

# Living Like People Who Die Slowly: The Need for Right to Health Compliant COVID-19 Responses

Executive Summary, September 2020



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## **Acknowledgments**

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## SUMMARY AND OVERVIEW

According to the World Health Organization, as of 31 August 2020 COVID-19 had infected a confirmed total of 25,118,689 people worldwide and contributed to at least 844,312 deaths.<sup>1</sup> International news and social media sources, to be sure, have conveyed some of the devastating impacts of COVID-19 in some of the hardest hit areas at different stages, including in China, the United States, the European continent, Brazil and South Africa. However, the overall global impact of the pandemic is less well documented, seldom presented as a composite picture, and infrequently evaluated against the legal obligations of States, individually and collectively, to respect, protect and fulfill the right to health of people under their jurisdiction.

As the UN Committee on Economic, Social and Cultural Rights has aptly noted, the devastation and “suffering” wrought by COVID-19 has not been equally distributed amongst all people.<sup>2</sup> Global statistics, as chilling as they are, cannot reveal the individual impacts and experiences of either persons who have died of COVID-19, or those who suffer the personal, social, economic and political consequences of the pandemic.

Mama Yuli, an Indonesian transwoman, explained that many elderly transwomen “feel like they live like people who die slowly” as a result of COVID-19.<sup>3</sup> Her statement of exasperation is perhaps an apt articulation of a more common sentiment of millions of people around the world. Referring to the difficulty of surviving COVID-19 in the context of extreme poverty, Sbu Zikode of the South African shack dwellers’ movement Abahlali BaseMjondolo observed that: “it does not seem possible to prevent this virus from spreading when we still live in the mud like pigs”.<sup>4</sup>

Fear, anxiety and pressure caused by COVID-19 itself,<sup>5</sup> coupled with the pandemic’s economic devastation, have driven many to extreme measures. Ginny Butcher, a wheelchair user in the United Kingdom said that she was “very anxious” because people in her position had been given “zero guidance” on how to effectively protect themselves from COVID-19 and this meant women with disabilities “were left wondering how they were going to get out of bed in the morning”.<sup>6</sup> Indigenous Malaysian activist, Bedul Chemai, told reporters that to survive COVID-19

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<sup>1</sup> WHO Coronavirus Disease (COVID-19) Dashboard (31 August 2020), available at: <https://covid19.who.int/>. The data on this site is updated regularly.

<sup>2</sup> UN Committee on Economic, Social and Cultural Rights, Statement on the coronavirus disease (COVID-19) pandemic and economic, social and cultural rights, U.N. Doc. E/C.12/2020/1 (7 April 2020): <https://undocs.org/E/C.12/2020/1> (“CESCR COVID-19 Statement”).

<sup>3</sup> A Amindoni, Transgender’s struggle during the coronavirus pandemic – “Living like a person who dies slowly” (2 May 2020), available at: <https://www.bbc.com/indonesia/indonesia-52500732>.

<sup>4</sup> S Ebrahim & TF Hodgson, Abahlali baseMjondolo: You can’t stop the virus while living in the mud (27 March 2020): <https://www.dailymaverick.co.za/article/2020-03-27-abahlali-basemjondolo-you-cant-stop-the-virus-while-living-in-the-mud/>.

<sup>5</sup> WHO, Substantial investment needed to avert mental health crisis (14 May 2020): <https://www.who.int/news-room/detail/14-05-2020-substantial-investment-needed-to-avert-mental-health-crisis>; WHO, Mental health and psychosocial considerations during the COVID-19 outbreak (18 March 2020): [https://www.who.int/docs/default-source/coronaviruse/mental-health-considerations.pdf?sfvrsn=6d3578af\\_2](https://www.who.int/docs/default-source/coronaviruse/mental-health-considerations.pdf?sfvrsn=6d3578af_2).

<sup>6</sup> L Webster, Coronavirus: Why disabled people are calling for a Covid-19 inquiry (4 July 2020), available at: <https://www.bbc.com/news/uk-53221435>.

some indigenous Malaysians had been compelled to go “back into the forest, to isolate ourselves and find food”.<sup>7</sup>

The devastation wrought on public health has created an overwhelmingly difficult situation for healthcare workers worldwide, who have been central to States’ response to COVID-19. Peruvian doctor Jesus Valverde starkly describes the invidious position faced by health workers: “We started off so ill-equipped for this tragedy... We have to choose who will be saved and who won’t. It’s terrible... we’re exhausted, but we draw strength to go on from wherever we can”.<sup>8</sup>

These and numerous other experiences illustrate that the magnitude of the tragedy of COVID-19 is, in the words of distinguished Indian novelist and activist Arundhati Roy, “immediate, real [and] epic”.<sup>9</sup> In this context, perhaps unsurprisingly, the COVID-19 pandemic has had a ubiquitous impact on the protection of human rights globally.

The pandemic, and States’ responses to it, have had a dramatic effect on civil, cultural, economic, political and social rights. The declaration of COVID-19 as a global pandemic by the WHO in early March was accompanied by a statement that called on all States to “strike a fine balance between protecting health, minimizing economic and social disruption, and *respecting human rights*”.<sup>10</sup> Yet, at best, human rights –including the right to health – have been peripheral to much of the public discourse and official responses to COVID-19 globally.

COVID-19 is at its core a public health crisis of potentially catastrophic proportions. The response of State authorities to the pandemic should be evidence-based and must lean significantly on the guidance of public health experts. However, the individual and collective responses of States must also be shaped and guided by obligations and responsibilities that they themselves have assumed in respect of the right to health. Such obligations in terms of the right to health include obligations to adopt effective measures to ensure the prevention, treatment and control of epidemic, endemic, occupational and other diseases. This clearly includes obligations to take measures to ensure the prevention, treatment and control of COVID-19. And these obligations must be pursued not only through the individual laws, policies and practices of each State, but also through collective international cooperation.

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This report details the **international human rights law and standards in relation to the right to health**, with a particular focus on the International Covenant on Economic, Social and Cultural Rights (ICESCR). It highlights States’ obligations, including those which must be prioritized and given effect

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<sup>7</sup> R Latiff et al, Malaysia's indigenous people flee into forests to escape coronavirus (3 April 2020): <https://www.thejakartapost.com/seasia/2020/04/03/malaysias-indigenous-people-flee-into-forests-to-escape-coronavirus.html>.

<sup>8</sup> New York Times, In Harms Way (24 June 2020), available at: <https://www.nytimes.com/interactive/2020/world/coronavirus-health-care-workers.html>.

<sup>9</sup> A Roy, The Pandemic is a Portal (3 April 2020), available at: <https://www.ft.com/content/10d8f5e8-74eb-11ea-95fe-fcd274e920ca>.

<sup>10</sup> WHO, WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020 (11 March 2020), available: <https://www.who.int/dg/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020>.

immediately. It also emphasizes the responsibilities of non-State actors including international agencies like the WHO and businesses.

While a wide range of international human rights are engaged by the COVID-19 pandemic, **because it is a public health crisis that engagement necessarily runs particularly deep in relation to the right to health.** A number of international authorities, such as UN Treaty Bodies, independent experts of the UN Human Rights Councils, UN agencies, and CSOs including the International Commission of Jurists have recognized the critical importance of a rights-based approach involving in particular the right to health.<sup>11</sup> Protection of the right to health nonetheless must be applied in conjunction with other human rights obligations, since human rights interrelated, interdependent and mutually reinforcing.

States must **respect, protect and fulfill the right to health**, through measures that are non-discriminatory. While some aspects of the right may be realized progressively over time, a minimum core of the right must be observed at all times. Indeed, almost all States have taken legal and practical measures to address the public health emergency caused by COVID-19. The measures, whether through declarations of states of emergency, disaster or any other measures, must comply with international human rights obligations irrespective of a State's national law arrangements.

While certain limitations on human rights may be undertaken to confront the public health crisis, such **limitations must be for a specific public health purpose**, established by law, non-discriminatory and necessary and proportionate to addressing public health. Any derogation from civil and political rights obligations due to a public health emergency (including restrictions to movement which have been widespread) must also be necessary and proportionate to specific threats posed by COVID-19. Certain rights are never subject to derogation.

As a general principle of law, all measures taken by States **must comply with the prohibition of discrimination** of any kind. The prohibition on discrimination prohibits both formal discrimination, which is often explicit, and substantive discrimination which may result from formally neutral policies and laws which nevertheless have discriminatory impacts.<sup>12</sup> States are obliged to ensure provision of health services, goods and facilities to *all* persons within its jurisdiction without any discrimination. This includes access to prevention measures, testing and treatment for COVID-19 and any other necessary measures. States must use the maximum of their available resources in protecting the right to health, including financial resources, natural resources, human resources (importantly including healthcare workers) and technological resources.

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<sup>11</sup> International Commission of Jurists, Human Rights in the time of COVID-19: Front and Centre – ICJ news, articles, op-eds, legal blogs, videos (6 April 2020) available at: <https://www.icj.org/human-rights-in-the-time-of-covid-19-front-and-centre/>. See in particular I Siederman & TF Hodgson, COVID-19 Symposium: COVID-19 Responses and State Obligations Concerning the Right to Health (Part 1) (1 April 2020), available at: <http://opiniojuris.org/2020/04/01/covid-19-symposium-covid-19-responses-and-state-obligations-concerning-the-right-to-health-part-1/>; I Siederman & TF Hodgson, COVID-19 Symposium: COVID-19 Responses and State Obligations Concerning the Right to Health (Part 2), 1 April 2020), available at: <https://opiniojuris.org/2020/04/01/covid-19-symposium-covid-19-responses-and-state-obligations-concerning-the-right-to-health-part-2/>.

<sup>12</sup> Discrimination under international human rights law is prohibited on a non-exhaustive list of grounds including: race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth sexual orientation, gender identity; age; gender; citizenship; nationality or migration status; health status; disability; socio-economic status; or "other status".

States should **expand their existing pool of resources** to combat the COVID-19 pandemic, including through international co-operation and assistance with other States and international agencies such as the WHO, as well as through either voluntary or compelled private contributions (including from companies).

States must also **regulate the conduct of private participants in the healthcare sector**, including hospitals, pharmaceutical companies, and laboratories. Given the inequitable access to healthcare services, goods and facilities in many countries, extraordinary measures may be necessary to ensure that resources held by private healthcare actors are mobilized towards combatting COVID-19. Denying COVID-19 testing and treatment or failing to deploy available resources towards combatting COVID-19 may constitute a dereliction of responsibilities of private participants in healthcare. These responsibilities are, for example, engaged in the role private pharmaceutical companies will play in the development and distribution of prospective COVID-19 vaccines.<sup>13</sup>

To date there have been a wide array of disproportionate and discriminatory impacts that COVID-19 responses have had on individuals from groups that have been rendered particularly vulnerable to violations of their right to health. **Migrants, refugees and stateless persons** often face discrimination in healthcare services, while COVID-19 response measures often directly exclude non-citizens. Even in countries where COVID-19 testing and treatment has been made available to non-citizens, they often lack access to other critical needs, such as food, water, sanitation and/or housing. There is also a well-documented pattern of heightened vulnerability of **older persons**, to serious sickness and death from COVID-19. Older persons have struggled to access essential healthcare services, while lockdown measures place especially onerous restrictions on their freedom of movement. Blanket rules about movement, work and other aspects of life which are based solely on age may amount to prohibited discrimination. Older persons living in “nursing facilities” and other institutions face even further compounded vulnerability to COVID-19.

Globally, **women and girls** commonly undertake the role of primary caregivers for children and sick family members, exposing them to greater risk of COVID-19 transmission and increasing their burden of unpaid domestic labour. Women also comprise the significant majority of healthcare workers, therefore increasing their disproportionate exposure to COVID-19. There has been a marked increase in domestic and gender-based violence during lockdown periods when women have often been confined to their homes with potential abusers. Such violence has serious short and long-term health consequences for women. In many States, the criminalization of and discrimination against **LGBT persons** persist. Some States have taken COVID-19 responses that have had adverse impacts on access to healthcare services of LGBT persons. The deprioritization of sexual and reproductive health services to which LGBT persons are entitled, purportedly in order to focus efforts on COVID-19 responses, has also resulted in discrimination against LGBT persons. Many LGBT persons have faced increased risks of violence during the COVID-19 pandemic, including in their own homes.

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<sup>13</sup> UNAIDS et al, Uniting behind a people’s vaccine against COVID-19, (14 May 2020): [https://www.unaids.org/en/resources/presscentre/featurestories/2020/may/20200514\\_covid19-vaccine-open-letter](https://www.unaids.org/en/resources/presscentre/featurestories/2020/may/20200514_covid19-vaccine-open-letter).



**Persons with disabilities** are often particularly vulnerable to sickness including COVID-19 transmission. Inadequate State responses to ensure support measures sometimes necessary for persons with disabilities to live independently, increases the risk of COVID-19 transmission to persons with disabilities. For a large proportion of persons with disabilities, there is an increased chance of presence of “co-morbidities” increasing the chance of serious sickness and death upon transmission. These risks are even more severe for those compelled to live in institutions. Persons with disabilities have also faced discrimination in accessing lifesaving COVID-19 treatment because of triage processes which may even exclude them purely on the basis of disability.

In the context of COVID-19, **persons deprived of their liberty** are vulnerable to COVID-19 transmission and often do not receive adequate healthcare services if they are infected. Detainees have also experienced restrictions to their right to challenge the lawfulness of their detention in line with COVID-19 response measures. Unhygienic and overburdened quarantine facilities have also resulted in COVID-19 transmission to healthcare workers and family members visiting their loved ones to ensure they are provided with basic necessities such as food.

**Healthcare workers** acting to combat COVID-19 often operate under severely inadequate and unsafe conditions. Shortages of basic PPE are commonplace and widespread in countries, regardless of their status or level of economic development, resulting in a higher risk of COVID-19 infection for healthcare workers. Healthcare workers have been refused access to public transport and had their children forced to leave daycare centres. They have been threatened with eviction or actually evicted and chased away from homes.

The lives of **sex workers** in the majority of the world have been upended by COVID-19, with the majority having lost major sources of their income and nearly all of their work opportunities. COVID-19 relief measures typically exclude sex workers whose work remains criminalized in the majority of the world. Sex workers who continue to operate in person despite COVID-19 face significantly increased risks of COVID-19 transmission. Sex workers have also commonly experienced limitations in access to essential healthcare services.

The obligation of States to respect and protect the **rights to freedom of expression and information, privacy and health** are directly engaged in the context of COVID-19. Facilitating freedom of expression and information and providing extensive, accurate, transparent and regular health information improves the success of efforts to combat COVID-19. Yet States have often attempted to justify restrictions on such rights as necessary to combat COVID-19. Internet shutdowns or restrictions are a clear example of measures which unduly restrict access to health information and thereby significantly harm efforts to combat COVID-19 and protect the right to health. States have also used overly broad and unwarranted measures, purportedly to prohibit the spread of false information online during the pandemic, to crack down on political participation and expression disfavoured by authorities. Many States have implemented expanded surveillance mechanisms, most particularly through “contact tracing” applications, to assist in curbing the spread of COVID-19. Though carefully designed contact tracing measures may be effective, if adequate protections or safeguards for the rights to privacy and health are not provided, such measures risk serious and unjustifiable rights violations.

The **rights to health, housing, water, sanitation** and food are critical in themselves and as “social determinants” of health. Without access to housing, water, sanitation and food of an adequate level it is not possible for persons to enjoy the right to health. States must ensure a continuous and constant provision of water, soap and sanitizer to communities and individuals who do not have access to them during the COVID-19 pandemic. However, for many people living in poverty across the world, such basic resources remain unavailable. In addition, governments in many countries have failed to provide even emergency water access to many people and continue to allow disconnections of water and sanitation services for those who cannot afford to pay for them.

**Forced evictions** continue in many parts of the world and, even in States where moratoriums have been implemented, they have often been unduly limited to narrow categories of persons or for limited periods. Evictions do not only lead to large movements of people, which increases COVID-19 transmission, but also make it impossible to “stay at home”, a critical measure to combat COVID-19. Where they do exist, shelters for those without housing are often inadequate and lack provision for basic necessities for inhabitants.

**Limited access to food and water** directly and clearly impacts on the healthcare of persons so deprived and increases chances of COVID-19 transmission. Already, there have been reports of starvation deaths resulting from COVID-19 lockdown measures. In other instances, lacking any means of employment, persons are forced to wait for food parcels in long queues which increase their risk of COVID-19 transmission. In some places people have been assaulted or harassed by police when attempting to access food from community kitchens.

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Historically pandemics have often catalyzed significant social change. As historian of epidemics Frank Snowden puts it: “epidemics are a category of disease that seem to hold up the mirror to human beings as to who we really are”.<sup>14</sup> Simply put, one way or another, “the world we live in will never be the same”.<sup>15</sup>

For human rights to remain real and not illusory in the context of COVID-19, State and non-State actors will have to dramatically increase their efforts to produce human rights and rule of law-compliant COVID-19 responses. It is these individual and collective responses of State and non-State actors that could, as this report shows, ultimately serve as exemplars for a more humane future rather than “cautionary tales” of a painful and embarrassing past.<sup>16</sup>

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<sup>14</sup> I Chotiner Q&A with Frank Snowden, How Pandemics Change History (3 March 2020): <https://www.newyorker.com/news/q-and-a/how-pandemics-change-history>; F Snowden, Epidemics and Society: From the Black Death to the Present (26 November 2019) New Haven: Yale University Press.

<sup>15</sup> President Cyril Ramaphosa, Statement by President Cyril Ramaphosa on further economic and social measures in response to the COVID-19 epidemic (21 April 2020), available at: <http://www.thepresidency.gov.za/speeches/statement-president-cyril-ramaphosa-further-economic-and-social-measures-response-covid-19>.

<sup>16</sup> Per Sotomayor J in *Lady Curtis Valentine v Bryan Collier* 590 US SC (14 May 2020), available at: [https://www.supremecourt.gov/opinions/19pdf/19a1034\\_new\\_kifl.pdf](https://www.supremecourt.gov/opinions/19pdf/19a1034_new_kifl.pdf).

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