# **Human Rights and Infertility**

# Research paper\*

# Introduction

Globally, one in six people experience infertility in their lifetimes, regardless of the resource levels of the countries they live in.<sup>1</sup> However, the actual number of individuals and couples facing infertility may be significantly greater given that infertility is often not accurately measured in national surveys and because it is often a taboo and an invisible issue. Infertility occurs around the world, but has causes and distinct impacts on individuals, including due to, inter alia, gender, race, religion, sexual orientation, gender identity, sex characteristics, and socioeconomic and poverty status.

Even though not all infertility is preventable, data shows that there are numerous factors along an individual's life course (beginning as early as childhood and adolescence) that can determine their (in)fertility. The causes of infertility are often the cumulative result of denials of human rights, and can manifest in many forms, including State failures to meet their international human rights obligations (see section III). For example, failing to address barriers to health care to cure and prevent STIs and/or State action to actively reduce births amongst people belonging to certain population groups (e.g., forced, coercive and otherwise involuntary sterilization<sup>2</sup> of ethnic minorities or migrant women, women living with HIV, women with disabilities, indigenous women, and transgender and intersex people). Addressing the known preventable causes of infertility can minimize the need for costly and difficult-to-access treatments,<sup>3</sup> as well as significant and lifelong physical, mental, social, and economic consequences. <sup>4</sup> It can also reduce the far-reaching human rights impact of preventable infertility.

It is important to note that infertility is both a question of individuals and individual rights, and an element of collective concern because of the central role nations and communities assign to producing children as an essential aspect of their future sustainability. This key role assigned to 'reproducing the future' underlies many of the coercive pressures placed on individuals, primarily women, to produce progeny or

<sup>\*</sup> The Office of the High Commissioner for Human Rights appreciates the research and preparation of earlier drafts of this research paper by Jaime M. Gher and Payal K. Shah, fellows at the University of Toronto, International Reproductive and Sexual Health Law Program, Faculty of Law. OHCHR also benefited from the technical expertise of James Kiarie, Gitau Mburu, and Aasa Hanna Mari Nihlén from the UNDP-UNFPA-UNICEF-WHO-World Bank Special Programme of Research, Development and Research Training in Human Reproduction (HRP), Department of Sexual and Reproductive Health and Research, World Health Organization (WHO).

<sup>&</sup>lt;sup>1</sup> WHO, <u>Infertility prevalence estimates (1990-2021)</u>, Geneva, 2023.

<sup>&</sup>lt;sup>2</sup> See: An Inter-agency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, Eliminating forced, coercive and otherwise involuntary sterilization, 2014.

<sup>&</sup>lt;sup>3</sup> WHO, Key Facts: Infertility (3 April 2023).

<sup>&</sup>lt;sup>4</sup> Abdallah S. Daar, Zara Merali, <u>Infertility and social suffering: the case of ART in developing countries</u>, in: Effy Vayena, Patrick J. Rowe & P. David Griffin (eds), *Current Practices and Controversies in Assisted Reproduction: Report of a meeting on "Medical, Ethical and Social Aspects of Assisted Reproduction"*, World Health Organization, 2002.

to be restrained from reproduction, depending on the racial, ethnic and other cultural ideologies of the collective/nation.<sup>5</sup>

Gender stereotypes,<sup>6</sup> as well as assumptions about age, sexuality, sex characteristics, abilities (or perceived lack thereof) and other characteristics or aspects of identity, underlie many of these pressures, some of which are related to State policy. The issue of infertility, therefore, reveals the "multitude of ways that States may, through action or inaction, privilege the reproduction of some while dissuading the reproduction of others".<sup>7</sup> For example, States may promote high fertility rates amongst "desired" populations through pro-natalist policies, in an attempt to ensure national strength, economic growth and protection from outside aggression, as well as to preserve a "national identity".<sup>8</sup> This despite that international human rights law and standards explicitly requires that States enable all women to exercise their bodily autonomy.<sup>9</sup> Yet, individuals' capacity to control their reproductive decisions varies based in their race, sexual orientation, gender identity, sex characteristics, gender, class and socioeconomic status<sup>10</sup> and other status.

While there has been an increasing focus on access to infertility treatment, particularly on assisted reproductive technologies (ART), including in-vitro fertilization, there has been comparatively less attention paid to prevention of infertility and/or to addressing the human rights impacts of preventable loss of fertility. The aim of this research paper is to shine a light on the underlying causes that lead women and particular groups to experience preventable infertility or to be presumed infertile. The paper will also surface the breadth of human rights harms that result from infertility globally, which in many cases can impact nearly every aspect of individuals' lives. Additionally, because infertility, whatever its origins, can have distinct adverse rights impacts for affected persons, this paper also addresses some of the human rights consequences of actual or presumed infertility more generally.

<sup>&</sup>lt;sup>5</sup> According to UNFPA, "[p]opulation targets are often implicitly coercive, pushing people towards reproductive choices that they might not otherwise make themselves. This process unfolds along a spectrum, from public campaigns and persuasion, to subtle or overt discrimination, and even to the forced use or denial of contraception and other sexual and reproductive health services." in United Nations Population Fund (UNFPA), <u>State of the World Population: 8 billion lives, infinite possibilities: the case for rights and choices</u>, 2023, p.14.

<sup>&</sup>lt;sup>6</sup> Stereotypes can be defined as "[g]eneralised views or preconceptions about attributes or characteristics that are or should be possessed by members of a particular social group or the roles that are or should be performed by members of a particular social group. See: Office of the High Commissioner for Human Rights (OHCHR), Gender Stereotyping as a Human Rights Violation (commissioned report), 2013.

<sup>&</sup>lt;sup>7</sup> Arthur Greil, Julia McQuillan, and Kathleen Slauson-Blevins, *The Social Construction of Infertility*, in Sociology Compass, Vol. 5 (8), pp. 736-746, 2011.

<sup>&</sup>lt;sup>8</sup> The Working Group on Discrimination against Women and Girls has stated, for example, that "[t]hroughout their life cycle, women's bodies are instrumentalized and their biological functions and needs are stigmatized and subjected to a politicized patriarchal agenda. States have also often treated women instrumentally as tools with which to implement population programmes and policies." in Human Rights Council, *Report of the Working Group on Discrimination against Women and Girls*, <u>A/HRC/32/44</u> (2016), paras. 61-62. *See also* UNFPA, *State of the World*, *2023*, *supra* note 5, in particular, p. 30-33 providing an overview of the long history of population debates.

<sup>&</sup>lt;sup>9</sup> See: <u>A/HRC/32/44</u> (2016), para. 106(e); and, Committee on Economic Social and Cultural Rights, *General Comment No.* 16 on the right to sexual and reproductive health, <u>E/C.12/GC/22</u> (2016), para. 25.

<sup>&</sup>lt;sup>10</sup> United Nations General Assembly, *Report of the Special Rapporteur on the right to physical and mental health*, <u>A/76/172</u> (2021), para. 4.

Section I of this paper sets forth the methodology for the research. Section II summarizes prevailing definitions of infertility and presents a human rights-based reconceptualization of infertility. Following this, Section III begins by providing an overview of the key human rights implicated by infertility. After the overview, this section enumerates the human rights causes and consequences of preventable infertility and outlines States' obligations to address them in accordance with international human rights law and standards. The paper does not provide a comprehensive analysis of regional human rights law and standards, but instead highlights them where especially relevant in filling a gap related to issues around infertility in international human rights law and standards. The research paper concludes by inviting relevant stakeholders to raise the profile of the human rights causes and consequences of preventable infertility.

# I. Methodology

The research paper is largely based on research conducted for the Office of the High Commissioner for Human Rights (OHCHR) by two independent consultants. <sup>11</sup> The analysis in the paper is the culmination of a comprehensive literature review, desk-based research, and interviews with key experts and stakeholders in nearly every region of the world with professional and lived experience around fertility, infertility, gender, sexuality, health and human rights. Four regional group discussions were held in Asia, East and West Africa, and Latin America.

OHCHR is grateful to all stakeholders who agreed to be interviewed, participated in a focus group discussion and/or provided information during this research.

# II. Definitions, parameters and scope of infertility

There are a range of definitions of infertility. Historically, infertility has been viewed primarily through a biomedical lens. However, over time, the range of factors that impact individuals' fertility and/or exercise of their fertility, as well as the differentiated and disparate impact of these factors on women and particular groups of individuals, has been increasingly acknowledged. It is essential to bear this in mind when assessing the scope of infertility, as definitions and conceptual frameworks influence and impact research and statistics around fertility and resulting legal and policy responses. <sup>12</sup> Current statistics may be underinclusive and fail to portray the whole picture of experiences of infertility nationally and worldwide. Set forth below, is the biomedical definition of infertility used by the World Health Organization (WHO) and other medical and scientific institutions, an overview of social understandings of infertility, and a broader human rights conceptualization of infertility that may be useful to develop human rights-based responses.

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<sup>&</sup>lt;sup>12</sup> For more information about fertility research gaps and measurement challenges see: WHO, supra note 1, chapter 4.

# A. Biomedical definitions of infertility

The WHO defines infertility as "a disease of the male or female reproductive system characterized by the failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse." Therefore, the **biomedical causes** of infertility are rooted in disorders with an individuals' reproductive organs (see text box 1). Biomedical infertility can manifest as primary or secondary infertility. **Primary infertility** is when a pregnancy has never been achieved by a person<sup>14</sup> and is caused by anatomical, genetic, endocrinological, and immunological problems. **Secondary infertility** is when at least one prior pregnancy has been achieved<sup>15</sup> and is usually caused by sexually transmitted infections (STIs), substandard health care practices, including unsafe abortion and poor maternal health care, exposure to toxins, and socio-cultural practices such as endogamous marriages (marriage between relatives), and female genital mutilation (FGM). **Secondary infertility is more common** than primary infertility **and is relatively preventable**. For example, it has been estimated that about 10.5% of women around the world have experienced secondary infertility, and roughly 2% have experienced primary infertility. <sup>16</sup>

In general, biomedical definitions of infertility are underinclusive as they have been developed on the experience of cisgender, heterosexual, able-bodied individuals (largely women) in sexual relationships. <sup>17</sup> As such, biomedical definitions fail to account for the experiences of lesbian, gay, bisexual, transgender and intersex (LGBTI) individuals who may retain reproductive capacity biomedically but who are unable to utilize their own fertility to have children <sup>18</sup> due to legal, social and cultural factors. This is important to bear in mind as how one defines infertility impacts data collection on the prevalence of infertility and may

<sup>&</sup>lt;sup>13</sup> *Ibid.*, and, WHO, *supra* note 3.

<sup>&</sup>lt;sup>14</sup> WHO, *supra* note 3.

<sup>&</sup>lt;sup>15</sup> Ibid.

<sup>&</sup>lt;sup>16</sup> Sara Hodin, *The Burden of Infertility: Global Prevalence and Women's Voices from Around the World*, in Maternal Health Task Force (MHTF) Blog, 18 January 2017. See also: Mascarenhas MN, Flaxman SR, Boerma T, Vanderpoel S, Stevens GA (2012) *National, Regional, and Global Trends in Infertility Prevalence Since 1990: A Systematic Analysis of 277 Health Surveys*, in: PLoS Med 9(12), stating that "in 2010, 1.9% of women aged 20–44 years who wanted to have children were unable to have their first live birth (primary infertility), and 10.5% of women with a previous live birth were unable to have an additional live birth (secondary infertility)." "These findings also suggests that global levels of primary and secondary fertility hardly changed between 1990 and 2010."

<sup>&</sup>lt;sup>17</sup> Also, as causes of biomedically infertility tend to be distinguished based on male or female reproductive systems, it is important to note that utilizing binary categorizations of reproductive systems ("male" and "female"), can be underinclusive and inaccurate. For example, individuals born with variations of sex characteristics (intersex people) may have a reproductive system that does not squarely fit within typical "male" or "female" categorizations. Additionally, some transgender individuals undergo interventions, which can range from hormone therapy to surgical interventions to organ transplants, which can enable them to change their category of reproductive system or make it so that they do not fall within a particular reproductive category or span more than one. *See, e.g.*, Emily Wiesenthal, BA, Kristy Cho, MD, FRCSC, Jeffrey Roberts, MD, FRCSC, Caitlin Dunne, MD, FRCSC. Fertility options for transgender and gender-diverse people. BCMJ, Vol. 64, No. 2, March 2022, pp. 75-80; and, Mindy Jane Roseman, *The Fruits of Someone Else's Labour?: Gestational Surrogacy in the Twenty-First Century*, in Andreas von Arnauld, Kerstin von der Decken; and, Mart Susi, eds. *The Cambridge Handbook of New Human Rights: Recognition, Novelty, Rhetoric*, Cambridge University Press, 2020, p. 314 (stating that as defined, medical infertility "presumes the heterosexuality of individuals involved and biologic dysfunction in their reproductive systems...").

<sup>&</sup>lt;sup>18</sup> For the purposes of this paper, the expressions "to utilize their own fertility to have children" and "to have children" are used interchangeably. It should also be noted that "[f]ertility desires are private choices regarding whether to have any children, to delay or stop having children. They are an expression of individual preference, which is linked to bodily autonomy, sexuality and reproduction. Consequently, everyone should be empowered to make an informed decision regarding if, how many and when to have children." See Gitau Mburu et al, Fulfilment of fertility desires for the attainment of Global Sustainable Development Goals, in BMJ Global Health, 2023.

impede the design and implementation of effective legal and policy responses which uphold the rights of all persons without discrimination. <sup>19</sup> Notably, there is little information on the prevalence of infertility among single cisgender women, as well as lesbian, gay, bisexual, transgender and intersex people. However, as discussed throughout this paper, State laws and policies and direct and indirect action by State and non-state actors can lead these individuals to facing significant barriers to utilizing their own fertility to have children.

#### Text Box 1: Biomedical Causes of Infertility

In its 2023 Key Facts on infertility, the WHO has outlined several leading causes of biomedical infertility, including:

- Tubal disorders such as blocked fallopian tubes, which are in turn caused by untreated sexually transmitted infections (STIs) or complications of unsafe abortion, postpartum sepsis or abdominal/pelvic surgery;
- Uterine disorders which could be inflammatory in nature (such as endometriosis), congenital in nature (such as septate uterus), or benign in nature (such as fibroids);
- Disorders of the ovaries, such as polycystic ovarian syndrome and other follicular disorders;
- Disorders of the endocrine system causing imbalances of reproductive hormones. The endocrine system includes hypothalamus and the pituitary glands. Examples of common disorders affecting this system include pituitary cancers and hypopituitarism.
- Obstruction of the reproductive tract causing dysfunctionalities in the ejection of semen. This blockage can occur in the tubes that carry semen (such as ejaculatory ducts and seminal vesicles). Blockages are commonly due to injuries or infections of the genital tract;
- Hormonal disorders, including cancers, leading to abnormalities in hormones produced by the pituitary gland, hypothalamus and testicles that regulate sperm production.
- Testicular failure to produce sperm, for example due to varicoceles or medical treatments that impair sperm-producing cells (such as chemotherapy); and
- Abnormal sperm function and quality. Conditions or situations that cause abnormal shape (morphology) and movement (motility) of the sperm negatively affect fertility.

Some of the disorders listed in text box 1 may be caused or exacerbated by State failures to prevent ill-health, provide preventative health care, respect reproductive autonomy, or ensure the underlying determinants of sexual and reproductive health, including access to healthy working conditions and environment, and access to health-related education and information and effective protection from all forms of violence, and discrimination.<sup>20</sup>

# B. Social definitions and understandings of infertility

The social/situational causes of infertility are rooted on the myriad legal, regulatory, cultural or social barriers that impede individuals' ability to have children rather than on physiological factors. Some refer

 $<sup>^{19}</sup>$  See: WHO,  $supra\ note\ 1$  and UNFPA,  $supra\ note\ 5$ .

<sup>&</sup>lt;sup>20</sup> E/C.12/GC/22 (2016), para. 7.

to this as "social infertility,"<sup>21</sup> "situational" infertility,<sup>22</sup> "structural infertility"<sup>23</sup> or "conditional childlessness".<sup>24</sup> Same-sex couples, single individuals who wish to have children in the absence of a partner, couples in which one or both partners are transgender, persons with disabilities and people living with HIV could fall, depending on the legal, regulatory, cultural and social context, under the category of social infertility. Often, these couples or individuals are confronted with stereotypes around individuals' bodies, sexuality and reproduction impacting their ability to utilize their own fertility to have children. Sometimes these couples or individuals may retain reproductive capacities but may require medical assistance to have children. However, discriminatory legislation limiting access to fertility treatments only to, for example, heterosexual married couples impede access to reproductive technologies for some of them.<sup>25</sup>

On a practical level, many individuals are perceived or perceive themselves to be infertile even when they do not fit biomedical definitions. <sup>26</sup> This may be rooted in lack of awareness around fertility and/or cultural norms, such as those that set short periods for women to achieve a pregnancy before being considered infertile. Additionally, situational factors impact individuals' perceptions of their fertility. For example, individuals may only regard themselves as infertile once they are actively seeking to have children. <sup>27</sup> Similarly, once individuals can access assisted reproductive technologies (ART) or surrogacy, they may no longer consider themselves infertile even if they meet a biomedical definition. Regardless of whether one receives a medical diagnosis of infertility or not, the human rights impacts can be the same. As such, references to people experiencing infertility and presumed to be infertile are used, at times, interchangeably throughout this report.

# C. Reconceptualizing infertility in human rights terms

While biomedical definitions capture some amount of infertility, a reconceptualization of infertility which includes its social/situational and structural causes, and its human rights implications can more comprehensively reflect the experiences of those who cannot realize their intentions to utilize their own fertility to have children due to biomedical, legal, social, cultural, environmental, and/or other factors. <sup>28</sup> It can also better equip States to prevent infertility and its human rights impacts, as well as provide redress for human rights violations due to actual or perceived infertility. This reconceptualization can broaden

<sup>&</sup>lt;sup>21</sup> Lisa Campo-Engelstein, *How Should we Define Infertility and Who Counts as Infertile?*, in Bioethics Today, 20 April 2015; Anna Louie Sussman, *The Case for Redefining Infertility*, The New Yorker, 18 June 2019.

<sup>&</sup>lt;sup>22</sup> Interview with key expert, 19 October 2020.

<sup>&</sup>lt;sup>23</sup> Judith F. Daar, *Accessing reproductive technologies: invisible barriers, indelible harms*, in Berkeley Journal of Gender, Law and Justice, 23 (2008), pp. 24

<sup>&</sup>lt;sup>24</sup> Martha F. Davis and Rajat Khosla, *Infertility and Human Rights: A Jurisprudential Survey*, in Columbia Journal of Gender and Law, Vol. 40, No. 1 (2020), pp. 9-10. There are also social constructions and definitions of infertility not fully explored in this research paper. See, *e.g.*, Lisa C. Ikemoto, *The In/Fertile*, the Too Fertile, and the Dysfertile, 47 Hastings L.J. 1007, 1996.

<sup>&</sup>lt;sup>25</sup> See for example: Judith F. Daar, supra note 23; and, Martha F. Davis and Rajat Khosla, supra note 24.

<sup>&</sup>lt;sup>26</sup> OHCHR, Asia Focus Group Discussion (5 November 2020); OHCHR, East Africa Focus Group Discussion (12 November 2020); OHCHR, West Africa Focus Group Discussion (18 November 2020); and OHCHR, Latin America Focus Group Discussion (20 November 2020).

<sup>&</sup>lt;sup>27</sup> Zubia Mumtaz et al., <u>Understanding the impact of gendered roles on the experiences of infertility amongst men and women in Puniab</u>, in Reproductive Health Journal, Vol. 10, No. 3; Arthur Greil *et al.*, *supra* note 7.

<sup>&</sup>lt;sup>28</sup> Mindy Jane Roseman, supra note 17, p. 314.

scientific, scholarly and human rights analysis of infertility and better place key stakeholders to hold States accountable for direct and indirect State action that impedes individuals' fertility and/or prioritizes the fertility of some over others in a discriminatory manner.

It is important to note that individuals may choose not to have children. Such choices should be respected, supported, and not result in stigma, discrimination, and other human rights related harms. States must respect and promote support for the diversity of life choices.

# III. Human Rights Dimensions of Preventable Infertility

Infertility was identified as a key sexual and reproductive health issue in international conferences, such as the International Conference on Population and Development (ICPD) Programme of Action<sup>29</sup> and the Beijing Platform for Action.<sup>30</sup> Over time, however, lack of implementation of global commitments around infertility, including within the 2030 agenda for Sustainable Development,<sup>31</sup> has contributed to the little attention infertility-related human rights issues receive and the consequent lack of accountability for related violations. Globally, measures to enable women to prevent unwanted pregnancy have been prioritized yet measures to ensure preservation of fertility and realization of individuals' fertility intentions remain unaddressed.

Measures to prevent unwanted pregnancies are essential to reproductive autonomy and to the full realization of human rights, equally important are broader efforts to also ensure people have an equal opportunity to have children, for those who desire to do so. At present, individuals are disparately and differently impacted by infertility, based on factors such as their gender, race, ethnicity, sexual orientation, gender identity, sex characteristics and socioeconomic and poverty status. In this context, interviewees for this research paper emphasized the importance of recognizing that for women and certain groups of individuals, autonomy to make decisions around pregnancy—including specifically the decision to become pregnant— is often actively impeded and constitutes a tool of oppression.

Given this reality and the number and diversity of people impacted by infertility, there is an urgent need to examine the human rights implications of preventable infertility, particularly through the sexual and reproductive health and rights framework. There are several key human rights related to preventable infertility and fertility-related consequences, including the rights to bodily autonomy, health, found a family, and non-discrimination.

<sup>&</sup>lt;sup>29</sup> "All countries should strive to make accessible through the primary health-care system, reproductive health to all individuals of appropriate ages...Reproductive health care in the context of primary health care should, *inter alia*, include:... prevention and appropriate treatment of infertility..." See: United Nations, *Programme of Action*, International Conference on Population and Development, Cairo, 5-13 September 1994, <u>A/CONF.171/13/Rev.1</u> (1995), chapter VII, para. 7.6.

<sup>&</sup>lt;sup>30</sup> "...infertility affect growing numbers of women and may be preventable, or curable, if detected early." See: United Nations, Beijing Declaration and the Platform for Action, Fourth World Conference on Women, Beijing, China, Sept. 4-15, 1995, A/CONF.177/20 (1995), para. 100.

<sup>&</sup>lt;sup>31</sup> It has been stated that "while global efforts on sexual and reproductive health and rights have contributed to progress on Sustainable Development Goals (SDGs), fulfilment of fertility desires is still suboptimal." See Gitau Mburu et al, supra note 18. For information on the SDGs see United Nations, Department of Economic and Social Affairs, Sustainable Development, The 17 Sustainable Development Goals (SDGs), in particular SDGs 3 and 5.

#### Text Box 2: Overview of Key Human Rights Related to Preventable Infertility

The ability to decide if, when, and how often to reproduce is grounded in a range of human rights, including but not limited to equality and non-discrimination, bodily autonomy, health, and to found a family. Preventable infertility and its harmful gendered consequences interfere with individuals' ability to exercise these rights:

- > Gender, intersectional, and structural forms of discrimination lead to barriers for individuals to enjoy their sexual and reproductive health and rights and are key drivers of preventable infertility, thus implicating the **right to equality and non-discrimination**. Restrictive gender norms and stereotypes can also exacerbate the human rights harms and violations related to one's inability or decision to not have children, which essentially punish individuals primarily women and girls for failing to fulfill and/or transgressing their gender role. Gender, racial, and other discriminatory stereotypes around "motherhood" lead to certain individuals' reproduction being privileged while preventing or discouraging the reproduction of others.
- Addressing preventable infertility and its harmful consequences is essential to ensuring that individuals can exercise their bodily autonomy and integrity, which is a central component of the rights to life, privacy, liberty and security, physical and mental integrity, amongst others, and includes individuals' rights to make informed decisions about their bodies, to determine the number and spacing of their children, and to be free from torture, cruel or inhuman and ill-treatment, coercion and violence.
- Infertility-related information and services are guaranteed under the **right to enjoyment of the highest attainable standard of physical and mental health**, which includes the right to sexual and reproductive health. Several causes of infertility are linked to broader barriers to sexual and reproductive health services and denials of the underlying determinants of health (e.g. **safe and healthy working conditions and environment**, access to health-related **education and information**, and **freedom from violence**). Unequal power distribution and social inequalities based on gender, ethnic origin, age, disability, and other factors known as social determinants of health also shape patterns of sexual and reproductive health across borders, including infertility.
- When individuals experience infertility and are unable to have children, if they desire to do so, to pursue their own life paths, their rights to found a family and to private and family life are implicated. Patterns of preventable infertility may reflect States' or societies' view of what constitutes the "ideal" or "acceptable" family, who is allowed and/or worthy of forming a family, and/or who is counted as experiencing infertility.

These rights, together with others, give rise to robust State obligations to ensure prevention, diagnosis, and treatment of infertility and to address the discriminatory stereotypes, practices, and structures that exacerbate the harmful consequences of preventable infertility.

Squarely situating preventable infertility within the international human rights framework is essential to recognizing violations individuals can suffer, identifying the underlying and social determinants and structural drivers of infertility, and outlining States' obligations to prevent infertility and remedy violations that both lead to and are based on infertility. State obligations include the obligations to respect, protect and fulfill human rights. Non-state actors may also be implicated, for example, when occupational hazards contribute to preventable infertility risks.

Raising the profile of these important human rights issues may also lay the groundwork for prioritizing infertility prevention and treatment within larger sexual and reproductive health and rights and the 2030 Agenda for Sustainable Development and contribute to the implementation of the infertility related commitments included in the ICPD and the Beijing Platform.<sup>32</sup> To provide comprehensive rights protection, free of gender stereotypes, efforts to increase attention to infertility prevention must be coupled with substantial efforts to destigmatize the decision to not have children. Rights are intended to enable decision-making across a wide variety of futures for all persons to imagine.

The two subsections below will highlight the main causes and consequences of infertility and outline States' obligations to prevent infertility and infertility-related violations and harms, as well as providing redress for those. Due to the diverse and overlapping nature of the causes and consequences of infertility, this section is not organized according to distinct rights, but rather by issue. The aim of this approach is to show the interconnections between and cumulative impact of the diverse causes of infertility and the human rights violations that can follow. It also seeks to provide clarity that the realization of States' existing obligations to respect, protect and fulfill human rights (particularly to sexual and reproductive health and rights) would go a long way in combatting infertility and human rights violations that are based on the inability of some individuals to have children.

# A. Human rights causes of preventable infertility

While not all infertility is preventable, <sup>33</sup> addressing known avoidable causes of infertility can minimize the need for costly and difficult-to-access treatments, <sup>34</sup> as well as significant and lifelong physical, mental, social, and economic consequences. <sup>35</sup> As previously mentioned, many causes of infertility are often the cumulative result of denials of human rights. Preventable infertility has biomedical, social/situational, and structural causes.

**Biomedical and social/situational causes** (see section II) **can intersect**, such as where a woman experiences a preventable reproductive disorder due to structural barriers to healthcare arising from her identity or socio-economic status. Infertility may also result from broader **structural causes** impacting reproductive decision-making due to income inequality and lack of social safety nets; systemic barriers to healthcare for marginalized groups; high prevalence of violence against children of a certain population,

<sup>32</sup> See supra notes 29 and 30.

<sup>&</sup>lt;sup>33</sup> "Several causes of infertility are preventable, such as infertility caused by STIs, post-partum infections and unsafe abortions, lifestyle factors if good quality sexual and reproductive health and rights information and services are available. However, PCOS [polycystic ovary syndrome], POI [primary ovary insufficiency], male factors, uterine and tubal abnormalities, endometriosis, repeated miscarriages, immunological issues are all unpreventable. A focus on prevention of infertility is much needed, however, it also needs to be recognized that not all infertility cases can be prevented. For people affected by these causes, there needs to be proper, counselling and management and treatment of infertility." See Share-Net International, <u>Breaking the Silence around Infertility: A Narrative Review of Existing Programmes, Practices and Interventions in Low and Lower-Middle Income Countries, 2019.</u>

<sup>&</sup>lt;sup>34</sup> WHO, *supra* note 3.

<sup>&</sup>lt;sup>35</sup> Abdallah S. Daar, Zara Merali, <u>Infertility and social suffering: the case of ART in developing countries</u>, *in* Current Practices and Controversies in Assisted Reproduction: Report of a meeting on "Medical, Ethical and Social Aspects of Assisted Reproduction held at WHO Headquarters in Geneva, Switzerland 17-21 September 2001 (2002),

which can lead to avoiding childbearing; criminalization and over incarceration of certain groups that can inhibit reproduction by restricting sexual contact or access to assisted reproductive technology (ART); and/or structural racism.<sup>36</sup> For example, certain marginalized people, including people living with HIV, people with disabilities, LGBTI individuals, criminalized populations and migrants, may face multiple human rights violations and abuses over their life course that together can contribute to infertility. The Committee on Economic, Social and Cultural Rights (CESCR) and WHO recognize such non-medical factors that limit sexual and reproductive health decision-making as social determinants of health.<sup>37</sup>

The **social/situational and structural causes**, and the **human rights impacts of preventable infertility are deeply gendered**, in part, due to longstanding gender stereotypes around individuals' bodies, sexualities and reproduction, such as those linked to women's presumed roles as "mothers" and "caretakers."<sup>38</sup> As women face significant pressure to have children, if they are unable to or choose not to, they are often made to feel that they have failed to achieve their role in society and/or treated as if they are damaged and unworthy, <sup>39</sup> even in cases where a couple is dealing with male-factors of infertility. <sup>40</sup> While men can also experience great shame around infertility, they do not face the same threats of social, financial and health insecurity as women in similar circumstances. <sup>41</sup> The persistence of social norms that base women's value on their ability to reproduce fuels stigma and discrimination against women who face infertility or who choose not to have children, which plays a significant role in fueling and exacerbating the human rights violations that ensue.

A concerted effort to transform gender norms and eradicate gender stereotypes that lead to and exacerbate the human rights impacts of infertility is also a key component of States' obligations to prevent the grave suffering that individuals, in particular women, face as a result of stigma, violence and discrimination based on infertility<sup>42</sup> (see below subsection on stigma and mental health harm).

<sup>&</sup>lt;sup>36</sup> Interview with key expert, 19 October 2020 (referring to structural causes of infertility as "situational causes").

<sup>&</sup>lt;sup>37</sup> E/C.12/GC/22 (2016), paras. 7-8; see also WHO, Commission on Social Determinants of Health, Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health – Final Report of the Commission on Social Determinants of Health, 2008.

<sup>38</sup> Artavia Murillo et al. v. Costa Rica, Inter-American Court of Human Rights, 2012, paras. 294-295, 297-298, 302; and, OHCHR, Gender Stereotyping, supra note 6.

<sup>&</sup>lt;sup>39</sup> Nahar Papreen, Anjali Sharma, Keith Sabin, Lutfa Begum, S. Khaled Ahsan & Abdulla H. Baqui, <u>Living with infertility: Experiences among urban slum populations in Bangladesh</u>, Reproductive Health Matters, Vol. 8, No. 15, 2000, pp. 33-44.

<sup>&</sup>lt;sup>40</sup> OHCHR, Asia Focus Group Discussion (5 November 2020), Latin America Group Discussion (20 November 2020), East Africa Focus Group Discussion (12 November 2020), West Africa Group Discussion (18 November 2020). "Globally, the main cause of infertility reported in a large WHO multi-country study involving 8500 couples in 25 countries was due to female factors in 37% of cases, both male and female factors in 35%, and male factors in 8%." See: World Health Organization (1992), *Recent advances in medically assisted conception: report of a WHO scientific group* [meeting held in Geneva from 2 to 6 April 1990], World Health Organization.

<sup>&</sup>lt;sup>41</sup> *Ibid. See* also Mumtaz, Z., Shahid, U., Levay, A., <u>Understanding the impact of gendered roles on the experiences of infertility amongst men and women in Puniab</u>, Reproductive Health Matters, Vol. 10, No. 3, 2013. (The article compares the impact of infertility between women and men in Pakistan, noting that while infertile women are unable to access the status, power, and marital security that motherhood provides and face abuse, exclusion and stigmatization, infertile men do not suffer from marital insecurity and may only face taunting from friends).

<sup>&</sup>lt;sup>42</sup> See Artavia Murillo et al. v. Costa Rica, supra note 38.

Preventable infertility can also be analyzed through the prism of reproductive oppression—that is, the control and exploitation of women, girls, and individuals through their bodies, sexuality, labor, and reproduction, which often manifests intersectionally.<sup>43</sup> Indeed, discrimination itself is linked to infertility.<sup>44</sup> On a global level, there has historically been an underinvestment in infrastructure and financing by international donors to prevent infertility due to the prioritization of efforts to control population growth in low- and middle- income countries.<sup>45</sup> At the national and community level, structural discrimination and discriminatory stereotypes are drivers of certain groups experiencing State neglect of preventable infertility and/or policies and practices that lead to forced or coerced deprivation of reproductive capacity. Across the causes discussed in this section, it is critical to recognize that these drivers are at the root of why preventable causes of infertility persist.

This section enumerates **several causes of preventable infertility** from a human rights lens and sets forth state obligations to address these causes under international human rights law and standards.

## 1. Lack of access to quality sexual and reproductive health services

Lack of access to preventative health services, including sexual and reproductive health care, is a cause of infertility for some individuals. As Preventable infertility is linked to barriers in accessing safe abortion, contraceptive information and services, maternal health care, and treatment for sexually transmitted infections (STIs) and other pelvic or reproductive tract infections (RTIs). Untreated STIs and complications from unsafe abortion, postpartum sepsis, or abdominal or pelvic surgery can lead to tubal disorders such as blocked fallopian tubes.

In regions where there are high rates of unsafe abortion and poor maternity health care leading to post-partum (including post-abortion) infections, women often experience secondary infertility as the result of untreated reproductive tract infections (RTIs) causing tubal blockage. <sup>49</sup> In sub-Saharan Africa, more than 85% of cases of infertility in women are estimated to be caused by poorly managed or untreated RTIs, compared with 33% of women worldwide. <sup>50</sup> Individuals interviewed for this research paper also noted

<sup>&</sup>lt;sup>43</sup> Loretta Ross, *What is Reproductive Justice?*, in <u>Reproductive Justice Briefing Book: A Primer on Reproductive Justice and Social Change</u>, Hampshire College, The Civil Liberties and Public Policy Program.

<sup>&</sup>lt;sup>44</sup> For instance, one interviewee noted, the ongoing trauma of racism is a cause of infertility for Black women in America due the mental and physical stress it places on individuals' bodies. *See* also, Prather C, Fuller TR, Marshall KJ, Jeffries WL 4<sup>th</sup>, *The Impact of Racism on the Sexual and Reproductive Health of African American Women*, Journal of Women's Health, Vol. 25 (7), 2016, pp. 664-671; Yetunde Ibrahim and Temeka Zore, *The pervasive issue of racism and its impact on infertility patients: what can we do as reproductive endocrinologists?*, Journal of Assisted Reproduction and Genetics, Vol. 37 (7), July 2020, pp. 1563–1565; Dorothy Roberts, *Killing the Black Body: race, reproduction and the meaning of liberty*, 2017, p. xi-xxi (preface).

<sup>&</sup>lt;sup>45</sup> F. Van Balen, <u>Involuntary childlessness: a neglected problem in poor-resource areas</u>, in *ESHRE Monographs*, Volume 2008, Issue

<sup>1,</sup> July 2008, pp. 25–28; Arthur Greil *et al., supra* note 7.

<sup>&</sup>lt;sup>46</sup> Latin America Focus Group Discussion (20 November 2020).

<sup>&</sup>lt;sup>47</sup> WHO, *supra* note 3.

<sup>48</sup> Ihid

<sup>&</sup>lt;sup>49</sup> Marcia C. Inhorn and Pasquale Patrizio, *Infertility around the globe: new thinking on gender, reproductive technologies and global movements in the 21st century, in* Human Reproduction Update, Volume 21, Issue 4, July/August 2015, pp. 411–426. <sup>50</sup> Mascarenhas MN, Flaxman SR, Boerma T, and Vanderpoel S Stevens GA, *National, regional, and global trends in infertility prevalence since 1990: a systematic analysis of 277 health surveys, in PLoS Med, Vol. 9, Issue 12, December 2012, pp. 1–12.* 

that barriers to menstrual health and unmanaged reproductive health conditions such as polycystic ovary syndrome and fibroids are linked to infertility.<sup>51</sup> While these conditions may be unpreventable, comprehensive reproductive health care could include treatment.<sup>52</sup>

While male infertility is often considered difficult or impossible to prevent due to unknown causes or its genetic origins, preventable male infertility is often rooted in STIs that cause obstructions along the seminal tract.<sup>53</sup> It has been reported for example that in Central and Southern Africa almost half of men have a medical history of STIs.<sup>54</sup>

Barriers to sexual and reproductive health services include cost, lack of physical or information accessibility, insufficient availability, or poor-quality care. Laws and policies that criminalize or restrict abortion and access to the full range of contraceptive methods, require third-party authorization, over-medicalize reproductive health, or fail to include sexual and reproductive health-care services in national health coverage also constitute significant barriers.<sup>55</sup>

Marginalized groups often face distinct barriers to quality sexual and reproductive health services to prevent infertility, due to structural discrimination. For women and girls with disabilities, interviewees noted that laws that require third-party consent for services represent serious obstacles. <sup>56</sup> Similarly, adolescents also face barriers to sexual and reproductive health services due to taboos around adolescent sexuality and attached stigma impeding access to condoms that can prevent STIs, treatment for STIs, or other services critical to retain fertility. <sup>57</sup> Criminalization of certain populations, including sex workers, people living with HIV/AIDS, people who use drugs, and LGBT people, also deters individuals from seeking preventative and curative health care or leads to individuals being denied care or harassed when they do seek care. <sup>58</sup> Furthermore, the scarcity of research and information about health services for transgender men, including pregnancy services and other sexual and reproductive health services lead to further stigma and prejudice against them <sup>59</sup> and lack of quality and appropriate healthcare, including on fertility. <sup>60</sup> Structural racism also impacts fertility; interviewees noted that "[while in certain contexts] Black women

<sup>&</sup>lt;sup>51</sup> OHCHR, West Africa Focus Group Discussion (18 November 2020); Interview with key expert (9 November 2020).

<sup>&</sup>lt;sup>52</sup> Ann M Starrs, MIA, Alex C Ezeh, PhD, Gary Barker, PhD, Prof Alaka Basu, MSc, Prof Jane T Bertrand, PhD, Prof Robert Blum, PhD, et al, <u>Accelerate progress—Sexual and reproductive health and rights for all: Report of the Guttmacher—Lancet Commission</u>, (2018).

<sup>&</sup>lt;sup>53</sup> Marcia C. Inhorn and Pasquale Patrizio, *supra* note 49.

<sup>&</sup>lt;sup>54</sup> Marcia Inhorn, <u>Right to Assisted Reproductive Technology: Overcoming Infertility in Low-Resource Countries</u>, International Journal of Gynecology and Obstetrics, Vol. 106, Issue 2, 2009, pp. 172-174.

<sup>&</sup>lt;sup>55</sup> <u>A/HRC/32/44</u> (2016).

<sup>&</sup>lt;sup>56</sup> OHCHR, Latin America Focus Group Discussion (20 November 2020).

<sup>&</sup>lt;sup>57</sup> Mahmoud Fathalla, <u>Current Challenges in Assisted Reproduction</u>, in WHO, Current Practices and Controversies in Assisted Reproduction: Report of a meeting on "Medical, Ethical and Social Aspects of Assisted Reproduction", 2002.

<sup>&</sup>lt;sup>58</sup> OHCHR, Asia Focus Group Discussion (5 November 2020).

<sup>&</sup>lt;sup>59</sup> Human Rights Council, Report of the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, <u>A/HRC/50/27</u> (2022), para. 71.

<sup>&</sup>lt;sup>60</sup> See: Emily Wiesenthal et al., supra note 17; and, National Center for Transgender Equality, <u>Transgender Sexual and Reproductive Health: Unmet Needs and Barriers to Care</u>, (2012).

may have access to contraceptive health information and services through the public health system, the system fails to ensure services to remove long-acting removable contraceptives."<sup>61</sup>

# i. States' Human Rights Obligations

**Sexual and reproductive health and rights are an integral component of the right to health**. <sup>62</sup> The CESCR has confirmed that the right to health includes the enjoyment of sexual and reproductive health without discrimination. This includes both ensuring the absence of disease and provision of care to prevent poor sexual and reproductive health, as well the underlying and social determinants of sexual and reproductive health and to take steps to prevent ill-health in that regard. <sup>63</sup>

Ensure the AAAQ<sup>64</sup> of the full range of sexual and reproductive health goods, facilities, and services: The right to health further requires ensuring sexual and reproductive health goods, health facilities, and services are available, accessible including physically and economically, acceptable to needs of the community and minorities, and of good quality, <sup>65</sup> and "adopt[ing] appropriate legislative, administrative, budgetary, judicial, promotional and other measures to ensure the full realization of the right to sexual and reproductive health." <sup>66</sup> The CESCR has specifically called on States to ensure universal access without discrimination to a full range of quality sexual and reproductive health care, including, among other things, "diagnosis and treatment of infertility, reproductive cancers, sexually transmitted infections and HIV/AIDS...". <sup>67</sup>

As a distinct sexual and reproductive health condition, States have an obligation under the right to health to prevent, detect, and treat infertility. Ensuring sexual and reproductive health and rights in line with international human rights law and standards would result in great progress in preventing infertility. Further, States can prevent several leading causes of infertility by providing safe abortion services (including post-abortion care), quality maternal health care, contraceptive information and services, and measures to prevent, rapidly diagnose, and treat infections including those that are sexually transmitted and medically iatrogenic (e.g., relating to illness caused by medical examination or treatment). <sup>68</sup>

<sup>&</sup>lt;sup>61</sup> Interview with key expert (19 October 2020).

<sup>62</sup> E/C.12/GC/22 (2016), para. 1; Committee on Economic Social and Cultural Rights, General Comment No. 14 on the right to the highest attainable standard of health, E/C.12/2000/4 (2000), paras. 2, 8, 11, 16, 21, 23, 34 and 36; CEDAW, art. 12(1); Committee on the Elimination of Discrimination against Women, General Recommendation No. 24 on women and health, A/54/38/Rev.1, Chap. I (1999), paras. 11, 14, 18, 23, 26, 29, 31 (b); CRC, arts. 17, 23-25 and 27; Committee on the Rights of the Child, General Comment No. 15 on the right of the child to the enjoyment of the highest attainable standard of health, CRC/C/GC/15 (2013); CRPD, arts. 23 and 25; CERD, art. 25; ACHPR, art. 16(1); United Nations Declaration on the Rights of Indigenous Peoples, A/RES/61/295 (2007), arts. 21, 23, 24; A/CONF.171/13/Rev.1 (1995), Principle 8; A/CONF.177/20 (1995), paras. 89 – 105.

<sup>&</sup>lt;sup>63</sup> E/C.12/GC/22 (2016), paras. 7-8; see also WHO, Commission on Social Determinants of Health, Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health – Final Report of the Commission on Social Determinants of Health, 2008.

<sup>&</sup>lt;sup>64</sup> Availability, Accessibility, Acceptability and Quality. See: <u>E/C.12/GC/22</u> (2016), paras. 11 to 21 which unpack the AAAQ.

<sup>&</sup>lt;sup>65</sup> E/C.12/GC/22</sup> (2016), para. 20, 62.

<sup>&</sup>lt;sup>66</sup> E/C.12/GC/22</sup> (2016), para. 45.

<sup>&</sup>lt;sup>67</sup> E/C.12/GC/22 (2016), para. 45.

<sup>&</sup>lt;sup>68</sup> Ann M Starrs *et al., Report of the Guttmacher-Lancet Commission, supra* note 52; Marcia C. Inhorn and Pasquale Patrizio, *supra* note 49.

Remove barriers to sexual and reproductive health services: States also have a specific obligation to remove all barriers to comprehensive sexual and reproductive health services, goods, education and information and guarantee the equal enjoyment of sexual and reproductive health and rights for all people. Finis requires repealing or reforming laws and policies that impede individuals ability to realize their right to sexual and reproductive health without discrimination and to ensure equal access to the full range of sexual and reproductive health information, goods and services for all people. Along these lines, criminal and other punitive laws that dissuade or impede individuals from accessing sexual and reproductive health services and negatively impact their health, must be repealed and removed. Specifically, "criminalization of or other failure to provide services that only women require, such as abortion and emergency contraception, constitute discrimination based on sex".

The CESCR has also recognized that individuals belonging to particular groups may be disproportionately affected by intersectional discrimination in the context of sexual and reproductive health, requiring special measures to guarantee substantive equality. <sup>73</sup> To this end, States must take positive measures to identify, combat and eliminate discrimination against marginalized groups in the context of infertility. This includes taking positive measures to expose and modify harmful gender stereotypes within the health sector. <sup>74</sup> Human rights mechanisms have also called on States to address systemic and structural discrimination in access to healthcare which lead to health inequalities, particularly intersectional discrimination against, for example, women of African-descent and people with diverse sexual orientations, gender identities and sex characteristics. <sup>75</sup> States must formulate adequate policy responses to address sexual and reproductive health disparities. <sup>76</sup>

<sup>&</sup>lt;sup>69</sup> E/C.12/GC/22</sup> (2016), paras. 28, 46, 48, 63.

<sup>&</sup>lt;sup>70</sup> <u>E/C.12/GC/22</u> (2016), para. 34.

<sup>&</sup>lt;sup>71</sup> Human Rights Council, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, <u>A/HRC/14/20</u>, (2010); Global Commission on HIV and Law, <u>Report: HIV and the Law:</u> <u>Risks, Rights & Health</u>, 2012.

<sup>&</sup>lt;sup>72</sup> Joint Statement by the UN Special Rapporteurs on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, on the situation of human rights defenders, on violence against women, its causes and consequences, the Working Group on the issue of discrimination against women in law and in practice; and, Rapporteur on the Rights of Women of the Inter-American Commission on Human Rights and the Special Rapporteurs on the Rights of Women and Human Rights Defenders of the African Commission on Human and Peoples' Rights, "The 2030 Agenda for Sustainable Development and its implementation mark a unique opportunity to ensure full respect for sexual and reproductive health and rights which must be seized", 24 September 2015

<sup>&</sup>lt;sup>73</sup> E/C.12/GC/22 (2016), paras. 5, 10, 30. ("...groups including but not limited to poor women, persons with disabilities, migrants, indigenous or other ethnic minorities, adolescents, lesbian, gay, bisexual, transgender and intersex persons, and people living with HIV/AIDS".)

<sup>&</sup>lt;sup>74</sup> Committee on the Elimination of Discrimination against Women, *Views adopted by the Committee at its fiftieth session, 3 to 21 October 2011, L.C. v. Peru*, <u>CEDAW/C/50/D/22/2009</u>; see also OHCHR, *Gender Stereotyping... supra* note 6.

<sup>&</sup>lt;sup>75</sup> See, e.g., Committee on the Elimination of Discrimination against Women, General Recommendation 35 on gender-based violence against women, updating general recommendation No. 19 (1992), CEDAW/C/GC/35 (2017), para. 12; Human Rights Council, Report of the Working Group of Experts on People of African Descent on its mission to the United States of America, A/HRC/33/61/Add.2 (2016), paras. 57, 117; A/HRC/50/27 (2022).

<sup>&</sup>lt;sup>76</sup> See e.g., Human Rights Council, Report of the Working Group on Discrimination against Women in Law and in practice on its mission to the United States of America, <u>A/HRC/32/44/Add.2</u> (2016), para. 95.

# 2. Lack of fertility information and awareness, including due to lack of comprehensive sexuality education

Lack of awareness and misconceptions about fertility perpetuate and create barriers to addressing infertility. To Often, individuals lack awareness about the fundamentals of fertility, including menstruation cycles, knowledge about the periods during which successful conception is most likely, and behavioral or age-related factors influencing fertility. There are also gaps in understanding fertility-related risk factors arising from tobacco and alcohol use, insulin resistance or diabetes, and occupational or environmental exposure to certain chemicals. In Individuals, in particular women can be treated as infertile by spouses, families and community members even when they do not meet clinical definitions of infertility. For example, in some parts of Asia and Africa, women are expected to become pregnant within months of becoming married or even on their wedding night. Achieving pregnancy in limited time periods is complicated further by lack of information about fertile periods or absence of partners during fertile windows due to migration, work or other demands.

The WHO has also emphasized the role of misconceptions as a preventable cause of infertility. For instance, due to the high social value ascribed to childbearing, in some settings, individuals mistakenly fear that contraceptive use will cause infertility. <sup>82</sup> This, unfortunately, may lead to greater risk of infertility due to STIs or unsafe abortion. Further, infertility is predominantly considered a "woman's problem", despite data to the contrary. <sup>83</sup> Failing to address male factors of infertility contributes to couples continuing to experience infertility. <sup>84</sup>

Cultural, political, and religious barriers often promote behaviors that undermine what evidence shows about how best to preserve fertility. Interviewees from East Africa expressed that infertility is often understood as the product of improper behavior or transgression of social norms. In some cases, women considered infertile are made to engage in sexual activity to "correct" the infertility, which conversely can lead to greater risks of infertility due to rape that can result in STIs and unsafe abortions. <sup>85</sup> This is particularly a risk for lesbian and bisexual women. <sup>86</sup> Interviewees also highlighted that gender stereotypes amongst healthcare providers can lead to marginalized groups being denied accurate and unbiased

<sup>&</sup>lt;sup>77</sup> OHCHR, East Africa Focus Group Discussion (12 November 2020).

<sup>&</sup>lt;sup>78</sup> Share-Net International, *supra* note 33, p. 21.

<sup>&</sup>lt;sup>79</sup> *Ibid.* p. 20; Marcia C. Inhorn and Pasquale Patrizio, *supra* note 49.

<sup>&</sup>lt;sup>80</sup> OHCHR, Asia Focus Group Discussion (5 November 2020); OHCHR, West Africa Focus Group Discussion (18 November 2020).

<sup>81</sup> OHCHR Asia Focus Group Discussion (5 November 2020).

<sup>&</sup>lt;sup>82</sup> WHO *supra* note 3; OHCHR, East Africa Focus Group Discussion (12 November 2020).

<sup>&</sup>lt;sup>83</sup> OHCHR, Asia Focus Group Discussion (5 November 2020); see also Marcia Inhorn, America's Arab Refugees: Vulnerability and Health on the Margins, Stanford University Press, 2018.

<sup>&</sup>lt;sup>84</sup> Share-Net International, *supra* note 33; OHCHR, East Africa Focus Group Discussion (12 November 2020). *See also* Andrew K. Leung et al, *Gaps in male infertility health services* in TAU, Vol. 7, Supplement 3, 24 July 2018; Robert S Gerhard, Wayland Hsiao et al, Awareness and attitudes towards infertility and its treatment: a cross-sectional survey of men in a United States primary care population, Asian Journal of Andrology, Vol. 16, Issue No. 6, November-December 2014.

OHCHR, East Africa Focus Group Discussion (12 November 2020). See also Human Rights Watch, "We'll Show You You're a Woman": Violence and Discrimination against Black Lesbians and Transgender Men in South Africa, 2011.
 Ibid.

information about their fertility. For example, healthcare providers often lack accurate information on the impact of gender-affirming hormone therapy for transgender people on fertility, leading to improper counseling and unanticipated side effects.<sup>87</sup> Sex workers and women with disabilities are often denied information due to the presumption that they will not (or should not) reproduce.<sup>88</sup>

Interviewees from East and West Africa recognized lack of comprehensive sexuality education (CSE) as a "main challenge" to preventing infertility. Without access to CSE, individuals do not know how to prevent infertility and lack of knowledge of the role of timely and safe sexual and reproductive health care in preventing infertility and how to access such services. <sup>89</sup> Further, the systematic prohibition and repression of sexuality education perpetuates abuse, stigma, over-medicalization, and trauma within the health system. Currently, access to information about fertility is typically limited to private health care settings, which are out of reach for much of the population. <sup>90</sup> To the extent sexuality education is included in school curriculum in certain areas, fertility information and awareness is often not included. Rather, sexuality education is generally focused on unwanted pregnancy prevention, to promote population control or abstinence until marriage. As an interviewee working with marginalized populations stated, fertility education is "both mystified and stigmatized." <sup>91</sup> As a result, adolescents are often denied information on how to preserve fertility, despite the myriad of risk factors that occur in early adolescence, including tobacco and alcohol use, STIs and environmental exposure to toxic chemicals.

## i. States' Human Rights Obligations

Ensure comprehensive sexuality education and increase accurate fertility-related information: CESCR recognizes that "information accessibility includes the right to seek, receive and disseminate information and ideas concerning sexual and reproductive health issues generally and for individuals to receive specific information on their particular health status. All individuals and groups, including adolescents and youth, have the right to evidence-based information on all aspects of sexual and reproductive health, including maternal health, contraceptives, family planning, STIs and HIV prevention, safe abortion and post abortion care, infertility and fertility options, and reproductive cancers" <sup>92</sup> and States are required to ensure that all individuals and groups have access to this information.

Article 10 (h) of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) also grants a right to "specific educational information to help ensure the health and well-being of families, including information and advice on family planning." Further, as noted in the prior section, human rights mechanisms have established States must expose and modify harmful gender stereotypes,

<sup>87</sup> Interview with key expert (6 November 2020).

<sup>88</sup> OHCHR, Asia Focus Group Discussion (5 November 2020).

<sup>89</sup> OHCHR, East Africa Focus Group Discussion (12 November 2020); West Africa Focus Group Discussion (8 November 2020).

<sup>&</sup>lt;sup>90</sup> OHCHR, East Africa Focus Group Discussion (12 November 2020).

<sup>&</sup>lt;sup>91</sup> Interview with key expert (19 October 2020).

<sup>92</sup> E/C.12/GC/22 (2016), para. 18.

stigma and discrimination within the health sector and take measures to address disparities in reproductive health.<sup>93</sup>

# 3. Gender-based Violence as a cause of infertility

Gender-based violence can be a cause of infertility in several ways. 94 Where sexual violence leads to pregnancy and an abortion is denied or inaccessible, the resulting forced continuation of pregnancy can, as stated by an interviewee from Latin America, mean that "the whole concept of motherhood becomes tainted."95 For some individuals, the trauma from sexual violence can impact their desire to be sexually active thereafter, which eventually interferes with their ability and decision to utilize their own fertility to have children. 96 Further to the psychological harm, sexual violence, in particular rape, can also lead to STIs, unsafe abortions, and/or higher risk of unwanted pregnancies, and irreparable physical harm on the reproductive organs of survivors which can lead to infertility. 97 In addition, victims of sexual violence often face additional obstacles to access sexual and reproductive health services, including prevention of infertility care, due to fear of stigmatization and/or retaliations. 98

<sup>&</sup>lt;sup>93</sup> L.C. v. Peru, <u>CEDAW/C/50/D/22/2009</u> (2011). See also <u>CEDAW/C/GC/35</u> (2017), para. 12; <u>E/C.12/GC/22</u> (2016), para. 48; <u>A/HRC/33/61/Add.2</u> (2016), paras. 57, 117; OHCHR, Gender Stereotyping..., supra note 6.

<sup>&</sup>lt;sup>94</sup> While gender-based violence (GBV) can take many forms, this research paper only focuses on some forms of GBV and their link, as a cause or consequence, with infertility. See below section on GBV as a consequence of infertility. GBV can take place irrespective of the setting (e.g., non-conflict or conflict) and the perpetrator (e.g. State or non-State actors). The CEDAW Committee has affirmed that "violations of women's sexual and reproductive health and rights such as forced sterilization, forced abortion, forced pregnancy... are forms of gender-based violence, that depending on the circumstances, may amount to torture or cruel, inhuman or degrading treatment", see: CEDAW/C/GC/35 (2017), para. 18; OHCHR, Integrating a gender perspective into human rights investigations: guidance and practice (2018), pp. 7; For references on reproductive violence, see *infra* note 98 oHCHR, Latin America Focus Group Discussion (20 November 2020).

<sup>&</sup>lt;sup>96</sup> See e.g., Narjes Deyhoul et al, *Infertility-related Risk Factors: A Systemic Review*, International Journal of Women's Health and Reproduction Sciences, Vol. 5, No. 1, January 2017, p. 27. On the psychological consequences of male victims of rape, see e.g., Conference room paper of the Independent International Commission of Inquiry on the Syrian Arab Republic, "I lost my dignity": Sexual and gender-based violence in the Syrian Arab Republic, 2018, <u>A/HRC/37/CRP.3</u> (2018), para. 96.

<sup>&</sup>lt;sup>97</sup> See e.g., Conference room paper of the Commission on Human Rights in South Sudan, Conflict-related sexual violence against women and girls in South Sudan, <u>A/HRC/49/CRP.4</u> (2022), para. 138; UNMISS and OHCHR, <u>Access to health for survivors of conflict-related sexual violence in South Sudan</u>, May 2020, para. 37; Independent International Fact-Finding Mission on Myanmar, Sexual and Gender-based Violence in Myanmar and the gendered impact of its ethnic conflicts, 2019, <u>A/HRC/42/CRP.4</u>, para. 96, 171

<sup>&</sup>lt;sup>98</sup> See e.g., OHCHR, Integrating a gender perspective..., *supra* note 94, pp. 32-33.

Reproductive violence<sup>99</sup> acts, such as forced and coerced sterilization, forced contraception and forced abortions, have long been used to limit and control the fertility of "undesirable" populations. <sup>100</sup> These acts transgress individuals' reproductive autonomy. <sup>101</sup> They involve the non-consensual deprivation of reproductive capacity, impeding individuals' autonomy and ability to decide whether they want or not to have children free of coercion, violence and discrimination. As previously stated, the issue of infertility reveals the "multitude of ways that States may, through action or inaction, privilege the reproduction of some while dissuading the reproduction of others". <sup>102</sup> One interviewee described such practices as "a state-imposed form of infertility." <sup>103</sup> In some circumstances, reproductive violence acts may amount to torture, cruel or inhuman or degrading treatment and to international crimes. <sup>104</sup>

**Forced and coerced sterilization** is a contraceptive measure taken without the full, free and informed consent of the person concerned. Force and coercion can manifest in many ways, including women being given consent forms authorizing caesarian sections during labor, that also include provisions on sterilization without their knowledge, or spousal or parental consent being accepted in lieu of individual consent. Some women may also agree to sterilization based on lack of information or misinformation about their reproductive options and/or the irreversible nature of the intervention, thus not fulfilling

<sup>&</sup>lt;sup>99</sup> The term reproductive violence is not contained in any international law instrument; however, under international human rights law and international criminal law certain forms of reproductive violence constitute human rights violations and international crimes, respectively. See: Tanja Altunjan, Reproductive Violence and International Criminal Law, Chapter 3, 2021, TMC, Asser Press. Rose Mary Grey defines reproductive violence as "violence which involves a violation of reproductive autonomy or which is directed at people because of their reproductive capacity," in: Rosemary Grey, The ICC's First Forced Pregnancy Case in Historical Perspective, Journal of International Criminal Justice, Vol. 15, No. 905 (2017). It has also been argued that reproductive violence practices are often subsumed under the umbrella of sexual violence, which makes difficult to reveal the reproductive dimensions and implications and specific harms of these acts for victims, as they may result in "a profound modification in their life plan, in which they may have aspired to being a parent." See: Ciara Laverty and Dieneke de Vos, Reproductive Violence as a Category of Analysis: Disentangling the Relationship between 'the Sexual' and 'the Reproductive', in Transitional Justice, International Journal of Transitional Justice, 2021, p. 15, 1-11. For further information on efforts to categorize reproductive violence see, e.g., Rachelle Chadwick & Jabulile Mary-Jane Jace Mavuso (2021), On reproductive violence: Framing notes, Agenda, 35:3 (2021); Noemy Perez Vázquez and Liri Oja, A Change of Narrative: Protecting Sexual and Reproductive Rights in Post-conflict criminal justice, Columbia Journal of Gender and Law, Vol. 23 No. 1, pp. 31-66; and, Center for Reproductive Rights, An Examination of Reproductive Violence against women and airls during the Armed Conflict in Colombia, July 2020.

<sup>&</sup>lt;sup>100</sup> OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, <u>Eliminatina forced, coercive and otherwise involuntary sterilization: An interagency statement</u> (2014).

<sup>&</sup>lt;sup>101</sup> Rose Mary Grey, *Reproductive Crimes in International Criminal Law, in:* Indira Rosenthal, Valerie Oosterveld and Susana Sácouto (editors), Gender and International Criminal Law, Oxford, 2022

<sup>&</sup>lt;sup>102</sup> Arthur Greil *et al., supra* note 7.

<sup>&</sup>lt;sup>103</sup> OHCHR, Asia Focus Group Discussion (5 November 2020).

<sup>&</sup>lt;sup>104</sup> See below sub-section on atrocity crimes.

<sup>&</sup>lt;sup>105</sup> OHCHR et al., *Eliminating forced...*, *supra* note 100, p.1 For its part, WHO has emphasized the importance of enabling individuals to make informed contraceptive choices for themselves as well as the importance of the full and informed consent of individuals with respect to sterilizations. *See* WHO, *Selected practice recommendations for contraceptive use*, Third edition, 2016. <sup>106</sup> *Ibid*, p. 3. *See* also: Amnesty International, *The State as a Catalyst for Violence Against Women: Violence Against Women and Torture or other III Treatment in the Context of Sexual and Reproductive Health in Latin America and the Caribbean (Index: AMR 01/3388/201), 2016, p. 28 ("Sterilization under coercion" is when people give their consent to be sterilized but based on incorrect information or other coercive tactics such as intimidation, or that conditions are attached to sterilization, such as financial incentives or access to health services).* 

informed consent requirements.<sup>107</sup> Further, incentives or coercive pressures may be utilized to secure agreement to sterilization, including promises of food, money, or land or threats, fines, or punishments. <sup>108</sup>

Stereotypes about who constitutes a "good mother" and who "should" reproduce often drive forced and coerced sterilization. While men have also been targeted under sterilization campaigns, historically it is women who have been disproportionally subjected to forced and coerced sterilization in different contexts, particularly under coercive population policies. 109 Multiple interviewees confirmed that women and individuals who face intersectional discrimination due to race or ethnicity, caste, belonging to indigenous populations or minorities, HIV status, disability, refugee or migrant status, gender, sexual orientation, gender identity or sex characteristics are at particular risk of forced or coerced interventions. 110 Such stereotypes can lead to force and coercion when they are reflected in laws and policies, or shape how individual health providers treat certain individuals or groups.

#### Text Box 3a: Experiences of forced and coerced sterilization

Interviewees for this research paper and studies around the world have specifically documented longstanding and systemic practices of **forced and coerced sterilization** of indigenous women and women belonging to minorities. <sup>111</sup> These discriminatory practices are often founded on stereotypes portraying, for example, **indigenous and Roma women** as lazy, poor, promiscuous and unfit as mothers. <sup>112</sup> Such strategies often occur alongside practices to compel fertility, such as attempts to force indigenous women to have sexual intercourse and bear children from such relations with non-indigenous men as part of policies of cultural assimilation. <sup>113</sup>

<sup>&</sup>lt;sup>107</sup> OHCHR et al., *Eliminating forced..., supra* note 100, p. 3.

<sup>&</sup>lt;sup>108</sup> Ibid.

<sup>&</sup>lt;sup>109</sup> For a compilation of different contexts where forced and coerced sterilizations are carried out *see, e.g.,* C. Laverty and D. de Vos, *supra* note 99, p. 10; and, Rosemary Grey, *Reproductive Crimes..., supra* note 101.

<sup>110</sup> OHCHR et al., Eliminating forced..., supra note 100, p. 3; Kalpana Wilson, For reproductive justice in an Era of Gates and Modi: The Violence of India's Population Policies, Feminist Review, Vol. 119, Issue 1, July 2018, pp. 89-105; Committee on the Elimination of Discrimination against Women, Views Communication No. 4/2004, A.S. v. Hungary, CEDAW/C/36/D/4/2004 (2006), para. 11; European Court of Human Rights, N.B. v. Slovakia, Comm. No. 29518/10 (2012), para. 95; European Court of Human Rights, V.C. v. Slovakia, Comm. No. 18968/07 (2011), para. 154; European Court of Human Rights, I.G. and Others v. Slovakia, Comm. No. 15966/04 (2012).

<sup>111</sup> OHCHR, Latin America Focus Group Discussion (20 November 2020); Interview with key expert, (16 November, 2020). See also, Miranda JJ, Yamin AE. Reproductive health without rights in Peru. Lancet, 2004, 363:68–69; United Nations General Assembly, Report of the Special Rapporteur on Violence Against Women, its Causes and Consequences, A/67/227 (2012); United Nations Secretary-General, In-depth study on all forms of violence against women, A/61/122/Add.1 (2006); Collier-Wise K. Bearing witness: looking for remedies for forced sterilization of indigenous women. Vermillion, University of South Dakota School of Law, 2009; Report of the Standing Senate Committee on Human Rights, The scars that we carry: forced and coerced sterilizations of persons in Canada, June 2021; European Roma Rights Centre, Coercive and cruel: Sterilization and its consequences for Romani Women in the Czech Republic (1996-2016), 2016; OHCHR, Assessment of human rights concerns in the Xinjiang Uyghur Autonomous Region, People's Republic of China, 31 August 2022, pp. 32-33.

<sup>&</sup>lt;sup>112</sup> See e.g., OHCHR, Background paper on the role of the judiciary in addressing the harmful gender stereotypes related to sexual and reproductive health and rights: A review of case law, 2017; Ainhoa Molina Sierra, Sterlizations in Peru: Power and narrative configurations, Revista de Antropología Iberoamericana, Vol. 12, No. 1, 2017, pp. 31-52; Chaneesa Ryan, Abrar Ali, Christine Shawana, Forced or Coerced Sterilization in Canada: An Overview of Recommendations for Moving Forward, International Journal of Indigenous Health, Vol. 16, No. 1, 2021, p. 275-290.

<sup>113</sup> A/HRC/32/44 (2016), para. 54. See also: WGDWG, communication CZE 2/2013 and reply received (24 May 2013)...

#### Text Box 3a: Experiences of forced and coerced sterilization (cont.)

Although some women living with HIV may choose sterilization as a contraceptive method, practices of forced and coerced sterilizations against them have been documented in some countries. 114 Women living with HIV are often considered "unfit" for motherhood by health providers and others due to pervasive misconceptions about HIV transmission between pregnant women and their fetuses and stereotypes of women with HIV as being "promiscuous". 115 Such stereotypes not only stigmatize but impose to significant social pressure on women living with HIV to avoid reproduction and can lead to sterilization. 116

Harmful practices, such as female genital mutilation (FGM), can also have a direct impact on sexual and reproductive health and ultimately on women's fertility. <sup>117</sup> For example, FGM can have both immediate and/or long-term health consequences, including severe pain, shock, infections and complications during childbirth, and long-term gynecological problems such as fistula which may affect the fertility, particularly of women and young women. Child, early and forced marriage is often followed by early and frequent pregnancy and childbirth, that may result in maternal morbidity and mortality and secondary infertility. <sup>118</sup>

**Mistreatment in health care facilities** can also lead to reluctance to seek preventative health care or treatment for medical conditions that impact fertility. Interviewees from Latin America noted that prejudices and heteronormativity within the medical sector can translate into lesbian women facing violence when they seek gynecological care. This creates a fear of going to health facilities, which translates into greater risk of infertility due to untreated STIs. Trauma from harmful reproductive health care experiences may also lead women to choosing sterilization to avoid such pain in the future. <sup>119</sup>

Women, girls, and individuals from marginalized groups that experience intersecting forms of discrimination on the basis of, *inter alia*, gender, race, ethnicity, or socioeconomic status, may also face specific forms of gender-based violence which can lead to infertility. For example, institutional violence experienced in health care settings—often perpetuated against marginalized racial or ethnic groups—can create distrust in healthcare providers and barriers to prevention and treatment of infertility. 120

<sup>&</sup>lt;sup>114</sup> OHCHR et al., *Eliminating forced...*, supra note 100, p. 3.

<sup>&</sup>lt;sup>115</sup> Interview with key expert (30 September 2020).

 $<sup>^{\</sup>rm 116}$  OHCHR, West Africa Focus Group Discussion (18 November 2020).

<sup>117</sup> Ibid; OHCHR, Fact Sheet No. 23, Harmful Traditional Practices Affecting the Health of Women and Children.

<sup>&</sup>lt;sup>118</sup> See Human Rights Council, Follow-up report of the United Nations High Commissioner for Human Rights, A/HRC/45/19 (2020), pp. 10-12; Human Rights Council, Report of the Office of the United Nations High Commissioner for Human Rights, A/HRC/29/20 (2015), para. 22; and, Joint CEDAW, General Recommendation 31/ CRC, General Comment 18, CEDAW/C/GC/31-CRC/C/GC/18 (2019).

<sup>&</sup>lt;sup>119</sup> OHCHR, Latin America Focus Group Discussion (20 November 2020).

<sup>&</sup>lt;sup>120</sup> Interview with key expert (19 October 2020).

#### Text Box 3b: Experiences of forced and coerced sterilization

- > Transgender persons also often face forced and coerced sterilization, including under laws which require sterilization or other medical treatment prior to being permitted to receive gender-affirmative hormone treatment or change their gender identity on their identity documents. 121 Furthermore, the causes of preventable infertility among intersex people include medically unnecessary surgeries and treatment undertaken to make their bodies appear more in line with gender stereotypes about male or female bodies during infancy or childhood, often without their informed consent, that results in permanent infertility as well as long-term physical and psychological pain and suffering. 122 These causes are rooted in gendered stereotypes that intersex people are unable to reproduce or should not reproduce to avoid "passing on" their condition. 123
- ➤ Women and girls with disabilities are disproportionately subject to forced and coerced sterilization, hysterectomies, or abortions throughout the world. 124 Laws often permit parents or guardians to consent to abortion or sterilization without regard to the person with disabilities' preference. 125 Additionally, women and girls may face forced or coerced sterilization during caesarian sections or under the guise of "a procedure to manage menstruation". 126 Laws and policies rarely focus on supporting decision-making for persons with disabilities. 127 Men with intellectual disabilities may also face sterilization or procedures to suppress sexual drive, including possibly castration. 128

# i. States' Human Rights Obligations

**Individuals experience gender-based violence when they are denied reproductive autonomy, including as a result of forced reproductive health procedures**. The CEDAW Committee has affirmed that "violations of women's sexual and reproductive health and rights, such as forced sterilization, forced abortion, forced pregnancy, criminalization of abortion, denial or delay of safe abortion and/or postabortion care, forced continuation of pregnancy, and abuse and mistreatment of women and girls seeking sexual and reproductive health information, goods and services, are forms of gender-based violence that, depending on the circumstances, may amount to torture or cruel, inhuman or degrading treatment" and to international crimes. The Special Rapporteur on torture and cruel, inhuman, and degrading

<sup>121</sup> OHCHR, Asia Focus Group Discussion (5 November 2020); OHCHR et al., Eliminating forced..., supra note 100.

<sup>&</sup>lt;sup>122</sup> Interview with key expert (6 November 2020). See also: OHCHR, <u>Born Free and Equal: Sexual Orientation, Gender Identity and Sex Characteristics in International Human Rights Law</u> (second edition), p. 35.

<sup>&</sup>lt;sup>123</sup> Interview with key expert (6 November 2020); Blas Radi, *Reproductive injustice, trans rights, and eugenics*, in Sexual and Reproductive Health Matters, Vol. 28, issue 1, 2020.

<sup>124</sup> OHCHR, Latin America Focus Group Discussion (20 November 2020); West Africa Focus Group Discussion (18 November, 2020). See also, CRPD Committee, General Comment No. 3 on women and girls with disabilities, <a href="CRPD/C/GC/3"><u>CRPD/C/GC/3</u></a> (2016); United Nations General Assembly, Report of the Special Rapporteur on the Rights of Persons with Disabilities, <a href="A/72/133">A/72/133</a> (2017), paras. 29-33.

<sup>&</sup>lt;sup>125</sup> OHCHR, Latin America Focus Group Discussion (20 November, 2020); <u>CRPD/C/GC/3</u> (2016).

<sup>&</sup>lt;sup>126</sup>OHCHR, Latin America Focus Group Discussion (20 November, 2020); see also Steele, L. and Goldblatt, B., The Human Rights of Women and Girls with Disabilities: Sterilization and Other Coercive Responses to Menstruation, in Chris Bobel, Inga T. Winkler et al., The Palgrave Handbook of Critical Menstruation Studies, Palgrave Macmillan, 2020, pp. 77-91..

<sup>&</sup>lt;sup>127</sup> OHCHR et al., *Eliminating forced..., supra* note 100, p. 11.

<sup>&</sup>lt;sup>128</sup> *Ibid.*, p. 11.

<sup>&</sup>lt;sup>129</sup> <u>CEDAW/C/GC/35</u> (2017), paras. 18 -21; <u>A/54/38/Rev.1</u>, <u>chap. I</u> (1999), paras. 11, 14.

<sup>&</sup>lt;sup>130</sup> CEDAW/C/GC/35 (2017), para. 16.

treatment has stated that forced sterilization is an act of violence and a form of social control, which violates the prohibition of torture and other forms of cruel, inhuman or degrading treatment.<sup>131</sup>

Respect autonomous decision-making concerning sexual and reproductive health and reproductive functions: Individuals' and couples' ability to utilize their own fertility to have children also implicates the rights to privacy<sup>132</sup> and to private and family life. <sup>133</sup> Issues of sexuality, reproduction and family formation comprise some of the most intimate decisions in individuals' and couples' lives. Along these lines, article 17 of the International Covenant on Civil and Political Rights (ICCPR) explicitly protects women's and girls' rights to enjoy privacy, including regarding sexual and reproductive health and functions. <sup>134</sup> The Human Rights Committee has confirmed that there is a discriminatory interference with women's right to privacy where governments "fail to respect women's privacy with regards to the reproductive functions. <sup>135</sup> The Working Group on Discrimination against Women and Girls (WGDAWG) has also observed that the right of women and girls to make autonomous decisions about their bodies and reproductive functions, lies "at the very core of [their] fundamental right to equality and privacy, involving intimate matters of physical and psychological integrity, and is a precondition for the enjoyment of other rights. "<sup>136</sup>

Guarantee the right to free and informed consent to medical interventions and treatment, which is a key component of the right to sexual and reproductive health. <sup>137</sup> The CEDAW Committee has stated that acceptable sexual and reproductive health services are those "that are delivered in a way that ensures that a woman gives her fully informed consent, respects her dignity, guarantees her confidentiality and is sensitive to her needs and perspectives." <sup>138</sup> Likewise, the Committee on the Rights of Persons with

<sup>&</sup>lt;sup>131</sup> Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhumane or degrading treatment or punishment*, <u>A/HRC/ 31/57</u> (2016), para. 45. See also <u>CAT/C/PER/CO/4</u>, (2006), para. 23. Regional human rights courts have similarly recognized that forced and coerced deprivation of reproductive capacity violate human rights. *See e.g.*,: Inter-American Commission on Human Rights: Report No. 72/14, Case 12.655 Merits *I.V. v. Bolivia* (15 August 2014); Report No. 52/14, Petition 112-09, Admissibility *F.S. v. Chile* (21 July 2014). European Court of Human Rights: Application No. 18968/07, *V.C. v. Slovakia*, judgement of 8 November 2011; *N.B. v. Slovakia*, No. 29518/10 (2012); and, *I.G. and Others v. Slovakia*, Comm. No. 15966/04 (2012).

<sup>&</sup>lt;sup>132</sup> ICCPR, art. 17; American Convention on Human Rights, art. 11

<sup>133</sup> European Convention on Human Rights, art. 8.

<sup>134</sup> Human Rights Committee, General Comment No. 28, HRI/GEN/1//Rev.9 (Vol.1), (2000), para. 20.

HRI/GEN/1//Rev.9 (Vol.1), (2000), para. 20. The Human Rights Committee has also found states in violation of women's right to privacy when denying access to abortion. See, for example, Mellet v. Ireland, CCPR/C/116/D/2324/2013 (2016); Whelan v. Ireland, CCPR/C/119/D/2425/2014 (2017); K.L. v. Peru, CCPR/C/85/D/1153/2003 (2005), para. 6.4. The European Court of Human Rights has confirmed in Evans v. United Kingdom, that the term "private life" under the European Convention on Human Rights "incorporates the right to respect for both the decisions to become and not to become a parent. See ECtHR, Evans v. The United Kingdom, App. No. 6339/05, 2007, para. 71.

 $<sup>^{136}</sup>$  Human Rights Council, Report of the UN Working Group on Discrimination against Women in Law and Practice ,  $\underline{\text{A/HRC/38/46}}$  (2018), para 35; see also ICCPR, Arts. 3 and 17.

<sup>&</sup>lt;sup>137</sup> As confirmed by the CESCR, the right to health includes the right to control one's health and body and the "right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation." *In:* E/C.12/2000/4 (2000), para. 8. *See also* CEDAW/C/BEL/CO/7 (2014), para. 35 (underscoring that in the context of female sterilization, states must "ensure that, in practice, there is not any non-consensual sterilization of women with intellectual and/or psychosocial disabilities...and that those women are provided with the support necessary to decide whether they wish to give their informed consent to sterilization."); CEDAW/C/FIN/CO/7 (2014), paras. 28-29 (recommending to the State party to "take immediate steps to repeal section 2 of the Sterilization Act, which permits the sterilization of women with disabilities who have limited legal capacity or who have been deprived of their legal capacity without their consent.").

<sup>138</sup> A/54/38/Rev.1. chap. I (1999), para. 22.

Disabilities (CRPD Committee) requires that health professionals provide care to persons with disabilities of equality as to others, including based on free and informed consent.<sup>139</sup> The CEDAW Committee has specifically called on States to not permit any form of coercion, such as non-consensual sterilization that violates the right to informed consent and dignity.<sup>140</sup>

Comply with due diligence obligations to prevent, investigate, prosecute and punish perpetrators, and provide effective remedy and reparations for acts of gender-based violence committed by State and non-State actors, including acts of reproductive violence, such as forced and coerced sterilization, forced contraception and forced abortions. All measures undertaken by States should integrate a gender and age perspective, be victim/survivor-centered, acknowledge victims/survivors as right holders and promote their agency and autonomy. All States should, for example:

- Adopt and implement effective legislative and other appropriate preventative measures to address patriarchal attitudes and stereotypes and other underlying causes of gender-based violence.<sup>143</sup> This includes capacity building for members of the judiciary, lawyers and law enforcement officers, legislators, and health care professionals on sexual and reproductive health, including on STIs and HIV prevention and on the responses to address the role of gender stereotypes and bias in gender-based violence.<sup>144</sup>
- Ensure victims'/survivors' effective access to justice and to an effective remedy and reparations.<sup>145</sup> This includes ensuring that allegations of gender-based violence are investigated, promptly, thoroughly and effectively through independent and impartial bodies, and that those responsible are punished.<sup>146</sup>
- Adopt and implement effective age and gender-sensitive protection measures for victims'/survivors' of gender-based violence before, during and after legal proceedings.<sup>147</sup>

<sup>&</sup>lt;sup>139</sup> CRPD, art. 25(d).

<sup>&</sup>lt;sup>140</sup> A/54/38/Rev.1, chap. I (1999), para. 22. Similarly, the CAT has called for the adoption laws and policies to prevent and criminalize sterilization without consent, and to clearly define "the requirements of free, prior and informed consent with regard to sterilization and by raising awareness among Indigenous women and medical personnel of that requirement.". See: CAT/C/CAN/CO/7 (2018).

<sup>&</sup>lt;sup>141</sup> CEDAW/C/GC/35 (2017); Committee on the Elimination of Discrimination against Women, General Recommendation No. 33 on access to justice, CEDAW/C/GC/33 (2015); CEDAW, General Recommendation No. 30 on women in conflict prevention, conflict and post-conflict situations, CEDAW/C/GC/30 (2013), para. 65(a); Committee Against Torture, General Comment, CAT/C/GC2 (2008), para. 18; CRPD/C/GC/3, 2016, para. 26; CEDAW/C/GC/31-CRC/C/GC/18 (2019), para. 10. See also Jessica Lenahan (Gonzales) v. United States, Inter-American Commission on Human Rights, Case 12.626, Report No. 80/11, July 2011, para 126.

<sup>&</sup>lt;sup>142</sup> <u>CEDAW/C/GC/35</u> (2017), para. 28; <u>CEDAW/C/GC/33</u> (2015).

<sup>143</sup> CEDAW/C/GC/35 (2017), para. 30(b).

<sup>144 &</sup>lt;u>CEDAW/C/GC/35</u> (2017), para. 30(e).

<sup>&</sup>lt;sup>145</sup> <u>CEDAW/C/GC/35</u> (2017), paras. 29 (b), 32, 33.

<sup>&</sup>lt;sup>146</sup> Human Rights Committee, General Comment No. 31 on the nature of the general legal obligation imposed on States Parties to the Covenant, CCPR/C/21/Rev.1/Add. 13 (2003), para. 15; CEDAW/C/GC/33 (2015); CAT/C/GC/3, (2012), para. 23. The CAT has called to "ensure that all allegations of forced or coerced sterilization are impartially investigated, that the persons responsible are held accountable and that adequate redress is provided to the victims." See: CAT/C/CAN/CO/7 (2018).

147 CEDAW/C/GC/35 (2017), para. 31.

Furthermore, the impacts of gender-based violence on the fertility of victims should be assessed whenever they seek justice and reparations for the psychological and physical harms suffered as a result of, for example, sexual violence. Importantly, such an assessment should be gender-sensitive and victim-centred.

**Amend/Repeal discriminatory legislation.** States should repeal legal provisions that allow, tolerate, or condone forms of gender-based violence, including harmful practices and provisions that allow medical procedures to be performed on women, including with disabilities without their consent, and that criminalize abortion. Furthermore, treaty bodies have specifically called on States to halt non-consensual deprivations of reproductive capacity for marginalized populations including transgender and intersex people, people with disabilities, Roma women, and indigenous women. For instance:

- The CEDAW Committee has recommended to amend legislation to ensure that "gender recognition is carried out without requiring transgender persons to conform to stereotypical ideas of masculine or feminine appearance or behavior and that it does not require individuals to consent to sterilization." 149 It has also called to repeal legislation "which permits the sterilization of women with disabilities who have limited legal capacity or who have been deprived of their legal capacity without their consent." 150
- The CRPD Committee has explicitly also confirmed that "[a]|| women with disabilities must be able to exercise their legal capacity by taking their own decisions, with support when desired with regard to medical and/or therapeutic treatment, including decisions on: retaining their fertility, reproductive autonomy, their right to choose the number and spacing of children, to consent and accept a statement of fatherhood, and the right to establish relationships." 151

#### **Text Box 4a: Atrocity Crimes and Control of Reproduction**

Some forms of reproductive violence linked to infertility have been defined as international crimes in the Rome Statute of the International Criminal Court (ICC). <sup>152</sup> These are forced sterilization recognized as a war crimes and a crime against humanity, <sup>153</sup> and genocide by "imposing measures intended to prevent births within the group." <sup>154</sup> Furthermore, the Genocide Convention defines "imposing measures to prevent births' within national, ethnic,

<sup>&</sup>lt;sup>148</sup> CEDAW/C/GC/35 (2017), para. 29(c)(i).

<sup>&</sup>lt;sup>149</sup> <u>CEDAW/C/FIN/CO/7</u> (2014), para. 28.

<sup>&</sup>lt;sup>150</sup> CEDAW/C/FIN/CO/7 (2014), paras. 28, 29(b); CEDAW/C/NLD/CO/5 (2010), paras. 46, 47.

<sup>&</sup>lt;sup>151</sup> <u>CRPD/C/GC/3</u> (2016), para. 44; <u>CRPD/C/GC/1</u> (2014), para. 35.

<sup>&</sup>lt;sup>152</sup> Decades before the adoption of the Rome Statute, acts of forced sterilization ('medical experiments') committed in concentration camps were considered as war crimes and crimes against humanity by the Nuremberg Military Tribunals under Control Council Law 10 and resulted in convictions. The 'medical experiments' were categorized as "murders, brutalities, cruelties, tortures, atrocities and other inhuman acts." *See:* Tanja Altunjan, *Reproductive Violence and International Criminal Law*, International Criminal Justice Series, Vol. 29, T.M.C. Asser Press, 2021, p. 102.

<sup>&</sup>lt;sup>153</sup> Rome Statute of the International Criminal Court (entered into force on 1 July 2002), articles 7 (1) (g) on crimes against humanity; art. 8 (2) (e) (vi) on war crimes. However, the international crime of forced sterilization is yet to be charged by the ICC. <sup>154</sup> Rome Statute of the International Criminal Court (entered into force on 1 July 2002), article 6 (d).

racial or religious group as an act of genocide, when committed with a genocidal intent."<sup>155</sup> For instance, direct and indirect harm to fertility and reproductive capacity is a primary way that women and girls experience genocidal violence. <sup>156</sup> Likewise, the targeting of fertility reflects women's and girls' stereotypical role in society as "mothers… bearers of future life [and] keepers of community and family honor." <sup>157</sup> The articulation of atrocity crimes related to reproduction sheds light on the breadth of ways that infertility may be enforced and the potential impact of such actions on the survival of entire communities and the reproductive autonomy of women. However, international criminal law jurisprudence with respect to reproductive crimes is still limited. <sup>158</sup>

The crime of genocide by 'imposing measures to prevent births' was interpreted for the first time by an international tribunal in the *Akayesu* case. The International Criminal Tribunal for Rwanda Trial Chamber articulated that measures to prevent births could include rape, sexual mutilation, the practice of sterilization, forced birth control, separation of the sexes, prohibition of marriages, impregnation of a woman to deprive group identity, and mental trauma resulting in a reluctance to procreate. <sup>159</sup> According to the Trial Chamber, to constitute a genocidal act, such measures only need to be intended to prevent births; they do not need to succeed in actually preventing births nor do they need to be calculated to bring about destruction of the group in whole or in part <sup>160</sup>

Investigative bodies mandated by the Human Rights Council have also interpreted the crime of genocide by 'imposing measures to prevent births'. The Independent International Commission of Inquiry on the Syrian Arab Republic found that The Islamic States' (ISIS) ongoing genocide of the Yazidis includes imposing measures to prevent Yazidi children from being born by the separation of Yazidi men, forced conversion of adults, <sup>161</sup> and mental trauma from rape that has led to refusals to procreate. <sup>162</sup> Likewise, the Fact Finding Mission on Myanmar reported a context of "obsession with the procreation of the Rohingya" <sup>163</sup> in which the authorities, including the Tatmadaw, "have actively propagated the narrative of "uncontrollable" Rohingya birthrates that constitute a threat to the nation." <sup>164</sup> It added that in such a context, the widespread sexual violence against women and girls in Rakhine State in the context of the 'clearance operations', "may have been aimed at affecting their reproductive capacity" <sup>165</sup>. It further noted that rape "can be a measure intended to prevent births when the person raped refuses subsequently to procreate, in the same way that members of a group can be led, through threats or trauma, not to procreate." <sup>166</sup>

<sup>155</sup> Convention on the Prevention and Punishment of the Crime of Genocide (entered into force 12 January 1951), article 2 (d).

<sup>&</sup>lt;sup>156</sup> Global Justice Center, Beyond Killings: Gender, Genocide, and Obligations Under International Law (2018). Slavery is another example of an atrocity crime linked to fertility, including forced procreation. Viseur Sellers, Patricia and Getgen Kestenbaum, Jocelyn, *The International Crimes of Slavery and the Slave Trade: A Feminist Critique*, in: Indira Rosenthal et al., *supra* note 101, pp.167-168.

<sup>&</sup>lt;sup>157</sup> Global Justice Center, Beyond Killings: Gender, Genocide, and Obligations Under International Law (2018).

<sup>&</sup>lt;sup>158</sup> Not every case of wide-ranging reproductive violence has necessarily been brought to the attention of international criminal courts. For instance, at the national level, various countries in Latin America have recognized acts of reproductive violence as war crimes, crimes against humanity and genocide. See: Daniela Kravetz, *Gender and the implementation of international criminal law in the Latin American region*, in: Indira Rosenthal et al, *supra note* 101, pp. 325-345.

<sup>&</sup>lt;sup>159</sup> Global Justice Center, Beyond Killing: Gender, Genocide, & Obligations Under International Law (December 2018) (citing *Prosecutor v. Jean-Paul Akayesu*, Case No. ICTR-96-4-T, Judgment, para. 507, Sept. 2, 1998).

<sup>&</sup>lt;sup>160</sup> Global Justice Center, Discrimination to Destruction: A Legal Analysis of Gender Crimes Against the Rohingya, 2018, p. 58-59.

<sup>&</sup>lt;sup>161</sup> Under religious norms, both parents must be Yazidi for a child to be considered Yazidi. *See* Human Rights Council, "They came to destroy": ISIS Crimes Against the Yazidis, <u>A/HRC/32/CRP.2</u> (2016).

<sup>&</sup>lt;sup>162</sup> A/HRC/32/CRP.2 (2016). paras. 142-6.

Human Rights Council, Report of the detailed findings of the Independent International Fact-Finding Mission on Myanmar, A/HRC/39/CRP.2 (2018), para. 1410

<sup>&</sup>lt;sup>164</sup> Ibid.

<sup>&</sup>lt;sup>165</sup> Ibid.

<sup>&</sup>lt;sup>166</sup> Ibid.

# 4. Environmental conditions, including workplace conditions, toxin exposure, and safety

Fertility is also impacted by underlying determinants of health, including environmental conditions. Whether individuals have safe and healthy living and working environments can impact their reproductive decision-making and health. Toxin exposure through workplace conditions or environmental pollution can be also linked to infertility.

Working environments can impact fertility in many ways. Labor conditions such as long hours, heavy manual labor without accommodation, or workforce trends that do not accommodate pregnancy or childcare during peak fertile years can create social circumstances that interfere with realizing fertility intentions, in particular for women. <sup>167</sup> Beyond this, decisions about the number and spacing of children are also impacted by lack of access to jobs with a livable wage or dependency on work to provide social supports such as health insurance. <sup>168</sup> Women are also particularly vulnerable to work conditions linked to negative health outcomes, including violence, harassment, and lower wages. <sup>169</sup> Women who experience multiple and intersecting forms of discrimination have more limited job options, including jobs with greater risk of abuse and low pay. Additionally, migration due to limited local employment opportunities can create barriers to achieving pregnancy and lead women to be considered infertile despite limited sexual intercourse, due to spouses traveling during fertile windows and lack of fertility awareness. <sup>170</sup> Migrant women workers may also experience constraints on autonomy around pregnancy due to mandatory pregnancy testing and pressure to terminate pregnancies to maintain employment. <sup>171</sup>

Workplace toxin exposure can be a cause of infertility and the inability to carry a pregnancy to term. <sup>172</sup> While exposure to weapons or radiation in the military has been linked to infertility in men, <sup>173</sup> women represent a significant proportion of workers in occupations with greater risk of toxic exposure (e.g., pesticides, industrial chemicals and metals), such as manufacturing and agriculture, services and informal work, <sup>174</sup> and waste-picking. <sup>175</sup> This exposure can lead to reproductive health harm. The Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes has noted that women are more likely to store higher levels of environmental pollutants in their adipose tissues than men. <sup>176</sup> During pregnancy, women face heightened susceptibility to health impacts from toxic exposures and adverse health effects can occur at extremely

 $<sup>^{167}</sup>$  Interview with key expert (19 October 2020).

<sup>&</sup>lt;sup>168</sup> Loretta Ross, Reproductive Justice Beyond Biology, 15 March 2017, published online in American Porgress.

 $<sup>^{169}</sup>$  Human Rights Council, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health,  $\frac{A/HRC}{20/15}$  (2012), para. 48.

<sup>&</sup>lt;sup>170</sup> OHCHR, Asia Focus Group Discussion (5 November 2020).

 $<sup>^{171}</sup>$  OHCHR, Asia Focus Group Discussion (5 November 2020);  $\underline{\text{A/HRC/32/44}}$  (2016), para. 53.

<sup>&</sup>lt;sup>172</sup> Human Rights Council, Report of the Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes, A/HRC/39/48 (2018), para. 5; A/HRC/20/15 (2012), para. 48. 
<sup>173</sup> Interview with key expert (9 November 2020); Center for Reproductive Rights, Access to IVF for Service members and Veterans (2020).

<sup>&</sup>lt;sup>174</sup> A/HRC/39/48 (2018), para. 48.

<sup>&</sup>lt;sup>175</sup> Interview with key expert (9 October 2020).

<sup>&</sup>lt;sup>176</sup> A/HRC/39/48 (2018), para. 6.

low levels of exposure.<sup>177</sup> In fact, it has been documented that women face increased risk of miscarriage from manufacture of electronics.<sup>178</sup> For women, infertility due to toxin exposure is compounded by the fact that work-related diseases affecting women are often underdiagnosed and undercompensated as compared to men.<sup>179</sup> The risks of such harm are even greater for workers living in poverty and from low-income countries, migrant or temporary workers, workers with disabilities, and older workers, among others because of, *inter alia*, economic insecurity, limited better job opportunities, and political powerlessness.<sup>180</sup>

Environmental conditions and toxin exposure more broadly may also have implications on fertility and reproductive decision-making. For example, shifting environmental conditions, including growing, production and use of toxins may directly impact both biomedical fertility, as well as decision-making about whether it is "safe" to bring children into the world. For instance, exposure to environmental pollutants and toxins can be directly toxic to gametes (eggs and sperm), resulting in their decreased numbers and poor quality.<sup>181</sup> These environmental pollutants include endocrine-disrupting chemicals (EDCs), which may affect hormones related to reproduction. <sup>182</sup> The Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes has recognized the link between infertility and the growing toxification of the planet. 183 Environmental toxin exposure can arise from many sources, including pollution, toxic industrial chemicals, pesticides, weapons of war, wastes and other substances with intrinsic hazards. Notably, sperm counts and testosterone levels have fallen dramatically among men since the 1940s, suspected to be linked to endocrine (hormone)-disrupting chemicals in the environment.<sup>184</sup> The Special Rapporteur has further noted that exposure levels tend to be higher in low-income, minority, indigenous and marginalized communities, raising concerns about "environmental racism" and "environmental injustice" 185 It has been reported, for example, that toxin exposures from pesticides, military contamination, and long-range transport of persistent organic pollutants have led to significant reproductive harm amongst the Yaqui 186 and Yupik<sup>187</sup> indigenous communities, including miscarriages and stillbirths. <sup>188</sup> Alarmingly, exposures to toxic substances even early in development can lead to infertility generations later. 189

<sup>&</sup>lt;sup>177</sup> A/HRC/39/48 (2018), para. 7.

<sup>&</sup>lt;sup>178</sup> <u>A/HRC/39/48</u> (2018), para. 48.

<sup>&</sup>lt;sup>179</sup> A/HRC/20/15</sup> (2012), para. 48.

<sup>&</sup>lt;sup>180</sup> <u>A/HRC/39/48</u> (2018), paras. 45-54.

<sup>&</sup>lt;sup>181</sup> Gore AC, Chappell VA, Fenton SE, et al., <u>EDC-2: The Endocrine Society's Second Scientific Statement on Endocrine-Disruptina Chemicals. Endocrine Reviews</u>, Endocr. Rev. 2015 Dec;36(6); and, Segal TR, Giudice LC. <u>Before the beginning: environmental exposures and reproductive and obstetrical outcomes</u>, Fertility and Sterility, 2019, vol. 112, Issue 4, pp. 613-21.

<sup>&</sup>lt;sup>182</sup> WHO, UNEP and IOMC. <u>State of the science of endocrine disrupting chemicals 2012</u>, Edited by Åke Bergman A., Heindel J.J, Jobling S., Kidd K.A, and Zoeller R.T. 2013. Geneva: WHO.

<sup>&</sup>lt;sup>183</sup> United Nations General Assembly, Report of the Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes,  $\underline{A/74/480}$  (2019), paras. 52-54, 79.

<sup>&</sup>lt;sup>184</sup> Human Rights Council, Report of the Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes, <u>A/HRC/33/41</u> (2018), para. 9.

<sup>&</sup>lt;sup>185</sup> A/HRC/33/41 (2018), para. 6. See also A/74/480 (2019), para. 52.

<sup>&</sup>lt;sup>186</sup> The Yaqui is a Uto-Aztecan-speaking indigenous people of Mexico

<sup>&</sup>lt;sup>187</sup> The Yupik if one of the indigenous groups in Alaska.

<sup>&</sup>lt;sup>188</sup> The 3rd International Indigenous Women's Symposium on Environment and Reproductive Health Focus: Advancing research and assessing impacts of Environmental Violence on Indigenous Women and Girls, Columbia University, 14-15 April 2018. <sup>189</sup> A/74/480 (2019), paras. 8, 25, 70.

Reproductive justice advocates have noted that sexual and reproductive health and rights must include the right to a safe and healthy environment in which to parent one's own children. <sup>190</sup> Climate change, in particular, is altering environments in a manner that may indirectly contribute to infertility or cause individuals to feel it is unsafe to reproduce and raise children. In Bangladesh, for example, flooding created an increase in gynecological infections due to lack of access to clean water, hygienic supplies, and sanitation. <sup>191</sup> Increasing incidence or impact of natural disasters is often linked to migration as well as food and water insecurity and may also contribute to individuals choosing not to have children out of fear for their safety or well-being.

## i. States' Human Rights Obligations

The General Assembly and the Human Rights Council have recognized the right to a clean, healthy and sustainable environment related other human rights and existing international law. <sup>192</sup> The CESCR establishes safe and healthy working conditions and environment as an underlying determinant of sexual and reproductive health that States must ensure. <sup>193</sup>

Safeguard sexual and reproductive health by ensuring safe and healthy working environments and just and fair conditions of work: The Universal Declaration of Human Rights (UDHR) and the International Covenant on Economic Social and Cultural Rights (ICESCR) recognize the right of everyone to just and favourable conditions of work. <sup>194</sup> The International Labour Organization (ILO) further recognizes the right to a safe and healthy working environment and the protection of workers against sickness, disease, and injury from employment as fundamental human rights. <sup>195</sup> States' obligations to realize the right to just and favorable conditions of work, includes ensuring a decent and non-discriminatory wage, freedom from pregnancy discrimination, and freedom from violence. <sup>196</sup> The CESCR has emphasized the harmful impact of gender and intersectional discrimination on enjoyment of this right. The WGDAWG has similarly recognized that women who experience multiple and intersecting forms of discrimination may particularly have limited opportunities for education and employment, culminating in a "poverty trap." <sup>197</sup> These factors can hinder reproductive decision-making. Addressing discrimination may require temporary special measures.

<sup>&</sup>lt;sup>190</sup> Loretta Ross, *supra* note 43.

<sup>&</sup>lt;sup>191</sup> Abul Kalam Azad, Khondoker Mokaddem Hossain, and Mahbuba Nasreen, Flood-Induced Vulnerabilities and Problems Encountered by Women in Northern Bangladesh, International Journal of Disaster Risk Science, Volume 4, issue 4, 2013, pp. 190–199.

<sup>&</sup>lt;sup>192</sup> <u>A/HRC/RES/48/13</u> (2021) and <u>A/76/L.75</u> (2022).

<sup>&</sup>lt;sup>193</sup> E/C.1<u>2/GC/22</u> (2016), para. 7.

<sup>194</sup> Universal Declaration of Human Rights (art. 23) and International Covenant on Economic, Social and Cultural Rights (art. 7).

<sup>&</sup>lt;sup>195</sup> International Labour Organization (ILO), Health and life at work: A basic human right, World Day for Safety and Health at Work, 28 April 2009, (2009), p. 5.

<sup>&</sup>lt;sup>196</sup> Committee on Economic Social and Cultural Rights, *General comment No. 23 on the right to just and favourable conditions of work,* E/C.12/GC/23 (2016), para. 65.

<sup>&</sup>lt;sup>197</sup> Human Rights Council, *Report of the Working Group on discrimination against women and girls*, <u>A/HRC/44/51</u> (2020), paras. 17,30, 58.

States' core obligation to eliminate discrimination in the workplace specifically requires safeguarding sexual and reproductive health from hazardous working conditions. <sup>198</sup> To this end, the CEDAW Convention requires States parties to "provide special protection to women during pregnancy in types of work proved to be harmful to them." <sup>199</sup> Achieving this requires States to create safe working conditions in all industries, rather than preventing women from being employed in certain areas. <sup>200</sup> Similarly, the Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes has stated that special care must be taken to ensure such measures do not lead to women and girls being deprived of employment or income; rather, the best approach is to eliminate toxic substances at work. <sup>201</sup> States must further ensure information about health and safety information about toxic substances is not kept confidential. Greater data is needed on the impact of toxic exposure for workers, including on women of reproductive age. <sup>202</sup>

Prevent environmental toxin exposure and infertility-related harm: Toxin exposure more broadly implicates sexual and reproductive health and rights, including because it can be linked to an inability to carry pregnancies to term as well as to infertility. <sup>203</sup> States have a duty to prevent exposure under international human rights law, including the rights to life, health, adequate and nutritious food and safe and potable water, adequate housing, and safe and healthy working conditions. This obligation also is reflected in the right to full respect for bodily autonomy and integrity of the person, which reinforces that every person should have the right to control what happens to their own body. <sup>204</sup> The Human Rights Committee has recognized that States may be in violation of the rights to life and a life with dignity when they fail to take sufficient measures to prevent chronic exposure to hazardous substances, whether from the environment, workplace, consumer products or other sources. <sup>205</sup> States must also prevent infertility-related harm from toxin exposure. The CEDAW Committee has issued concluding observations expressing concern regarding high rates of infertility and miscarriage due to lead contamination and recommended to ensure that women and girls affected by lead contamination have access to health care and that the impact of contamination is continuously monitored with a view to providing necessary medical interventions. <sup>206</sup>

# 5. Lack of access to quality infertility care services, including assisted reproductive technologies

Infertility care includes services for the prevention, diagnosis, counselling, and treatment of infertility. While not all infertility can be overcome through treatment, the lack of access to diagnosis and treatment is a barrier in many cases where pregnancy is still possible through access to medicines or technology.

 <sup>198</sup> A/HRC/39/48 (2018), para. 32; CEDAW, art. 11.1(f).
 199 CEDAW, art. 11.2(d).
 200 Medevedeva v. Russia, Comm. No. 60/2013, CEDAW/C/63/D/60/2013 (2016).
 201 A/HRC/39/48 (2018), para. 33.
 202 A/HRC/39/48 (2018), para. 26.
 203 A/74/480 (2019), para. 32.
 204 A/74/480 (2019), para. 6.
 205 Human Rights Committee, General Comment No. 36 on the right to life, CCPR/C/GC/36 (2018), para. 62.
 206 CEDAW/C/NGA/CO7-8 (2017), paras. 37(e) and 38(f).

Treatment of infertility includes drugs that can induce ovulation to address ovulation disorders, intrauterine insemination for low sperm count or unexplained infertility, surgery to address blocked tubes or uterine fibroids or other reproductive tract abnormalities.<sup>207</sup> Assisted reproductive technologies (ART),<sup>208</sup> including in vitro fertilization (IVF), are useful for any of these conditions, and can also be critical for specific populations including women with medical issues that impact infertility such as cancer, HIV serodiscordant couples, and LGBTI persons.<sup>209</sup>

The WHO has stated that equal and equitable access to fertility care services remains a challenge in most countries, particularly in low and middle-income countries. <sup>210</sup> National universal health coverage benefits packages rarely prioritize fertility care, which is more often only available in the private sector. <sup>211</sup> The cost of diagnosis and treatment for infertility means it is largely unaffordable and inaccessible beyond the most privileged socio-economic groups, <sup>212</sup> despite the broad range of risk factors for infertility disproportionately experienced by low income and marginalized women. <sup>213</sup> Public health systems often fail to offer infertility services in a systematic way and there are often a lack of regulations, guidelines, and standards for infertility treatment and care in many contexts.

In addition to cost, there are often legal barriers to infertility care services that exclude or prohibit certain people from accessing ART, including same-sex couples, single individuals and couples in which one or both partners are transgender. <sup>214</sup> Similarly, there may be legal restrictions on otherwise fertile individuals with disabilities or people living with HIV from accessing reproductive technologies. <sup>215</sup>

Other barriers to infertility care services include limited knowledge and concerns about infertility treatments, language barriers and lack of cultural sensitivity particularly for immigrant populations.<sup>216</sup> Stigma and stereotypes may also create social barriers to infertility care. For example, interviewees reported that women with disabilities often face immense social pressure to not reproduce, <sup>217</sup> which acts as a deterrent from seeking infertility care services. Interviewees noted that "[in certain contexts] Black

<sup>&</sup>lt;sup>207</sup> Ann M Starrs et al., Report of the Guttmacher-Lancet Commission, supra note 52.

<sup>&</sup>lt;sup>208</sup> WHO defines ART as "all treatments or procedures that include the in vitro handling of both human oocytes and sperm or of embryos for the purpose of establishing a pregnancy. This includes, but is not limited to, in vitro fertilization and embryo transfer, gamete intrafallopian transfer, zygote intrafallopian transfer, tubal embryo transfer, gamete and embryo cryopreservation, oocyte and embryo donation, and gestational surrogacy." F. Zegers-Hochschild et al., International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) *Revised Glossary of ART Terminology*, in Fertility and Sterility, Vol. 92, No. 5, November 2009, pp. 1520-1524.

<sup>&</sup>lt;sup>209</sup> Ann M Starrs et al., Report of the Guttmacher-Lancet Commission, supra note 52.

<sup>&</sup>lt;sup>210</sup> WHO *supra* note 3

<sup>&</sup>lt;sup>211</sup> Share-Net International, supra note 33, p. 8,

<sup>&</sup>lt;sup>212</sup> *Ibid.*, pp. 25, 26.

<sup>&</sup>lt;sup>213</sup> OHCHR, Asia Focus Group Discussion (5 November 2020).

<sup>&</sup>lt;sup>214</sup> Martha F. Davis and Rajat Khosla, supra note 24, pp. 9-10,

https://privpapers.ssrn.com/sol3/papers.cfm?abstract\_id=3636206&dgcid=ejournal\_htmlemail\_public:health:law:policy:ejournal\_abstractlink.

<sup>&</sup>lt;sup>215</sup> Martha F. Davis and Rajat Khosla, *supra note* 24, pp. 9-10,

<sup>&</sup>lt;sup>216</sup> Share-Net International, *supra* note 33.

<sup>&</sup>lt;sup>217</sup> OHCHR, East Africa Focus Group Discussion (12 November 2020).

women are often presumed to not need infertility care due to stereotypes about hyperfertility and therefore are less likely to be referred to fertility specialists by clinicians."<sup>218</sup>

#### i. States' Human Rights Obligations

The right to sexual and reproductive health includes information, services, and goods related to diagnosis and treatment of infertility, including fertility and infertility options. <sup>219</sup> The CESCR has stated that "the failure or refusal to incorporate technological advances and innovations in the provision of sexual and reproductive health services such as assisted reproductive technologies jeopardizes the quality of care." <sup>220</sup> The Human Rights Committee has called for the elimination of excessive restrictions on the use of assisted reproductive technologies. <sup>221</sup> The CEDAW Committee has recognized that States must ensure access to assisted reproductive services for all women, without restrictions. <sup>222</sup>

Ensure non-discrimination regarding sexual and reproductive health services, including infertility care: States' obligations to ensure non-discrimination in the right to sexual and reproductive health, including on the basis of disability, HIV status, sexual orientation, gender identity, or sex characteristics, <sup>223</sup> requires ensuring that all individuals and groups have equal access to the full range of sexual and reproductive health services, including by repealing or reforming laws and policies that nullify or impair the ability of certain individuals and groups to realize their sexual and reproductive health and rights. <sup>224</sup> The Human Rights Committee has expressed concern regarding the right to non-discrimination where the State denied access to IVF to LGBTI persons, and called for reform to provide equal access to the procedure. <sup>225</sup>

Remove barriers to ART: Access to ART also relates to the rights to benefits from scientific progress, to found a family, and to private life. The Human Rights Committee has stated that, "[t]he right to found a family implies, in principle, the possibility to procreate and live together." <sup>226</sup> At the regional level, the European Court of Human Rights has stated that, ""the right of a couple to conceive a child and to make use of medically assisted procreation for that purpose is ... an expression of private and family life" protected by human rights norms, but that the interpretation of this area of international law "is subject to a particularly dynamic development in science and law...." <sup>227</sup> The European Court of Human Rights has struck down legal barriers to IVF where a couple sought to utilize it to avoid passing on a genetic disorder. <sup>228</sup> The Inter-American Court has found that a total prohibition of IVF violates the American

<sup>&</sup>lt;sup>218</sup> Interview with key expert (30 October, 2020); Kaara Baptiste, Well-born: Black Women and the Infertility Crisis No One is Talking About, CUNY Academic Works, 2014, p. 3; Quinn, M. and Fujimoto, V., Racial and ethnic disparities in assisted reproductive technology access and outcomes, in Fertility and Sterility, Vol. 105, issue 5, 2016.

<sup>&</sup>lt;sup>219</sup> E/C.12/GC/22</sup> (2016), paras. 18, 45; <u>CRPD/C/GC/3</u> (2016), para. 40, pp.10

<sup>&</sup>lt;sup>220</sup> <u>E/C.12/GC/22</u> (2016), paras. 21.

<sup>&</sup>lt;sup>221</sup> <u>CCPR/C/CRI/CO/6</u> (2016), paras. 19-20.

<sup>&</sup>lt;sup>222</sup> CEDAW/C/PRT/CO/8-9 (2015), paras. 44-45.

<sup>&</sup>lt;sup>223</sup> <u>E/C.12/GC/22</u> (2016), para. 23.

<sup>&</sup>lt;sup>224</sup> E/C.12/GC/22 (2016), para. 34.

<sup>&</sup>lt;sup>225</sup> CCPR/C/ITA/CO/6, 2017, paras. 10-11.

<sup>&</sup>lt;sup>226</sup> Human Rights Committee, General Comment No. 19: article 23 (the family), HRI/GEN/1/Rev.9 (Vol. I), p. 152, 1990, para. 5.

<sup>&</sup>lt;sup>227</sup> See, e.g., ECtHR, <u>S.H. and Others v. Austria</u> [GC], no. 57813/00, Judgment of 3 November 2011, paras. 82, 118.

<sup>&</sup>lt;sup>228</sup> ECtHR, Costa and Pavan v. Italy, App. no. 54270/10, Judgment of 28 August 2012.

Convention's protections on humane treatment, privacy, personal liberty, and rights of the family because it constituted a "severe interference in relation to [the couples'] decision-making concerning the methods or practices they wished to attempt in order to procreate a biological child". <sup>229</sup> The Inter-American Commission has also emphasized that bans on IVF is discriminatory, including against women due to the impact of gender stereotypes and against individuals with lower socioeconomic status as they lack the resources to travel to another country. <sup>230</sup>

# B. Human Rights Consequences of Preventable Infertility

Where States fail to fulfill their obligations to prevent infertility, there are profound consequences on individuals' lives, some of which can constitute human rights violations. For example, women who are unable to have children can experience mental health impacts such as guilt, self-blame, helplessness and depression, familial and marital tension and dissolution, gender-based violence, social alienation and abuse, and even death.<sup>231</sup> It should be also recognized that communities can also suffer compounded human rights harms when the denial of the reproductive capacity of an individual within the community is coupled with historic and/or longstanding efforts to reduce or eradicate their populations. This is particularly the case for indigenous peoples and other marginalized groups.

States' obligations to respect, protect and fulfill the rights to found a family, to private and family life, to life, privacy, and liberty, to determine the number and spacing of their children, to health and to be free from coercion and violence, to equality and non-discrimination, and to self-determination not only apply to preventing infertility, but also to preventing and redressing human rights violations that result because one's infertility, presumed infertility or decision to not have children. As previously stated in this paper, a key component of States' obligations to prevent the suffering that can result from infertility is a concerted effort to transform gender norms and eradicate gender stereotypes that lead to and exacerbate the human rights impacts of infertility. Set forth below, is an overview of the human rights harms and violations that individuals can suffer due to their infertility, presumed infertility and States' international human rights obligations in that regard.

<sup>&</sup>lt;sup>229</sup> Artavia Murillo et al. v. Costa Rica, supra note 38, para. 161.

<sup>&</sup>lt;sup>230</sup> Artavia Murillo et al. v. Costa Rica, supra note 38.

<sup>&</sup>lt;sup>231</sup> See Abdallah S. Daar, Zara Merali, <u>Infertility and social suffering: The case of ART in developing countries</u>, in Current Practices and Controversies in Assisted Reproduction: Report of a meeting on "Medical, Ethical and Social Aspects of Assisted Reproduction held at WHO Headquarters in Geneva, Switzerland 17-21 September 2001; see also WHO, Fact-Sheet: Infertility, 2020; see also Abdallah S. Daar, Zara Merali, Infertility and social suffering: The case of ART in developing countries, in Current Practices and Controversies in Assisted Reproduction: Report of a meeting on "Medical, Ethical and Social Aspects of Assisted Reproduction held at WHO Headquarters in Geneva, Switzerland 17-21 September 2001 (2002). See also Ombelet, W., <u>Global access to infertility care in developing countries: A case of human rights, equity and social justice</u>, FACTS VIEWS VIS OBGYN. 2011; 3(4): 257–266.

## 1. Stigma and mental health harm

People who are unable to have children often experience immense shame, stigma, self-blame, depression and anxiety. <sup>232</sup> Interviewees explained that women, in particular, feel that their bodies are broken and experience great shame if they cannot "fulfill their gender roles". <sup>233</sup> Women are also stigmatized for failing to fulfil their "maternal function," <sup>234</sup> and humiliated by being called derogatory names and accused of witchcraft and/or extramarital affairs. <sup>235</sup> This intense level of stigmatization can lead to mental distress and feelings of desperation. <sup>236</sup> In these situations, interviewees explained that women may seek any means necessary to conceive, even resorting to undertaking unproven and ineffective traditional measures or visiting healers or "charlatans" that can cause more harm than good. <sup>237</sup> Some women even resort to suicide, <sup>238</sup> as they feel they can no longer handle life without a child and all the societal consequences that follow. <sup>239</sup> The stigma that results from social norms that place women's value on their ability to reproduce also harms individuals who choose not to have children.

With regard to men's experiences, interviewees noted that men who experience infertility may not be considered "real" men,<sup>240</sup> and that, as a whole, men avoid fertility testing.<sup>241</sup> For those who do undergo testing, they can become paranoid and severely depressed upon receiving an infertility diagnosis.<sup>242</sup> In general, people facing infertility tend to suffer negative feelings and diminishing self-worth alone and in silence.<sup>243</sup> However, infertility-related stigma and shame can also "extend[] to the wider family, including siblings, parents and in-laws, who are deeply disappointed for the loss of continuity of their family and contribution to their community... [which] amplifies the guilt and shame felt by the infertile individual."<sup>244</sup>

Gender norms and stereotypes play a significant role in the context of infertility-related stigma, discrimination, and violence. When women and girls fail to ascribe to longstanding gendered norms and expectations about their reproductive function or outright transgress those norms, they are subjected to

<sup>&</sup>lt;sup>232</sup> See generally Alex Domar, et al., The Psychological Impact of Infertility: A Comparison with Patients with Other Medical Conditions, 14 JOURNAL OF PSYCHOSOMATIC OBSTETRICS GYNECOLOGY 45, 1993.

<sup>&</sup>lt;sup>233</sup> OHCHR, Asia Focus Group Discussion (5 November 2020); East Africa Focus Group Discussion (12 November 2020); West Africa Focus Group Discussion (18 November 2020); OHCHR, Latin America Focus Group Discussion (20 November 2020); Interview with key expert, (19 October 2020).

<sup>&</sup>lt;sup>234</sup> East Africa Focus Group Discussion (12 November 2020).

<sup>&</sup>lt;sup>235</sup> OHCHR, Asia Focus Group Discussion (5 November 2020); OHCHR, East Africa Focus Group Discussion (12 November 2020); see also Nahar P, The link between infertility and poverty: Evidence from Bangladesh, HUM FERTIL, 2012, 15: 18-26.

<sup>&</sup>lt;sup>236</sup> OHCHR, East Africa Focus Group Discussion (12 November 2020); *See e.g.,* Sternke, E.A., Abrahamson, K. Perceptions of Women with Infertility on Stigma and Disability. Sex Disabil 33, 3–17 (2015); Klemetti Reija, et al. Infertility, mental disorders and well-being – a nationwide survey. Acta Obstetricia et Gynecologica Scandinavica (2010).

<sup>&</sup>lt;sup>237</sup> OHCHR, East Africa Focus Group Discussion (12 November 2020); OHCHR, West Africa Focus Group Discussion (18 November 2020).

<sup>&</sup>lt;sup>238</sup>OHCHR, Asia Focus Group Discussion (5 November 2020).

<sup>&</sup>lt;sup>239</sup> OHCHR, West Africa Focus Group Discussion (18 November 2020).

<sup>&</sup>lt;sup>240</sup> OHCHR, East Africa Focus Group Discussion (12 November 2020).

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<sup>&</sup>lt;sup>242</sup> OHCHR, West Africa Focus Group Discussion (18 November 2020).

<sup>&</sup>lt;sup>243</sup> OHCHR, Asia Focus Group Discussion (5 November, 2020); OHCHR, East Africa Focus Group Discussion (12 November 2020); West Africa Focus Group Discussion (18 November, 2020); Latin America Focus Group Discussion (20 November, 2020).

<sup>&</sup>lt;sup>244</sup> Mother or nothing: The agony of infertility, Bulletin of the World Health Organization, 88 (12), 881-882 (2010), p. 1; C. Stellar et al., A systematic review and narrative report of the relationship between infertility, subfertility, and intimate partner violence, International Journal of Gynaecology and Obstetrics (2015). pp. 6-8.

intense stigmatization. That stigma, in turn, can legitimize and perpetuate violence and other human rights violations against them. Until these restrictive gender norms which continue to base women's value on their ability to reproduce are transformed, the cycle of infertility-related human rights harms and violations will persist.

# i. States' Human Rights Obligations

Eliminate infertility-related stigma: The prominent role that stigma plays in legitimizing human rights violations has been recognized. <sup>245</sup> The foremost step to combatting infertility-related stigma is to transform discriminatory gender norms that primarily ascribe women's value to their ability to reproduce and punish those who fail to ascribe to that role. The CESCR has confirmed that States must take measures to eradicate social barriers such as "norms or beliefs that inhibit individuals of different ages and genders, women, girls and adolescents from autonomously exercising their right to sexual and reproductive health", as well as modify "social misconceptions, prejudices and taboos about menstruation, pregnancy, delivery, ...and fertility", so as not to obstruct an individual's enjoyment of the right to sexual and reproductive health. <sup>246</sup> Similarly, article 5 of the CEDAW Convention compels States to take all appropriate measures to modify social and cultural patterns to eliminate prejudices and customary and all other practices "which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women". These obligations compel States to modify persistent gender norms that hinge women's worth on the exercise of their fertility and are particularly pressing when a State plays a direct role instigmatizing individuals who cannot have children through laws, policies, actions and inactions.

Address the harmful health impacts of infertility-related stigma: Infertility-related stigma has profound impacts on individuals' mental health. The Special Rapporteur on the right to health has confirmed that the right to mental health is dependent on non-discrimination in the enjoyment of all other human rights and is itself a critical determinant of mental health and well-being. 247 States' obligation to respect, protect and fulfil the right to health, includes mental health and particularly the underlying determinants to promote mental health. 248 This requires, in part, "increasing financial support to sustainable, cross-cutting programs that reduce poverty, inequalities, discrimination on all grounds and violence in all settings, so that the main determinants of mental health are effectively addressed...." States must further "facilitate, provide and promote conditions in which mental health and well-being can be realized." To this end, eliminating myths, misconceptions and misinformation that often underlie infertility-stigma and

<sup>&</sup>lt;sup>245</sup> See, e.g., Human Rights Council, Report of the United Nations High Commissioner for Human Rights, <u>A/HRC/39/36</u> (2018); and, WHO and OHCHR, <u>Mental Health, human rights and leaislation: Guidance and practice</u>, World Health Organization and United Nations, 2023.

<sup>&</sup>lt;sup>246</sup> E/C.12/GC/22 (2016), para. 48.

<sup>&</sup>lt;sup>247</sup> Human Rights Council, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, <u>A/HRC/41/34</u> (2019), para. 36.

<sup>&</sup>lt;sup>248</sup> A/HRC/41/34 (2019)para. 18.

<sup>&</sup>lt;sup>249</sup> Human Rights Council, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. <u>A/HRC/44/48</u> (2020), para. 86 (e).

<sup>&</sup>lt;sup>250</sup> A/HRC/44/48 (2020), para. 67.

discrimination, and harmful gender and other stereotypes is critical to reducing and combatting stigma, abuse, violence, social exclusion and abandonment, and a binding State obligation. <sup>251</sup>

## 2. Gender-based violence as a consequence of infertility

Gender-based violence can be a consequence of infertility in different ways. It can be experienced as a continuum where infertility was caused by forms of gender-based violence, with particularly severe consequences on individuals' physical and mental health and well-being. For example, indigenous women who have been subjected to forced or coerced sterilization have reported suffering intense emotional trauma and physical health impacts such as endometriosis, drastic hormonal fluctuations and decreased libido. Others reported to resorting to destructive use of alcohol and drugs to cope with their pain, which can lead to other health complications and loss of their children. Start Forced and coerced sterilization can even lead to death. Furthermore, women who are infertile, deemed infertile or simply decide not to have children can be also subjected to both physical and psychological gender-based violence. Start In some cases, women may be killed when they are perceived as not fulfilling gender stereotypical societal or community expectations regarding maternal or reproductive roles.

Infertility-related violence can be inflicted on women by their husbands, in-laws, and their extended families.<sup>257</sup> For example, a study in nine low-income and middle-income countries found that at least one in two women experiencing infertility in these contexts where subjected to intimate partner violence over their lifetime and that they often experience infertility-related violence by other members of their family.<sup>258</sup> Research has also found that infertile women identify themselves as victims of violence and this was strongly associated with infertility status,<sup>259</sup> and many reported physical abuse by men and in-laws irrespective of whether a couple's infertility was due to male or female-factors.<sup>260</sup> As referenced earlier,

<sup>&</sup>lt;sup>251</sup> See CEDAW, Art. 5(a) (States are required to "modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary practices that are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women."); see also Human Rights Council, Report of the Working Group on the issue of discrimination against women in law and practice, A/HRC/29/40 (2015), para. 73(a)(3).

<sup>252</sup> Interview with key expert (11 December 2020).

<sup>&</sup>lt;sup>253</sup> Dr. Yvonne Boyer, Dr. Judith Bartlett, <u>External Review: Tubal Ligation in the Saskatoon Health Region: The Lived Experience of Aboriginal Women</u>, 2017, p. 23.

<sup>&</sup>lt;sup>254</sup> In 2014, fifteen women who were Dalit, Adivasi (Indigenous) and considered OBC (Other Backward Classes) died after being sterilized under appalling conditions in sterilization camps in the Bilaspur district of Chhattisgarh, India. *See:* Kalpana Wilson, *supra* note 110.

<sup>&</sup>lt;sup>255</sup> Stellar C, Garcia-Moreno C, Temmerman M, van der Poel S, *A systematic review and narrative report of the relationship between infertility, subfertility, and intimate partner violence*, in International Journal of Gynecology & Obstetrics, 2016; 133: 3–8. <sup>256</sup> OHCHR, East Africa Focus Group Discussion (12 November 2020).

<sup>&</sup>lt;sup>257</sup> Sami N, Ali TS, Psycho-social consequences of secondary infertility in Karachi, J PAK MED ASSOC. 2006, 56: 19-22.

<sup>&</sup>lt;sup>258</sup> Yuanyuan Wang, Yu Fu, Parastou Ghazi et al., <u>Prevalence of intimate partner violence against infertile women in low-income and middle-income countries: a systematic review and meta-analysis</u>, Lancet Global Health, 10 (6): e820-30, 2022.

<sup>&</sup>lt;sup>259</sup> Mumtaz, Z., Shahid, U., Levay, A., *supra* note 40, p. 3, (citing\_Sami N, Ali TS, Domestic violence against infertile women in Karachi, Pakistan, ASIAN REV Soc Sci. 2012, 1: 15-20.

<sup>&</sup>lt;sup>260</sup> Moghadam ZB, Ardabily HE, Salsali M, Ramezanzadeh F, Nedjat S, Physical and psychological violence against infertile women, J FAM REPROD H. 2010, 4: 65-67; Yilidizhan R, Adali E, Kolusari A, Kurdoglu M, Yilidizhan B, Sahin G, Domestic violence against infertile women in a Turkish setting, *Int J Gynaecol Obstet*. 2009, 104.

interviewees from East Africa noted that lesbian and bisexual women are subjected to "corrective rape"<sup>261</sup> based on perceptions that they are transgressing gender norms and stereotypes about sexuality and gender identity. While this violence is not related to infertility per se and can be committed by nonfamily members, it can be linked to condemnation of a perceived rejection of their social role as "mothers".

Women and adolescent girls are particularly vulnerable to gender-based violence because of their actual or perceived infertility in the first few months of marriage when they are expected to promptly have a child. <sup>262</sup> This is acutely the case for women and girls living in poverty and where familial structures depend on large families for security. Interviewees explained, for example, that in many contexts adolescent girls subjected to child, early and forced marriage face immense pressure to "prove" their fertility and are at risk of gender-based violence if they do not become pregnant soon after marriage, regardless of whether their bodies are sufficiently developed for pregnancy and childbirth. <sup>263</sup>

**Violence and harm when seeking infertility treatment.** In some cases, women resort to alternative infertility remedies and treatments because they cannot access treatment within formal healthcare settings and/or due to past experiences of gender-based discrimination and violence within those settings. However, alternative or traditional remedies services can be less safe or unsafe. One interviewee reported, for example, that some women have experienced harmful side effects from substances given to them by traditional healers to stimulate fertility.<sup>264</sup>

Unfortunately, while infertility-related gender-based violence can be inflicted at the hands of both State and non-state actors, accountability for such human rights violations can be difficult, particularly when the violence is perpetuated by healthcare providers. One interviewee explained that due to power imbalances between healthcare providers and patients, there can be delivery of misinformation, gaps in record-keeping, lack of transparent and effective complaint mechanisms, and/or retaliation against staff who raise issues or complaints about medical care provision.<sup>265</sup>

## i. States' Human Rights Obligations

**Fulfill due diligence obligations for infertility-related gender-based violence**: As referenced earlier, States' have the obligation to prevent, investigate, prosecute and punish perpetrators, and provide effective remedy and reparations for acts of gender-based violence committed by State and non-State actors (see sub-section on gender-based violence as a cause of infertility), and this includes healthcare providers. In the specific case of children, States are required to protect them from all forms of physical

<sup>&</sup>lt;sup>261</sup> OHCHR, East Africa Focus Group Discussion (12 November 2020). For references on so-called "corrective rape", *see, e.g.,* Human Rights Council, *Report of the Special Rapporteur on violence against women, its causes and consequences on her mission to South Africa*, <u>A/HRC/32/42/Add.2</u> (2016), para. 33; Human Rights Council, Report of the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, <u>A/HRC/38/43</u> (2018), para. 42.

<sup>&</sup>lt;sup>262</sup> OHCHR, Asia Focus Group Discussion (5 November 2020); OHCHR, East Africa Focus Group Discussion (12 November 2020); OHCHR, West Africa Focus Group Discussion (18 November 2020); Interview with key expert (2 December 2020).

<sup>&</sup>lt;sup>263</sup> Interview with key expert (21 October 2020); Interview with key expert (11 November 2020).

<sup>&</sup>lt;sup>264</sup> OHCHR, East Africa Focus Group Discussion (12 November 2020).

<sup>&</sup>lt;sup>265</sup> Interview with key expert (30 September 2020); OHCHR, Latin America Focus Group Discussion (20 November 2020).

and mental violence, injury, abuse, neglect, maltreatment and sexual abuse. <sup>266</sup> The CRC has recognized adolescents girls in child or forced marriages as particularly vulnerable to violence, meriting heightened protection by States. <sup>267</sup> Along these lines, the CEDAW Committee has specifically called on States to "[r]epeal all legal provisions that discriminate against women, and thereby enshrine, encourage, facilitate, justify or tolerate any form of gender-based violence against them; including in customary, religious and indigenous laws. <sup>268</sup> Finally, as discussed throughout this report, States' non-discrimination obligations and particularly, the obligation to combat harmful gender norms and gender and other stereotypes, are critical to preventing infertility-related violence. <sup>269</sup>

#### 3. Social exclusion and economic harm

Infertility-related stigma can also lead to social exclusion<sup>270</sup> and economic harm, including from marital instability and dissolution.<sup>271</sup> For example, interviewees explained that women or adolescent girls who are unable to have children can be excluded from family events such as weddings<sup>272</sup> and funerals, and prohibited from touching babies and children.<sup>273</sup> They can also be deprived of food, clothes, or fuel.<sup>274</sup> Women facing infertility have further lamented feeling isolated, being treated as inhuman, or accused of being cursed.<sup>275</sup> In some contexts, one's inability to have children is seen as an "indication of disharmony with the living and/or between the living and the dead", a failure to ascribe to traditions and customs, or the result of witchcraft or sorcery.<sup>276</sup>

The inability of married women and girls to reproduce can also lead to their ejection from their marital and family home, <sup>277</sup> or rejection by their communities, with severe social, economic and health impacts and, in some cases, resulting in a wholesale deprivation of resources. Interviewees across regions confirmed that if a woman or adolescent girl cannot have a child within the first 6 months to a year after marriage, their husbands may divorce or abandon them, have extra-marital affairs or take another wife. <sup>278</sup>

<sup>&</sup>lt;sup>266</sup> See CRC, art. 19; CRC/C/GC/13 (2011).

<sup>&</sup>lt;sup>267</sup> CRC/C/GC/13 (2011), para. 72(g).

<sup>&</sup>lt;sup>268</sup> CEDAW/C/GC/35 (2017), para. 29 (c); see also CEDAW, art. 16, para. 2; CEDAW/C/GC/31-CRC/C/GC/18 (2019), paras. 42, 55 (f) (establishing that minimum age of marriage is 18 years for girls and boys with or without parental consent).

<sup>&</sup>lt;sup>269</sup> L.C. v. Peru, CEDAW/C/50/D/22/2009 (2011); Artavia Murillo et al. v. Costa Rica, supra note 38, para. 302. See also OHCHR, Gender Stereotyping..., supra note 6.

<sup>&</sup>lt;sup>270</sup> Rouchou B, Consequences of infertility in developing countries, PERSPECT. PUBLIC HEALTH 2013; 133: 174–79.

<sup>&</sup>lt;sup>271</sup> See Rutstein SO, Shah IH, *DHS comparative reports 9, Infecundity, infertility, and childlessness in developing countries*, ORC Macro, 2004.

<sup>&</sup>lt;sup>272</sup> Sami N, Ali TS, *Perceptions and experiences of women in Karachi, Pakistan regarding secondary infertility: Results from a community-based qualitative study*, OBSTET. GYNECOL. INTERNATIONAL, 2012.

<sup>&</sup>lt;sup>273</sup> Dyer SJ, Patel M. *The economic impact of infertility on women in developing countries - a systematic review.* FACTS VIEWS VIS OBGYN. 2012;4(2):102-109.

<sup>&</sup>lt;sup>274</sup> Ibid.

<sup>&</sup>lt;sup>275</sup> Richards, Sarah, "Spoiling the Womb": Definitions, Aetiologies and Responses to Infertility in North West Province, Cameroon, AFRICAN JOURNAL OF REPRODUCTIVE HEALTH, Vol. 6, No. 1, 2002, p. 88.

<sup>&</sup>lt;sup>276</sup> Ibid., p. 88-89.

<sup>&</sup>lt;sup>277</sup> Sami N, Ali TS, Psycho-social consequences of secondary infertility in Karachi, J PAK MED Assoc. 2006, 56: 19-22

<sup>&</sup>lt;sup>278</sup> OHCHR, Asia Focus Group Discussion (5 November 2020); OHCHR, East Africa Focus Group Discussion (12 November 2020); OHCHR, West Africa Focus Group Discussion (18 November 2020); Interviews with key experts (1 November 2020, 3 November 2020, 6 November 2020, 9 November 2020 and 2 December 2020).

Polygamous marriage can impose mental distress on the woman/wife facing infertility, <sup>279</sup> and threaten their sexual and reproductive health due to the increase of STIs and HIV transmission with the introduction of new sexual partners. <sup>280</sup> Notably, in contexts of patrilineal descent, diagnosis of male-factor infertility can lead to widespread pressure on men to become polygynous. <sup>281</sup>

Infertility can cause severe economic hardship not only on women and girls, but on families, which can lead to further marital stress. <sup>282</sup> Infertility can involve a long stressful journey whereby individuals and couples search for remedies and cures, yet with few options. Even in countries and communities where fertility clinics exist, many people do not know about them or cannot afford them, making fertility treatment virtually inaccessible. <sup>283</sup> Couples living in poverty may feel compelled to exhaust all resources in seeking infertility treatment, <sup>284</sup> which can have devastating economic impacts on their families, particularly in low- and middle-income countries. <sup>285</sup> In many contexts, alternative means to form families such as adoption or assisted reproduction are not acceptable and/or raise ethical and moral issues within their families and religious communities.

Infertility-related financial strain can have generational impacts, particularly in low-income countries depend on their children for economic survival. <sup>286</sup> For example, interviewees from Latin America spoke about the impact of the coerced sterilization and resulting death of an indigenous woman on her surviving husband and seven children. In addition to immense psychological loss, the family's socio-economic status quickly diminished. The children were compelled to leave school to work to support the family, which in turn, perpetuated the family's cycle of poverty. The trajectory of the family was essentially disrupted and each individual family member's ability to pursue their own "life project" was sidelined. <sup>287</sup>

## i. States' Human Rights Obligations

**Ensure women's right to equality within the family:** International human rights law explicitly recognize equal rights and responsibilities of women and men as to marriage, during marriage and at its dissolution.<sup>288</sup> The WGDAWG has confirmed that States have an obligation to respect women's right to

<sup>&</sup>lt;sup>279</sup> S. Dierickx, *et al.*, Women with infertility complying with and resisting polygyny: an explorative qualitative study in urban Gambia, 16 REPROD. HEALTH 103, 2019, J.J. Fledderjohann, 'Zero is not Good for Me': Implications of Infertility in Ghana, 27 HUM. REPROD. 1383, 2012 (describing marital instability arising from infertility).

<sup>&</sup>lt;sup>280</sup> Georges Reniers & Rania Tfaily, Polygyny and HIV in Malawi, 19 DEMOGRAPHIC RES., 2008, p. 1811.

<sup>&</sup>lt;sup>281</sup> Bregje Christina de Kok et al., *Infertility in Malawi: exploring its impact and social* consequences, Center for Research on Families and Relationships, Briefing, 2008, p. 41.; Marcia C. Inhorn, "The Worms Are Weak": Male Infertility and Patriarchal Paradoxes in Egypt, 5 Men and Masculinities 236 (2003).

<sup>&</sup>lt;sup>282</sup> Dyer SJ, Patel M, *supra* note 273.

<sup>&</sup>lt;sup>283</sup> OHCHR, East Africa Focus Group Discussion (12 November 2020).

<sup>&</sup>lt;sup>284</sup> Interview with key expert (3 November 2020).

<sup>&</sup>lt;sup>285</sup> Njagi P, et al., *Economic costs of infertility care for patients in low-income and middle-income countries: A systematic review protocol,* BMJ OPEN 2020. *See also* Silke J Dyer, Latiefa Vinoos, John E Ataguba, *Poor recovery of households from out-of-pocket payment for assisted reproductive technology,* Human Reproduction, Volume 32, Issue 12, December 2017, Pages 2431–2436, <sup>286</sup> Hammarberg, K., & Kirkman, M., *Infertility in resource-constrained settings: Moving towards amelioration*, REPRODUCTIVE BIOMEDICINE ONLINE, 26(2), 2013, 189–195, p. 191.

<sup>&</sup>lt;sup>287</sup> OHCHR, Latin America Focus Group Discussion (20 November 2020).

<sup>&</sup>lt;sup>288</sup> CEDAW, art. 16(1) (c).

equality within the family and should eliminate any laws, including customary or religious laws, <sup>289</sup> that discriminate against women and any discriminatory acts carried out by State authorities. <sup>290</sup> The Working Group has further recognized that States' obligation to protect women and girls' right to equality in the family includes preventing discrimination by private actors. <sup>291</sup> To this end, States must punish and end impunity for gender-based discrimination within family life, and to provide redress for all forms of harm and violence that women and girls face within family life, including compensation, restitution, guarantees of non-repetition and preventative measures. <sup>292</sup>

Protect women's economic rights within and outside of marriage: CEDAW recognizes the same rights and responsibilities to women and men during marriage and at its dissolution. <sup>293</sup> Furthermore, the CEDAW Committee has stated that States are obliged to "provide . . . for equality between the parties in the division of all property accumulated during the marriage". <sup>294</sup> Ensuring this right would drastically reduce the economic and other harmful consequences for women and girls who face divorce due to infertility. For those whose marital partner has taken on another spouse due to the women or girl's perceived failure to have a child, both the CEDAW and the Human Rights Committees<sup>295</sup> have called on States to prohibit polygamy on the grounds that it contravenes women's right to equality with men and can have serious emotional and financial consequences for women and their dependents. <sup>296</sup> The CEDAW Committee has called on States to take all legislative and policy measures needed to abolish polygamous marriages and to protect the economic rights of women leaving polygamous marriages. <sup>297</sup>

Increase women's access to education and income-earning capacities: States must further challenge cultural and gender norms and stereotypes that discriminate against women, as well as change attitudes and behaviors towards women and increase their access to employment, education and income. <sup>298</sup> The WGDAWG specifically calls on States to ensure that girls' can access to education on an equal basis as boys, women are free to participate in economic activities outside their house or village, without the supervision of male relatives, and "women, on an equal footing with men, and girls, on an equal footing with boys, have the right to at least half the family property and inheritance in the event of divorce or widowhood." <sup>299</sup> Enabling women and girls to not solely rely on the institution of marriage for their survival, is essential to reducing the impact of family and dissolution in cases of infertility.

<sup>&</sup>lt;sup>289</sup> CEDAW, General Recommendation 21 on equality relations and family relations (1994), para. 44.

<sup>&</sup>lt;sup>290</sup> A/HRC/29/40 (2015), para. 62.

<sup>&</sup>lt;sup>291</sup> A/HRC/29/40</sup> (2015), para. 65.

<sup>&</sup>lt;sup>292</sup> A/HRC/29/40</sup> (2015), para. 65.

<sup>&</sup>lt;sup>293</sup> CEDAW, art. 16 (1) (c).

<sup>&</sup>lt;sup>294</sup> Committee on the Elimination of Discrimination against Women, General Recommendation No. 29 on the economic consequences of marriage, family relations and dissolution, <u>CEDAW/C/GC/29</u> (2013), para. 46.

<sup>&</sup>lt;sup>295</sup> Human Rights Committee, General Comment 28 on the equality of rights between men and women, <a href="CCPR/C/21/Rev.1/Add.10">CCPR/C/21/Rev.1/Add.10</a> (2000), para. 24.

<sup>&</sup>lt;sup>296</sup> CEDAW, General Recommendation 21, para. 14.

<sup>&</sup>lt;sup>297</sup> CEDAW, General Recommendation 19, para. 28.

<sup>&</sup>lt;sup>298</sup> <u>A/HRC/29/40</u> (2015), para. 66.

<sup>&</sup>lt;sup>299</sup> A/HRC/29/40 (2015), para. 73(d)(i)-(iii).

# Conclusion

Despite the sheer number of people who face preventable infertility and the fact that infertility has been identified as a key sexual and reproductive health issue for over 40 years, the issue has been given insufficient attention, enabling infertility-related human rights harms to continue without accountability. Similar to patterns that emerge within broader sexual and reproductive health and rights violations, those most marginalized and stigmatized suffer human rights harms and violations leading to and resulting from preventable infertility at disproportionate rates.

A wide spectrum of State inaction and deliberate action cause preventable infertility. Ultimately, many of the drivers of preventable infertility mirror the barriers to full realization of individuals' human rights. Like other negative sexual and reproductive health and rights outcomes such as maternal mortality and morbidity, unsafe abortion, and unplanned pregnancies, preventable infertility in turn leads to violations of wide range of human rights.

The harms caused to individuals based on their actual or perceived infertility largely persist due to State failure to address its root causes including gender-based discrimination and harmful stereotypes around sexuality, gender and reproduction, infertility-related stigma, and misconceptions that often inaccurately place the blame for infertility on women. Other stigmas directed at men impugn their 'masculinity', while differently gendered persons face hostility in trying to use their fertility. Stigma about failing to become a parent harm not only individuals who are unable to have a child or are presumed to be infertile, but also negatively impacts individuals who choose not to have children. Families and communities cut off individuals based on their actual or perceived infertility, causing immense mental health trauma, and exposing individuals to severe gender-based violence.

As this research paper has discussed, international human rights law and standards articulate a wide range of State obligations to prevent infertility and mitigate its harmful consequences. While the human rights framework can play a significant role in guiding States on how to comprehensively address preventable infertility, thus far this issue has yet to be considered holistically as a human rights concern. The current patchwork of standards and fragmented human rights guidance (often siloed by gender identity, or pathway to infertility) obscure the broader structural forms of discrimination that often underlie preventable infertility. It is therefore critical to consolidate international human rights standards on this issue to articulate meaningfully and clearly what a human rights-based approach to infertility entails, and how to ensure such responses consider the broader social inequalities and discrimination that are key determinants of infertility.

In the current political and social environment, rife with division, environmental destruction, political instability and conflict, the risk and severity of human rights violations in the context of fertility and reproduction is only increasing. However, during these charged times there are rising calls for combatting

<sup>300</sup> Share-Net International, *supra* note 33 (noting that reproductive health, including fertility challenges, has been included in WHO programming since 1972).

racial injustice and ensuring gender equality, and targeted efforts to mitigate environmental destruction. As these critical conversations take place within the United Nations, regional and multi-lateral spaces, Member States, key stakeholders, advocates and community members are well-placed to raise the profile of the human rights causes and consequences of preventable infertility. There are opportunities to raise these pressing issues within advocacy around access to universal healthcare, racial, migrant, reproductive and environmental justice movements, and business and human rights.