



Talking Points: Zika, Microcephaly, Women's Rights, and Disability Rights

April 15, 2016

The news is filled with discussions regarding the Zika virus, microcephaly, access to abortion, and women's sexual and reproductive rights—sometimes from a medical perspective, sometimes from a community health perspective, sometimes from a women's rights perspective, and occasionally from a disability rights perspective. When confronted with such an emotional issue in a climate of medical uncertainty and insecurity, nuanced language is often not reflected in the dialogues. After reading many of these perspectives, Women Enabled International (WEI) sets out a more nuanced perspective to frame a discussion that reflects the inherent rights and dignity of all affected by the Zika virus based on an intersectional disability and women's human rights perspective. We begin with an overview of the key medical facts as we understand them based on current scientific evidence, recognizing that new information is emerging on a regular basis, to ensure that this conversation is grounded in a common understanding of existing evidence. We conclude with an overview of some of the core international legal obligations that underpin the perspectives we layout in this document.

Current Scientific and Medical Information on the Zika Virus

- Knowledge about the full impact of Zika infection on pregnant women is still incomplete.
- Studies are still ongoing to better understand the link between microcephaly and Zika, as well as the broader health implications of Zika. However, the World Health Organization has determined that scientific consensus now supports a causal link between Zika infection and microcephaly.¹ The likelihood that Zika infection in a pregnant woman will result in microcephaly, however, is still unknown.²
- Microcephaly typically cannot be diagnosed until late in the second trimester or early third trimester of pregnancy. However, the accuracy of prenatal diagnosis depends on a number of factors, and it is not always possible to detect microcephaly before birth.³ According to the Boston Children's Hospital, microcephaly is not always detectable even at birth, and some babies born with

¹ World Health Organization, Emergencies: Zika Situation Report, <http://www.who.int/emergencies/zika-virus/situation-report/7-april-2016/en/> (April 7, 2016).

² Michaeleen Doucleff, "Zika Is Linked to Microcephaly, Health Agencies Confirm," NATIONAL PUBLIC RADIO (NPR) (Mar. 31, 2016), available at <http://www.npr.org/sections/thetwo-way/2016/03/31/472607576/health-agencies-confirm-zika-is-linked-with-microcephaly>.

³ Center for Disease Control and Prevention (CDC), Zika Virus: Questions and Answers for Healthcare Providers Caring for Pregnant Women and Women of Reproductive Age with Possible Zika Virus Exposure, <http://www.cdc.gov/zika/hc-providers/qa-pregnant-women.html> (last visited Feb. 29, 2016).

microcephaly may not present signs until several weeks, or even months, after birth.⁴

- The impact of microcephaly on a child's physical and mental development can vary considerably. In more severe cases, microcephaly can lead to significant learning and memory difficulties, as well as physical complications, such as seizures. However, some children with microcephaly have average intelligence and no physical symptoms beyond a smaller than average head.⁵
- There are early interventions, such as physiotherapy and game playing, that can have a beneficial impact on motor skills and cognitive development of infants born with microcephaly.⁶
- Despite rumors linking the pesticide pyriproxyfen (used to kill mosquito larvae) to an increase in microcephaly, there is no current evidence to support such a link.⁷
- Recent studies suggest that, in addition to microcephaly, the Zika virus may also increase risk of miscarriage and stillbirth, as well as other possible pregnancy-related complications such as poorly developed placentas, low or no amniotic fluid, and severe growth restriction.⁸
- In addition to transmission by mosquito bite and from mother to fetus (in utero) or infant (during childbirth), recent evidence suggests that Zika virus can survive in semen longer than it does in blood and can be spread from men to women via sexual transmission.⁹

Women Blaming, Women Shaming, and Women's Rights

- As countries respond to challenges created by the spike in Zika virus infections and a significant increase in the number of babies born with microcephaly, it is essential to ensure that the burden to respond to this epidemic not be placed exclusively on women's shoulders.
- Low-income women are particularly at risk for Zika infection due to substandard housing and sanitation and stagnant water, as well as work and family

⁴ Boston Children's Hospital, Microcephaly Symptoms and Causes, <http://www.childrenshospital.org/conditions-and-treatments/conditions/microcephaly/symptoms-and-causes> (last visited Feb. 29, 2016).

⁵ Boston Children's Hospital, Microcephaly Symptoms and Causes, <http://www.childrenshospital.org/conditions-and-treatments/conditions/microcephaly/symptoms-and-causes> (last visited Feb. 29, 2016).

⁶ Hannah Kuper, "Focus on Disability: 'Zika babies' need support now," SciDev.Net, <http://m.scidev.net/global/children/analysis-blog/zika-babies-support-brazil.html> (Feb. 24, 2016).

⁷ See, e.g., Yasmin Tayag, "Birth Defects in Brazil Are Not Cased by Pesticide, Say Zika Experts," <https://www.inverse.com/article/11611-birth-defects-in-brazil-are-not-caused-by-pesticide-say-zika-experts> (Feb. 17, 2016).

⁸ Dana Meaney-Delman, et al., CDC, *Zika Virus Infection Among U.S. Pregnant Travelers – August 2015 – February 2016* (Feb. 26, 2016), available at http://www.cdc.gov/mmwr/volumes/65/wr/mm6508e1er.htm?s_cid=mm6508e1er_e; Rob Stein, "Study Finds Multiple Problems in Fetuses Exposed to Zika Virus," NPR (Mar. 4, 2016), available at <http://www.npr.org/sections/health-shots/2016/03/04/469179452/study-finds-multiple-problems-in-fetuses-exposed-to-zika-virus>.

⁹ CDC, Zika Virus: Transmission & Risks, <http://www.cdc.gov/zika/transmission/> (last visited Mar. 29, 2016).

obligations that can make it difficult to avoid exposure to mosquitos; low-income women are also less likely to have access to quality health care or affordable mosquito repellents.¹⁰ It is essential that governments ensure that all women have access to quality health care, including comprehensive sexual and reproductive health care and prenatal care. Governments must also take steps to address sanitation, housing, and other conditions that put low-income women at heightened risk of Zika infection.

- Governments' calls to women in Zika-affected areas to solve the public health crisis on their own by refraining from having babies places the burden and responsibility on women and overlooks both the role of men in human reproduction and the legal obligations of States to respect, protect, and fulfil the right to health, among other fundamental rights.
- It is neither practical nor appropriate to tell women to refrain from becoming pregnant over the next two years, particularly in the face of laws and policies that restrict women's ability to make their own voluntary and informed decisions about their sexual and reproductive health and the lack of access to birth control.
- In circumstances where a woman has given birth to a child with microcephaly, her husband or partner may abandon her and the child, blaming the woman for the child having microcephaly or for carrying the pregnancy to term.¹¹ Women must not be expected to have the sole responsibility for caring for children born with microcephaly; states must ensure that families of children with microcephaly have the support, training, and services necessary for raising a child with a disability.
- Services and facilities in communities affected by the Zika virus must also be responsive to the needs of pregnant women exposed to Zika and their families. It is essential that communities respond and adapt to meet a growing number of families who may require assistance and support services based in their communities to minimize the risk of isolation, segregation, and stigma for women who give birth to children with microcephaly.

Sexual and Reproductive Health and Rights

- In general, all women need access to a full range of contraceptive services to prevent unwanted pregnancies; this holds true in this time of heightened concern around the Zika epidemic, but this obligation extends beyond such limited circumstances.

¹⁰ See, e.g., Debora Diniz, "Op-Ed: The Zika Virus and Brazilian Women's Right to Choose," THE NEW YORK TIMES (Feb. 8, 2016), available at <http://www.nytimes.com/2016/02/08/opinion/the-zika-virus-and-brazilian-womens-right-to-choose.html>; Alex Cuadros, "Zika exposes class differences in Brazil, where most victims are poor," THE WASHINGTON POST (Feb. 24, 2016), available at <https://www.washingtonpost.com/news/world/wp/2016/02/24/zika-exposes-class-differences-in-brazil-where-most-victims-are-poor/>.

¹¹ See, e.g., Lourdes Garcia-Navarro, "Moms and Infants Are Abandoned in Brazil Amid Surge in Microcephaly," NPR, http://wamu.org/programs/all_things_considered/16/02/18/moms_and_infants_are_abandoned_in_brazil_amid_surge_in_microcephaly (Feb. 18, 2016).

- Pregnant women who are exposed to, or infected with, Zika should have access to the information necessary to enable them to make their own informed decisions about their pregnancy. For women to make such decisions, States must ensure they have access to accurate, comprehensive, and unbiased information about:
 - their pregnancies (with the understanding that prenatal screenings, ultrasounds, and other diagnostic testing must be with the informed consent of the pregnant woman);
 - the risks of the Zika virus on fetal development;
 - what raising a child with microcephaly might entail; and
 - the availability of educational, health, financial, social and other support resources necessary for raising a family, such as those required under the U.N. Convention on the Rights of Persons with Disabilities (CRPD).¹²
- Governments must also actively combat misinformation surrounding the Zika epidemic and its effect on pregnancy, as such misinformation can contribute to a climate of fear and panic and may unduly influence decision-making by pregnant women exposed to Zika and the advice they receive from medical providers.
- Pregnant women who are exposed to, or infected with, Zika must also have access to quality maternal health care that is responsive to the specific health risks associated with Zika.
- The Zika virus has been linked to a heightened risk of miscarriage, stillbirth, and other pregnancy-related complications; the full impact of a Zika infection during pregnancy is unknown; and it may not be possible to diagnose what impact a Zika infection has had on fetal development. The anxiety and uncertainty that a pregnant woman infected with Zika faces, as well as the physical and psychological effects of a potential miscarriage or stillbirth, can have a significant impact on the woman's physical and mental health.
- Women and their families are in the best position to evaluate the available information—as well as the psychological, physical, and emotional health implications of continued pregnancy—to determine whether their unique life circumstances mean they should continue a pregnancy to term.
- Due to highly restrictive abortion laws, roughly 95% of abortions in Latin America are unsafe, leading to heightened risk of maternal mortality and morbidity.¹³ Due to health concerns around continued pregnancy after Zika infection, as well as the climate of fear and panic that currently surrounds the discourse around Zika and pregnancy, more women are seeking access to abortion in countries with restrictive abortion laws,¹⁴ and many of these women are or will be doing so in

¹² See, e.g., Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, U.N. Doc. A/Res/61/106, arts. 24, 25, 26, and 28 (Dec. 13, 2006) (hereinafter CRPD).

¹³ See, e.g., Guttmacher Institute, *In Brief: Facts on Abortion in Latin America and the Caribbean* (Nov. 2015) (noting that at least 10% of maternal deaths in Latin America were due to unsafe abortion), available at https://www.guttmacher.org/pubs/IB_AWW-Latin-America.pdf.

¹⁴ See, e.g., Michael E. Miller, "With abortion banned in Zika countries, women beg on web for abortion pills," WASH. POST (Feb. 17, 2016), available at <https://www.washingtonpost.com/news/morning-mix/wp/2016/02/17/help-zika-in-venezuela-i-need-abortion/>; Sarah Boseley and Bruce Douglas, "Zika outbreak raises fears of rise in deaths from unsafe abortions," THE GUARDIAN (Jan. 29, 2016), available at <http://www.theguardian.com/world/2016/jan/29/zika-virus-unsafe-abortions-contraception-latin-america>.

unsafe and clandestine circumstances, with attendant risks to their life and health.

- The criminalization of abortion can also exacerbate the mental health implications of Zika infection for pregnant women, as women in these settings face additional fears and anxiety in their decision-making when abortion carries a risk of imprisonment and death.
- Women affected by Zika should not be pressured or coerced to abort, nor should they be restricted from obtaining an abortion. Women who decide to terminate a pregnancy due to the risks from Zika should have access to safe and legal abortion services.
- Pregnant women need to be able to make autonomous and informed decisions about whether or not to carry their pregnancy to term, and laws and policies should support their autonomous decision-making.

Economic and Social Rights of Families with Children with Microcephaly or other Disabilities

- For women who give birth to babies with microcephaly or other disabilities, women and their families should be supported to nurture their children and raise them without stigma to the family or the child.
- The dignity and humanity of children with disabilities, including children with microcephaly, must be respected, and they must get the care they need.
- Reports indicate that babies with microcephaly are at risk of abandonment by their parents, especially after the first year or two of life; this suggests that rates of abandoned children may rise rapidly over the next few years.¹⁵ It is essential that States allocate sufficient resources to training and support programs to empower families of children with microcephaly to care for their children in their home to minimize the risk of abandonment. States must also allocate sufficient resources and support to public and private institutions to ensure appropriate care to a growing number of children who may require State assistance.
- States must ensure that women and their families have access to accurate, comprehensive, and unbiased information about the availability of educational, health, financial, social and other support resources necessary for raising a child with a disability, such as those required under the CRPD.¹⁶
- States must further ensure that educational, health, financial, social, and other support resources to support individuals with disabilities and their families, such as those required under the CRPD, are available, affordable, and located within the local community.¹⁷
- There are many steps that governments can take to provide support both to parents of children born with microcephaly and the children themselves. For

¹⁵ See, e.g., Lourdes Garcia-Navarro, “Moms and Infants Are Abandoned in Brazil Amid Surge in Microcephaly,” NPR, http://wamu.org/programs/all_things_considered/16/02/18/moms_and_infants_are_abandoned_in_brazil_amid_surge_in_microcephaly (Feb. 18, 2016).

¹⁶ See, e.g., CRPD, arts. 24, 25, 26, and 28.

¹⁷ See, e.g., CRPD, arts. 19, 24, 25, 26, and 28.

instance, community-based intervention programs can help children with microcephaly in strengthening motor skills and cognitive development. Support groups for parents can provide emotional and practical support, helping parents cope with anxiety and isolation they may feel, as well as giving them the tools to better respond to their children's development needs.¹⁸

- Services and facilities in communities affected by the Zika virus must also be responsive to the needs of children with microcephaly and their families. Inclusion of and support for children with disabilities and their families begins at the community level, and it is essential that communities respond and adapt to meet a growing number of families who may require assistance and support to continue living within the community.¹⁹

Disability Stigma, Stereotyping, and Choice of Language and Images

- Loaded terms such as “devastating,” “tragic,” “abnormal,” “defective,” or “birth defects” are not unbiased. Use of such language in describing the Zika epidemic and its impact can contribute to stigma and discrimination against children born with microcephaly, reinforcing the idea that children born with microcephaly are somehow “defective” or less deserving of fundamental rights than children born without microcephaly.
- Pregnant women who may be exposed to Zika need access to unbiased and comprehensive information on the Zika virus and microcephaly. The use of biased or loaded language around microcephaly may unduly influence both medical providers in how they advise pregnant women and women faced with making a decision about whether to continue a pregnancy to term.
- The way in which the media, advocates, and other actors addressing the impact of Zika portray babies with microcephaly and their mothers can have a profound influence on how individuals and the society generally perceive microcephaly. Seeing babies being cared for by their mothers like any other baby (rather than showing the baby on an examination table, for example) can underscore the humanity of babies born with microcephaly.

Human Rights Framework

The concerns and positions outlined in these talking points are grounded in States' international legal obligations. By signing and ratifying international human rights treaties, states have undertaken to respect, protect, and fulfill a range of rights that bear on the human rights of all who are impacted by the Zika epidemic. Specifically, core United Nations human rights treaties obligate states to:

¹⁸ Hannah Kuper, “Focus on Disability: ‘Zika babies’ need support now,” SciDev.Net, <http://m.scidev.net/global/children/analysis-blog/zika-babies-support-brazil.html> (Feb. 24, 2016).

¹⁹ See, e.g., CRPD, art. 19.

- Take steps to eliminate prejudices and practices that are grounded in stereotyped roles for women.²⁰
- Take steps to combat stereotypes, prejudices and harmful practices relating to persons with disabilities.²¹
- Raise awareness throughout society, including at the family level, regarding persons with disabilities, and foster respect for the rights and dignity of persons with disabilities.²²
- Ensure availability of and access to underlying determinants for the right to health, including adequate sanitation facilities.²³
- Ensure access to comprehensive, scientifically accurate, and unbiased information regarding contraceptive methods,²⁴ and provide such information in a language and format that is understandable and accessible.
- Ensure that a full range of contraceptive goods and services are available, accessible, acceptable, and of good quality, and that individuals are able to make informed and voluntary choices about the contraceptive method that is most suitable for them.²⁵
- Ensure access to unbiased, comprehensive, and scientifically accurate information on sexual and reproductive health, including the information necessary to prevent unwanted pregnancy and information about the legal availability of abortion.²⁶

²⁰ Convention on the Elimination of All Forms of Discrimination against Women, art. 5(a), G.A. Res. 34/180, U.N. GAOR, 34th Sess., Supp. No. 46, at 193, U.N. Doc. A/34/46 (1981).

²¹ See, e.g., CRPD, art. 8(b).

²² See, e.g., CRPD, art. 8(a).

²³ See, e.g., Committee on Economic, Social and Cultural Rights (ESCR Committee), *General Comment No. 14: The right to the highest attainable standard of health*, ¶ 12(a) (2000), U.N. Doc. HRI/GEN/1/Rev.9 (Vol. I), at 78 (2008).

²⁴ See, e.g., Committee on the Elimination of Discrimination against Women (CEDAW Committee), *General Recommendation No. 21: Equality in marriage and family relations*, para. 22 (1994), U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II), at 337 (2008); Committee on the Rights of the Child (CRC Committee), *General Comment No. 4: Adolescent health and development in the context of the Convention on the Rights of the Child*, para. 28 (2003), U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II), at 410 (2008).

²⁵ See, e.g., Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, *Interim rep. of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, para. 65(d), U.N. Doc. A/66/254 (2011).

²⁶ Human Rights Committee (CCPR Committee), *General Comment No. 28: Article 3 (The equality of rights between men and women)*, para. 10 (2000), U.N. Doc. HRI/GEN/1/Rev.9 (Vol. I), at 168 (2008); CEDAW Committee, *Concluding Observations: Benin*, para. 158, U.N. Doc. A/60/38 (2005); CEDAW Committee, *Concluding Observations: Bosnia and Herzegovina*, para. 36, U.N. Doc. CEDAW/C/BIH/CO/3 (2006); CEDAW Committee, *Concluding Observations: Burkina Faso*, para. 350, U.N. Doc. A/60/38 (2005); CEDAW Committee, *Concluding Observations: Cape Verde*, para. 30, U.N. Doc. CEDAW/C/CPV/CO/6 (2006); CRC Committee, *Concluding Observations: Antigua and Barbuda*, para. 54, U.N. Doc. CRC/C/15/Add.247 (2004); CRC Committee, *Concluding Observations: Chile*, para. 56, U.N. Doc. CRC/C/CHI/CO/3 (2007); ESCR Committee, *Concluding Observations: Benin*, para. 42, U.N. Doc. E/C.12/Add.78 (2002); ESCR Committee, *Concluding Observations: Bolivia*, para. 43, U.N. Doc. E/C.12/1/Add.60 (2001); ESCR Committee, *Concluding Observations: Mexico*, para. 43, U.N. Doc. E/C.12/1/Add.41 (1999); Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, *Interim rep. of the Special Rapporteur on the right of*

- Ensure access to good quality and affordable maternal health care.²⁷
- Ensure voluntary²⁸ access to safe abortion where legal, and take steps to ensure legal abortion in certain instances, including where continued pregnancy poses a risk to the life or health of the pregnant woman.²⁹
- Ensure that children with disabilities, including those born with microcephaly, have access to necessary health services in general and specific to their disability, “including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities.”³⁰ Necessary health services must be as close as possible to people's own communities, including in rural areas.³¹ States must also provide habilitation and rehabilitation services aimed at enabling individuals with disabilities to attain full physical, mental, and social ability.³²
- Ensure an inclusive education system³³ and take steps to safeguard the right to an adequate standard of living for persons with disabilities and their families, including through the provision of social protection and poverty reduction programs.³⁴ For families of persons with disabilities living in poverty, States must provide assistance with disability-related expenses, including adequate training, counselling, financial assistance, and respite care.³⁵

© Copyright Women Enabled International 2016

Info@WomenEnabled.org

everyone to the enjoyment of the highest attainable standard of physical and mental health, para. 65(l), U.N. Doc. A/66/254 (2011).

²⁷ See, e.g., CEDAW Committee, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, ¶ 22 (1999), U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II), at 358 (2008) International Covenant on Economic, Social and Cultural Rights, art. 10(2), G.A. Res. 2200A (XXI), U.N. GAOR, Supp. No. 16, U.N. Doc. A/6316 (1966).

²⁸ See, e.g., Committee on the Rights of Persons with Disabilities, *Concluding Observations: Argentina*, para. 32, U.N. Doc. CRPD/C/ARG/CO/1 (2012) (emphasizing the State's obligation to ensure that the pregnant woman herself give informed consent for a legal abortion, rather than substituted decision-making by a guardian).

²⁹ See, e.g., *L.C. v. Peru*, CEDAW Committee, No. 22/2009, paras. 9(b)(i), 9(b)(iii); CEDAW Committee, *Concluding Observations: Sri Lanka*, para. 283, U.N. Doc. A/57/38, Part I (2002); CRC Committee, *Concluding Observations: Chad*, para. 30, U.N. Doc. CRC/C/15/Add.107 (1999); CRC Committee, *Concluding Observations: Chile*, para. 56, U.N. Doc. CRC/C/CHL/CO/3 (2007); CRC Committee, *Concluding Observations: Guatemala*, para. 40, U.N. Doc. CRC/C/15/Add.154 (2001); CCPR Committee, *Concluding Observations: Dominican Republic*, para. 15, U.N. Doc. CCPR/C/DOM/CO/5 (2012); CCPR Committee, *Concluding Observations: Guatemala*, para. 20, U.N. Doc. CCPR/C/GTM/CO/3 (2012); CCPR Committee, *Concluding Observations: Panama*, para. 9, U.N. Doc. CCPR/C/PAN/CO/3 (2008); ESCR Committee, *Concluding Observations: Chile*, para. 53, U.N. Doc. E/C.12/1/Add.105 (2004); ESCR Committee, *Concluding Observations: Costa Rica*, paras. 25, 46, U.N. Doc. E/C.12/CRI/CO/4 (2008); ESCR Committee, *Concluding Observations: Nepal*, para. 55, U.N. Doc. E/C.12/1/Add.60 (2001); Committee against Torture, *Concluding Observations: Peru*, para. 23, U.N. Doc. CAT/C/PER/4 (2006).

³⁰ See, e.g., CRPD, art. 25(b).

³¹ See, e.g., CRPD, art. 25(c).

³² See, e.g., CRPD, art. 26.

³³ See, e.g., CRPD, art. 24.

³⁴ See, e.g., CRPD, arts. 28(1), 28(2)(b).

³⁵ See, e.g., CRPD, art. 28(2)(c).