

CENTERING HUMAN RIGHTS IN THE RESPONSE TO ZIKA

Linkages between the ongoing Zika epidemic in the Americas and the health of women's pregnancies have created a critical opportunity for states to reaffirm their commitment to advancing women's reproductive rights at the national, regional, and global level.

The scientific community has reached a consensus that Zika is a cause of microcephaly, which can—but does not always—result in cognitive and neurological issues, including learning disabilities and impaired motor functions.¹ Further, evidence continues to emerge around other risks Zika may pose to women during pregnancy, including ongoing research into the heightened risk of miscarriage.² Given that the consequences of Zika are disproportionately borne by women—both in their experience during pregnancy and due to socialized gender roles around childcare—it is essential that states guarantee women the information, tools and resources to meaningfully exercise their reproductive autonomy. Yet, despite the High Commissioner for Human Rights³ and World Health Organization⁴ reinforcing the central nature of women's human rights during this Zika outbreak, significant inadequacies remain in how states have incorporated these principles into their responses to this epidemic. Instead, in many states, measures to address Zika have been plagued by invidious forms of discrimination, perpetuating harmful gender stereotypes and undermining women's human rights.

As is characteristic of public health crises, the areas that are worst affected by the Zika outbreak are the poorest and most marginalized, which face greater difficulty in preventing transmission of the virus, accessing health and social services, and receiving timely and accurate information. Zika disproportionately affects low-income women living in rural areas where there is lack of infrastructure and social services, including access to quality health care and counseling. For many of these women and their families, the lack of adequate health care and social services for children with disabilities magnifies the risks for children born with microcephaly or other genetic conditions or disabilities that require long-term care. Consequently, the women and families who experience multiple forms of legal and structural discrimination are the most at risk of serious human rights violations.

This statement calls for a human rights-based approach to the Zika epidemic. It identifies states' obligations to respect, protect and fulfill the human rights of all impacted by the Zika virus—including the reproductive rights of pregnant and parenting women, and the rights of persons with disabilities—while emphasizing the need to prioritize populations disproportionately affected by the virus as a result of social and economic marginalization. A rights-based response to Zika ensures that women have the information and services necessary to make the reproductive decisions that are best for them and their families, and it ensures that all women and families have adequate social and economic supports to thrive.

The Right to Comprehensive Reproductive Health Information and Services

In reaction to the potential effects of Zika on pregnancy, numerous governments have strongly advised women against becoming pregnant. Yet these states have taken few measures to guarantee women access to the information, services, and resources they need to meaningfully exercise their right to decide if and when to bear children. Placing this burden on women perpetuates the misconception that only women are responsible for planning or preventing

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pregnancy, and enables governments to shirk their responsibility to realize women's reproductive rights. A human rights based response to Zika must prioritize women's autonomy and self-determination by ensuring the right to comprehensive reproductive health information and services, including the following components:

-) **Respect for women's decision-making.** Women's autonomy and right to make meaningful, informed decisions about their sexual and reproductive health and rights must be central to states' response to Zika. States must further be responsive to the social, economic, and political realities women face each day in exercising their reproductive rights. The Zika epidemic disproportionately affects populations who generally have less access to adequate health information and services, hindering their ability to fully exercise their sexual and reproductive rights. To enable women to meaningfully exercise reproductive self-determination and realize gender equality, states must guarantee all women access to comprehensive sexual and reproductive health services, including a range of contraceptive options, including emergency contraception, safe and legal abortion care, and quality maternal health care. Further, states must prioritize the delivery of sexual and reproductive health information and services to women living in the Zika-affected communities that have historically lacked access.
-) **Access to accurate and comprehensive information.** States must ensure that all women have access to accurate, unbiased and evidence-based information on the effects of the Zika virus to enable them to make informed decisions about pregnancy and childbearing. As further information and evidence develops, states must ensure that such information is being immediately transmitted to health care providers and women, particularly those in isolated communities, in a manner that is understandable and accurately reflects emerging information. States must take measures to actively combat rumors and misinformation about the Zika virus' effects on pregnancy. Women must have access to accurate and unbiased information about parenting a child with microcephaly or other conditions caused by Zika and the availability of appropriate social, health, and educational services to support their choices. States should also recognize that the right to information includes the right to refuse information, meaning that women should never be compelled to receive health-related information against their will.
-) **Access to contraception.** For women seeking to delay or avoid pregnancy, states have an obligation to ensure affordable access to a full range of contraception options, including short-term, long-term and permanent methods, in order to meet their individual preferences and needs. Inability to negotiate contraceptive use and high rate of sexual violence against women demonstrate the acute need for guaranteeing all women access to emergency contraception. Given the emerging evidence that the Zika virus can be sexually transmitted, states should further ensure access to both male and female condoms.
-) **Access to abortion.** All women must have the right to decide whether to carry a pregnancy to term. As in other situations, where women have been infected by the Zika virus, they are in the best position to determine what is best for them and their families. Every woman's story and situation is unique and no one can presume to know all the circumstances surrounding the highly personal decision to have an abortion. Women must be empowered and supported to make these decisions through the provision of comprehensive, evidence-based and unbiased information concerning all options available to them. Restrictive abortion laws, lack of access to legal abortion services, and fear and misconceptions about the Zika virus could compel women to seek unsafe abortion, with attendant risks to their lives and health. Indeed, recent evidence shows a marked increase in the number of women requesting medical abortion pills online in countries with restrictive abortion laws and active

Zika infection.⁵ Guaranteeing all women access to safe abortion services and quality post-abortion care is essential for preserving women's lives and health and enabling them to exercise their reproductive autonomy.

-) **Access to maternal health care.** For women who freely decide to carry a pregnancy to term, it is essential that they are provided access to quality maternal health care. Although to date, much attention has centered on the Zika virus' link to microcephaly, there is ongoing research into the ways that Zika may otherwise effect pregnancy and fetal development, including the risk of stillbirth or miscarriage.⁶ The health risks associated with pregnancy and childbirth, particularly if there is a heightened risk of miscarriage or stillbirth, requires that women have access to quality maternal health care that is tailored to the unique risks associated with the Zika outbreak.

Right to Adequate Social and Economic Support for Women and Families

The emerging evidence of Zika's effects on fetal development make it imperative that states prioritize the provision of adequate economic and social supports to women and families raising children with disabilities who may need particular assistance throughout their life course to ensure the full realization of their human rights. Many of the areas that are hardest hit by the Zika epidemic are poor and rural, and must contend with lack of resources and social services to adequately respond to the needs of women and families. These deficiencies exacerbate the challenges for women with disabilities who are pregnant and may need specialized attention during pregnancy, as well as parents of children with disabilities who will need longer-term support systems. By ensuring access to these necessary services and resources, women exposed to Zika will be empowered to make meaningful decisions about their pregnancy and parenting options.

-) **Social and economic supports for families.** To ensure the inclusion of children and adults with disabilities in economic and social life, states must provide inclusive education and employment opportunities. This includes reasonable accommodations in public spaces, including schools and the workplace, as well as individualized support services when needed. Individuals and families must further be provided with the tools and resources to raise children with disabilities, starting with immediate needs such as rehabilitative health care. Further, community-based social support services for families ensure that children with disabilities can live and thrive in the community, help parents enjoy a meaningful relationship with their child, and provide parents with a necessary support network.
-) **Combatting stigma against persons with disabilities.** Stigma against people with disabilities is rooted in harmful stereotypes, including that their lives are less valuable or their life prospects more limited. States must accelerate efforts to combat these negative stereotypes about the abilities of people with disabilities, which are enshrined in laws and policies that limit their rights and dignity, and address the intersectional dimensions of discrimination against women with disabilities. Such efforts include eliminating discrimination against people with disabilities in law and practice to ensure their full participation in public life and social inclusion. Women with disabilities, in particular, should be included in decision-making about policies and programs that affect their lives and well-being.

Recommendations

-) **Guarantee all women access to comprehensive sexual and reproductive health care,** including a range of contraceptive options, quality maternal health care, and safe abortion services. To this end, states must repeal restrictive laws, such as those limiting women's right to certain forms of contraception or legal abortion services; ensure the distribution of

health clinics reaches rural and other marginalized populations; and ensure health care providers have the information, training and resources to provide a full range of reproductive health services. States must further ensure that all women who may need specialized attention during pregnancy and childbirth, including women with disabilities, have access to appropriate, quality care.

-) **Ensure the provision of accurate information about the effects of the Zika epidemic**, particularly as it relates to pregnancy and childbearing. States should ensure that newly emerging information is disseminated in a timely manner and reaches the poorest and most marginalized populations. Further, states should proactively work to dispel any rumors and misconceptions about the Zika virus and its effects on pregnancy and the health or well-being of the fetus.
-) **Guarantee full equality for people with disabilities by eradicating formal and structural discrimination** against people with disabilities in law and practice. Take measures to address stigma rooted in harmful stereotypes about people with disabilities, including the notion that the lives of people with disabilities are less valuable. States should further take positive measures to ensure the social inclusion and support for children with disabilities and their families. In particular, states should guarantee access to quality health care, community-based services, rehabilitation, inclusive education, and economic supports for children born with microcephaly or other Zika-related conditions.
-) **Proactively and meaningfully engage affected populations**, including members of the most marginalized communities, in devising and implementing specific measures to address the Zika virus and its attendant risks. States should further utilize the extensive knowledge and expertise of both reproductive rights and disability rights advocates in crafting policy solutions that simultaneously advance the rights of women and persons with disabilities.
-) **Invest in and coordinate research on the impact of the Zika virus** on pregnancy and women's health. States should identify best practices to address the public health crisis using a human rights-based approach.

Endnotes

- ¹ For more information about Zika, see Centers for Disease Control and Prevention (CDC), Zika, <http://www.cdc.gov/zika/index.html>. The CDC is also investigating links between Zika and Guillain-Barré syndrome, a weakening of the nervous system that can lead to paralysis. See <http://www.cdc.gov/zika/about/gbs-ga.html>.
- ² CDC, Prevent Infections during Pregnancy, updated 29 June 2016, available at <http://www.cdc.gov/features/prenatalinfections/>. The World Health Organization (WHO) identifies as a priority research on the association between Zika virus and miscarriage and stillbirth. WHO, Pregnancy Management in the Context of Zika Virus Infection, Interim Guidance Update, 13 May 2016, U.N. Doc. WHO/ZIKV/MOC/16.2 Rev.1, available at http://apps.who.int/iris/bitstream/10665/204520/1/WHO_ZIKV_MOC_16.2_eng.pdf?ua=1.
- ³ UN High Commissioner for Human Rights Zeid Ra'ad Al Hussein, "Upholding women's human rights essential to Zika response," 5 Feb. 2016, at <http://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=17014&LangID=E#sthash.i0wkcYV1.dpuf>.
- ⁴ WHO, Interim Guidance Update, *supra* note 2.
- ⁵ Aiken AR, Scott JG, Gomperts R, Trussell J, Worrell M, Aiken CE. Requests for Abortion in Latin America Related to Concern about Zika Virus Exposure. *New England Journal of Medicine* June 22, 2016; Jun 22 available at http://www.nejm.org/doi/full/10.1056/NEJMc1605389?query=featured_zika.
- ⁶ Meaney-Delman D. Zika virus infection among US pregnant travelers: August 2015–February 2016. *MMWR. Morbidity and mortality weekly report*. March 4, 2016; 65 (08) available at <http://www.cdc.gov/mmwr/volumes/65/wr/mm6508e1.htm>. The CDC's U.S. Zika Pregnancy Registry compiles data from state, tribal, local and territory health departments to track pregnancy and infant outcomes in pregnancies with laboratory evidence of Zika virus infection, <http://www.cdc.gov/zika/geo/pregnancy-outcomes.html>.