

**El Salvador's Compliance with the  
Convention on the Rights of the Child:  
Women's and Girls' Rights**

**Women's Link Worldwide**

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## I. Introduction

Women's Link Worldwide (hereinafter "Women's Link") is an international non-governmental organization with offices in Latin America and Europe and expanding partnerships in East Africa. Through regional and international litigation and advocacy, Women's Link advances the human rights of women and girls, particularly those who face multiple inequalities based on socioeconomic status, race, sexual orientation, or disability. Women's Link strengthens human right standards on issues such as sexual and reproductive rights, gender discrimination and gender-based violence, and transitional justice.

In June and July of 2017, Women's Link conducted more than 35 interviews in El Salvador with representatives from the government, national media outlets, civil society organizations, health care providers, international organizations, scientific associations, community leaders, and women. The interviews centered on the Zika virus, which exacerbated gender and socioeconomic inequalities in El Salvador. Then, in May of 2018, Women's Link conducted a focus group with women and their families from the department of San Miguel, El Salvador, who were pregnant during the Zika epidemic and experienced the effects of the virus on their pregnancies.<sup>1</sup> Here, we present a summary of the conclusions reached upon analysis of the focus group and interviews.

The results of months of on-site research emphasized El Salvador's disregard for sexual and reproductive rights in its response to the Zika virus. The State failed to treat the epidemic as an ongoing public health concern and instead implemented temporary emergency measures aimed at elimination of mosquito breeding grounds, which ignored the direct connection between the virus and sexual and reproductive health. Indeed, the State largely disregarded the impact of sexual behaviour on transmission of the virus until the height of the epidemic had passed. Even when the State finally issued Zika-related campaigns directed at girls and women, the information was limited to those who were already pregnant and failed to address the entire reproductive-age population.

The State's failure to provide comprehensive, youth-sensitive sexual and reproductive health services and information during the Zika epidemic had a disproportionate impact on Salvadoran girls and women of reproductive age, particularly those who are youngest and have the least access to resources. In addition, the State has failed to provide adequate support for children with Zika-related disabilities and their families, many of whom face financial obstacles in seeking comprehensive care. The State's inadequate response to the

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<sup>1</sup>One focus group participant was the mother of a woman who gave birth during the Zika epidemic. This participant provided her observations on the experiences of her daughter and granddaughter.

Zika virus thus violates several rights recognized by the Convention on the Rights of the Child (hereinafter “CRC”), including the right to enjoy the highest attainable standard of health, the right to information, the right of children with disabilities to enjoy a full and decent life, and the right to non-discrimination. Each of these rights is discussed in further detail below.

Although the current Zika epidemic in Latin America has passed, the mosquito that transmits the Zika virus is endemic to El Salvador and finds favorable conditions both in the State’s physical environment and in its insufficient sexual and reproductive health infrastructure. There is still no vaccination to prevent transmission of the virus, and Zika-related health conditions such as Congenital Zika Syndrome have long-term consequences, particularly for the poorest girls and women and their children. Further, scientists predict that the virus will eventually make a resurgence.<sup>2</sup> It thus remains crucial that this Committee monitor the State’s efforts to protect those most affected by the virus and to prevent future violations of sexual and reproductive rights and rights of persons with disabilities.

## **II. The Right to Enjoy the Highest Attainable Standard of Health**

### *Abortion*

This Committee has noted that children’s right to enjoy the highest attainable standard of health is indispensable for the realization of all other rights protected in the CRC.<sup>3</sup> The right to health encompasses access to safe abortion services and post-abortion care for girls of reproductive age, irrespective of whether abortion itself is legal.<sup>4</sup> This is particularly important in the context of the Zika virus, which has profound consequences for reproductive health, including a heightened risk of miscarriage, stillbirth, and other pregnancy-related complications such as poor placental development and severe fetal growth restriction.<sup>5</sup>

The Zika virus can also be transmitted from a pregnant girl or woman to her fetus, leading to an increased risk of microcephaly and Congenital Zika Syndrome,<sup>6</sup> both of which impact

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<sup>2</sup>Amanda Grennel, “What happened to Zika?”, PBS News Hour, July 6, 2018, <https://www.pbs.org/newshour/science/what-happened-to-zika>.

<sup>3</sup>Committee on the Rights of the Child, *General Comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24)*, CRC/C/GC/15 (2013), para. 7 [hereinafter “CRC”].

<sup>4</sup>*Id.* at para. 70.

<sup>5</sup>Women Enabled International, “Talking Points: Zika, Microcephaly, Women’s Rights, and Disability Rights,” Apr. 15, 2016, p. 4 [hereinafter “WEI”].

<sup>6</sup>Centers for Disease Control and Prevention, “Congenital Zika Syndrome & Other Birth Defects,” May 23, 2018, <https://www.cdc.gov/pregnancy/zika/testing-follow-up/zika-syndrome-birth-defects.html>.

a child's physical and mental development and may lead to lifelong intellectual or motor disabilities requiring rehabilitation and special care.<sup>7</sup> Further, adolescent girls in El Salvador face high rates of fertility and early pregnancy,<sup>8</sup> which lead to low rates of school attendance.<sup>9</sup> Thus, in the context of the Zika virus, the decision about whether to continue with a pregnancy is complicated and has short- and long-term effects on the physical and emotional health of pregnant girls, particularly those who are young or have few resources.

In its 2010 review of El Salvador, this Committee expressed concern that the State's absolute prohibition of abortion may force girls to undergo "unsafe and clandestine abortion practices" with grave consequences.<sup>10</sup> The Committee recommended that the State consider revision of the relevant Penal Code provisions.<sup>11</sup> The concern over El Salvador's Penal Code has been echoed by several other United Nations treaty bodies.<sup>12</sup> States parties should modify laws that totally criminalize abortion and, at a minimum, legalize abortion in cases of danger to the pregnant woman's mental or physical health, fatal fetal abnormalities, and rape or incest.

Even in the context of the State's total prohibition of abortion, girls who seek post-abortion care should not fear disclosure of their medical information to State authorities or other third parties. The State is encouraged to strictly respect adolescents' rights to privacy and confidentiality, and health care providers are obligated to keep confidential medical information concerning adolescents.<sup>13</sup> In El Salvador, the patient's right to confidentiality stems from the concept of professional secrecy and is protected in the Penal Code,<sup>14</sup> the Procedural Penal Code,<sup>15</sup> the Health Code,<sup>16</sup> and under the Law of Patients' Rights.<sup>17</sup> The

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<sup>7</sup>Centers for Disease Control and Prevention, "Facts about Microcephaly," November 21, 2017, <https://www.cdc.gov/ncbddd/birthdefects/microcephaly.html>.

<sup>8</sup>Committee on the Elimination of Discrimination against Women, *Concluding observations on the combined eighth and ninth periodic reports of El Salvador*, CEDAW/C/SLV/CO/8-9 (2017), para. 34 [hereinafter "CEDAW"].

<sup>9</sup>*Id.* at para. 30.

<sup>10</sup>CRC, *Concluding observations: El Salvador*, CRC/C/SLV/CO/3-4 (2010), para. 60.

<sup>11</sup>*Id.* at para. 61(d).

<sup>12</sup>See CEDAW, *supra* note 8, at 36-37; Human Rights Committee, *Concluding Observations on the seventh periodic report of El Salvador*, CCPR/C/SLV/CO/7 (2018), para. 16 [available in Spanish only]; Committee on Economic, Social and Cultural Rights, *Concluding observations on the combined third, fourth and fifth periodic reports of El Salvador*, E/C.12/SLV/CO/3-5, para. 22.

<sup>13</sup>CRC, *General Comment No. 4: Adolescent health and development in the context of the Convention on the Rights of the Child*, CRC/GC/2003/4 (2003), para. 11.

<sup>14</sup>Art. 187.

<sup>15</sup>Art. 265.

<sup>16</sup>Arts. 37 and 38.

<sup>17</sup>Art. 20.

latter law also enshrines the corresponding obligation of health care providers to protect information learned within the context of the physician-patient relationship.<sup>18</sup>

However, the Supreme Court of Justice of El Salvador (“the Court”) has held that professional secrecy does not apply to information gathered by health care providers from physical rather than oral evidence. This means that providers who attend girls and women with complications resulting from unsafe abortion procedures no longer bear the legal duty to keep such information confidential. The Court also opened the possibility that crimes committed against the “life of a human being, already born or in formation” surpass the limits of professional secrecy.<sup>19</sup> In addition, health care providers who assist a girl or woman in terminating her pregnancy may receive sentences of six to 12 years in prison,<sup>20</sup> and Article 312 of the Penal Code establishes the crime of omission.<sup>21</sup> The Penal Code provisions and the standards voiced by the Court encourage health care providers to denounce patients who seek medical care for obstetric emergencies resulting from unsafe or spontaneous abortions, premature labor, or other complications of pregnancy. This in turn prevents girls and women from seeking necessary post-abortion care.

Despite the State’s total ban on abortion, the Ministry of Health issued the “Norm for Comprehensive Care of Persons in their Life Cycle” in 2013, which incorporates the duty of post-abortion care and management of pregnancy-related complications.<sup>22</sup>

Notwithstanding, guidelines on how to provide effective post-abortion care have not been distributed, and efforts to partially decriminalize abortion have not yet seen success. As a result, girls and women are still pushed to undergo unsafe and illegal abortion procedures that put their life and health at risk.

In sum, El Salvador’s complete prohibition of abortion and attendant Penal Code provisions encourage health care providers to reveal confidential medical information of girls and women, a problem that is magnified for patients who seek help in the midst of anxiety and uncertainty posed by a national health epidemic like the Zika virus. Criminalization of abortion also “exacerbate[s] the mental health implications of Zika infection”<sup>23</sup> for pregnant girls and women and prompts them to seek unsafe abortion procedures, violating their right to enjoy the highest attainable standard of health.

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<sup>18</sup>Legislative Assembly of the Republic of El Salvador, Decree No. 307, *Law of Patients’ Rights [Ley de Deberes y Derechos de los Pacientes y Prestadores de Servicios de Salud]* (2016), art. 20 [hereinafter “Legislative Assembly”].

<sup>19</sup>Supreme Court of Justice of El Salvador, Sentencias de Indulto 22-IND-2014, 18-IND-2014, 19- IND-2014, 21-IND-2014 and 24- IND-2014.

<sup>20</sup>Legislative Assembly, Decree No. 1030 of 1997, *Penal Code*, art. 135.

<sup>21</sup>*Id.* at art. 312.

<sup>22</sup>Ministry of Health of El Salvador, Ministerial Agreement 716, *Norm for Comprehensive Care of Persons in their Life Cycle [Norma para la atención integral de la persona en el ciclo de vida]* (2013), art. 20.

<sup>23</sup>WEI, *supra* note 5, at 5.

## *Safe Motherhood*

Children's right to health also encompasses the care that girls and women receive before, during, and after their pregnancy, which profoundly impacts the development of their children.<sup>24</sup> As this Committee notes, "timely and good-quality care" through pregnancy, childbirth, and the post-partum period is essential in preventing the transmission of ill health from mother to child.<sup>25</sup> The State's duty to provide health care extends beyond birth and encompasses support for pregnant women, who are often the primary caregivers.<sup>26</sup> This is especially important for mothers of children born with Congenital Zika Syndrome or other complications, who may require more frequent or specialized medical attention.

International organizations interviewed by Women's Link confirmed that the State response to the Zika virus was late and insufficient, which prevented reproductive-age girls and women from enjoying safe motherhood. When alerts about transmission of Zika from pregnant women to children were finally issued, circulation of the virus was already in its epidemic phase. Further, guidelines issued by the Ministry of Health on the provision of care for pregnant girls and women exposed to the Zika virus did not provide information on the importance of advising patients broadly, clearly, and scientifically of the complications the virus may entail for pregnancies. The State's response thus prevented pregnant girls and women from monitoring themselves for signs of Zika and planning for the potential effects of the virus on their health and that of their baby, which disproportionately impacted those who have the least access to financial and social resources.

States should provide "health behaviour education; birth preparedness; early recognition of management of complications" and "essential care at childbirth."<sup>27</sup> However, all focus group participants recounted the inadequate care they received during pregnancy and in the post-partum period. One participant confirmed that her daughter's fetus had symptoms of Zika during pregnancy, but her daughter did not receive an ultrasound until her fifth month, when a private clinic confirmed that the fetus had microcephaly. Neither the hospital nor the private clinic administered an examination to confirm whether the participant's daughter had contracted the Zika virus. Another participant gave birth to a daughter whose head size is smaller than average and who has limited mobility in one arm and one leg. Though the participant received authorization to visit a rehabilitation center with her daughter, she has been unable to schedule an appointment because of delays in response by the center.

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<sup>24</sup>Convention on the Rights of the Child, *adopted* Nov. 20, 1989, G.A. Res. 44/25, U.N. Doc. A/RES/44/25 (*entered into force* Sept. 2, 1990), art. 24(2)(d).

<sup>25</sup>CRC, *supra* note 3, at para. 53.

<sup>26</sup>CRC, *supra* note 3, at paras. 18, 53.

<sup>27</sup>CRC, *supra* note 3, at para. 54.

As the realization of children's rights depends largely on the "well-being and resources available to those with responsibility for their care,"<sup>28</sup> and child care falls disproportionately on the shoulders of women, El Salvador should provide mothers of all ages with quality care and support before, during, and after pregnancy to ensure their health and that of their children, including children born with disabilities.

## *Access to Contraceptives*

The right to health encompasses access to sexual and reproductive health services, including contraception.<sup>29</sup> States parties should guarantee access to short-term contraception such as condoms, hormonal methods, and emergency contraception, as well as long-term and permanent contraception.<sup>30</sup> In addition, all children and adolescents of reproductive age should have knowledge of and access to contraceptive methods in sufficient quantity and without discrimination.<sup>31</sup> Children in situations of disadvantage garner special focus in the development of efforts to provide contraception.<sup>32</sup>

The Ministry of Health distributed three technical documents to guide health personnel in the provision of care during the Zika epidemic. These documents delineate standards of care for pregnant girls and women and newborns with neurological complications stemming from the Zika virus. However, none of the guidelines contain explicit reference to national policies and guidelines on sexual and reproductive health, which minimizes the importance of sexual behavior in the transmission of Zika. Moreover, the guidelines do not discuss condoms as a means to prevent sexual transmission of Zika nor provide instruction on age-appropriate counselling in contraceptive options for young patients.

In its 2010 review of El Salvador, this Committee recommended that the State promote and ensure access to youth-sensitive reproductive health services for all adolescents.<sup>33</sup> However, during the Zika epidemic, health care providers mainly promoted the use of condoms in prenatal checkups. Such advice was limited to girls and women who were already pregnant and did not reach the entire reproductive-age population. In "Technical Guidelines for Comprehensive Care of Persons with Zika," issued by the Ministry of Health in July of 2016, the word "contraceptive" does not appear. Instead, the guidelines indicate that every woman of child-bearing age who wishes to become pregnant must attend a "pre-conception consultation in order to receive necessary information."

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<sup>28</sup>CRC, *General Comment No. 7: Implementing child rights in early childhood*, CRC/C/GC/7/Rev.1 (2006), para. 20.

<sup>29</sup>CRC, *supra* note 3, at paras. 24, 69-70.

<sup>30</sup>CRC, *supra* note 3, at para. 70.

<sup>31</sup>CRC, *supra* note 3, at paras. 113, 114(a).

<sup>32</sup>CRC, *supra* note 3, at para. 11.

<sup>33</sup>CRC, *supra* note 10, at para. 61(b).

The lack of State guidance in the importance of age-appropriate contraceptive counselling exacerbates the power dynamic between health care providers and young female patients, who may face financial barriers or fear social stigma and retribution for attending a pre-conception consultation. One focus group participant, who became pregnant at age 16, indicated that she did not seek counselling on contraceptives for fear of judgment by medical providers based on her age. She consequently became pregnant during the Zika epidemic. Her baby was born with microcephaly and clubfoot, which her doctors indicated were the result of the Zika virus. She now struggles to afford transportation to her daughter's physical therapy appointments and can no longer fulfill her dream of studying medicine. The stigma she felt in seeking contraception thus prevented her from "participat[ing] actively in planning and programming for [her] own health and development."<sup>34</sup>

Focus group participants asserted that in addition to social barriers in discussing contraception with health care providers, girls and women often face opposition to condom usage by their male partners. It may be particularly difficult for young girls to overcome such opposition given their age. Despite obstacles to condom usage, there is no evidence that health care providers promoted emergency contraception in its place. Further, the State faced a shortage of contraceptives during the height of the Zika epidemic in 2016, despite its duty to "ensure that there are functioning children's [...] goods, services and programmes in sufficient quantity."<sup>35</sup> Sources interviewed by Women's Link confirmed that this is a common occurrence in the public health care system.

Given that the Zika virus can be transmitted sexually and has short- and long-term reproductive health consequences, it is essential that the State guarantee access to contraception and youth-sensitive contraceptive counselling for girls of reproductive age. The State should pay special attention to girls who face economic and other disadvantages.

### **III. Right to Information**

The right to information encompasses access to materials that promote children's physical and mental health, including accurate and appropriate information on sexual and reproductive health.<sup>36</sup> For adolescents, access to youth-sensitive information on family planning, contraceptives, and the prevention of sexually transmitted disease is fundamental for both health and development.<sup>37</sup> Adolescent girls, specifically, should have access to information on the harm that early pregnancy can cause, and those who become pregnant

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<sup>34</sup>CRC, *supra* note 13, at para. 39(d).

<sup>35</sup>CRC, *supra* note 3, at para. 113(a).

<sup>36</sup>Convention on the Rights of the Child, art. 17; CRC, *supra* note 13, at paras. 26, 28.

<sup>37</sup>CRC, *supra* note 13, at para. 28.

should have access to comprehensive obstetric care and counselling sensitive to their specific needs.<sup>38</sup>

Comprehensive school-based sexual education is essential in providing children access to information on sexual and reproductive health. In its 2017 review of El Salvador, the Committee on the Elimination of all Forms of Discrimination Against Women (hereinafter “CEDAW Committee”) recommended that the State strengthen the capacity of teaching staff in comprehensive sexual education and reinforce “age-appropriate school-based education on sexual and reproductive health and rights.”<sup>39</sup> The CEDAW Committee’s recommendation is especially pertinent in the context of the Zika virus. During an outbreak, all girls of reproductive age require access to information on the consequences of the virus in order to make educated decisions about their sexual behavior and reproductive health.

Despite the CEDAW Committee’s recommendation and the grave impact of the Zika virus on sexual and reproductive health, Salvadoran legislators recently voted to reject a bill on school-based sexual education, citing religious concerns.<sup>40</sup> The bill, “Law of Education in Responsible Affection and Sexuality,”<sup>41</sup> aimed to address adolescent pregnancy and sexually transmitted diseases and would have required schools to include a course on “responsible affection and sexuality” in their curriculum.<sup>42</sup> Rejection of the bill represents the State’s larger failure to reinforce comprehensive sexual education.

In the context of the Zika epidemic, the State’s provision of sexual and reproductive health information outside the classroom was late, incomplete, and inaccurate. In January of 2016, the Ministry of Health advised Salvadoran women to postpone their pregnancies yet did not explain the impact of the Zika virus on sexual and reproductive health. The message to postpone pregnancy was isolated and did not form part of the State’s larger response to the virus. In addressing Zika, the State merely implemented existing measures to prevent the spread of Dengue and Chikungunya, despite the fact that Zika has unique effects on sexual and reproductive health not shared by other mosquito-borne diseases.

The State did not tailor Zika-related sexual health information to girls and women until June of 2017, once the epidemic had largely concluded. The Secretary of Health issued a

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<sup>38</sup>CRC, *supra* note 13, at para. 31.

<sup>39</sup>CEDAW, *supra* note 8, at para. 31(b).

<sup>40</sup>Legislative Assembly, “Legislators support rejection of the initiative to adopt education on sexuality” [“Avalan que es improcedente iniciativa para adoptar educación sobre sexualidad”], July 13, 2018, <https://www.asamblea.gob.sv/node/7461> [only available in Spanish].

<sup>41</sup>In Spanish, “Ley de Educación en Afectividad y Sexualidad Responsable.”

<sup>42</sup>Edgardo Rivera, “Classes on ‘responsible sexuality’ are proposed” [“Proponen clases de ‘sexualidad responsable’”], *El Mundo*, July 4, 2018, <http://elmundo.sv/proponen-clases-de-sexualidad-responsable/> [only available in Spanish].

public campaign, “Mom is safe, baby is safe from Zika,”<sup>43</sup> which focused on pregnant women to the exclusion of other girls and women of reproductive age. Although the campaign mentioned the use of contraceptives in preventing pregnancy generally, it only recommended condoms to prevent sexual transmission of Zika. The campaign failed to mention emergency oral contraception, which is a critical tool for female victims of sexual violence, over 70% of whom are under 17 years of age.<sup>44</sup>

Several health care providers, journalists and community leaders interviewed by Women’s Link agreed that the State’s failure to provide information about the effects of Zika on sexual and reproductive health negatively impacted risk perception among girls and women of child-bearing age and prevented implementation of effective prevention measures. One focus group participant indicated that there were no Zika campaigns in her community, and she was unaware that Zika could be transmitted sexually until after her daughter was born with clubfoot and microcephaly. Another participant became pregnant during the Zika epidemic, received five ultrasounds, and gave birth to a child with microcephaly before her doctors finally informed her that Zika could be transmitted sexually.

Further, focus group participants emphasized the failure of health care providers to provide timely, accurate, and complete information about the short- and long-term effects of the Zika virus on their pregnancies and on the health of their children, despite the fact that “children with disabilities and their caregivers should have access to information concerning their disabilities.”<sup>45</sup>

In some cases, participants received false, misleading, or biased information. After giving birth to a child with microcephaly, one participant’s granddaughter was falsely informed that her baby would only live six months and would “convulse frequently.” She received no information on the specific forms of care required by her baby. Another participant first learned that her son had microcephaly when she gave birth, despite having received several ultrasounds and confirmation from doctors that her son had been developing normally. Upon birth, doctors removed the participant’s baby and prohibited her from seeing him until a week later, citing a health “problem” that they did not explain to her in further detail. Although the participant confirmed that she had contracted the Zika virus, her doctors never conducted a test to determine whether her son’s microcephaly had resulted from the virus. They also failed to provide her with specific information on caring for a child with microcephaly, despite the fact that she was the sole caretaker with few financial resources.

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<sup>43</sup>In Spanish, “Mamá segura, bebé seguro de Zika.”

<sup>44</sup>See Organización de Mujeres Salvadoreñas por la Paz (ORMUSA), “Indicadores de Violencia,” 2018, <http://observatoriodeviolencia.ormusa.org/violenciasexual.php>.

<sup>45</sup>CRC, *General Comment No. 9: The rights of children with disabilities*, CRC/C/GC/9 (2007), para. 37.

Both the lack of information and the provision of false or misleading information have particularly harmful consequences for children, who because of their age face more barriers in seeking answers on their own and may be more likely to follow the advice of authorities without asking questions. Providing reproductive-age girls and their children with timely, comprehensive, and youth-sensitive information is essential in promoting their health and development and addressing the sexual and reproductive effects of the Zika virus.

#### **IV. Right to Non-Discrimination and Right of Children with Disabilities to Enjoy a Full and Decent Life**

##### *Right to Enjoy a Full and Decent Life*

The State's inadequate response to the Zika epidemic violated the rights not only of girls and women but also of their children. Newborns and children with Congenital Zika Syndrome and other Zika-related conditions have the right to "enjoy a full and decent life, in conditions which ensure dignity."<sup>46</sup> This right encompasses the State's duty to extend appropriate support, including specialist assistance, to children affected by Zika and their caregivers.<sup>47</sup>

El Salvador has failed to provide adequate assistance to children born with Zika-related conditions and their mothers, who are largely the primary caretakers. Although the State issued guidelines on the care of children with microcephaly, information about available services was not readily accessible to the public. Even organizations dedicated to serving persons with disabilities or children lacked access to concrete information and were thus unable to monitor affected families. Further, there is no evidence that the State has designed a policy for comprehensive care of children born with Zika-related conditions beyond their first few years of life. The State has failed to issue guidance that responds to their needs in both the short and long terms.

Focus group participants confirmed the existence of obstacles in seeking care for their children. One participant has struggled to provide her son, who has microcephaly, with the physical rehabilitation he needs. There are often no specialists present when she arrives to her son's appointments. The participant has no choice but to seek private therapy for her son, which she can only afford with the help of several family members. Another participant received authorization to enroll her daughter, who was born with limited mobility, in physical therapy. She has been unable to schedule an appointment because the center has yet to respond to her. A third participant asserted that she does not know of government programs to assist families of children with Zika-related conditions but

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<sup>46</sup>Convention on the Rights of the Child, art. 23(1).

<sup>47</sup>*Id.* at art. 23(2); CRC, *supra* note 28, at para. 36(d).

confirmed knowledge of the “teletón,” a model of charitable donations for persons with disabilities that is incompatible with the Convention on the Rights of Persons with Disabilities.<sup>48</sup>

In addition to its failure to provide adequate assistance to children born with Zika-related conditions, the State has failed to intervene to prevent the development of such conditions, particularly within the most vulnerable communities of reproductive-age girls. This Committee has recognized that most causes of disability, including illness and poverty, are preventable with timely intervention and has recommended that States carry out the most effective actions to prevent the development of disability.<sup>49</sup> However, El Salvador has not established accurate, standardized mechanisms to collect data on the effects of the Zika virus on reproductive-age women and girls and their children,<sup>50</sup> which is essential in establishing actions to prevent the development of Zika-related conditions.

Sources interviewed by Women’s Link confirmed that health care providers often failed to document cases of Zika during the epidemic, either intentionally or because some pregnant girls and women with Zika lacked access to specialized medical care and thus did not come to the attention of health care providers. In addition, a shortage of resources and failure to return the results of laboratory tests increased difficulty in confirming cases of Zika.

The State’s failure to provide assistance to children with Zika-related conditions and their caretakers, in addition to a lack of data-collection mechanisms and emphasis on the charity model of disability, have prevented the development of actions to support affected children and families. Children with Zika-related disabilities are thus unable to enjoy a full and decent life.

### *Right to Non-Discrimination*

In its 2013 review of El Salvador, the Committee on the Rights of Persons with Disabilities (“CRPD”) expressed concern about the absence of campaigns designed to combat negative stereotypes of persons with disabilities.<sup>51</sup> The CRPD recommended that the State “launch public information campaigns on the Convention [on the Rights of Persons with Disabilities] and its application in the various spheres of life”<sup>52</sup> as well as “set up specific programmes to guarantee the rights of children with disabilities *on equal terms*.”<sup>53</sup>

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<sup>48</sup>Committee on the Rights of Persons with Disabilities, *General Comment No. 6 (2018) on equality and non-discrimination*, CRPD/C/GC/6 (2018), para. 2 [hereinafter “CRPD”].

<sup>49</sup>CRC, *supra* note 45, at para. 1.

<sup>50</sup>CRC, *supra* note 45, at para. 19.

<sup>51</sup>CRPD, *Concluding observations on the initial report of El Salvador*, CRPD/C/SLV/CO/1 (2013), para. 21.

<sup>52</sup>*Id.* at para. 22.

<sup>53</sup>*Id.* at para. 20 (emphasis added).

Focus group participants attested to the existence of discrimination against children born with Zika-related conditions in El Salvador. One participant recounted negative treatment by the neurologist examining her son, who has microcephaly. The neurologist frequently becomes angry with the participant's son when he cries or fusses during his appointments. A second participant described treatment of her granddaughter, who was born with microcephaly. Health care providers treating the participant's granddaughter told her that her granddaughter would be a "burden" and a "vegetable" and that she would spend all of her time crying. The neurologist who sees her at the hospital also becomes angry with the mother of the child because the child's head is not growing properly.

Negative stereotypes and discrimination against children with disabilities, including in biased language used by health care providers, contribute to stigma and may prevent families from seeking assistance.<sup>54</sup> Children born with microcephaly and other Zika-related conditions are at risk of abandonment by their families, particularly after the first years of life.<sup>55</sup> As the State confronts the ongoing consequences of the Zika epidemic, it is crucial that health care providers, State agents, and the general public receive unbiased information and training on the rights of children with disabilities and the resources available to them in order to integrate them with the larger community on equal footing.

## **V. Recommendations**

In light of the above information, we respectfully ask this Committee to recommend that El Salvador adopt the following measures:

1. Issue wide-reaching informative campaigns through the Ministry of Health about illnesses transmitted by mosquitos, including the Zika virus, directed toward the entire reproductive-age population and accessible to adolescents and those with few resources. Such campaigns should contain clear information on the use of short- and long-term contraceptive methods, including emergency contraception, to prevent sexual transmission of the virus and should indicate where to obtain contraception free of charge. Campaigns should explain the consequences of the virus on pregnancy and on newborns and children in a way that is unbiased, non-discriminatory, and sensitive to disability. To ensure that this information is accessible to all reproductive-age girls and women and persons with disabilities, the Ministry of Health should forge alliances with regional and local organizations and activists who work with these populations.
2. Revise and integrate the Ministry of Health's technical guidelines on sexual and reproductive health and the Zika virus to provide clear emphasis to health care providers of

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<sup>54</sup>WEI, *supra* note 5, at 6.

<sup>55</sup>WEI, *supra* note 5, at 5.

the link between the two issues. The “Technical Guidelines for Comprehensive Care of Persons with Zika”<sup>56</sup> should include express reference to “Technical Guidelines for the Provision of Contraceptive Services”<sup>57</sup> and should discuss prevention of sexual transmission of Zika through the use of all contraceptive options for the entire reproductive-age population, not just for pregnant women; current information about vertical transmission; the obligation to inform patients of the impact of Zika on sexual and reproductive health; information about available services for children with Zika-related disabilities and their families; and guidelines for counselling young patients. Guidelines should emphasize the importance of imparting information to patients in a way that is unbiased and sensitive to disability.

3. Strengthen actions to prevent shortage of all contraceptive methods, especially in areas of poverty and limited access. Ensure that a full range of contraception is available, accessible, and acceptable.

4. Issue specific technical guidelines to health care professionals on prevention of unsafe abortion through quick and effective identification of risk to the life of a pregnant girl or woman and provision of post-abortion medical attention and attention in obstetric emergencies. Guidelines should contain clear instructions on abortion counselling and the duty of professional confidentiality and should emphasize the importance of keeping confidential all information received by children and adolescents, both orally and visually.

5. Bring El Salvador in line with international human rights standards by decriminalizing abortion, at a minimum, when the life or health of the pregnant girl or woman is at risk, when the pregnancy is the result of rape or incest, and when there is a fatal fetal abnormality.

6. Ensure safe motherhood by providing mothers of all ages with quality care and support before, during, and after pregnancy to ensure their health and that of their children, including children born with disabilities.

7. Ensure that girls and women of reproductive age who are exposed to the Zika virus, including those with few resources, have access to all information necessary to make informed, autonomous decisions about their sexual and reproductive health. This includes access to age-appropriate, comprehensive, and scientifically accurate information about the availability of contraception; the risks of the Zika virus on pregnancy and fetal development; what raising a child with Zika-related conditions may entail; the availability

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<sup>56</sup>In Spanish, “Lineamientos técnicos para la atención integral de personas con Zika.”

<sup>57</sup>In Spanish, “Lineamientos técnicos para la provisión de servicios de anticoncepción.”

of post-abortion care and counselling; and the availability of resources during pregnancy and after birth.

8. Strengthen age-appropriate school-based education on sexual and reproductive health and rights, with emphasis on informed sexual behavior and access to services in the context of mosquito-borne illness such as the Zika virus. Strengthen the capacity of teaching staff in comprehensive sexual education.

9. Develop accurate, standardized mechanisms to collect data on the effects of the Zika virus on reproductive-age girls and women and their children. Data should be provided to State officials, legislators, and health care providers for use in developing laws and policies that better promote the human rights of girls and women as well as children with Zika-related disabilities.

10. Provide this Committee with detailed and supported information on the number of suspected and confirmed cases of Congenital Zika Syndrome and other Zika-related conditions in newborns and infants. Describe services the State is providing to these children, female caregivers, and families.

11. Monitor and document compliance with and sufficiency of technical guidelines directed at care of children with Zika-related disabilities and their caretakers, including “Technical Guidelines for Care of Children with Microcephaly”<sup>58</sup> and “Instructions on Basic Psychosocial Support of Pregnant Women and Families Affected by Microcephaly and Other Neurological Complications in the Context of the Zika Virus.”<sup>59</sup> The State should implement, strengthen, and integrate these guidelines with the State’s existing social programs and ensure satisfaction of the needs of children affected by Zika and their caretakers, both in the short and long terms.

12. Immediately inform the public in a clear, accessible, and age-appropriate way of the services available to children born with Congenital Zika Syndrome and other Zika-related conditions and how to access them.

13. Ensure that all State-issued information regarding the potential effects of the Zika virus on pregnancy is presented in an impartial and non-discriminatory way and avoids use of derogatory language in reference to persons with disabilities. Information should always be accompanied by a list of available services for children with Zika-related conditions and

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<sup>58</sup>In Spanish, “Lineamientos técnicos para la atención de niños y niñas con microcefalia.”

<sup>59</sup>In Spanish, “Instructivo para apoyo psicosocial básico de las embarazadas y las familias afectadas por la microcefalia y otras complicaciones neurológicas en el contexto del virus de Zika.”

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their families and should take special care to address young mothers and families with few resources.