

# DIGNITY DENIED

Violations of the Rights of HIV-Positive  
Women in Chilean Health Facilities



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FOR  
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RIGHTS

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## **THE CENTER'S MISSION**

The Center for Reproductive Rights uses the law to advance reproductive freedom as a fundamental human right that all governments are legally obligated to protect, respect, and fulfill.

## **THE CENTER'S VISION**

Reproductive freedom lies at the heart of the promise of human dignity, self-determination, and equality embodied in both the U.S. Constitution and the Universal Declaration of Human Rights. The Center works toward the time when that promise is enshrined in law in the United States and throughout the world. We envision a world where every woman is free to decide whether and when to have children; where every woman has access to the best reproductive healthcare available; where every woman can exercise her choices without coercion or discrimination. More simply put, we envision a world where every woman participates with full dignity as an equal member of society.

## **VIVO POSITIVO'S MISSION**

To expand and strengthen a comprehensive response to the challenges of HIV/AIDS and to improve the quality of life of persons living with, and affected by, the disease.

## **VIVO POSITIVO'S VISION**

Vivo Positivo is a consolidated social movement that seeks through inclusion, participation, and representation, to generate social and cultural changes, to open paths, and to create allegiances between civil society and people living with, and affected by, HIV/AIDS to respond to emerging issues in the national and international spheres.

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# GLOSSARY AND COMMON ACRONYMS

**AIDS:** Acquired immune deficiency syndrome. The stage at which an individual's immune system is weakened by HIV to the point where he or she may develop any number of diseases or cancers, or where a laboratory test shows his or her immune system to be severely damaged.

**American Convention:** American Convention on Human Rights. International convention that promotes and protects human rights in the Americas region.

**ART:** Antiretroviral therapy. Any of a range of treatments that include antiretroviral medications.

**CEDAW:** Convention on the Elimination of All Forms of Discrimination against Women. International treaty codifying States' duties to eliminate discrimination against women.

**CEDAW Committee:** Committee on the Elimination of Discrimination against Women. U.N. body responsible for monitoring States parties' compliance with CEDAW.

**The Center:** Center for Reproductive Rights. A nonprofit, legal advocacy organization that promotes and defends the reproductive rights of women worldwide.

**Civil and Political Rights Covenant:** International Covenant on Civil and Political Rights. International treaty protecting individuals' civil and political human rights worldwide.

**Convention on the Rights of the Child:** International treaty upholding the human rights of children.

**Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment:** International treaty aimed at preventing torture.

**Convention of Belém do Pará:** Inter-American Convention on the Prevention, Punishment and Eradication of Violence Against Women. International treaty codifying States' duties to prevent, punish, and eliminate violence against women in the Americas region.

**Economic, Social and Cultural Rights Covenant:** International Covenant on Economic, Social and Cultural Rights. International treaty protecting individuals' economic, social, and cultural human rights.

**ESCR Committee:** Committee on Economic, Social and Cultural Rights. U.N. body responsible for monitoring States parties' compliance with the Economic, Social and Cultural Rights Covenant.

**FIGO:** International Federation of Gynecologists and Obstetricians. A global organization constituted of professional organizations of obstetricians and gynecologists from around the world.

**FLACSO-Chile:** Facultad Latinoamericana de Ciencias Sociales-Chile. The Chilean branch of FLACSO, an autonomous inter-governmental organization in Latin America and the Caribbean dedicated to the promotion, research, and teaching of social sciences.

**HIV:** Human immunodeficiency virus. A retrovirus that infects cells of the immune system, destroying or impairing their function. As the infection progresses, the immune system becomes weaker, and the person becomes more susceptible to infections.

**HIV Prevalence:** The percentage of the adult population (aged 15–49) living with HIV.

**Human Rights Committee:** U.N. body responsible for monitoring States parties' compliance with the Civil and Political Rights Covenant.

**Infectology:** Medical specialty focused on the study and treatment of infectious diseases, including HIV/AIDS.

**International Conference on Population and Development:** U.N. conference held in Cairo in 1994, where world leaders, high-ranking officials, representatives of NGOs, and U.N. agencies gathered to agree on a Programme of Action to address issues related to population and development.



**International Guidelines on HIV/AIDS and Human Rights:** Guidelines prepared by the Office of the High Commissioner for Human Rights and UNAIDS that address human rights violations experienced by people living with HIV/AIDS, including discrimination, poverty, and violence, and that compile best practice standards.

**MTCT:** Mother-to-Child Transmission. The transmission of HIV/AIDS from mother to child during pregnancy, labor and delivery, and/or breastfeeding.

**NGO:** Nongovernmental organization.

**Pan-American Health Organization:** An international public health agency devoted to researching and promoting public health in the Americas region. It serves as the specialized organization for health of the Inter-American System, as well as the Regional Office for the Americas of the WHO.

**PAP test:** The Papanicolau test. A screening test used in gynecology to detect premalignant and malignant or cancerous changes in the cervix.

**Serodiscordant relationship:** A personal relationship in which one partner is HIV positive and the other is HIV negative.

**Serological status:** A person's HIV status. A person who is HIV positive is seropositive, while an HIV-negative individual is seronegative.

**Special Rapporteur:** An independent expert appointed by the U.N. Human Rights Council to investigate, monitor, and recommend solutions to human rights problems.

**Sterilization:** A permanent contraceptive method. Surgical sterilization involves an operation in which the fallopian tubes are cut or blocked in order to prevent fertilization. Medical and chemical sterilization are non-surgical methods that involve either the placement of a coil in the fallopian tubes or the administration of a medication that causes the fallopian tubes to seal.

**Treaty monitoring bodies:** U.N. treaty monitoring bodies. Committees responsible for monitoring States parties' fulfillment of their obligations under the U.N. human rights treaties.

**U.N.:** United Nations.

**UNAIDS:** Joint United Nations Programme on HIV/AIDS. U.N. agency devoted to global action on HIV/AIDS.

**UNFPA:** United Nations Population Fund. U.N. agency devoted to funding and supporting population and reproductive health programs in low-income countries.

**Vertical transmission:** See *MTCT*.

**Viral load:** Measurement of the presence of HIV in the blood used to monitor the status of the disease and inform treatment options. The higher a person's viral count, the more advanced the HIV disease and deterioration of the immune system. In contrast, if the viral load is undetectable, there are insufficient HIV strands in the blood stream for the test to register its presence; the number of viral strands that will result in an "undetectable" viral load varies according to the sensitivity of the test.

**Vivo Positivo:** A nongovernmental organization that advocates on behalf of individuals living with or affected by HIV/AIDS in Chile.

**WHO:** World Health Organization. U.N. agency devoted to researching and promoting public health worldwide.

**HIV-POSITIVE WOMEN IN  
CHILE ARE ROUTINELY  
PRESSURED TO PREVENT  
PREGNANCY AND COERCIVE  
STERILIZATION IS A  
SYSTEMIC PROBLEM.**



# INTRODUCTION

**“ They humiliated me . . . saying that I could not hug or kiss my baby because I was going to infect him. And other bad things. It was then that I learned what it is to discriminate against a person. ”**

*– Daniela, a 26-year-old HIV-positive woman from Arica*

Women account for roughly 50% of the 33.4 million people living with HIV/AIDS worldwide.<sup>1</sup> Although the total percentage of women living with HIV/AIDS has stabilized in the last few years, individual countries, including Chile, continue to see a rise in women’s rates of infection.<sup>2</sup>

Biological, social, and cultural factors all contribute to women’s heightened vulnerability to HIV infection. Physiologically, women are two to four times more susceptible than men to contracting HIV,<sup>3</sup> and social and cultural factors—including gender-based violence, entrenched gender stereotypes, power dynamics within relationships, and economic dependence—increase women’s risk of contracting the virus. Recognizing that gender equality is central to HIV prevention programs, international agreements and consensus documents have increasingly called for gender-sensitive responses to the global pandemic, and emphasize women’s empowerment and the abolition of discriminatory practices as central elements of HIV/AIDS prevention strategies.<sup>4</sup>

Yet, despite a strong international commitment to gender-sensitive HIV prevention and treatment programs, a wide gap exists between international standards and women’s daily realities. Women worldwide continue to struggle against a heightened risk of contracting HIV, and if they do acquire the virus, they face pervasive stigma and discrimination that further limits their full and equal participation in society.

The experiences of Chilean women offer a stark example of such realities.

Although Chile has established a stable democracy in the two decades since the Pinochet dictatorship ended, economic development and political stability have not translated into full and equal enjoyment of women’s fundamental human rights. For instance, Chile legalized divorce only in 2004, and the country has one of the most restrictive abortion laws worldwide, criminalizing abortion without exception, even where necessary to save the life of the pregnant woman.

With respect to HIV, Chile has relatively low HIV prevalence, at 0.3% (roughly 31,000 people),<sup>5</sup> and the Chilean government has made great strides in responding to HIV—it has adopted a national plan on the prevention, testing, and treatment of HIV/AIDS and 82% of Chileans with advanced HIV infection are currently receiving antiretroviral therapy (ART).<sup>6</sup> Yet social and cultural factors continue to expose Chilean women to a high risk of contracting HIV, and HIV-positive women in Chile encounter significant barriers to quality, acceptable healthcare, including reproductive healthcare. A 2004 study of women living with HIV/AIDS documented widespread coercion around motherhood and HIV in the healthcare sector, and found coercive sterilization of HIV-positive women to be a systemic problem. Fifty-six percent of the women surveyed reported being pressured by health workers to prevent pregnancy, and of the women who had undergone surgical sterilization after learning of their HIV status, 50% were sterilized under pressure or by force.<sup>7</sup> The experiences of the women we interviewed, along with anecdotal reports, indicate that the practice of coercive and

forced sterilizations, as well as other discriminatory treatment in the healthcare sector, persists.

The Chilean government has ratified regional and international human rights treaties signifying its commitment to respect, protect, and fulfill basic human rights. These fundamental rights are premised on notions of inherent human dignity and equality, regardless of an individual's sex or HIV status. However, the stigma and discrimination that HIV-positive women encounter in Chilean healthcare facilities belie this commitment. The actions of healthcare workers documented in this report discriminate against Chilean women living with HIV/AIDS, treating them as less than human and denying them their inherent dignity.

## A Global Phenomenon: Rights Violations of HIV-Positive Women

**Abuses of HIV-positive women within the healthcare setting, similar to the experiences of Chilean women recounted in this report, are a global phenomenon.**

HIV-positive women are routinely pressured or forced to undergo surgical sterilization as a result of their HIV status. The practice of coercive and forced sterilizations has been documented in the Dominican Republic,<sup>8</sup> Mexico,<sup>9</sup> Namibia,<sup>10</sup> South Africa,<sup>11</sup> and Venezuela,<sup>12</sup> and anecdotal reports indicate that it is an increasingly global occurrence.

HIV-positive women also experience delays and denials of healthcare in emergency, and sometimes life-threatening, situations. In India, a pregnant woman was discharged from the hospital once her doctors learned that she was HIV positive, despite the fact that she was in pain and on the verge of delivering her baby. She gave birth outside of the hospital, without medical assistance and without any key interventions to reduce the risk of transmitting HIV to her child. She was forcibly prevented from reentering the hospital after her delivery. Two days later, she sought care for serious pregnancy-related complications. Although she was finally admitted to the hospital, she was left unattended for hours. She died three days after giving birth due to sepsis and excessive bleeding.<sup>13</sup>

# METHODOLOGY AND STRUCTURE OF THE REPORT

## Methodology

This report is based on research and interviews conducted by the Center for Reproductive Rights (the Center) and Vivo Positivo between March 2009 and July 2010. Through in-depth interviews, the Center and Vivo Positivo gathered the experiences of 27 HIV-positive Chilean women in the regions of Tarapacá, Maule, Biobío, Araucanía, and the Metropolitan Region of Santiago. The Center and Vivo Positivo also conducted site visits to public health facilities and spoke with public health officials and healthcare providers who treat patients living with HIV/AIDS. Additionally, the Center and Vivo Positivo reviewed national and international guidelines, policies, and manuals on issues pertaining to HIV/AIDS and reproductive health services, as well as quantitative and qualitative reports released by nongovernmental and international organizations working in Chile. To protect their confidentiality, women's real names are not used in this report. For the same reason, identifying information for other interviewees has also been withheld. The stigma surrounding HIV occasionally presented challenges in researching this report, as some women were unwilling to speak with us out of fear of being identified as HIV positive.

## Scope and Structure of the Report

This report is not an exhaustive examination of the abuses and violations that HIV-positive women encounter in Chile but rather an exploration of the obstacles to quality care that women encounter in healthcare facilities, including lack of pre- and post-test counseling, breaches of confidentiality, discriminatory or abusive treatment, discrimination around motherhood, and coercive and forced sterilization.

Section One provides an overview of the factors that contribute to Chilean women's risk of contracting HIV. Section Two discusses HIV-positive women's experiences in Chilean healthcare facilities, as well as some of the structural barriers that impede access to quality health services and the repercussions of discriminatory healthcare treatment. Section Three provides an overview of the legal and human rights implications of the rights violations identified in the report. Section Four offers some recommendations to key stakeholders based on the findings of the report and input from the women and medical providers with whom the Center and Vivo Positivo spoke.

# Women, HIV, and Risk

## Women and HIV at a Glance

- Globally, there are around 33.4 million people living with HIV/AIDS. Women account for roughly 50% of this population.<sup>14</sup>
- More than four-fifths of new infections in women occur in marriage or in long-term relationships with primary partners.<sup>15</sup>
- Young women are 1.6 times more likely to be HIV positive than young men.<sup>16</sup>
- The Caribbean—which has the highest HIV prevalence outside of sub-Saharan Africa—mirrors global statistics, with women accounting for roughly 50% of HIV infections in the region. Young women in the region are at particularly high risk of contracting the virus.<sup>17</sup>
- In Latin America, women comprise a smaller percentage of people living with HIV/AIDS when compared to high-risk groups, such as men who have sex with men.<sup>18</sup> However, as epidemics mature, heterosexual transmission increases. In Peru, for instance, heterosexual transmission accounts for roughly 43% of all new HIV infections.<sup>19</sup>
- Marginalized women are particularly vulnerable. In the United States, AIDS-related illnesses are the leading cause of death among African-American women aged 25–34, and in Canada, indigenous women are almost three times more likely than non-indigenous women to be HIV positive.<sup>20</sup>
- The only safe and effective woman-controlled HIV prevention method currently available—the female condom—is not widely accessible. Barriers to access include the comparatively high cost of the female condom and lack of information and education around this contraceptive method.<sup>21</sup>

## Violence against Women and HIV/AIDS

The connection between gender-based violence and HIV/AIDS is widely recognized,<sup>22</sup> and violence against women and HIV/AIDS intersect in many different and complex ways, as both a cause and a consequence of HIV infection. Rape and other forms of sexual violence greatly increase a woman's risk of infection, both because women are unable to negotiate condom use to protect themselves from HIV transmission and because the physical trauma of forced intercourse can lead to an increase in lacerations or abrasions where the virus can enter the bloodstream.<sup>23</sup> Fear of violence can also prevent women from negotiating condom use in

### ***Violence against Women and HIV/AIDS*** (continued)

consensual sexual encounters<sup>24</sup> or from seeking HIV testing when they believe they may have been exposed to the virus.<sup>25</sup>

Violence against women is pervasive throughout Latin America. In Chile, a woman dies every week at the hands of her partner, and one study found that roughly 50% of Chilean women have been victims of domestic violence.<sup>26</sup> In Peru, 41% of women have suffered physical violence at the hands of their spouses and 28% have experienced violence by other men.<sup>27</sup> In Nicaragua, 40% of women of reproductive age have been victims of physical violence by their partners.<sup>28</sup>

Women who have been victims of gender-based violence face a higher risk of contracting HIV. In a study of HIV-positive women in Argentina, Brazil, Chile, and Uruguay, a majority of respondents report having been victims of gender-based violence before learning of their HIV status: 79% in Argentina, 62% in both Brazil and Uruguay, and 56% in Chile.<sup>29</sup>

HIV-positive women may be at greater risk of domestic violence or abandonment on disclosure of their HIV status,<sup>30</sup> and as the experiences of women related in this report demonstrate, HIV-positive women are also at greater risk of institutional violence.

## **Other Social and Cultural Factors Expose Women to Greater Risk of HIV Infection**

**Gender norms and economic dependence also inhibit women's ability to protect themselves from HIV infection. In many cultures, femininity is inextricably linked with motherhood, and a woman's ability to conceive may affect her status within her community, as well as her financial security.**<sup>31</sup> Women, especially

young women, can encounter pressure to bear children,<sup>32</sup> which may hinder their use of contraceptive methods to prevent transmission of sexually transmitted infections (STIs), including HIV. Similarly, stereotypes about masculinity and a man's virility can contribute to unsafe sexual practices.<sup>33</sup> A woman's economic dependence on her partner may also give her little power in negotiating safe and consensual sex.<sup>34</sup> Discriminatory cultural practices can also limit women's and girls' access to education and information on sexual and reproductive health necessary for protecting themselves from STIs, including HIV, and unwanted pregnancies.<sup>35</sup>



**VIOLENCE AGAINST WOMEN IS BOTH  
A CAUSE AND CONSEQUENCE OF HIV  
INFECTION. CHILEAN WOMEN EXPERIENCE  
HIGH RATES OF VIOLENCE —  
A CHILEAN WOMAN DIES EVERY  
WEEK AT THE HANDS OF HER PARTNER.**



# SOCIAL AND CULTURAL FACTORS EXPOSE CHILEAN WOMEN TO A HIGH RISK OF CONTRACTING HIV

Women make up an increasing percentage of all HIV/AIDS cases in Chile. In 2007, women accounted for 28% of people living with HIV/AIDS in Chile, up from 26% in 2001.<sup>36</sup>

Despite this trend, Chilean women continue to underestimate their risk of acquiring HIV. Women in Chile, like women worldwide, face significant obstacles to preventing HIV infection, including socio-cultural norms, gender-based violence, and lack of sexuality education and information. Yet the country's low HIV prevalence combined with strong associations of HIV with homosexuality and promiscuity fuel misconceptions about the risk of infection.

*Puertas Adentro*, a study by FLACSO-Chile (*Facultad Latinoamericana de Ciencias Sociales-Chile*), attributes Chilean women's vulnerability to HIV to several cultural norms around gender. In particular, the study points to power dynamics between men and women and strong associations of womanhood with motherhood that reduce a woman's ability to negotiate contraceptive use.

As the study notes, women in Chile are traditionally seen as subordinate to men, a paradigm that often results in "the subordination of the needs and desires of women to those of their partners,"<sup>37</sup> including sexual needs and desires. This framework makes women vulnerable to non-consensual sex, both within and outside marriage,<sup>38</sup> and increases obstacles to negotiating condom use.<sup>39</sup> Many of the women interviewed for *Puertas Adentro* reported that they do not use condoms because their partners do not like the way condoms feel.<sup>40</sup> Prejudice against condom use is so pervasive that it has given way to myths that male condoms "can cause men to lose their virility and erection."<sup>41</sup> Not using condoms is seen "as an act of trust, surrender and love of one's partner,"<sup>42</sup> whereas attempts to introduce condoms into stable partnerships implicate distrust or infidelity.<sup>43</sup> Indeed, the prejudice against condoms is so

ingrained that HIV-positive women have reported difficulties in negotiating condom use with their HIV-negative partners.<sup>44</sup>

Additionally, femininity in Chile is closely linked to women's roles as mothers and caretakers.<sup>45</sup> As FLACSO-Chile's study states, "maternity has historically been the principle axis of the construction of womanhood in our [Chilean] culture: 'you will not be a complete woman as long as you are not a mother.'"<sup>46</sup> In contrast, men in Chile are granted "a certain sexual license."<sup>47</sup> Together, these gender norms expose Chilean women to significant risk of infection. On the one hand, men are encouraged to have multiple sexual partners. On the other, women are discouraged from using condoms both for the reasons discussed above and because they prevent women from fulfilling their "natural role" as mothers.

Violence against women is another factor contributing to Chilean women's risk of HIV infection. A 2004 survey by Vivo Positivo of Chilean women living with HIV/AIDS found that 77% of the respondents had suffered some form of violence, including psychological or physical violence, sexual abuse, and rape.<sup>48</sup> Attempts to negotiate condom use can also expose women to violence, given the strong stigma around male condoms.<sup>49</sup>

Gender norms also make it difficult for women to obtain the information necessary to protect against infection. Sexuality is frequently treated as a taboo subject within the family,<sup>50</sup> sexuality education in schools is erratic,<sup>51</sup> and healthcare providers often do not provide information on STIs because of the short amount of time that they have with each patient.<sup>52</sup> Female respondents in FLACSO-Chile's study revealed that friends were their primary source of information around sexuality,<sup>53</sup> and in Vivo Positivo's study on women living with HIV/AIDS, 85% of the women

responded that they had scant or no information on HIV/AIDS before being notified of their HIV-positive status.<sup>54</sup>

Lack of information on HIV prevention combined with deeply entrenched stigma around HIV/AIDS and low HIV prevalence translates to a low perceived risk of HIV infection. Misconceptions around HIV transmission are commonplace, even among healthcare professionals themselves. For instance, one woman in FLACSO-Chile's study recalled hearing healthcare workers saying, "I know who I do it with, if he is clean, if he bathes every day, or before we do it I make him bathe."<sup>55</sup> In particular, because HIV is strongly linked with homosexuality, promiscuity, and infidelity in Chile, the virus is perceived as "something for *other people*, for homosexuals."<sup>56</sup> The experience of Julia, related in the next section, illustrates how these associations persist even within the healthcare setting: due to her HIV status, healthcare providers assumed she had multiple sex partners, despite the fact that she had contracted HIV in what she believed was a monogamous relationship. Chilean women also tend to gauge their risk of acquiring the virus based on the number of sexual partners they have had, only secondarily considering their partners' sexual histories.<sup>57</sup>

These factors lead women to greatly underestimate their risk of infection, and point to the need for comprehensive sexuality education and information around the risks and realities of STIs, including HIV. Low perception of risk means that women are less likely to negotiate condom use, and can hinder other public health efforts aimed at prevention. A healthcare provider in Temuco, for instance, recounted the story of one woman who transmitted the virus to her child after refusing routine HIV testing because she did not think it was possible that she was HIV positive.<sup>58</sup> Such experiences highlight the importance of pre-test counseling and the provision of accurate, non-discriminatory information to ensure that women are able to make informed decisions around HIV testing.

# PERVASIVE STIGMA AROUND HIV LEADS TO DISCRIMINATORY TREATMENT IN THE HEALTH SYSTEM

## Julia's Story: Discrimination and Denial of Care

Julia, a 36-year-old woman from Santiago, learned that she was HIV positive in November 2003. She did not receive any counseling before she underwent the test. When the result came back positive, she was grilled about her sexual history. Healthcare workers assumed that Julia's HIV-positive status was an indication of multiple sex partners, despite the fact that she had contracted the virus during a long-term relationship that she believed to be monogamous. She was referred to a psychologist, but the psychologist did not know anything about HIV. It was only through educational talks organized by Vivo Positivo that she began to learn how to care for herself as an HIV-positive woman.

In 2004, Julia received the good news that her viral load was undetectable. With this improvement in her health and after witnessing other HIV-positive women give birth to healthy, HIV-negative children, Julia and her partner decided to try for a child in consultation with a private physician. However, despite the low risk of mother-to-child transmission (MTCT), healthcare professionals repeatedly chided Julia after she became pregnant, telling her, "What were you thinking? Don't you see that you are going to have a sick child?"

During the first trimester of her pregnancy, Julia began experiencing an orange-colored vaginal discharge. Concerned, she went to the hospital to have it checked out. Instead of treating her, however, hospital workers turned her away and told her to return for her regularly scheduled check-up. She was admitted to the hospital three days later, hemorrhaging and with severe abdominal pain, but she still sat untreated while the hospital staff attended all the HIV-negative patients first, including those who arrived after Julia. Her pregnancy ended in a miscarriage shortly thereafter, and a paramedic told her, "It is because God knows, because you were going to have a sick child."

Julia still wonders whether she would have miscarried if she had received immediate medical attention, and the mistreatment she experienced deters her from seeking further healthcare services at the hospital.

She also continues to experience delays in treatment. In March 2009, Julia scheduled her first gynecological exam since the miscarriage, but on the morning of the appointment the doctor's office inexplicably canceled the appointment. She tried to reschedule, but was told that she had to wait for them to call her to reschedule the appointment. A month later, she was still waiting to get an appointment.

"There are so few who put themselves in your place," Julia explained. "I wish that . . . above all they would humanize [the treatment]. If they aren't able to do it in the healthcare setting, how can we expect it of regular people who have little information [about HIV]?"<sup>59</sup>

# Preventing Mother-to-Child Transmission

MTCT of HIV/AIDS can occur during pregnancy or labor or through breastfeeding. Without any medical interventions, the risk of MTCT is roughly 20–45%.<sup>60</sup>

The risk of MTCT **can be reduced to less than 2%** in non-breastfeeding populations and less than 5% in breastfeeding populations with several key interventions:

- ART and/or antiretroviral prophylaxis according to the pregnant woman's viral load;
- cesarean deliveries; and
- safe infant feeding practices.<sup>61</sup>

According to international guidelines, appropriate infant feeding practices must be determined on a situational basis. HIV-positive mothers should be counseled to either exclusively use a breast-milk substitute or exclusively breastfeed. The decision to use a breast-milk substitute should take into consideration whether clean water for mixing infant formula is available, whether the mother or caregiver can reliably provide sufficient infant formula exclusively for the first six months of the infant's life, and whether there is familial support for avoiding breastfeeding. Where these factors are not met, the guidelines advise exclusive breastfeeding.<sup>62</sup>

Chilean regulations on the prevention of MTCT call for the exclusive use of breast-milk substitute.<sup>63</sup>

Given the widely held misconceptions around HIV in Chile, Chilean women face pervasive stigma if they do contract the virus. The stigma ascribed to women living with HIV/AIDS exposes HIV-positive women to discriminatory treatment at the interpersonal level, the community level, and the institutional level, with significant repercussions for both the victims of discrimination and the public health efforts aimed at prevention and treatment of HIV/AIDS.

HIV-related stigma and discrimination is grounded in the strong association of the virus with other highly stigmatized subjects, namely, sexual misconduct and injecting drug use. Because of these associations, HIV-positive people are presumed to have deviated from the social norm and are therefore often blamed for their HIV status.<sup>64</sup>

Women, in particular, living with HIV/AIDS encounter entrenched stigma due to a variety of factors. Despite the fact that roughly 80% of women contract HIV in monogamous relationships,<sup>65</sup> as in Julia's case, HIV-positive women are often presumed to be sex workers or to have had multiple sexual partners.<sup>66</sup> Chilean programs aimed

at preventing MTCT promote antenatal testing of pregnant women as a matter of course,<sup>67</sup> yet women rarely receive adequate pre-test counseling or give informed consent to the test. Routine prenatal testing can mean that women are often the first in their families to learn of their status, and women are often blamed for having brought HIV into the family.<sup>68</sup> HIV-positive women face additional stigma around motherhood, as they are associated with passing on the disease through MTCT, and they are usually the ones blamed for leaving behind orphans because of HIV-related illness and death.<sup>69</sup>

Such stigma carries both direct and indirect harms. Stigma paves the way for discriminatory treatment, including within health-related services,<sup>70</sup> and ignorance and misinformation about HIV transmission can fuel discriminatory behavior.<sup>71</sup> Because the sexual and reproductive health of women is integrally connected with HIV, quality and non-discriminatory sexual and reproductive health services are a key component of successful HIV prevention and treatment programs.<sup>72</sup> In practice, however, HIV-positive women frequently face discrimination in reproductive health

**WOMEN LIVING WITH HIV/AIDS  
ENCOUNTER ENTRENCHED  
STIGMA THAT PAVES THE  
WAY FOR DISCRIMINATORY  
TREATMENT IN THE  
HEALTHCARE SETTING.**



services, including delayed care, verbal abuse, pressure to not have children, forced or coerced sterilization or refusal of treatment.<sup>73</sup>

At the same time, more women and men of reproductive age are living with HIV/AIDS, and greater access to ART has essentially transformed HIV into a chronic manageable disease and has allowed women to either regain or retain their fertility. Additionally, key interventions can reduce the risk of MTCT of HIV/AIDS to less than 2% in countries like Chile, where adequate breast-milk substitute is available. Given this landscape, it comes as no surprise that HIV-positive individuals express similar desires as HIV-negative individuals to have children, with their HIV-positive status being one of many factors they may consider when deciding whether to have children.<sup>74</sup> Yet because of the persistent and pervasive stigma around HIV and motherhood, HIV-positive women face discriminatory treatment in the healthcare setting that infringes on their right to make autonomous reproductive decisions. This section documents instances of discriminatory behavior and treatment that HIV-positive women have experienced in Chilean healthcare facilities.

## Pre- and Post-Test Counseling

Despite legal protections mandating counseling and informed consent in Chilean health facilities,<sup>75</sup> a large majority of the women we interviewed reported not having received any counseling prior to testing for HIV. Roughly half of the women who did not receive any counseling were undergoing an HIV test because their child or sexual partner tested positive for the virus. In other words, despite their heightened risk for testing positive, they did not receive any counseling regarding the virus or prevention and treatment options. Lack of pre-test counseling indicates that these women's informed consent was not obtained prior to testing. Indeed, more than a third of the women reported that they did not know what they were consenting to or did not consent at all.

**Karina, a 33-year-old woman from Santiago who tested positive for HIV in 1997, was never informed that she and her young daughter were being tested for HIV. The nurse who informed her of her status asked her if she knew what her daughter had, and she said no. The nurse then asked her if she knew what AIDS was. She did not.**

**She was not prepared at all, and when she learned that she was HIV-positive, she felt devastated and isolated.<sup>76</sup>**

Post-notification counseling is similarly deficient in Chilean health facilities. Although required by Chile's law on HIV testing,<sup>77</sup> post-notification counseling is rarely comprehensive and in some cases completely absent. Vivo Positivo's 2004 study revealed that while 81% of respondents received information on the importance of exams for monitoring their viral load, only 62% received information on reinfection and slightly more than half reported getting information on adherence to treatment, family planning, and prevention of MTCT.<sup>78</sup> Many of the women interviewed for this report indicated that they did not receive any post-test counseling, or received incomplete or inaccurate information from healthcare workers.

**Ana, a 43-year-old woman from Santiago notified of her status in 2002, said the only post-test counseling she received was to keep all of her plates, cups, and flatware separate from those of her HIV-negative children and that they should not use the same bathroom as her.<sup>79</sup> This information is both inaccurate—HIV is not transmitted through shared utensils or bathroom facilities—and insufficient.**

**Pamela, a 37-year-old woman from Iquique, indicated that while she was given some information after testing positive, the information was overly technical and incomprehensible, and she was not provided with essential information such as condom use.<sup>80</sup>**

Almost one-third of the women interviewed reported never receiving information from healthcare workers on condom use to prevent reinfection or transmission to their partners, and only one healthcare worker we spoke with discussed the importance of empowering women to negotiate condom use.<sup>81</sup> Several interviewees said that any information they had on HIV was learned either from associations of people living with HIV/AIDS or from reading about it on their own, not from healthcare workers.<sup>82</sup> Some women also felt that, at times, they were more informed than the medical staff treating them.

**Julia, whose experiences with Chilean health facilities are recounted above, noted her disappointment with the hospital staff's level of**

**knowledge: “The people who work in healthcare, you would think they are the ones who know more and have more information about the illness.” However, she never received necessary information on self care or nutrition.<sup>83</sup>**

Women in Iquique and Curicó also noted that the hospitals there do not provide information to HIV-positive patients about organizations or associations of people living with HIV/AIDS.<sup>84</sup> Both these and other women emphasized the central role that such groups played in helping them come to terms with the illness, learn about the virus and self care, and understand and claim their rights.<sup>85</sup>

## Confidentiality

Confidentiality is also essential to treatment and prevention programs. When patients fear that their identity or HIV status will not be kept confidential, they may be less likely to seek HIV testing, treatment, or counseling.<sup>86</sup> Despite a strong mandate for confidentiality in Chile’s law on HIV,<sup>87</sup> almost half of the women we interviewed reported problems with confidentiality in the healthcare setting.

For example, women commonly complained that their medical charts indicated “HIV-positive” in giant letters at

# Confidentiality, Counseling, and Consent in HIV Testing

**The World Health Organization (WHO) and Joint United Nations Programme on HIV/AIDS (UNAIDS) have emphasized that, in order to be effective, HIV testing must be “confidential, be accompanied by counselling, [and] only be conducted with informed consent, meaning that it is both informed and voluntary.”<sup>88</sup>**

Pre-test counseling should cover the following:

- the benefits of knowing one’s HIV status, including accessing ART and preventing MTCT and other forms of transmission;
- what to expect if the patient does receive a positive result, including follow-up services and information on disclosure to sexual partners;
- the patient’s right to refuse the test; and
- tips for negotiating condom use for women seeking HIV testing.<sup>89</sup>

Such counseling is essential for allowing patients to make an informed decision about whether to test and preparing patients for any potential outcome of the test. Without guarantees of confidentiality and voluntariness, patients will be less likely to seek testing in the first place,<sup>90</sup> and may be deterred from seeking follow-up care. As the International Guidelines on HIV/AIDS and Human Rights acknowledge, mandatory or involuntary testing policies can “drive away the people most in need of such services and fail to achieve their public health goals of prevention through behavioural change, care and health support.”<sup>91</sup>

Post-test counseling is equally essential, as it helps patients understand and process the news of their HIV status and adhere to treatment programs. Post-test counseling should include information on self care, available treatment, the importance of condoms in preventing reinfection or transmission to partners, family planning, and prevention of MTCT for women of reproductive age.<sup>92</sup>

the top of the chart, often in red ink or highlighted, or that nametags or signage advertised the nature of that hospital unit.

**Teresa, a 51-year-old woman from Santiago, was concerned that her medical chart advertised her HIV-positive status to anyone entering her hospital room, including family members to whom she had not disclosed her status.<sup>93</sup>**

**Inés, a 37-year-old woman from Curicó, noted that the nurses in the unit that treats HIV-positive patients at the Hospital of Curicó wear nametags that say “Sexually Transmitted Infections,” advertising the purpose of the unit. “People are not stupid,” she said. Despite claims of confidentiality, the nametags indicate to others that patients treated in this unit are HIV positive.<sup>94</sup>**

Several women also reported problems with hospital staff disclosing their HIV status to other patients or family members.

**Natalia, a 43-year-old woman from Santiago, had been hospitalized for several days in the same room as a neighbor of hers. At one point when the nurses were changing shifts, one nurse informed the other, “‘This patient is a patient with HIV,’ at full volume. Really loudly. And the person next to me started staring at me. I felt so ashamed.”<sup>95</sup>**

Concerns about confidentiality deterred some women in Santiago from seeking necessary reproductive healthcare, including family planning services, PAP tests, and annual gynecological check-ups, because they are obligated to seek such treatment at neighborhood medical centers where a woman’s neighbors or other acquaintances might be more likely to discover her HIV status.<sup>96</sup>

**Patricia, a 52-year-old woman from Santiago, confided that she had not had a PAP test in the almost sixteen years since she learned of her HIV-positive status because she does not want her neighbors to discover that she is HIV positive. “I live next door to the medical center and everyone knows me there,” she said. “For me it is very complicated and so . . . it has been fifteen, sixteen years since I’ve had a PAP.”<sup>97</sup>**

While admitting that confidentiality can be an issue in hospitals, one of the medical practitioners interviewed stated

that disclosure of HIV status between medical personnel is necessary to ensure that staff takes necessary precautions with HIV-positive patients.<sup>98</sup> However, this is not sufficient justification to jeopardize patient confidentiality. Healthcare workers should always take universal precautions—simple interventions designed to protect healthcare workers and patients from contracting blood-borne pathogens such as HIV, such as the use of gloves and other protective gear and the safe disposal of needles—with all patients, not only those who are known to be HIV positive.<sup>99</sup> As the WHO has acknowledged, “it is not feasible, effective or cost-effective to test all patients for pathogens prior to giving care. . . . Thus, decisions regarding the level of precautions to use are based on the nature of the procedure and not on the actual or assumed serological status of the patient.”<sup>100</sup> When providers discuss patients’ serological status in front of other individuals, they violate the patients’ rights to confidentiality and privacy.

## Discriminatory Treatment

Despite domestic and international standards prohibiting discrimination on the basis of HIV status in healthcare facilities,<sup>101</sup> HIV-positive women report many different forms of discrimination, including significant delays in accessing necessary care, humiliating or abusive treatment, or refusal of treatment altogether. When asked whether healthcare providers respected their rights, 65% of respondents in a 2004 study indicated that their rights were either never or only sometimes respected.<sup>102</sup>

Many of the women we interviewed reported delays in receiving necessary healthcare.

**Julia, whose experiences are recounted above, was initially turned away from health services when she began experiencing complications with her pregnancy. When she returned later with hemorrhaging, she was still made to wait while the staff treated HIV-negative patients who had arrived after her.<sup>103</sup>**

**María, a 68-year-old woman from Concepción, experienced similar delays when she sought urgent care in 2008. After an IV was inserted, she was left unattended for hours. She recalled that several medical attendants stopped by to check on her, but after seeing her HIV status on her medical chart, they left without treating her.<sup>104</sup>**



In order to schedule appointments with specialists in other fields—such as gynecologists, dentists, dermatologists, or oncologists—HIV patients must be referred by the unit where they undergo HIV monitoring tests. Yet many women reported difficulties in obtaining these referrals or find that the referral process leads to delays in treatment, as these other specialists often avoid treating them because they are HIV positive.

**Teresa needed surgery in 2004 to remove a malignant tumor in her shoulder. She kept getting shuffled between different oncologists, and when she asked one of the doctors why none of them were performing the necessary operation, the doctor replied, “It’s very simple. . . . No doctor wants to operate on a *sidoso* [a derogatory term for a person living with HIV/AIDS].” She left the appointment crying.**<sup>105</sup>

Discrimination against HIV-positive patients can also lead to their being segregated from HIV-negative patients, which can have a significant psychological impact on the HIV-positive patients.

**Daniela, a 26-year-old woman from Arica, felt isolated after giving birth in 2004. She remarked that she was segregated from the other new mothers, who were all placed in recovery rooms together. She recalled, “I did not even receive visits from the nurse to bring me pills for the pain, because she walked through all the other rooms where there were more people, but it was like she forgot about me. . . . The impact was very strong.”**<sup>106</sup>

Despite the fact that HIV-positive women in Chile are counseled to avoid breastfeeding altogether to avoid the risk of vertical transmission, they sometimes experience delays in accessing the infant formula necessary to comply with this advice.

**Marcela, a 31-year-old woman from Santiago, said that when she went to the pharmacy at the Hospital Sótero del Río to fill her prescription for breast-milk substitute, she was told that they were out of stock and she needed to return at a later date. When she returned the next day, she was turned away again. This happened on three separate occasions. It was only when a representative of *Vivo Positivo* intervened on**

**her third trip to the hospital that the pharmacy acknowledged that it did have the milk substitute in stock. In addition to the frustration and concern for not being able to obtain the milk substitute she needed for her child, Marcela noted the financial burden of having to make multiple trips to the hospital in a single week.**<sup>107</sup>

**Claudia, a 34-year-old woman from Santiago, gave birth to twins at the same hospital, and was not given a prescription for breast-milk substitute when she was discharged. As a result, she was unable to obtain sufficient quantities of milk substitute to feed her two newborns.**<sup>108</sup>

Problems with accessing breast-milk substitute can cause mental anguish, as women are faced with the unhappy choice of either not providing their children with sufficient nourishment or using mixed feeding practices that can increase the risk of vertical transmission.<sup>109</sup> Both of these women were fortunate to find an association of people living with HIV/AIDS to intervene on their behalf, but, as Claudia noted, many women in this situation might have just breastfed for fear of letting their children go hungry.<sup>110</sup>

When HIV-positive women are able to access treatment, the treatment they receive is sometimes degrading or unscientific. Patricia, who volunteers with an association of people living with HIV/AIDS at the Hospital Sótero del Río in Santiago, said that she has been shocked by “the ignorance of the hospital staff about the issue [of HIV/AIDS]. It’s astounding.” Patricia cited examples of healthcare workers layering on two or three pairs of latex gloves before examining patients.<sup>111</sup> Claudia recalled that during her first prenatal exam, the attending gynecologist would not examine her abdomen because he did not want to touch her. Instead, he glanced at her chart and told her everything looked fine.<sup>112</sup>

Daniela recounted the humiliating, biased information that she received after giving birth to her son in 2005:

**I was attended by other doctors who I did not know. There they treated me badly. They, they humiliated me . . . saying that I could not hug or kiss my baby because I was going to infect him. And other bad things. It was then that I learned what it is to discriminate against a person.**<sup>113</sup>

# FRANCISCA'S STORY: FORCIBLY STERILIZED BECAUSE OF HER HIV STATUS

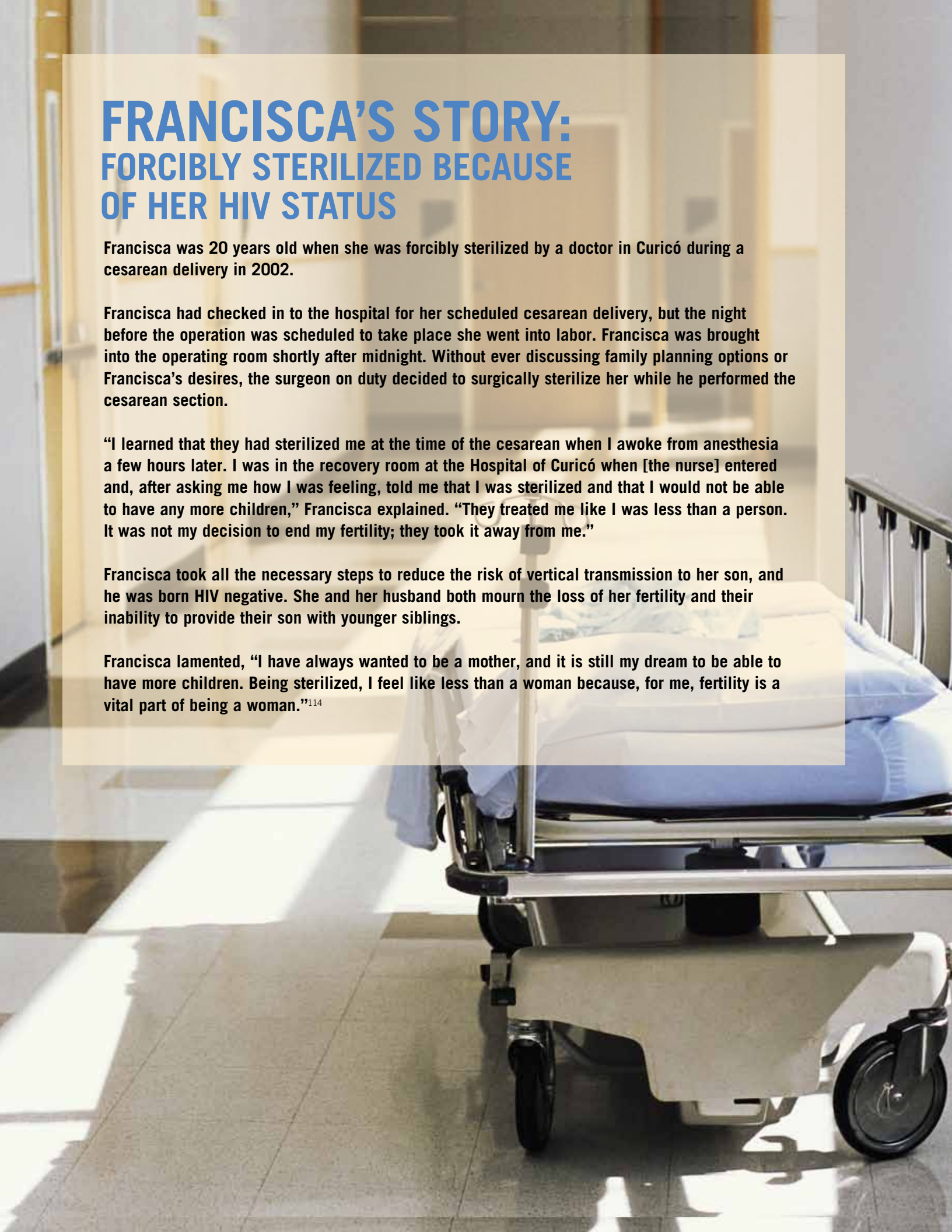
Francisca was 20 years old when she was forcibly sterilized by a doctor in Curicó during a cesarean delivery in 2002.

Francisca had checked in to the hospital for her scheduled cesarean delivery, but the night before the operation was scheduled to take place she went into labor. Francisca was brought into the operating room shortly after midnight. Without ever discussing family planning options or Francisca's desires, the surgeon on duty decided to surgically sterilize her while he performed the cesarean section.

"I learned that they had sterilized me at the time of the cesarean when I awoke from anesthesia a few hours later. I was in the recovery room at the Hospital of Curicó when [the nurse] entered and, after asking me how I was feeling, told me that I was sterilized and that I would not be able to have any more children," Francisca explained. "They treated me like I was less than a person. It was not my decision to end my fertility; they took it away from me."

Francisca took all the necessary steps to reduce the risk of vertical transmission to her son, and he was born HIV negative. She and her husband both mourn the loss of her fertility and their inability to provide their son with younger siblings.

Francisca lamented, "I have always wanted to be a mother, and it is still my dream to be able to have more children. Being sterilized, I feel like less than a woman because, for me, fertility is a vital part of being a woman."<sup>114</sup>



## Discrimination around Motherhood

Pressure or coercion to not have children is a common manifestation of discrimination against women living with HIV/AIDS. As discussed above, motherhood in the context of HIV/AIDS carries strong associations with harms like vertical transmission. Yet key interventions can reduce the risk of MTCT to less than 2%,<sup>115</sup> and international standards mandate that all women, including HIV-positive women, be able to decide freely on the number and spacing of their children.<sup>116</sup> Additionally, the International Federation of Gynecologists and Obstetricians (FIGO) notes that “HIV-positive women should not be discouraged from becoming pregnant,”<sup>117</sup> and the United Nations Population Fund’s (UNFPA) guidelines on care and treatment for women living with HIV/AIDS detail the manner in which health workers should provide assistance for HIV-positive women who are having trouble conceiving or who are in serodiscordant relationships.<sup>118</sup>

Despite these guidelines, HIV-positive women in Chile are frequently pressured to not become pregnant and in some instances are coercively or forcibly sterilized to prevent future pregnancies. Sixty-six percent of the respondents in a

2004 survey of women living with HIV/AIDS were informed by healthcare providers that “seropositive women should not get pregnant.”<sup>119</sup> Roughly half of the women interviewed for this report similarly noted that they were actively discouraged from having children.

**Julia recalled that medical providers treated her like she was crazy for getting pregnant when she knew she was HIV positive. The first time she went in for prenatal care, “they told me, ‘What were you thinking? Don’t you see you’re going to have a sick child?’”<sup>120</sup> Throughout her pregnancy she was repeatedly told by both doctors and nurses, “You know you’re not healthy, you know you are a sick person, so you can’t have children.” After her pregnancy ended in a miscarriage, one healthcare provider told her it was “because God knows, because you were going to have a sick child.”<sup>121</sup> This experience was all the more striking when compared to the prenatal treatment she received before she became HIV positive. “When you are a healthy mother,” Julia said, “it is a very different case from when you are a seropositive person. . . . You have all the doors open to you.”<sup>122</sup>**

## Elements of Informed Consent

**Informed consent is more than just a signature—it is a process of communication between a healthcare provider and the patient. For consent to surgical sterilization to be considered informed, it must be given:**

- freely and voluntarily, without threats or inducements;
- after the patient has been counseled on the risks and benefits of the procedure; and
- after the patient is aware that there are alternative, reversible forms of family planning that may be equally effective.<sup>123</sup>

While the process of obtaining informed consent may be difficult and time consuming, such difficulties do not absolve healthcare providers from meeting these criteria.<sup>124</sup>

**Claudia resisted pressure to undergo sterilization right before a cesarean delivery. She recalled the doctor asking her, “But how are you going to have more kids in your state?” I said, ‘What state?’ ‘You live with HIV.’”<sup>125</sup> She said that her HIV status has strongly influenced her decisions about her family size because “[i]f I did not have HIV, nobody would scold me for getting pregnant again.”<sup>126</sup>**

## Coercive or Forced Sterilization

Coercive or forced sterilizations are a pernicious manifestation of the stigma around motherhood for HIV-positive women. Of the sixteen women we spoke with who had been sterilized, only four reported making a fully informed and voluntary choice about sterilization. The remaining women reported experiencing a variety of tactics, such as directive counseling, misleading or incomplete information, and sterilization without their knowledge or consent during another procedure.

Chile has a history of medical professionals making decisions about sterilization for their female patients.<sup>127</sup> Indeed, prior to 2000, the law governing surgical sterilization codified medical practitioners’ ability to make decisions on their patient’s behalf in “serious cases,” in addition to restricting surgical sterilization to specific medical issues and requiring spousal consent.<sup>128</sup> Although HIV/AIDS was not explicitly included among the medical indications for sterilization, medical practitioners routinely read the “Other medical causes” provision to include HIV/AIDS, and used this provision to justify sterilization of HIV-positive women.

Most women we interviewed who had been notified of their HIV-positive status prior to 2000 recounted that sterilization was not a choice.

**Rocío, a 52-year-old woman from Santiago, said that she was forced to undergo a chemical sterilization in 2000. “At this time,” she said, “it was like ‘okay, you will sterilize because you have HIV,’” and that was the end of the discussion. She never received any information about sterilization or its possible side effects.**<sup>129</sup>

**Paola, a 38-year-old woman from Santiago, reported being coercively and forcibly sterilized on two separate occasions in the 1990s. In 1994, she was chemically sterilized with injections. Although she signed a consent form for the**

**injections, she felt she had no choice in the matter. “The first one was with consent, but I think it was actually forced because they told me that if I did not do it, they would not give me medical attention. . . . If I did not do it [and got pregnant again], the baby . . . would have AIDS and all my future children would have AIDS.”<sup>130</sup>**

However, Paola’s chemical sterilization did not completely seal her fallopian tubes as it was meant to, and in 1999, as a result of the incomplete sterilization, Paola suffered an ectopic pregnancy. While the doctor was operating to remove the fertilized egg from her fallopian tubes, he also decided to perform a surgical sterilization.

**“That time they did not ask me. Because I went to surgery . . . and while I was in the operating room, near death, the doctor decided to cut my [fallopian tubes] so that I would not have more children.” After the surgery, the doctor made clear to her that his concern was not for future ectopic pregnancies; he told her the sterilization was “so that I would not have more children with AIDS.”<sup>131</sup>**

Recognizing that its international legal obligations required informed consent, Chile revised its law governing sterilization in 2000. In particular, the revised law recognized that “[t]he decision to undergo sterilization is personal” and mandated that healthcare providers offer counseling on alternative forms of contraception, the irreversible nature of sterilization, and the potential risks involved before obtaining a patient’s written informed consent for the procedure.<sup>132</sup>

Despite this revision to the law, forced and coerced sterilizations of women living with HIV/AIDS continue to occur. Francisca’s experience, recounted above, is an example of a forced sterilization, as she was sterilized without her knowledge or consent during a cesarean surgery.

Other women reported being sterilized under pressure from their healthcare providers or without sufficient counseling to make an informed decision. Counseling and informed consent for sterilization are particularly important in the context of HIV/AIDS. As UNFPA has cautioned, the permanent nature of surgical sterilization means that “special care must be taken to ensure that every woman makes a voluntary informed choice of method. . . . Healthcare workers should ensure that women are not pressured or

coerced to undergo the procedure and that the decision is not made in a moment of crisis.”<sup>133</sup>

Women living with HIV/AIDS may be particularly vulnerable to healthcare providers’ influence, given that women depend on the practitioners for life-saving medical treatment. Accordingly, healthcare providers need to ensure that counseling around family planning choices and sterilization be provided in a non-directive manner and should emphasize the woman’s right to make decisions contrary to the healthcare professional’s opinion.<sup>134</sup> Furthermore, surgical sterilizations are often performed in conjunction with a cesarean delivery, at a time when most HIV-positive women are concerned primarily about delivering a healthy, HIV-negative child. Given the anxiety that many HIV-positive women experience during pregnancy, the decision to permanently end their reproductive capacity at this time is particularly fraught, and therefore requires special counseling. The decision to undergo surgical sterilization should not be a rushed one.

Several healthcare providers we spoke with recognized the vulnerability of HIV-positive women during pregnancy and acknowledged that suggestions to sterilize during pregnancy can result in involuntary sterilization. A nurse who attends HIV-positive patients in Temuco said that she does not bring up sterilization when discussing family planning with her HIV-positive patients because she does not want the women to feel pressure. She said that sterilization is an unpopular family planning method and acknowledged that female patients have reported feeling pressured to sterilize when doctors suggest it.<sup>135</sup> A gynecologist in Concepción who attends women living with HIV/AIDS said that he also does not discuss family planning with women during their pregnancies because the primary concern at that time is that the woman gives birth to an HIV-negative child. He reported that the only time family planning will come up during the pregnancy is when a woman requests of her own volition to be sterilized during the cesarean. He emphasized that such requests are rare and that counseling and the completion of consent forms for requested sterilization must happen before the woman enters the operating room.<sup>136</sup> In contrast, another physician who treats HIV-positive patients acknowledged that if a woman has at least one child, she will suggest that the woman undergo sterilization. She informed us that “[w]ith respect to family planning, I urge a woman who already has a child [to consider] the possibility of surgical sterilization. . . . In actuality, one . . . suggests

it, and the gynecologists will suggest it to them too. And in the same surgery as the cesarean, they will sterilize the women.”<sup>137</sup>

Karina’s experience highlights how such directive counseling can coerce decisions around sterilization:

**Karina agreed to undergo sterilization during her cesarean delivery in 2001, but she did not feel like the choice was an informed or voluntary one. Two weeks before her scheduled cesarean delivery, her doctor, unprompted, suggested that she get sterilized. Prior to this suggestion, she had not thought about sterilization, she had not received any counseling about it or other family planning methods, nor had she inquired about them. When the doctor made the suggestion, Karina’s primary concern was her current pregnancy, and she was not thinking of future pregnancies.**

**At the time, she said, “the only thing I wanted was for my child to be born healthy.” She never received information about alternatives to sterilization or the risks of the procedure. She also recalled feeling very vulnerable. “[A]t the time, I felt so alone. I felt, I felt so alone and I felt empty inside.”<sup>138</sup> She reported feeling rushed into the decision, and now regrets “having made such a hasty decision. Because they suggested it to me when my child was on the verge of being born and I had to have a cesarean, so I had to have an answer within a week. . . . It has made things very difficult for me now.”<sup>139</sup>**

Daniela similarly had not considered sterilization until her doctor suggested she get sterilized. Daniela learned that she was HIV positive at the beginning of her second trimester. Prior to that moment, she had wanted to have more children; but once she found out her HIV status, she became concerned about the health and safety of future children. When the doctor suggested that she get sterilized to prevent future pregnancies, she agreed to it.

**Daniela recalls the anxiety that she felt during her pregnancy. While the doctor informed her of alternatives to sterilization, it was her understanding that these reversible family planning methods were not as effective. She**

# Coercive and Forced Sterilization Violates a Range of Human Rights

“Forced sterilization is not only a fundamental violation of a woman’s reproductive rights; it has few benefits in terms of HIV prevention. Furthermore, it may undermine women’s negotiating power by removing the need for condoms as a form of birth control.”

– *Yakin Ertürk, former Special Rapporteur on Violence against Women, Its Causes and Consequences*<sup>140</sup>

“Women have the right to freely consent to or refuse services (including sterilization services) that are non-coercive and respectful of autonomy, privacy and confidentiality. . . . Reproductive freedom should never be limited by individuals or States as a family planning method, HIV/AIDS prevention, or any other public health agenda.”

– *Anand Grover, Special Rapporteur on the Right of Everyone to the Highest Attainable Standard of Health*<sup>141</sup>

Surgical sterilization is recognized as a permanent contraceptive method by the WHO,<sup>142</sup> FIGO,<sup>143</sup> and Chile’s Ministry of Health.<sup>144</sup> The coerced or forced sterilization of a woman because of her HIV-positive status carries serious and lasting consequences for her physical and mental health and violates a number of her internationally and constitutionally protected human rights. The physical and psychological effects of sterilization are well documented and are foreseeable consequences of the procedure.<sup>145</sup>

When a patient is sterilized against her will, the procedure permanently robs her of her reproductive capabilities and inflicts mental distress on her. Coercive sterilizations can lead to physical and mental suffering.<sup>146</sup> In addition, many women who have been coercively sterilized may suffer alienation from their partners or their families due to the loss of their fertility, particularly in cultures that closely associate womanhood with motherhood.

While surgery to reverse the procedure is available, such procedures are costly, not widely available, and not always successful.<sup>147</sup> Furthermore, reversal surgeries carry their own health consequences. In addition to the risks inherent in any surgical procedure, where tubal ligation reversals are successful, there is a heightened risk of ectopic pregnancy.<sup>148</sup>

Involuntary sterilization violates fundamental human rights, including the following:

- the right to be free from torture or cruel, inhuman or degrading treatment;
- the right to physical and mental integrity;
- the right to dignity;
- the right to health;
- the right to reproductive autonomy;
- the right to be free from gender-based violence;
- the right to personal liberty; and
- the right to privacy and family life.

reports that her anxiety around child-bearing persisted for roughly a year after giving birth to a healthy, HIV-negative child. She said, “I knew that if I took the [antiretroviral] medication, the baby would be born healthy. But as a mother, it is always . . . until the moment when you see the child is healthy, you cannot be calm.”<sup>149</sup> Once she was reassured about the possibility of giving birth to healthy children, her desire to have more returned, but it was too late: “Now I’m sterilized.”<sup>150</sup>

Both Claudia and Alejandra, a 23-year-old woman from Concepción, were repeatedly pressured to sterilize when they went to the hospital for their cesarean deliveries.

**The day before Claudia’s delivery in 2006, a nurse asked her to authorize surgical sterilization to take place during the cesarean, without any counseling or information about the procedure. Claudia knew her rights and options because of her work with an association of people living with HIV/AIDS; she refused to sign the authorization form because she did not want to be sterilized. The following day, however, after Claudia had been administered anesthesia, the doctor performing her delivery told her, “We should sterilize you too, taking advantage of the cesarean.” Claudia protested, saying that she did not want to be sterilized. The doctor then “told me that I was irresponsible, that I should do this because if I didn’t, I would always be on the verge of becoming pregnant, and putting the life, the future of the baby, the future of the child at risk.”<sup>151</sup>**

**When Alejandra checked in to the hospital in Concepción for her programmed cesarean in 2006, an administrative staff member who completed her intake into the maternity unit asked her, without any information or counseling, if she would agree to surgical sterilization. She declined. However, upon being brought into the operating room to deliver, the doctor who performed her cesarean asked her again if she would consent to sterilization.<sup>152</sup>**

Although both women refused to be sterilized, the act of repeatedly asking them to sterilize without adequate counseling—and especially at the moment right before

going into delivery—placed undue pressure on them and threatened their rights to free and informed decision making. Additionally, administrative staff members do not have the proper training or background to counsel women on family planning methods, particularly on irreversible methods such as sterilization, and should not be initiating such discussions with patients.

## Structural Barriers

Although healthcare providers are able to offer universal access to ART to their patients, they still encounter structural barriers to providing quality care, including lack of contraceptives, lack of trained personnel, and lack of space. In Temuco, the Infectology Unit did not have male condoms to distribute to prevent reinfection. A doctor at the unit said, “[T]hink about it—[the Ministry of Health] send[s] us these expensive drugs, and we don’t even have condoms.”<sup>153</sup>

In Santiago, hospitals are unable to provide reproductive health services to HIV-positive women; women must instead seek such services at the health centers in their neighborhoods. Because of the fear of stigma and discrimination on the part of neighbors or employers, several women indicated that they were reluctant to seek gynecological care in such settings where their confidentiality might be compromised.<sup>154</sup>

Throughout the country, both healthcare users and providers acknowledged problems with healthcare workers’ training on HIV/AIDS. One doctor in Temuco attributed this to the nature of the virus: “It is probably due to the fact that it is a new pathology, that every day we’re learning something new about it.”<sup>155</sup> Another doctor in Concepción noted that the trainings that healthcare workers do receive on HIV/AIDS are simply technical trainings on how to prevent infection, rather than trainings aimed at reducing HIV-related stigma and discrimination among healthcare providers and at sensitizing providers to the unique health needs and concerns of their HIV-positive patients.<sup>156</sup> Trainings that focus exclusively on transmission can fuel fear and stigma around HIV.

Because of this lack of training and capacity building, medical specialists in fields outside of infectology are reluctant to treat HIV-positive patients. This problem contributes to difficulties in implementing a referral system for HIV-positive patients, as documented in the section above on Discriminatory Treatment, with specialists

# Center for Comprehensive Sexual Healthcare: Promoting the Reproductive Rights of HIV-Positive Women in Concepción

HIV can cause reduced fertility in HIV-positive women and men, making it more difficult for women to conceive. UNFPA and the WHO recognize these physical challenges, and recommend that HIV-positive women who want to become pregnant “should be given full support and counselling and advised of their options, including . . . assisted reproduction.”<sup>157</sup>

The women’s experiences related in this report demonstrate that Chile has a long way to go before the reproductive rights of HIV-positive women are fully realized. However, not all the news coming out of Chile is bad. The work of the Center for Comprehensive Sexual Healthcare (*Centro de Atención Integral de Salud Sexual—CAISS*) in Concepción could serve as a model for facilities providing necessary healthcare to HIV-positive women throughout the country.

CAISS offers comprehensive, integrated services around sexual and reproductive health for people affected by STIs, including HIV. In particular, CAISS offers STI and HIV testing; comprehensive counseling to people living with HIV/AIDS, including counseling to help women negotiate condom use; family planning services; and annual gynecological exams. CAISS also liaises with the gynecological and pediatric units of the affiliated hospital on behalf of pregnant patients, and has a gynecologist on staff who specializes in prevention of MTCT.<sup>158</sup>

In addition, CAISS provides counseling to serodiscordant couples who are trying to conceive. Carmen’s story is exemplary of the model of support and encouragement around motherhood that CAISS provides to HIV-positive women.<sup>159</sup>

In 1999, shortly after her husband passed away from an AIDS-related illness, Carmen learned that she had contracted HIV from him. In 2005, she married an HIV-negative man. Carmen and her new husband thought that they would never be able to have children of their own because they did not want to risk transmission of the virus to either Carmen’s husband or a child. Through the staff at CAISS, however, Carmen learned that it was not only possible for a woman living with HIV/AIDS to give birth to healthy children but that artificial insemination could be used to help her become pregnant while preventing the risk of transmission to her husband. CAISS facilitated the artificial insemination, and in 2008, Carmen gave birth to a healthy, HIV-negative baby boy.<sup>160</sup>



delaying or denying appointments for HIV-positive patients. Chile's Ministry of Health has identified the difficulty in establishing an effective referral system as a primary barrier to implementing guidelines on treatment for HIV-positive patients.<sup>161</sup> Furthermore, the doctor in charge of the Infectology Unit in Temuco noted that if a patient is HIV positive, specialists in other areas will not recognize that patient as their patient. When an HIV-positive woman needs reproductive health or oncology care, the gynecologist and oncologist will continue to view her as an infectology patient.<sup>162</sup>

One nurse said that healthcare professionals working with HIV-positive patients do not receive enough support. There is a high burnout rate, and she mentioned that her salary was among the lowest for healthcare providers. She also mentioned that there was no emotional or psychological support for providers.<sup>163</sup>

A healthcare provider in Iquique expressed frustration over the lack of space and personnel at the Iquique Hospital, a concern that was reiterated by several HIV-positive patients in Iquique. The provider stated that the Infectology Unit has only one doctor and two part-time nurses responsible for treating 318 HIV-positive patients. As the only infectologist at the hospital, the doctor is also responsible for treating all other patients with infectious diseases, which limits the amount of time she is able to spend with her HIV-positive patients.<sup>164</sup> Pamela also mentioned the lack of space for the Infectology Unit, noting that at the height of the H1N1 flu outbreak in Chile, HIV-positive patients with diminished immune systems were crammed into a small waiting area alongside ill patients awaiting testing for suspected H1N1 flu.<sup>165</sup>

## Repercussions of Discriminatory Treatment

Discriminatory care carries significant consequences both for the individual women, whose physical and mental health is jeopardized when they are denied access to or driven away from necessary health services, and for the greater population.<sup>166</sup>

HIV-related stigma and discrimination hinder the process of prevention and treatment, and as the International Guidelines on HIV/AIDS and Human Rights acknowledge, "HIV prevention and care programmes with coercive or punitive

features result in reduced participation and increased alienation of those at risk of infection."<sup>167</sup> Ideally, people at risk of infection would be encouraged to test for HIV to begin lifesaving treatment and prevent the spread of the disease. However, stigma and discrimination discourage people from getting tested or seeking treatment. Women are at greater risk of violence or abandonment once their HIV-positive status has been revealed.<sup>168</sup> In addition, due to the perceived associations between HIV and sexual misconduct, people may be deterred from testing for fear of being labeled as belonging to a stigmatized group,<sup>169</sup> and many people who are not members of a stigmatized group erroneously believe that they are not susceptible to HIV.<sup>170</sup>

Mistreatment in healthcare facilities can also deter HIV-positive patients from returning for necessary treatment.<sup>171</sup> Several women who had experienced significant delays or denials of care reported that they avoid seeking necessary healthcare services out of fear of future mistreatment.

**Julia said that because of the poor treatment she received in the past, now "I tolerate as much pain as I can, until I cannot tolerate it anymore," before going to the hospital.<sup>172</sup> Francisca said that she goes to the hospital only to receive her ART, after having been forcibly sterilized by a surgeon there.<sup>173</sup>**

**After several instances of discrimination from healthcare providers, Teresa decided not to seek medical attention other than to obtain her ART. Recently, the nurse in charge of the HIV program at the Hospital Sótero del Río, where Teresa receives her ART, told another patient—without concern for Teresa's confidentiality—to pass on the message that she would stop providing ART if Teresa did not come in for regular check-ups.<sup>174</sup>**

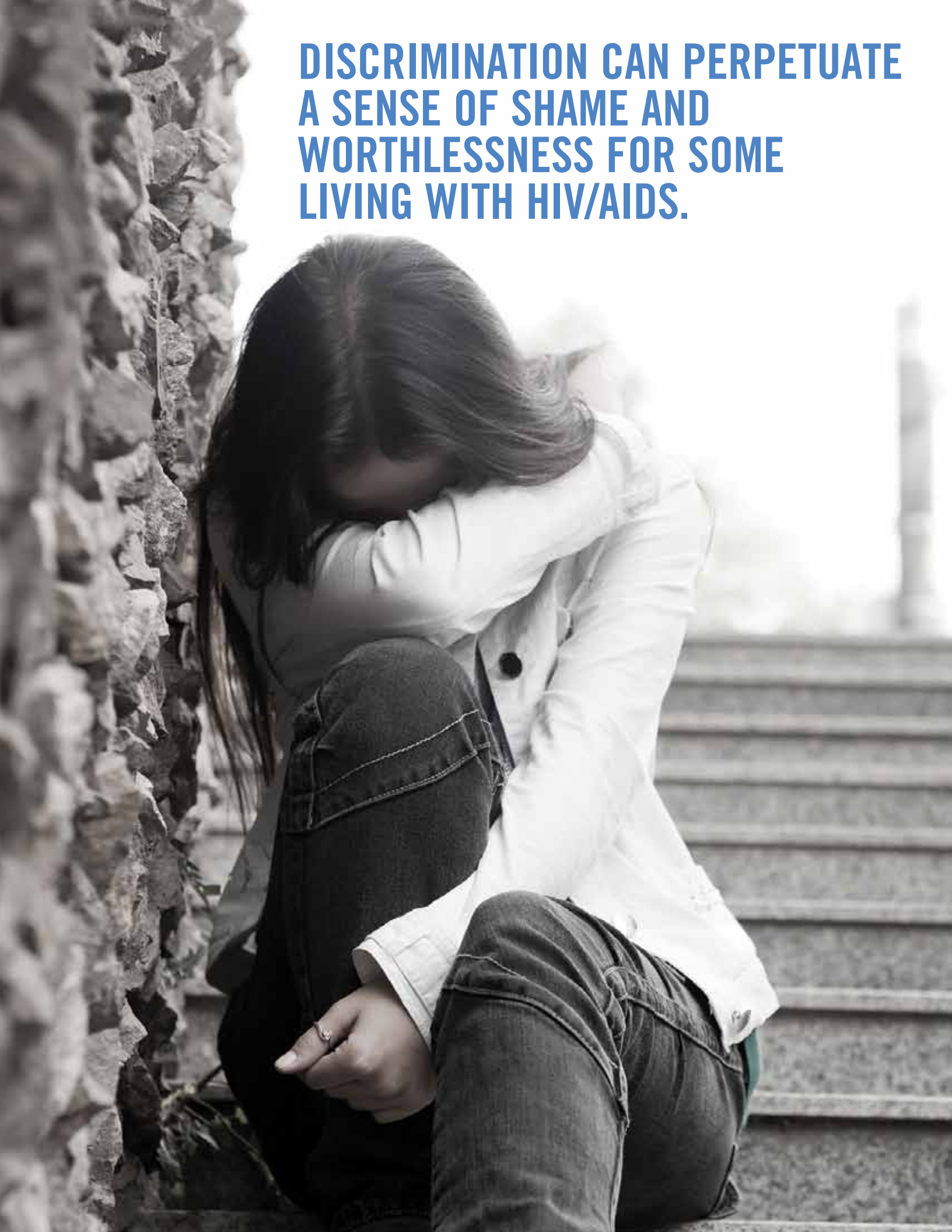
In addition to driving women away from treatment, discrimination can perpetuate a sense of shame and worthlessness for some women living with HIV/AIDS. Self-stigmatization can have negative consequences for the health and well-being of HIV-positive people, as "[i]t silences and saps the strength of already-weakened individuals and communities, and causes people to blame themselves for their predicament."<sup>175</sup> Negative or derisive comments by practitioners about a patient's HIV status can reduce the patient's capacity to care for herself and take control over her health and life. Julia said that one needs to think positive

thoughts in order to overcome the debilitating effects of the virus; “it affects me when [healthcare workers] tell me that I am a sick person.”<sup>176</sup>

Patients who are poorly treated do not always speak up about the mistreatment for fear of retribution.<sup>177</sup> Other women informed us that they no longer bother complaining because their complaints have either gone unanswered or resulted in worse treatment.<sup>178</sup> A volunteer at the hospital Sótero del Río in Santiago noted that the hospital has not taken any steps to respond to discriminatory treatment despite a high volume of complaints; instead, the hospital treats each complaint as an isolated incident.<sup>179</sup>

Discrimination in healthcare also carries significant public health consequences. In addition to disrupting treatment of individuals who know their HIV status, fear of discrimination can prevent others from testing to learn their status or from disclosing their status to healthcare providers, undermining treatment and prevention programs. For example, a nurse at the Infectology Unit in Temuco said that patients often confide their reluctance to inform healthcare providers of their HIV status for fear of the negative treatment likely to result.<sup>180</sup>

**DISCRIMINATION CAN PERPETUATE  
A SENSE OF SHAME AND  
WORTHLESSNESS FOR SOME  
LIVING WITH HIV/AIDS.**



# DISCRIMINATORY TREATMENT VIOLATES THE FUNDAMENTAL HUMAN RIGHTS OF HIV-POSITIVE WOMEN

The negligence and abuse documented in this report has more than just public health ramifications; the actions and omissions of healthcare providers also constitute serious violations of fundamental human rights protected under national, regional, and international law. The Chilean government is obligated to guarantee the right to health; the right to physical and mental integrity; the right to be free from torture or cruel, inhuman, or degrading treatment; the right to be free from gender-based violence; the right to dignity; the right to privacy and family life; and the right to non-discrimination.

## International and Regional Standards

Numerous regional and international treaties—including the American Convention on Human Rights (American Convention),<sup>181</sup> the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women (Convention of Belém do Pará),<sup>182</sup> the International Covenant on Civil and Political Rights (Civil and Political Rights Covenant),<sup>183</sup> the International Covenant on Economic, Social and Cultural Rights (Economic, Social and Cultural Rights Covenant),<sup>184</sup> the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW),<sup>185</sup> the Convention on the Rights of the Child,<sup>186</sup> and the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment<sup>187</sup>—provide important protections for the rights of women and girls throughout the Americas and globally.

Chile is a party to these treaties and, as such, has “establishe[d] on the international plane its consent to be bound.”<sup>188</sup> The government of Chile is therefore obligated under international law to protect the rights enumerated in these treaties. However, the violations identified here demonstrate Chile’s failure to comply with its international commitments to respect, protect, and fulfill these rights.

These legally binding human rights norms are complemented by politically binding international consensus documents on reproductive rights and HIV/AIDS.<sup>189</sup> By signing on to these documents as well, Chile has further demonstrated a commitment to uphold and support the realization of these international standards.

### ***The Right to Health***

International and regional treaties and agreements repeatedly recognize the fundamental right to the highest attainable standard of mental and physical health, and impose an obligation on states to enforce this right.<sup>190</sup> The Committee on Economic, Social and Cultural Rights (ESCR Committee) has explained:

*The right to health contains both freedoms and entitlements. The freedoms include the right to control one’s health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatments and experimentation. By contrast, the entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.*<sup>191</sup>

The ESCR Committee has further stated that the essential components of the right to health are “availability, accessibility, acceptability, and quality of health facilities, goods and services.”<sup>192</sup> The principle of accessibility requires that “health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds,”<sup>193</sup> including sex or health status.<sup>194</sup> Acceptability requires that such services “be respectful of medical ethics and culturally appropriate . . . [and] designed to respect confidentiality and improve the health status of those concerned.”<sup>195</sup>

Delaying treatment of patients living with HIV/AIDS, withholding care until after all HIV-negative patients have been attended, or denying HIV-positive patients care altogether violates this principle of non-discrimination and constitutes a serious violation of the right to health. Abusive treatment, such as verbal abuse or coercive sterilization, further jeopardizes the right to health. Such care not only fails to meet the standards of acceptability of healthcare; the psychological distress caused by these experiences can discourage HIV-positive patients from seeking necessary healthcare in the future. In Santiago, the requirement that women obtain basic gynecological care at their neighborhood clinics means that HIV-positive women may be denied de facto access to healthcare facilities because the fear of discrimination and lack of confidentiality prevents them from seeking these necessary services.

The right to health also includes the right to health information.<sup>196</sup> The Committee on the Elimination of Discrimination against Women (CEDAW Committee) has stated that healthcare services must be “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” in order to satisfy the right to health.<sup>197</sup> Failure to provide women living with HIV/AIDS with information on condom use or on HIV transmission violates these obligations, putting women and their partners at greater risk of infection or reinfection and fostering mistrust of healthcare providers.

The International Guidelines on HIV/AIDS and Human Rights state that “the content of the right to health . . . now explicitly includes the availability and accessibility of HIV prevention, treatment and care.”<sup>198</sup> To this end, international and regional human rights standards on the right to health obligate Chile to eliminate the barriers that HIV-positive women face in accessing necessary health services. In contrast, the discriminatory and abusive actions documented in this report fuel rather than stem the spread of HIV by providing inaccurate and biased information about HIV and driving women away from treatment programs.

### ***The Rights to Physical and Mental Integrity and to Be Free from Torture or Cruel, Inhuman, or Degrading Treatment***

The American Convention explicitly recognizes the right to physical and mental integrity.<sup>199</sup> This right goes hand in hand with the right to be free from torture or cruel, inhuman, or degrading treatment, which is protected by

both regional and international treaties.<sup>200</sup> The rights to physical and mental integrity and to be free from torture or cruel, inhuman, or degrading treatment not only prohibit acts that cause physical pain but also extend to acts that may have lasting physical or psychological effects, or that cause mental or psychological suffering.<sup>201</sup> Furthermore, an action that causes physical or mental pain or suffering may constitute cruel, inhuman, or degrading treatment even if it is negligently inflicted and without a specific purpose.<sup>202</sup>

Both the European Court of Human Rights and the Inter-American Court of Human Rights have stated that the gravity of the pain and suffering necessary to rise to the level of torture or cruel, inhuman, or degrading treatment is relative, and may depend on several factors, including the duration of the treatment and its physical or mental effects, and the sex, age, and health status of the victim.<sup>203</sup> Medical or scientific experimentation without the voluntary and informed consent of the person concerned violates these rights,<sup>204</sup> and the Human Rights Committee has explicitly noted that the prohibition of cruel, inhuman, or degrading treatment extends to actions within medical institutions.<sup>205</sup>

Sterilizing women because of their HIV-positive status violates this prohibition against torture or cruel, inhuman, or degrading treatment. Coercive sterilization has lasting physical and psychological effects, permanently robbing women of their reproductive capabilities and inflicting mental distress on them. Treaty monitoring bodies have linked coercive sterilization to the violation of the right to be free from cruel or inhuman treatment,<sup>206</sup> and the former Special Rapporteur on Violence against Women, Its Causes and Consequences has described forcible sterilization as “battery of a woman,” noting that it “is a method of medical control of a woman’s fertility without the consent of a woman.”<sup>207</sup>

Extended delays in the provision of medical care for women living with HIV/AIDS or the denial of post-partum pain medication also violate prohibitions against cruel, inhuman, or degrading treatment. HIV-positive women depend on medical providers for necessary, life-saving care. When women are unable to access necessary treatment, such as surgery to remove malignant tumors, these delays and denials of care can cause extreme physical and emotional suffering. The Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment has noted that the denial of pain relief can constitute cruel,

inhuman, or degrading treatment where it causes severe pain and suffering.<sup>208</sup>

Additional abuses, including subjecting pregnant women to HIV tests without their informed consent, denying new mothers access to breast-milk substitute to feed their infants, and verbally abusing or humiliating women as they seek necessary healthcare can all cause significant mental anguish, violating the prohibition against cruel, inhuman, or degrading treatment.

### ***The Right to Be Free from Gender-Based Violence***

International and regional conventions protect the rights of women to live their lives free of gender-based violence. The strongest articulation of this right can be found in the Convention of Belém do Pará, which acknowledges that “violence against women constitutes a violation of their human rights and fundamental freedoms, and impairs or nullifies the observance, enjoyment and exercise of such rights and freedoms.”<sup>209</sup> The CEDAW Committee has similarly stated that “gender-based violence is a form of discrimination that seriously inhibits women’s ability to enjoy rights and freedoms on a basis of equality with men.”<sup>210</sup> The Convention of Belém do Pará defines violence against women as “any act or conduct based on gender, which causes death or physical, sexual or psychological suffering to women, whether in the public or the private sphere.”<sup>211</sup> The CEDAW Committee has elaborated that “based on gender” refers to acts that are either directed at a woman because she is a woman or that affect women disproportionately.<sup>212</sup>

Chile has committed itself to protecting women’s right to be free from gender-based violence by domesticating the provisions of the Convention of Belém do Pará into national law.<sup>213</sup> The Convention obligates states to take concrete measures to prevent and punish violence against women, as well as to ensure that their authorities, officials, and institutions—including public hospitals and healthcare providers—refrain from committing acts of gender-based violence.<sup>214</sup> International bodies have consistently recognized coercive sterilization as a form of gender-based violence.<sup>215</sup> Chile’s failure to take appropriate steps to prevent healthcare providers from sterilizing women without their voluntary and fully informed consent violates its domestic and international legal obligations to prevent and eliminate violence against women.

### ***The Right to Dignity***

Human dignity is one of the most basic foundations of human rights.<sup>216</sup> Both the Civil and Political Rights Covenant and the Economic, Social and Cultural Rights Covenant are premised on the “inherent dignity of the human person,”<sup>217</sup> and the American Convention provides that “[e]veryone has the right to have his honor respected and his dignity recognized.”<sup>218</sup> The International Guidelines on HIV/AIDS and Human Rights affirm that “a rights-based approach to HIV is grounded in concepts of human dignity and equality which can be found in all cultures and traditions.”<sup>219</sup>

In the context of HIV, violations of the right to dignity are both a contributing factor to the prevalence of the virus and a consequence of it. The right to dignity is violated both when women are denied the necessary sexuality education to protect themselves from HIV transmission in the first place, and when they are denied subsequent information on condom use to prevent reinfection. This right is also violated when healthcare providers deny or delay treatment to HIV-positive women or when they verbally abuse or humiliate women because of their HIV status. The coercive sterilization of HIV-positive women is an egregious affront to these women’s dignity.<sup>220</sup>

### ***The Right to Privacy and Family***

The right to privacy and the right to health are closely linked in the context of HIV/AIDS. The Civil and Political Rights Covenant states that “no one shall be subjected to arbitrary or unlawful interference with his privacy, family, [or] home.”<sup>221</sup> The American Convention similarly prohibits “arbitrary or abusive interference with [one’s] private life, his family, [and] his home.”<sup>222</sup> The Inter-American Commission on Human Rights has explained that this right “guarantees that each individual has a sphere into which no one can intrude, a zone of activity which is wholly one’s own.”<sup>223</sup> Family life and decisions about whether and when to found a family fall within this zone of privacy.<sup>224</sup> When healthcare providers pressure HIV-positive women to not have children or force them to sterilize, they unlawfully interfere with these women’s rights to make autonomous decisions about motherhood and family life.

The right to privacy also extends to aspects of healthcare, including confidentiality for people living with HIV/AIDS and the decision to test for HIV. The Programme of Action from the International Conference on Population and Development pledged to “ensure that the individual rights

and the confidentiality of persons infected with HIV are respected.”<sup>225</sup> According to the ESCR Committee, the right to health encompasses “the right to be free from interference, such as the right to be free from . . . non-consensual medical treatment,”<sup>226</sup> which includes HIV testing. The International Guidelines on HIV/AIDS and Human Rights urge states to ensure that “HIV testing of individuals should only be performed with the specific informed consent of that individual.”<sup>227</sup> The Guidelines also emphasize that “[t]he individual’s interest in his/her privacy is particularly compelling in the context of HIV . . . by reason of the stigma and discrimination attached to the loss of privacy and confidentiality if HIV status is disclosed.”<sup>228</sup> By conducting HIV tests without a patient’s knowledge or informed consent, or advertising a patient’s HIV status to friends or family members, healthcare providers violate these women’s right to privacy, exposing them to further discrimination and potentially alienating them from necessary healthcare services.

### **The Right to Non-Discrimination**

The principle of non-discrimination and equal protection is “fundamental for the safeguard of human rights in both international and domestic law.”<sup>229</sup> Essentially every regional and international human rights document emphasizes this right to be free from discrimination.<sup>230</sup> These instruments prohibit discrimination “of any kind, such as . . . sex . . . or other status.”<sup>231</sup> The term “other status,” according to the U.N. Commission on Human Rights, “should be interpreted to cover health status, including HIV/AIDS.”<sup>232</sup> The ESCR Committee similarly interprets “other status” to encompass HIV status.<sup>233</sup>

The former Special Rapporteur on the Right to the Highest Attainable Standard of Health has recognized that gender-based discrimination increases women’s susceptibility to HIV: “[D]iscrimination based on gender hinders women’s ability to protect themselves from HIV infection and to respond to the consequences of HIV infection.”<sup>234</sup> Many of the social and cultural factors that expose Chilean women to risk of HIV infection, such as violence against women and inability to negotiate condom use, are grounded in gender-based discrimination.

Similarly, women often experience heightened discrimination on learning of their HIV-positive status, hindering prevention and treatment programs. According to the Pan-American Health Organization, the strong social stigma attached to

sex work, and women’s sexuality more generally, “is often extended to the many women who contract HIV from their husband or long-term partner — HIV infection is so strongly associated with promiscuity that women with the virus are frequently assumed to be promiscuous, irrespective of their sexual history.”<sup>235</sup> In this manner, gender-based discrimination and discrimination based on HIV status are frequently interrelated.

The International Guidelines on HIV/AIDS and Human Rights specifically address discrimination against women living with HIV/AIDS, stating that “[a]nti-discrimination and protective laws should be enacted to reduce human rights violations against women in the context of HIV, so as to reduce vulnerability of women to infection by HIV and to the impact of HIV and AIDS.”<sup>236</sup> The Guidelines suggest measures to combat this form of discrimination:

*Laws should also be enacted to ensure women’s reproductive and sexual rights, including the right of independent access to reproductive and STD [sexually transmitted disease] health information and services and means of contraception, . . . the right to determine [the] number and spacing of children, the right to demand safer sex practices and the right to legal protection from sexual violence, outside and inside marriage.*<sup>237</sup>

Nowhere is the principle of non-discrimination on the basis of HIV status more salient than in the context of healthcare services, which are central to the protection of the rights to health and life of people living with HIV/AIDS. The ESCR Committee has stated that “health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination.”<sup>238</sup> The U.N. Declaration of Commitment on HIV/AIDS highlights that governments are accountable for reaching time-bound targets for the prevention of HIV/AIDS and must eliminate discrimination in prevention and medical access.<sup>239</sup>

In accordance with these international and domestic legal standards, Chilean healthcare facilities must provide access to quality healthcare to all individuals, regardless of their serological status or gender. The differential treatment that HIV-positive women experience in Chilean healthcare facilities constitutes a flagrant violation of this right to

non-discrimination. Healthcare practitioners' reluctance to provide necessary healthcare to HIV-positive women, their refusal to provide new mothers with sufficient breast-milk substitute, their coercive sterilization of women living with HIV/AIDS, or the criticisms that they issue to women regarding women's decision to bear children all contravene the protections guaranteed by the rights to non-discrimination and equality before the law.

### ***National Law***

Chile's national laws similarly set forth protections for the rights enumerated above. The Chilean Constitution protects almost all of the rights outlined in this report. Article 1 of the Constitution provides that "[p]eople are born free and equal in dignity and rights."<sup>240</sup> Article 19 lays out the constitutionally protected rights, including the rights to life and to physical and mental integrity;<sup>241</sup> the rights to equal protection of the law<sup>242</sup> and equality before the law;<sup>243</sup> the right to privacy, personal dignity, and family life;<sup>244</sup> and the right to health.<sup>245</sup>

In addition, other domestic provisions protect the rights of women living with HIV/AIDS. In 1998, Chile passed a law domesticating the Convention of Belém do Pará, protecting the right to be free from gender-based violence at the national level.<sup>246</sup> Chile's Public Health Law mandates special protections for women during pregnancy and for a period of six months following birth.<sup>247</sup> Chile's law on HIV/AIDS prohibits discrimination against people on the basis of their HIV status; in the area of healthcare, the law provides that neither private nor public health institutions can deny access to healthcare services on the basis of a person's serological status.<sup>248</sup> The law on surgical sterilizations requires voluntary informed consent, noting that such protections are necessary to ensure that Chile is complying with its international obligations.<sup>249</sup> However, despite this strong legislative framework protecting the rights and freedoms of people living with HIV/AIDS, Chilean healthcare facilities have failed to fully implement these laws, leaving women living with HIV/AIDS vulnerable to the discriminatory whims of healthcare providers.



# RECOMMENDATIONS

The following recommendations are based upon the findings of this report. These recommendations do not exhaustively list the actions required of the Chilean government in order to comply with its international legal obligations, but instead target some of the key rights violations that we encountered during our investigation.

## TO THE GOVERNMENT OF CHILE

### **Make the full realization of the rights of HIV-positive women a priority.**

- Develop effective and detailed strategies for implementing existing legislation and international commitments on women's rights and informed consent and for enacting comprehensive sexual and reproductive health and rights legislation.
- Collect disaggregated data on women and HIV, including violence against women and HIV, to better understand and respond to the causes behind the feminization of the HIV/AIDS epidemic within Chile.
- Ensure that national efforts to reduce violence against women address the intersections of violence against women and HIV/AIDS.

### **Ensure that the rights of HIV-positive women are respected and protected when these women seek healthcare services.**

- Ensure that healthcare providers:
  - understand and maintain appropriate informed consent safeguards for HIV testing;
  - understand the obstacles that HIV-positive women may confront in accessing continuous and effective treatment, such as domestic violence and discrimination, so that providers can properly tailor counseling to women's needs; and
  - supply comprehensive, medically accurate counseling and information, particularly regarding family planning, pregnancy, motherhood, and HIV.

- Address the problem of unnecessary segregation of HIV-positive women in public health facilities.
- Reduce barriers for HIV-positive women to access breast-milk substitute.

### **Ensure that HIV-positive women have access to acceptable, quality sexual and reproductive health services.**

- Ensure that healthcare providers understand the rights of HIV-positive women to access family planning services, to be sexually active, and to bear children.
- Ensure that specialized reproductive healthcare is offered to HIV-positive women.
- Train providers of family planning services to counsel women living with HIV/AIDS and to provide them with appropriate information to make informed and voluntary family-planning decisions.
- Ensure that Resolution 2326 on Sterilization is adequately disseminated, implemented, and enforced to protect HIV-positive women from involuntary sterilization.

### **Ensure that proper testing, counseling, and confidentiality procedures are followed.**

- Ensure that healthcare providers:
  - understand the components of pre-test counseling for HIV and that they counsel patients about the benefits of knowing one's status, what to expect if a patient receives a positive result, existing follow-up and treatment services, the patient's right to refuse the test, and tips for negotiating condom use for women seeking HIV testing;
  - offer comprehensive, medically accurate post-test counseling for HIV/AIDS, including information on reinfection and the importance of condom use, even within seroconcordant relationships;

- understand and maintain appropriate informed consent safeguards for HIV testing, particularly for pregnant women;
- inform patients properly of their sero-status; and
- understand and maintain appropriate confidentiality safeguards for HIV-positive patients.
- Ensure that health facilities allocate adequate space and time to counseling around HIV testing.
- Employ HIV-positive women as HIV testing counselors.
- Provide information on local support groups or associations of people living with HIV/AIDS to patients who test positive.

#### **Address the barriers to accessing quality medical care.**

- Review the impact of the current referral system in causing delays in accessing specialized medical care.
- Establish a functional network of medical specialists who can provide quality, acceptable care to patients living with HIV/AIDS in a timely manner.
- Ensure access to specialized obstetric care for pregnant women living with HIV/AIDS.
- Ensure that male and female condoms are widely available.

#### **Address the factors that deter healthcare staff from providing appropriate and quality care to HIV-positive patients.**

- Ensure that all healthcare workers, including administrative staff, are trained in HIV transmission and the precautions that they can take while still providing quality care to patients living with HIV/AIDS.
- Conduct regular, mandatory trainings for all healthcare staff to keep them up to date on medical advances, best practices, and the rights of patients to receive quality healthcare, regardless of their HIV status.

#### **Incorporate comprehensive sexuality education into school curriculums.**

- Ensure access to evidence-based sexuality education to provide adolescents with the information they need to protect themselves from HIV transmission.

#### **Conduct a public awareness campaign to combat stigma and discrimination related to HIV/AIDS.**

- Emphasize the rights of people living with HIV/AIDS.
- Educate the public on the means of HIV transmission to minimize misconceptions that fuel discriminatory treatment.

- Discourage the use of violence or ostracism in reaction to learning of a partner or family member's HIV-positive status, and promote counseling between couples.
- Emphasize the rights of women living with HIV/AIDS to choose whether or not to be sexually active and whether or not to bear children.
- Address violence against women in both the home and the community as a cause and consequence of HIV infection.

#### **Strengthen structures to protect patients' rights and to hold providers accountable for rights violations.**

- Disseminate information around laws on informed consent and the rights of people living with HIV/AIDS to ensure that all healthcare facilities, public and private, are implementing current laws and policies.
- Conduct public awareness campaigns to educate patients about their rights.
- Ensure that information on patients' rights is immediately accessible within health facilities.
- Establish clear procedural guidelines for following up on complaints of rights violations and strengthen administrative accountability mechanisms.
- Create a monitoring and evaluation system to ensure the full implementation of laws and policies regarding the rights of patients living with HIV/AIDS.
- Provide information to judges and legal professionals on rights violations in the healthcare context and on gender-based rights violations to ensure that they are able to respond in a gender-sensitive manner.

#### **Strengthen Chile's human rights framework.**

- Ratify the Optional Protocol to CEDAW.
- Domesticize international human rights treaties and ensure that these laws are implemented at the national level.
- Strengthen domestic legislation to ensure comprehensive protection of sexual and reproductive health and rights, including explicit protections for the sexual and reproductive rights of women living with HIV/AIDS.

## **TO CIVIL SOCIETY**

#### **Hold the government accountable for its failure to adequately protect the rights of women living with HIV/AIDS.**

- Monitor the development and implementation of national laws and policies on the rights of women and persons

living with HIV/AIDS, including the adoption of a comprehensive law on sexual and reproductive health and rights.

- Engage with international and regional human rights monitoring bodies to keep them informed of ongoing human rights violations.

**Support awareness-raising and capacity-building efforts.**

**Facilitate data collection on intersections between gender and HIV, and violence against women and HIV, to improve government responses to the feminization of the epidemic.**

## **TO THE INTERNATIONAL DONOR COMMUNITY**

**Organizations financing public and private reproductive health, family planning, and HIV/AIDS programs should ensure that such programs are designed to improve healthcare and promote the exercise of women's rights, and should establish indicators for evaluating these projects, based on the criteria of efficiency, quality, and respect for women's rights.**

## **TO INTERNATIONAL AND REGIONAL HUMAN RIGHTS BODIES AND EXPERTS**

**Urge Chile to protect the rights of HIV-positive women seeking reproductive healthcare services and to provide redress and remedies for violations of these rights.**

# ENDNOTES

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- <sup>102</sup> MUJERES CHILENAS VIVIENDO CON VIH/SIDA, *supra* note 7, at 66.
- <sup>103</sup> Interview with Julia, *supra* note 59.
- <sup>104</sup> Interview with María, in Concepción (Aug. 10, 2009) (Center for Reproductive Rights trans.).
- <sup>105</sup> Interview with Teresa, *supra* note 93.
- <sup>106</sup> Interview with Daniela, in Temuco (May 7, 2009) (Center for Reproductive Rights trans.).
- <sup>107</sup> Interview with Marcela, *supra* note 85.
- <sup>108</sup> Interview with Claudia, *supra* note 85.
- <sup>109</sup> WHO ET AL., GUIDELINES ON HIV AND INFANT FEEDING 2010, *supra* note 62.
- <sup>110</sup> Interview with Claudia, *supra* note 85.
- <sup>111</sup> Interview with Patricia, *supra* note 96.
- <sup>112</sup> Interview with Claudia, *supra* note 85.
- <sup>113</sup> Interview with Daniela, *supra* note 106.
- <sup>114</sup> Declaración Jurada de F.S., Curicó, Chile (Jan. 19, 2009) (on file with the Center for Reproductive Rights) (Center for Reproductive Rights trans.) [hereinafter Affidavit of F.S.]; *see also*, *F.S. v. Chile*, Inter-Am. C.H.R., pending admissibility (*petition filed* Feb. 3, 2009).
- <sup>115</sup> WHO, PMTCT STRATEGIC VISION 2010-2015, *supra* note 60, at 6.
- <sup>116</sup> *See, e.g.*, Convention on the Elimination of All Forms of Discrimination against Women, art. 16(e), *adopted* Dec. 18, 1979, G.A. Res. 34/180, U.N. GAOR (34<sup>th</sup> Sess.), Supp. No. 46, at 193, U.N. Doc. A/34/46 (1979) (*entered into force* Sept 3, 1981) (*ratified by Chile* Jan. 6, 1990) [hereinafter CEDAW].
- <sup>117</sup> FIGO, *Pregnancy and HIV-positive patients*, *supra* note 101, Recommendation 6, at 78.
- <sup>118</sup> UNFPA, SRH GUIDELINES, *supra* note 22, at 25-26.
- <sup>119</sup> MUJERES CHILENAS VIVIENDO CON VIH/SIDA, *supra* note 7, at 81.
- <sup>120</sup> Interview with Julia, *supra* note 59.
- <sup>121</sup> *Id.*
- <sup>122</sup> *Id.*
- <sup>123</sup> FIGO, *Ethical Considerations in Sterilization*, in ETHICAL ISSUES IN OBSTET. & GYN. 98, 98 (Oct. 2009), *available at* <http://www.figo.org/files/figo-corp/Ethical%20Issues%20-%20English.pdf> [hereinafter FIGO, *Ethical Considerations in Sterilization*].
- <sup>124</sup> FIGO, *Guidelines Regarding Informed Consent*, in ETHICAL ISSUES IN OBSTET. & GYN., *supra* note 123, at 13, 14.
- <sup>125</sup> Interview with Claudia, *supra* note 85 (Center for Reproductive Rights trans.).
- <sup>126</sup> *Id.*
- <sup>127</sup> *See, e.g.*, Lidia B. Casas, *Mujeres y Reproducción: ¿Del Control a la autonomía?* [Women and Reproduction: From control to autonomy?], 18 Informe de Investigación 1 (June 2004).
- <sup>128</sup> República de Chile, Ministerio de Salud, Resolución 003: *Métodos Anticonceptivos Irreversibles o Esterilizaciones Quirúrgicas* [Resolution 003: Irreversible Contraceptive Methods or Surgical Sterilizations] (*published* Sept. 1, 1975).
- <sup>129</sup> Interview with Rocío, in Santiago (Apr. 20, 2009) (Center for Reproductive Rights trans.).
- <sup>130</sup> Interview with Paola, *supra* note 96 (Center for Reproductive Rights trans.).
- <sup>131</sup> *Id.*
- <sup>132</sup> República de Chile, Resolución Exenta 2326: *Fija Directrices para los servicios de salud sobre esterilización femenina y masculina* [Resolution 2326: Guidelines on feminine and masculine sterilization for healthcare services], arts. 2-4 (*published* Dec. 9, 2000) [hereinafter Sterilization Law (Chile)].
- <sup>133</sup> UNFPA, SRH GUIDELINES, *supra* note 22, at 23.
- <sup>134</sup> Nisha Anand et al., *Bridging the Gap*, *supra* note 31, at 8-9; PAHO, RESPONDING TO HIV/AIDS-RELATED STIGMA, *supra* note 66, at 23.
- <sup>135</sup> Interview with infectology nurse, *supra* note 58.
- <sup>136</sup> Interview with obstetrician/gynecologist, *supra* note 98.
- <sup>137</sup> Interview with infectologist, in Temuco (May 8, 2009) (Center for Reproductive Rights trans.).
- <sup>138</sup> Interview with Karina, *supra* note 76 (Center for Reproductive Rights trans.).
- <sup>139</sup> *Id.*
- <sup>140</sup> Yakin Ertürk, *Report of the Special Rapporteur on Violence against Women*, *supra* note 12, para. 69.
- <sup>141</sup> Anand Grover, *Report of the Special Rapporteur on the Rights of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health: The Right to Health and Informed Consent*, paras. 57-58, U.N. Doc. A/64/272 (Aug. 10, 2009).
- <sup>142</sup> WHO, MEDICAL ELIGIBILITY CRITERIA FOR CONTRACEPTIVE USE 95 (2004), *available at* [http://www.who.int/reproductivehealth/publications/family\\_plan-ning/9789241563888/en/index.html](http://www.who.int/reproductivehealth/publications/family_plan-ning/9789241563888/en/index.html).
- <sup>143</sup> FIGO, *Ethical Considerations in Sterilization*, *supra* note 123, at 99.
- <sup>144</sup> Sterilization Law (Chile), *supra* note 132, arts. 3-4.
- <sup>145</sup> *See, e.g.*, STEVEN G. GABBE ET AL., OBSTETRICS: NORMAL AND PROBLEM PREGNANCIES 704 (1996).
- <sup>146</sup> CEDAW Committee, *General Recommendation No. 19: Violence against Women* (11<sup>th</sup> Sess.), 1993, para. 22, U.N. Doc. A/47/38 at 1 (1993) [hereinafter CEDAW Committee, *General Recommendation No. 19*].
- <sup>147</sup> JOHNS HOPKINS POPULATION INFORMATION PROGRAM, THE ESSENTIALS OF CONTRACEPTIVE TECHNOLOGY: A HANDBOOK FOR CLINICAL STAFF sec. 9-22 (July 1997).
- <sup>148</sup> *Id.* secs. 9-5, 9-22.
- <sup>149</sup> Interview with Daniela, *supra* note 106.
- <sup>150</sup> *Id.*
- <sup>151</sup> Interview with Claudia, *supra* note 85.
- <sup>152</sup> Interview with Alejandra, *supra* note 85.
- <sup>153</sup> Interview with infectologist in Temuco, *supra* note 137.
- <sup>154</sup> Interview with Patricia, *supra* note 96; Interview with Paola, *supra* note 96.
- <sup>155</sup> Interview with infectologist, in Temuco, *supra* note 137.
- <sup>156</sup> Interview with obstetrician/gynecologist, *supra* note 98.
- <sup>157</sup> UNFPA, SRH GUIDELINES, *supra* note 22, at 25.
- <sup>158</sup> Interview with head nurse, *supra* note 81.
- <sup>159</sup> *Id.*; Interview with Carmen, *supra* note 82.
- <sup>160</sup> Interview with Carmen, *supra* note 82.
- <sup>161</sup> REPÚBLICA DE CHILE, MINISTERIO DE SALUD, GUÍA CLÍNICA 2009 SÍNDROME DE INMUNODEFICIENCIA ADQUIRIDA VIH/SIDA [CLINICAL GUIDE 2009: HIV/AIDS] 66 (2009), *available at* <http://www.redsalud.gov.cl/portal/url/item/7220fdc4340c44a9e04001011f0113b9.pdf>.
- <sup>162</sup> Interview with infectologist, in Temuco, *supra* note 137.
- <sup>163</sup> Interview with infectology nurse, *supra* note 58.
- <sup>164</sup> Interview with infectologist, in Iquique (Aug. 4, 2009) (Center for Reproductive Rights trans.).
- <sup>165</sup> Interview with Pamela, *supra* note 80.
- <sup>166</sup> Nisha Anand et al., *Bridging the Gap*, *supra* note 31, at 4 (“The violation of

- women's human rights to acceptable reproductive healthcare also undermines broader public health goals by dissuading women from seeking care and services. Women may be deterred 'from accessing care, because of the negative associations of HIV, or because they anticipate or experience prejudicial behavior from healthcare providers.'").
- <sup>167</sup> UNAIDS, INTERNATIONAL GUIDELINES ON HIV/AIDS, *supra* note 4, para. 96.
- <sup>168</sup> UNAIDS, *HIV/AIDS, Gender and Violence against Women* Factsheet, *supra* note 22.
- <sup>169</sup> UNAIDS, *Stigma and Discrimination*, *supra* note 64, at 5; PAHO, RESPONDING TO HIV/AIDS-RELATED STIGMA, *supra* note 66, at 9, 16-17.
- <sup>170</sup> PAHO, RESPONDING TO HIV/AIDS-RELATED STIGMA, *supra* note 66, at 17 ("the association between HIV/AIDS and stigma leads many people inside the social norm to consider themselves unaffected by the disease and to continue the practice of unsafe behaviors that place them at risk.").
- <sup>171</sup> UNAIDS, INTERNATIONAL GUIDELINES ON HIV/AIDS, *supra* note 4, para. 96.
- <sup>172</sup> Interview with Julia, *supra* note 59.
- <sup>173</sup> Affidavit of F.S., *supra* note 114.
- <sup>174</sup> Interview with Teresa, *supra* note 93.
- <sup>175</sup> UNAIDS, *Stigma and Discrimination*, *supra* note 64, at 10.
- <sup>176</sup> Interview with Julia, *supra* note 59.
- <sup>177</sup> Interview with Marcela, *supra* note 85; Interview with Daniela, *supra* note 106.
- <sup>178</sup> Interview with Catalina, in Santiago (Apr. 20, 2009) (Center for Reproductive Rights trans.); Interview with Doris, in Santiago (Apr. 28, 2010) (Center for Reproductive Rights trans.).
- <sup>179</sup> Interview with Patricia, *supra* note 96.
- <sup>180</sup> Interview with infectology nurse, *supra* note 58.
- <sup>181</sup> American Convention on Human Rights, O.A.S. Treaty Series No. 36, 1144 U.N.T.S. 124, *entered into force* July 18, 1978, *reprinted in* Basic Documents Pertaining to Human Rights in the Inter-American System, OEA/Ser.L.V/II.82 doc.6 rev.1 at 25 (*ratified by Chile* Aug. 10, 1990) [hereinafter American Convention].
- <sup>182</sup> Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women, 33 I.L.M. 1534 (1994) (*entered into force* Mar. 5, 1995) (*ratified by Chile* Oct. 24, 1996) [hereinafter Convention of Belém do Pará].
- <sup>183</sup> International Covenant on Civil and Political Rights, *adopted* Dec. 16, 1966, G.A. Res. 2200A (XXI), U.N. GAOR (21<sup>st</sup> Sess.), Supp. No. 16, at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171 (*entered into force* Mar. 23, 1976) (*ratified by Chile* Feb. 10, 1972) [hereinafter Civil and Political Rights Covenant].
- <sup>184</sup> International Covenant on Economic, Social and Cultural Rights, *adopted* Dec. 16, 1966, G.A. Res. 2200A (XXI), U.N. GAOR, Supp. No. 16, at 49, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 3 (*entered into force* Jan. 3, 1976) (*ratified by Chile* Feb. 10, 1972) [hereinafter Economic, Social and Cultural Rights Covenant].
- <sup>185</sup> CEDAW, *supra* note 116.
- <sup>186</sup> Convention on the Rights of the Child, *adopted* Dec. 18, 1979, G.A. Res. 44/25, annex, U.N. GAOR (44<sup>th</sup> Sess.), Supp. No. 49, at 166, U.N. Doc. A/44/49 (1989) (*entered into force* Sept. 2, 1990) (*ratified by Chile* Aug. 13, 1990) [hereinafter Children's Rights Convention].
- <sup>187</sup> Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, *adopted* Dec. 10, 1984, G.A. Res. 39/46, U.N. GAOR (39<sup>th</sup> Sess.), Supp. No. 51, at 197, U.N. Doc. A/39/51, 1465 U.N.T.S. 85 (*entered into force* June 26, 1987) (*ratified by Chile* Sept. 30, 1998) [hereinafter Convention against Torture].
- <sup>188</sup> Vienna Convention on the Law of Treaties, Vienna, Austria, May 23, 1969, art. 2.1(b), 1155 U.N.T.S. 331, 8 I.L.M. 679 (*entered into force* Jan. 27, 1980) (*ratified by Chile* Apr. 9, 1981).
- <sup>189</sup> Programme of Action of the International Conference on Population and Development, Cairo, Egypt, Sept. 5-13, 1994, U.N. Sales No. 95. XIII.18. U.N. Doc. A/CONF.171/13/Rev.1 (1995) [hereinafter ICPD Programme of Action]; Beijing Declaration and Platform for Action, *supra* note 4; Political Declaration on HIV/AIDS General Resolution of the U.N. General Assembly, U.N. Doc. A/RES/60/262; Declaration of Commitment on HIV/AIDS, General Resolution of the U.N. General Assembly, U.N. Doc. A/RES/S-26/2 (Aug. 2 2001) [hereinafter U.N. Declaration of Commitment on HIV/AIDS].
- <sup>190</sup> Economic, Social and Cultural Rights Covenant, *supra* note 184, art. 12; CEDAW, *supra* note 116, art. 12; ICPD Programme of Action, *supra* note 189, para. 7.3; Beijing Declaration and Platform for Action, *supra* note 4, para. 89; Children's Rights Convention, *supra* note 186, art. 24; American Convention, *supra* note 181, art. 26.
- <sup>191</sup> Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14: The right to the highest attainable standard of health*, para. 8, U.N. Doc. E/C.12/2000/4 (2000), *available at* <http://www.unhcr.ch/tbs/doc.nsf/%28symbol%29/E.C.12.2000.4.En> [hereinafter CESCR, *General Comment No. 14*].
- <sup>192</sup> *Id.* para. 12.
- <sup>193</sup> *Id.* para. 12(b).
- <sup>194</sup> *Id.* para. 18.
- <sup>195</sup> *Id.* para. 12(c).
- <sup>196</sup> *Id.* para. 12(b); CEDAW Committee, *General Recommendation No. 24: Women and health* (20<sup>th</sup> Sess.), para. 18, U.N. Doc. A/54/38, at 5 (1999) [hereinafter CEDAW Committee, *General Recommendation No. 24*].
- <sup>197</sup> CEDAW Committee, *General Recommendation No. 24*, *supra* note 196, para. 22.
- <sup>198</sup> UNAIDS, INTERNATIONAL GUIDELINES ON HIV/AIDS, *supra* note 4, at 6.
- <sup>199</sup> American Convention, *supra* note 181, art. 5(1).
- <sup>200</sup> *Id.* art. 5; Convention of Belém do Pará, *supra* note 182, art. 4; Civil and Political Rights Covenant, *supra* note 183, art. 7; Inter-American Convention to Prevent and Punish Torture, art. 6, O.A.S. Treaty Series No. 67, OEA/Ser.L.V/II.82 doc.6 rev.1, at 83 (*entered into force* Feb. 28, 1987) (*ratified by Chile* Sept. 15, 1988); Convention against Torture, *supra* note 187, art. 16; Universal Declaration of Human Rights, art. 5, *adopted* Dec. 10, 1948, G.A. 217A (III), at 71, U.N. Doc. A/810 (1948) [hereinafter Universal Declaration].
- <sup>201</sup> *See, e.g.,* Case of *Loayza-Tamayo v. Perú*, 1997 Inter-Am. Ct. H.R. (Ser. C) No. 33, para. 57 (Sept. 17, 1997) ("The violation of the right to physical and psychological integrity of persons is a category of violation that has several gradations and embraces treatment ranging from torture to other types of humiliation or cruel, inhuman or degrading treatment with varying degrees of physical and psychological effects."); *Michael Gayle v. Jamaica*, Case 12.418, Inter-Am. C.H.R., Report No. 92/05, OEA/Ser.LV/II.124 Doc. 5, para. 61 (2005) ("[T]he Commission has indicated that inhumane treatment includes unjustifiable conduct that causes severe physical, mental or psychological pain or suffering.").



- <sup>202</sup> See MANFRED NOWAK & ELIZABETH McARTHUR, THE UNITED NATIONS CONVENTION AGAINST TORTURE: A COMMENTARY 558 (2008); see also, Commission on Human Rights, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment: Civil and Political Rights Including the Questions of Torture and Detention* (62<sup>nd</sup> Sess.), para. 35, U.N. Doc. E/CN.4/2006/6 (2005).
- <sup>203</sup> *Ireland v. the United Kingdom*, App. No. 5310/71, Eur. Ct. H.R., Ser. A No. 25, para. 162 (Jan. 18, 1978); *Gómez-Paquiyaqui Brothers v. Perú*, Inter-Am. Ct. H.R., (Ser. C) No. 110, para. 113 (July 8, 2004).
- <sup>204</sup> Human Rights Committee (HRC), *General Comment No. 20: Article 7 (Prohibition of Torture, or Other Cruel, Inhuman or Degrading Treatment or Punishment)* (44<sup>th</sup> Sess.), para. 7, 1992, in *Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies*, U.N. Doc. HRI/GEN/1/Rev.6, at 151 (2003).
- <sup>205</sup> *Id.* para. 5.
- <sup>206</sup> See, e.g., HRC, *Concluding Observations: Slovakia*, para. 12, U.N. Doc. CCPR/CO/78/SVK (2003); *Czech Republic*, para. 10, U.N. Doc. CCPR/C/CZE/CO/2 (2007).
- <sup>207</sup> Radhika Coomaraswamy, *Report of the Special Rapporteur on Violence against Women, Its Causes and Consequences, Integration of the Human Rights of Women and the Gender Perspective, Addendum: Policies and practices that impact women's reproductive rights and contribute to cause or constitute violence against women*, para. 51, U.N. Doc. E/CN.4/1999/68/ Add.4 (Jan. 21, 1999) [hereinafter Radhika Coomaraswamy, *Report of the Special Rapporteur on Violence against Women*].
- <sup>208</sup> See Human Rights Council, *Promotion and Protection of all Human Rights, Civil, Political, Economic, Social and Cultural Rights, Including the Right to Development, Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment* (10<sup>th</sup> Sess.), para. 72, U.N. Doc. A/HRC/10/44 (2009).
- <sup>209</sup> Convention of Belém do Pará, *supra* note 182, at preamble.
- <sup>210</sup> CEDAW Committee, *General Recommendation No. 19, supra* note 146, para. 1.
- <sup>211</sup> Convention of Belém do Pará, *supra* note 182, art. 1.
- <sup>212</sup> CEDAW Committee, *General Recommendation No. 19, supra* note 146, para. 6.
- <sup>213</sup> República de Chile, Ministerio de Relaciones Exteriores [Ministry of Foreign Relations], Decreto No. 1640: *Promulga la Convención Interamericana para Prevenir, Sancionar y Erradicar la Violencia contra la Mujer* [Decree No. 1640: Promulgation of the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women] (*published* Nov. 11, 1998) [hereinafter Convention of Belém do Pará Law (Chile)].
- <sup>214</sup> Convention of Belém do Pará, *supra* note 182, art. 7.
- <sup>215</sup> Secretary-General Report on Violence against Women, *supra* note 30, para. 142; CEDAW Committee, *General Recommendation No. 19, supra* note 146, para. 22; Radhika Coomaraswamy, *Report of the Special Rapporteur on Violence against Women, supra* note 207, para. 51.
- <sup>216</sup> Universal Declaration, *supra* note 200, art. 1; Civil and Political Rights Covenant, *supra* note 183, at preamble; Economic, Social and Cultural Rights Covenant, *supra* note 184, at preamble; CEDAW, *supra* note 116, at preamble; Convention against Torture, *supra* note 187, at preamble; Children's Rights Convention, *supra* note 186, at preamble.
- <sup>217</sup> Civil and Political Rights Covenant, *supra* note 183, at preamble; Economic, Social and Cultural Rights Covenant, *supra* note 184, at preamble.
- <sup>218</sup> American Convention, *supra* note 181, art. 11(1).
- <sup>219</sup> UNAIDS, INTERNATIONAL GUIDELINES ON HIV/AIDS, *supra* note 4, para. 101.
- <sup>220</sup> See, e.g., CEDAW Committee, *General Recommendation No. 24, supra* note 196, para. 22.
- <sup>221</sup> Civil and Political Rights Covenant, *supra* note 183, art. 17.
- <sup>222</sup> American Convention, *supra* note 181, art. 11(2).
- <sup>223</sup> *X & Y v. Argentina*, Case 10.506, Inter-Am. C.H.R., Report No. 38/96, OEA/Ser.LV/II.95 Doc. 7 rev., at 50, para. 91 (1996).
- <sup>224</sup> CEDAW, *supra* note 116, art 16(e); CEDAW Committee, *General Recommendation No. 21: Equality in marriage and family relations* (13<sup>th</sup> Sess.), para. 22, U.N. Doc. A/49/38 at 1 (1994), *reprinted in* *Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies*, U.N. Doc. HRI/GEN/1/Rev.6 at 250 (2003); HRC, *K.L. v. Peru*, Communication No. 1153/2003, U.N. Doc. CCPR/C/85/D/1153/2003, para. 6.4 (2005); *Tysiāc v. Poland*, Application No. 5410/03, Eur. Ct. H.R., paras. 106-107 (Mar. 20, 2007); HRC, *General Comment No. 28: Equality of rights between men and women (Article 3)* (68<sup>th</sup> Sess.), para. 20, U.N. Doc. CCPR/C/21/Rev.1/Add.10 (2000); *I.V. v. Bolivia*, Petition 270-07, Inter-Am. C.H.R., Report N° 40/08, para. 80 (2008); Beijing Declaration and Platform for Action, *supra* note 4, para. 96.
- <sup>225</sup> ICPD Programme of Action, *supra* note 189, para. 8.29.
- <sup>226</sup> CESCR, *General Comment No. 14, supra* note 191, para. 8.
- <sup>227</sup> UNAIDS, INTERNATIONAL GUIDELINES ON HIV/AIDS, *supra* note 4, para. 20(b).
- <sup>228</sup> *Id.* para. 120.
- <sup>229</sup> *Juridical Conditions and Rights of Undocumented Migrants*, Advisory Opinion OC-18/03, Inter-Am. Ct. H.R. (Ser. A) No. 18, para. 88 (Sept. 17, 2003).
- <sup>230</sup> See, e.g., Universal Declaration, *supra* note 200, arts. 2, 7; Economic, Social and Cultural Rights Covenant, *supra* note 184, arts. 2(2), 3; Civil and Political Rights Covenant, *supra* note 183, arts. 2, 26; International Convention on the Elimination of All Forms of Racial Discrimination, *adopted* Dec. 21, 1965, G.A. Res. 2106, annex, U.N. GAOR, 20th Sess., Supp. No. 14, at 47, art. 2, U.N. Doc. A/6014 (1966) (*entered into force* Jan. 4, 1969) (*ratified by Chile* Oct. 20, 1971); Children's Rights Convention, *supra* note 186, art. 2; American Convention, *supra* note 181, arts. 1, 24; American Declaration on the Rights and Duties of Man, art. II, O.A.S. Res. XXX, *adopted by* the Ninth International Conference of American States, OEA/Ser.L.V/II.82 doc.6 rev.1, at 17 (1948).
- <sup>231</sup> Civil and Political Rights Covenant, *supra* note 183, art. 2(1); Economic, Social and Cultural Rights Covenant, *supra* note 184, art 2(2).
- <sup>232</sup> U.N. Sub-Commission on the Prevention of Discrimination and Protection of Minorities, *Sub-Commission on the Prevention of Discrimination and Protection of Minorities*, para. 1, U.N. Doc. E/CN.4/Sub.2/1995/51.
- <sup>233</sup> CESCR, *General Comment No. 14, supra* note 191, para. 18 (“[T]he Covenant proscribes any discrimination in access to healthcare and underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex... health

status (including HIV/AIDS)... which has the intention or effect of nullifying or impairing equal enjoyment or exercise of the right to health.”).

<sup>234</sup> Paul Hunt, *Report of the Special Rapporteur on the Rights of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health: The Rights to Sexual and Reproductive Health*, para. 30, U.N. Doc. E/CN.4/2004/49 (Feb. 16, 2004).

<sup>235</sup> PAHO, RESPONDING TO HIV/AIDS-RELATED STIGMA, *supra* note 66, at 14.

<sup>236</sup> UNAIDS, INTERNATIONAL GUIDELINES ON HIV/AIDS, *supra* note 4, para. 22(f).

<sup>237</sup> *Id.*

<sup>238</sup> CESCR, *General Comment No. 14*, *supra* note 191, para. 12(b).

<sup>239</sup> U.N. Declaration of Commitment on HIV/AIDS, *supra* note 189, para. 58.

<sup>240</sup> República de Chile, Constitución de la República, art. 1 (1980) (Chile).

<sup>241</sup> *Id.* art. 19.1.

<sup>242</sup> *Id.* art. 19.3.

<sup>243</sup> *Id.* art. 19.2.

<sup>244</sup> *Id.* art. 19.4.

<sup>245</sup> *Id.* art. 19.9.

<sup>246</sup> Convention of Belém do Pará Law (Chile), *supra* note 213.

<sup>247</sup> República de Chile, Ministerio de Salud Pública, Decreto No. 725: Código Sanitario [Decree No. 725: Public Health Code], art. 16 (*published* Jan. 31, 1968).

<sup>248</sup> HIV/AIDS Law (Chile), *supra* note 75, art. 7.

<sup>249</sup> Sterilization Law (Chile), *supra* note 132, at preamble.



**“I wish that . . . above all they would humanize [the treatment]. If they aren’t able to do it in the healthcare setting, how can we expect it of regular people who have little information [about HIV]?”**

- Julia, an HIV-positive woman from Santiago

*Dignity Denied* documents the systemic discrimination and abuse that HIV-positive women endure in Chilean health facilities. Based on women’s testimonies and those of healthcare providers, this report exposes the discriminatory and often dehumanizing experiences that Chilean women living with HIV/AIDS face when seeking healthcare, including failures to protect patient confidentiality, lack of adequate pre- and post-test counseling, delayed or abusive treatment, pressure to not bear children, and coercive and forced sterilization.

The Chilean government has ratified regional and international human rights treaties signifying its commitment to respect, protect, and fulfill basic human rights. These fundamental rights are premised on notions of inherent human dignity and equality, regardless of an individual’s sex or HIV status. However, the stigma and discrimination that women living with HIV/AIDS encounter in Chilean healthcare facilities belie this commitment. The actions of healthcare workers documented in this report discriminate against HIV-positive women, treating them as less than human and denying them their inherent dignity.

*Dignity Denied* is a call to action for the government of Chile, key stakeholders, and civil society to ensure that all women have access to acceptable, voluntary, and nondiscriminatory healthcare services irrespective of their HIV status.

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