schedule VII of the Constitution provide the basis for the power of the central government to have passed these health laws. Another legislation proposed at the central level, the CEA takes a different approach requiring individual states to adopt it. As a result, the CEA is implemented only in the 11 states that have adopted it.<sup>339</sup> At the same time, several states have already adopted or are considering state level right to health laws. Various elements of the right to healthcare feature prominently among those that have already been enacted or are being considered in states. The central health laws and the state-level right to health laws are discussed in greater detail in Working Paper 3 in this series.

Whether UHC in India ultimately has a central legal framework or is fragmented across state level legislations or implemented only though policies and programmes, the right to health requirements including those of progressive realisation, core obligations, non-discrimination, participation, non-retrogression, use of maximum available resources and the provision of remedies and accountability must be met. Additionally, as noted above, laws that criminalise, marginalise or discriminate against certain populations and communities impeding their access to health services would also have to be reviewed and amended to ensure that exclusions other than financial exclusions are also addressed in the implementation of UHC.

### 5.2 Indicators and benchmarks

Former UN Special Rapporteur on the Right to Health, Paul Hunt has written that the highest attainable standard of health is not just a rhetorical device, but also a tool that can save lives and reduce suffering, especially among the most disadvantaged. Hunt writes,

https://apps.who.int/iris/bitstream/handle/10665/39856/9241561262.pdf?sequence=1&isAllowed=y

<sup>&</sup>lt;sup>336</sup> Id. at 3, para 54.

<sup>&</sup>lt;sup>337</sup> Oakley, P. & World Health Organisation. (1989). *Community involvement in health development: An examination of the critical issues.* Available at

<sup>&</sup>lt;sup>338</sup> High Level Expert Group Report on Universal Health Coverage for India (2011). Chapter 6. Available at <u>https://nhm.gov.in/images/pdf/publication/Planning Commission/rep uhc0812.pdf</u> <sup>339</sup> Clinical Establishments (Project and Project and Pro

"The right to health asks awkward questions. As you devise this new health programme, how will you ensure that the voices of women and girls are heard and respected? How are you ensuring that the poor and marginal have access to these health services? How are you measuring the impact of that new irrigation scheme on the health of neighbouring communities? How are you measuring whether or not access to health care is being progressively improved? If you are using indicators and benchmarks, are they disaggregated on the grounds of sex, ethnicity and other prohibited grounds of discrimination? Why are maternal and infant mortality rates static - or worsening - for some ethnic minorities? Are your health programmes respectful of minority cultures? Are they available in common minority languages? But human rights not only ask these awkward questions, they also require answers – that is what accountability is all about."<sup>340</sup>

In the context of UHC, these "awkward" questions posed by the right to health could help in ensuring equity in healthcare access. Moreover, over the past few decades the work of the UN Special Rapporteurs on the Right to Health have helped evolve approaches to developing right to health benchmarks and indicators to measure and assess health programmes.

At the international level, there are two primary indicators used to monitor progress towards UHC as identified in the SDGs i.e., coverage of essential health services (SDG 3.8.1); and catastrophic health spending (and related indicators) (SDG 3.8.2).<sup>341</sup>

In order to measure equity in the implementation of UHC, the WHO and the World Bank have identified 14 essential health services in 4 categories that were selected for being well-established with data widely available in most countries. Importantly these indicators, "are only meant to be indicative of service coverage and should not be interpreted as a complete or exhaustive list of health services and interventions that are required to reach universal health coverage."<sup>342</sup> These are:<sup>343</sup>

"Reproductive, maternal, newborn and child health (RMNCH):

- Family planning (FP)
- Antenatal care, + 4 visits (ANC)
- DTP3 immunization (DTP3)
- Care seeking for suspected pneumonia (Pneumonia)

Infectious diseases:

- TB treatment (TB)
- HIV therapy (ART)
- Insecticide-treated nets (ITN)

• sanitation (WASH)

Non-communicable diseases:

- Non-elevated blood pressure (BP)
- Mean fasting plasma glucose (FPG)
- Tobacco non-use (Tobacco)

Service capacity and access:

- Hospital bed density (Hospital)
- Health worker density (HWF)

<sup>342</sup> World Health Organisation and The World Bank (2021). *Tracking Universal Health Coverage; 2021 Global Monitoring Report*. p. 62. Available at <u>https://cdn.who.int/media/docs/default-source/world-health-data-platform/events/tracking-universal-health-coverage-2021-global-monitoring-report\_uhc-day.pdf?sfvrsn=fd5c65c6\_5&download=true.</u>

<sup>&</sup>lt;sup>340</sup> Hunt, P. (2007). Poverty, Malaria and the Right to Health: Exploring the Connections. UN Chronicle. Available at <a href="https://www.un-ilibrary.org/content/journals/15643913/44/4/17/read">https://www.un-ilibrary.org/content/journals/15643913/44/4/17/read</a> 341 World Health Organisation (2022) Universal Health Coverage, Available at <a href="https://www.uho.int/news-room/fa">https://www.uho.int/news-room/fa</a>

<sup>&</sup>lt;sup>341</sup> World Health Organisation. (2022) *Universal Health Coverage*. Available at <u>https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc)</u>

<sup>&</sup>lt;sup>343</sup> Ibid at p. 64.

• IHR core capacity index (IHR)"

However, these indicators may not be sufficient for a right to health approach to UHC. For instance, the WHO approach to UHC indicators would not indicate whether people can access health services without discrimination, or whether there is participation of communities in designing or implementing UHC, or measures for accountability or redress if there is a failure to deliver health services. Notably, the WHO considers all these concerns central to the implementation of UHC, including making primary healthcare the cornerstone of UHC. But the above indicators would do little to capture these key issues.

Instead, scholars have proposed that the 'OPERA framework' (Outcomes, Policy Efforts and Resources to make an overall Assessment), designed to help in assessing the implementation of economic, social and cultural rights (of which the right to health is a part), may offer a more appropriate set of indicators and benchmarks. In an assessment for the WHO, Gorik Ooms and colleagues have adapted the OPERA framework to present right to health-based indicators for UHC programmes. Like Hunt, they also devised 'awkward' questions to guide policy makers in ensuring that right to health requirements can be met while implementing UHC. These questions include (see Annexure 1 for a detailed explanation of the questions):<sup>344</sup>

- 1. "Do the health services included in the UHC package respond to the priority health-care needs of the whole population?
- 2. Do the UHC plans identify marginalized and vulnerable groups in the country and the different regions?
- 3. If you have a mixed (public and private system) does your monitoring system disaggregate findings pertaining to private providers or insurers from findings pertaining to public providers or insurers?
- 4. Do you measure the progressivity of each of the funding streams of your pooled financing system to ensure that poorer households or people do not bear a disproportionate financial burden?
- 5. Do your UHC monitoring efforts include quality of care indicators?
- 6. Is your national public health strategy and plan of action designed and periodically reviewed on the basis of a participatory and transparent process?
- 7. Do your UHC monitoring efforts look at the medium term expenditure framework (MTEF) and the budget for UHC for the years to come?
- 8. Does your level of domestic public health financing meet international or regional targets?
- 9. Does your level of development assistance for health meet international or regional targets?
- 10. If you have ratified the Covenant do you comply with its periodic reporting obligations regarding the right to health?"

Based on these questions and the various elements of the right to health, Ooms and colleagues then propose a series of indicators and benchmarks that are produced in full in Annexure 2.<sup>345</sup> These indicators include measuring the extent to which non-discrimination on various grounds is ensured in access to healthcare services by looking at disaggregated socio-economic indicators by gender, religion, region, income group and so on. Progressive realization is proposed to be examined by looking at the socio-economic indicators over time. Satisfaction surveys and quality and monitoring and evaluation tools are proposed to determine the extent to which the AAAQ requirements of the right to health are met.

These questions and indicators provide guidance for countries like India to develop their own questions and indicators and benchmarks to ensure that the implementation of UHC meets the requirements of the right to health. For instance, in India where the regulation of private healthcare already poses significant challenges and still appears to be the primary option being used by the

<sup>344</sup> Id. at 30.

<sup>&</sup>lt;sup>345</sup> Ibid.

government to deliver health services, policy makers may want to consider steps beyond indicators and benchmarks. In a detailed examination of the potential adverse effects of privatization of essential services, the UN Special Rapporteur on extreme poverty in their 2018 report has proposed that policy makers should "…insist that appropriate standards be set by public and private actors involved with privatization to ensure that data on human rights impacts are collected and published, and that confidentiality carve-outs are strictly limited; undertake systematic studies of privatization's impact on human rights in specific areas, and on poor and marginalized communities; insist that arrangements for the privatization of public goods specifically address the human rights implications…"<sup>346</sup>

### 5.3 Remedies and Accountability

Perhaps the most critical aspect in the implementation of UHC within a rights framework would be the issue of remedies and accountability. As Hunt notes, the questions posed by the right to health require answers, not for the purposes of blaming but to ensure accountability.<sup>347</sup> General Comment 14 states that any person or group whose right to health is violated should be able to approach the court or have access to other remedies and identifies a range of institutional mechanisms apart from court such as ombudsmen, human rights commissions, consumer forums and patients' rights associations that should be involved in addressing these violations.<sup>348</sup>

In India, violations of the right to health by the public sector can form the basis of special leave petitions or PILs before the courts. Violations by the private sector can be addressed through consumer courts or medical negligence complaints or criminal cases. Litigation in India is however, extremely expensive, protracted and usually pits individual patients against either the State machinery or powerful private interests. The few cases where patients win compensation in consumer courts seldom result in institutional changes that would prevent violations of the right to health from recurring. Some laws have now established ombudsmen to provide an alternative to litigation. Some health programmes have established helplines. Social sector legislations outside the health field have also instituted other mechanisms for accountability and participation like social audits. These myriad grievance redress and accountability mechanisms are discussed in greater detail in Working Paper 3 in this series. If UHC in India relies largely on private hospitals and private insurance companies, then the issue of grievance redress and accountability will require particular attention from policy makers.

### 6. CONCLUSION AND KEY MESSAGES

### "It is health that is the real wealth and not pieces of gold and silver." Mahatma Gandhi

For the hundreds of thousands in India that have lost their lives during the COVID-19 pandemic, the many more who will live with the debilitating aftereffects of the virus and their families, friends and loved ones, this simple assertion has hit far too close to home. The adverse effects of successive lockdowns on other health services, the resultant worsening of the social determinants of health and the now increasingly documented threats to the hard-fought progress on TB, HIV and other health conditions make the challenge of achieving UHC in India at once daunting and urgent. The Lancet Citizens' Commission on Reimagining India's Health System has its work cut out.

As this paper has demonstrated, any roadmap to achieving UHC in India must be firmly rooted in the constitutionally and internationally recognised framework and obligation of the right to the highest attainable standard of health. The evolution of the right to health, the scholarship around it and the

<sup>&</sup>lt;sup>346</sup> Special Rapporteur on extreme poverty and human rights. (2018). *Report of the Special Rapporteur on extreme poverty and human rights*. Available at: <u>https://documents-dds-</u>

<sup>&</sup>lt;u>ny.un.org/doc/UNDOC/GEN/N18/299/45/PDF/N1829945.pdf?OpenElement</u>. <sup>347</sup> Id. at 340.

<sup>&</sup>lt;sup>348</sup>Id. at 3.

many ways in which it has been used in judicial interventions, laws and policies provide considerable guidance for the Commission and its workstreams for using the right to health framework in its work.

To this end, certain key messages emerging from the inextricable links between the right to health and UHC are summarised below:

- The Right to Health is well-recognised and enforced in international and Indian law, through statute, judicial rulings, and policy underpinnings.
- Universal Health Coverage is firmly anchored in the right to health, and unsustainable without a rights-based approach.
- The roadmap to UHC in India must take into account key principles of the right to health, and be guided by this framework of analysis to ensure equitable delivery:
  - Addressing healthcare as well as the social determinants of health
  - Progressive Realisation and Core obligations
  - Use of maximum available resources
  - Non-discrimination and the prioritisation of vulnerable and marginalised populations
  - Focus on the principles of availability, accessibility, acceptability and quality (AAAQ)
  - Non-retrogression
  - Participation
  - Accountability, grievance redressal and remedies
- There is considerable scholarship, guidance and examples on defining right to health-based indicators and benchmarks in the design and implementation of UHC.

There are several practical ways in which the right to health framework can help guide the work of the Commission. For instance, one of the guiding questions identified in this paper relating to UHC and the right to health is whether the UHC programme being designed addresses the priority health needs of the country. These should include the social determinants of health. Without identifying these priority health needs, determining financial and budgetary allocations required in the short, medium and long term would be difficult.

While the Commission has identified citizens' engagement as crucial to its work, within a right to health framework, UHC in India would also have to cover non-citizens (including migrants, refugees, asylum seekers and others). The participation and voices of non-citizens would also have to be factored into the UHC roadmap. The right to health also requires participation on an ongoing basis and the roadmap could consider creating community and people-based monitoring and review mechanisms.

While examining issues related to human resources, the right to health framework would require that the training and education of healthcare providers include legal and ethical issues such as informed consent, confidentiality and non-discrimination. A rights-based focus on human resources would also identify and address issues of gender inequality in the health work force; the overwhelming number of women who are community health workers in India also requires a gender perspective on working conditions, safety, pay etc.

The right to health framework can also assist in identifying both the benefits and limitations of relying on technology to address gaps in access to healthcare. As noted in this paper, there are several dimensions to the issues of availability, affordability, acceptability and quality not all of which would have technological solutions. The use of technology itself can raise human rights concerns related to consent, privacy and discrimination (such as digital divides).

Perhaps the most challenging tasks in the context of the right to health arise in the context of governance. The health sector in India is governed by a complex and overlapping multitude of laws,

court decisions, rules and regulations. The issue of governance is further complicated by health being addressed at the central, state and local levels. Key social determinants of health like sanitation in particular are issues that are addressed at local/district levels. Despite the abundance of laws and policies, from a right to health perspective there are glaring gaps in the legal framework surrounding health and healthcare in India. Addressing and preventing discrimination is one such gap. The lack of effective remedies and grievance redressal mechanisms is another.

While this paper makes evident the centrality of the right to health framework to UHC, it should be read with other working papers in this series (RTH-UHC Working Papers) that highlight how right to health issues and concerns have been reflected in Indian law and policy. This includes Working Paper 2 that focuses on how the judiciary in India has engaged with the right to health, and the perspectives of courts on centre-state relations in the area of health and on the regulation of the private sector. Working Paper 3 examines the implementation of health-related laws, policies and programmes as well as those of rights-based social sector legislation. Working Paper 4 concerns itself with the interface of digital technologies and the delivery of healthcare and UHC in the context of legal-ethical, policy and rights issues that this fast-changing area reveals.

### ANNEXURE 1: Guiding Questions for policy makers on UHC in the context of Right to Health Obligations framed by Gorik Ooms et al<sup>349</sup>

### Key guiding questions

These questions, tailored for national health sector policy-makers, aim at ensuring that the actions the health sector takes to advance towards UHC can also contribute to realizing the right to health in a given country. Health sector policy-makers are reminded that the realization of the right to health depends on other sectors as well. They are encouraged to contribute to advancing the right to health beyond the health-care system, by, at a minimum, assuming responsibility for advocacy aimed at other sectors that have an impact on health, including education, sanitation, water and nutrition.

## **1.** Do the health services included in the UHC package respond to the priority health-care needs of the whole population?

The existence of a UHC package or package of basic services is not sufficient in itself because the package on offer may not be the appropriate package to respond to the priority health-care needs of the whole population. Additionally, the package on offer must be flexible and responsive to changes in priority health-care needs of the whole population.

### 2. Do the UHC plans identify marginalized and vulnerable groups in the country and the different regions?

Identifying and removing the multiple barriers stemming from socioeconomic exclusion and/or discrimination is certainly vital to advancing UHC but it is not sufficient in itself. Efforts are required to identify the specific groups that are vulnerable or marginalized in a given country and region(s) and include them in UHC plans to ensure that health coverage is truly universal.

# 3. If you have a mixed (public and private system) does your monitoring system disaggregate findings pertaining to private providers or insurers from findings pertaining to public providers or insurers?

Efforts to monitor UHC should ensure that a mixed system does not lead to discrimination or exclusion on the basis of socioeconomic status. Disaggregating findings can help determine whether or not private for-profit providers and insurers cover all health-care seekers.

## 4. Do you measure the progressivity of each of the funding streams of your pooled financing system to ensure that poorer households or people do not bear a disproportionate financial burden?

Using pooled financing as a means of moving away from out-of-pocket payments for health services should assist poorer households or people, but it does not necessarily result in equitable financing. Applying the Kakwani index can assist in measuring the progressivity of funding streams or pools.

<sup>&</sup>lt;sup>349</sup> World Health Organization (2015), Anchoring universal health coverage in the right to health: What difference would it make? Available at: <u>https://apps.who.int/iris/bitstream/handle/10665/199548/9789241509770\_eng.pdf</u>

### 5. Do your UHC monitoring efforts include quality of care indicators?

Agreeing on indicators of quality of care is a difficult process, but agreeing on and monitoring such indicators is key to advancing UHC.

## 6. Is your national public health strategy and plan of action designed and periodically reviewed on the basis of a participatory and transparent process?

The development of the national public health strategy and plan of action needs to consider input gathered through a participatory and transparent process. The periodic review of the strategy and plan of action should also be a participatory and transparent process which feeds into strengthening accountability.

## 7. Do your UHC monitoring efforts look at the medium term expenditure framework (MTEF) and the budget for UHC for the years to come?

UHC is not a goal that can be fully achieved but a dynamic process that requires constant attention. Therefore efforts to advance UHC need to look forward not just back; thus, including MTEF and budget projections in monitoring efforts helps in assessing the sustainability of progress.

### 8. Does your level of domestic public health financing meet international or regional targets?

Monitoring efforts to comply with international or regional commitments on domestic public health financing requires identifying the domestic public health financing targets your country has committed to at the international or regional level (e.g. the Abuja Declaration). Tracking compliance with these targets over time will help to identify progress.

### 9. Does your level of development assistance for health meet international or regional targets?

Monitoring efforts to comply with international or regional commitments on financing development assistance for health requires identifying the international or regional targets your country has committed to (e.g. the 0.7% of GDP target). Tracking compliance with these targets over time will help to identify progress.

## 10. If you have ratified the Covenant do you comply with its periodic reporting obligations regarding the right to health?

Efforts to make progress towards UHC can be viewed as practical efforts to realize the right to health. Those states that have ratified the Covenant should highlight their efforts to progress towards UHC as a fundamental element of their commitment to realizing the right to health.

## The OPERA framework<sup>1</sup>

	PROJECT		
	WHAT CONCEPTS ARE WE MEASURING?	HOW CAN WE MEASURE THEM?	ELEMENTS
Measure aggregate levels of rights	Minimum core obliga- tions: Widespread deprivation suggests obligations (e.g. to reach minimum essential levels of a right) are not being met.	Compare socio-eco- nomic outcome in- dicators to relevant	Package of services
enjoyment		benchmarks and/or comparable coun-	Essential medicines
		tries. Deviations can point to whether or not a country's performance is reasonable.	Geographical access
			Millennium Development Goals (MDGs)
Measure disparities in rights enjoy- ment	Non-discrimination and equality: rights raise concerns about possible discrimination or failure to address disadvantage.	Disaggregate socio- economic indicators by relevant social groups (e.g. ethnic- ity, religion, gender, region, income, etc.) to uncover any particular or inter- secting disparities.	Gender
			Marginalized groups
			Income quintiles/ deciles
			Different tiers (public-private)
			Level of educa- tion
Measure progress over time	Progressive realization and non-retrogression: Identifying trends in the enjoyment of a right over time indicates whether there is progress or backsliding and whether disparities are growing or reducing.	Compare the same socio-economic indicators over time (aggregate or disag- gregated).	Package of services/essential medicines/ geographical access
			MDGs
			Gender
			Marginalized groups
			Income quintiles/ deciles
			Different tiers (public-private)

<sup>&</sup>lt;sup>350</sup> Ibid.

Identify legal and policy commitments	Obligation to take steps: Whether the government is taking adequate legis- lative, judicial, adminis- trative, social and other measures towards the full realization of rights.	Identify indicators that demonstrate commitments made and analyse the provisions of relevant laws and policies against international stan- dards, guidelines, etc.	ICESCR International
			declaration
			National law
			Administrative directive
Examine policy content and implemen-	ceptable, appropriate and of good quality (AAAAQ): Whether the goods and services needed to fulfil a right are increasingly available, accessible, acceptable and of ad- equate quality, without discrimination.	niques can be used to gather primary	Satisfaction surveys
		that measure these criteria. Cross-coun- try comparisons, disaggregated and temporal data all help in judging the reasonableness of the state's perfor-	Quality of monitoring and evaluation tools
Analyse policy processes	Participation, transpar- ency, right to a remedy: Whether rights holders can actively participate in the design, implementa- tion and oversight of poli- cies and have avenues to hold government to account or seek redress when they are negatively affected by them.	Qualitative tech- niques (e.g. focus groups, interviews) can gather feed- back from particular rights holders. Quantifiable studies (e.g. perception surveys and gover- nance indicators) may provide a general overview.	Parliamentary debate
			Participatory decision-making at national level
			Participatory decision-making at local level
			Litigation
Analyse resource allocation and expenditure	Progressive realization according to maximum available resources: Whether expenditures (planned and actual) in relevant sectors are a transparent, equitable and effective use of avail- able resources.	Allocation ratios, judged against relevant refer- ence points and over time, show reasonableness of amounts earmarked for key sectors and population groups. Various governance tools (e.g. social audits) review the disbursement of funds.	Government health expenditure as percentage of THE
			Government health expenditure as percentage of government budget
			Medium-Term Expenditure Framework (MTEF)
			Allocation pri- mary/ secondary/ tertiary
			Allocation urban/ rural
			Ring-fenced allocation vulnerable groups



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