

---

**The Zika Crisis: Focusing on Children with Disability.**

---

Marina Atalla & Peter Rosenbaum  
Op-Ed

**The Zika Crisis**

Right on the heels of the Ebola crisis, the global community now faces its fourth Public Health Emergency of International Concern (PHEIC), widely covered as the ‘Zika crisis’. Although the declaration of a PHEIC pertains specifically to “the recent cluster of microcephaly cases and other neurological disorders”, the World Health Organization’s (WHO) first Strategic Response Framework was almost exclusively preoccupied with the Zika virus and its vector, the *aedes aegypti* mosquito.<sup>1</sup> The Framework’s objectives focused on surveillance, vector control, promotion of protective behaviours, and fast-tracking research and development of diagnostic tests and vaccines. However, the WHO revised its Strategic Response since then, drawing greater attention to the support that families and children with Congenital Zika Syndrome (CZS) will need in the short- and long-term in order to reach their full potential.<sup>2</sup> Using the ‘F-words of childhood disability’ — function, fitness, family, friends, fun, and future — as a guide, this article identifies and discusses important responses to the PHEIC that have received little to no attention by any of the organizations self-reporting to the WHO’s ‘4Ws Emergency Portal’ as of 18 June 2016.<sup>3</sup>

**1. Inclusion in Mainstream Health Services**

The few responses targeting children with CZS focus primarily on the provision of specialized care and services such as community-based rehabilitation and assistive technology.<sup>2</sup> In addition to the provision of specialized care, responses need to ensure that children with CZS are also included in mainstream public health initiatives. This may seem like a basic and nonspecific response to the PHEIC at hand. However, taking a closer look at the vector in question shows how critically important this response is by providing insight into the population most susceptible to Zika virus infection, and consequently CZS. The same mosquito currently wreaking havoc across Latin

America and the Caribbean is the very same vector of two neglected tropical diseases (NTDs) — dengue and chikungunya.<sup>4</sup> NTDs are so defined by their disproportionate representation among, and impact on, the poor (historically considered a ‘tropical’ problem).<sup>5</sup>

Although Brazil, the country most affected by the crisis, is a middle-income country, there is vast disparity in the geographical distribution of wealth and disease; unsurprisingly, the severe poverty of the northeastern provinces correlates with their disproportionate burden of NTDs, Zika, and CZS.<sup>6</sup> Identifying the breeding preferences of the Zika vector further illustrates why the poorest of the poor are hit the hardest: those without access to air conditioning or indoor plumbing are more likely to be exposed to the Zika-carrying *aedes aegypti* mosquito.

Additionally, children with CZS may miss out on public health programs due to their absence from areas of healthcare provision, such as schools, where childhood vaccination programs are often administered. Other healthcare centres and services may not be physically accessible, as illustrated in a recent Washington Post article describing the three-hour journey of Carla Severina de Silva, a single mother-of-three, to reach an urban clinic offering free health care for her daughter, Eloise.<sup>7</sup> These examples compel us to recognize that families and children with CZS may struggle to access mainstream public health programs. By extension, those least likely to access basic health services are more likely to be ‘missed’ in the specialized programs currently in development. It is not innovative to call for the provision of basic health care services for marginalized communities; however, in current recommendations the interconnected disadvantages of poverty and inaccessibility have been absent from the discussion.

---

---

**The Zika Crisis: Focusing on Children with Disability.**

---

---

Marina Atalla & Peter Rosenbaum  
Op-Ed, *cont'd*

## **2. Addressing Child Abandonment**

As stories of children being discarded on the doorsteps of clinics and churches surface, the issue of child abandonment due to disability is a serious concern which has garnered a resounding silence.<sup>8,9</sup> There is concern that national authorities may respond to the abandonment of children with CZS with institutionalization in orphanages, state facilities, or residential care institutions. This response would pose a serious threat to the development and wellbeing of children with CZS. With low standards of care, a high risk of neglect and exploitation, and rampant abuse and violence, institutions across the world have a very poor record of providing for the needs of their residents.<sup>10,11</sup> Even in the absence of such blatant abuse, the detrimental psychological, behavioural, or emotional effects of institutional environments are seemingly universal.<sup>12,13</sup> There seems to be something about the very nature of institutions that renders them inadequate environments for child growth and development, particularly for children with developmental delay who may be in greater need of consistent caregiver attention and stimulation. Furthermore, the displacement of children with disabilities from communities reinforces their invisibility and fosters the attitude that children with disabilities are undesirable.

Despite a global trend of de-institutionalization, last year, the 2015 Committee on the Rights of Persons with Disabilities cited that the foremost challenge for Brazil was in fact, the institutionalization of persons with disabilities.<sup>14</sup> Moving forward, there is an immediate need for research to understand the factors that contribute to abandonment of children with CZS. Are there negative attitudes, myths, or beliefs towards CZS? Do parents who cannot care for the child consider child abandonment a culturally or religiously acceptable alternative to abortion? Only with an understanding of why child abandonment occurs can appropriate preventive measures be implemented.

Despite best efforts to provide psychosocial, financial, and technical support, children with CZS will still undoubtedly be abandoned, orphaned, or otherwise left without a family. Several alternatives to institutionalization exist, including kinship care and adoption. While it is ideal for children to be born into or adopted by loving and well-equipped families, this will not be the reality for all children. For some, an alternative to the family setting, such as a small group home (Save the Children recommends a maximum of 6-8 children) situated in the community, may be needed.<sup>12</sup> Residential care for children with disabilities should, however, always be considered a last resort.

## **3. Inclusion in Mainstream Educational Systems**

Looking to the future, the inclusion of children with CZS in mainstream educational systems is another point that has received little attention.<sup>15</sup> Yet, the question arises: Do children with severe disabilities, such as CZS, belong in mainstream schools? Focusing on children with CZS necessitates consideration of an aspect of the conversation on inclusive education that is often neglected — that is, the usefulness of educating children who are perceived as unable to capitalize on the benefits of an education.

Fueling the perception that children with severe impairments can gain little to nothing from inclusion in mainstream school systems is the assumption that they lack core skills needed for meaningful participation in the school setting. Yet, in order to create a receptive environment for children with disabilities, we need to move beyond focusing solely on what is lacking from a child's repertoire of skills. In an insightful case study exploring the lived experiences of Georgia, a young girl with Retts syndrome, Evans and Meyer argue that an accepting social environment is one that is invested in reading what they termed 'minimal cues'.<sup>16</sup> When in an environment responsive to her 'minimal cues' (such as eye

---

## The Zika Crisis: Focusing on Children with Disability.

---

Marina Atalla & Peter Rosenbaum

Op-Ed, *cont'd*

contact), Georgia was able to express her preferences, choices, and wishes, exerting a degree of self-determination in social interactions that surpassed assumptions based on her inability to communicate 'normally'. At the same time, there is a risk that, in the zealous pursuit of inclusive education, children with unique needs and skills will be haphazardly placed into classrooms but fail to be truly included in the pedagogical goals of the educational system: in other words, tokenism. Respecting the right to education mandates designing meaningful learning opportunities for all children that extend beyond the acquisition of basic 'academic' skills (such as arithmetic and language).

Inclusion that would be beneficial to children with severe disabilities necessitates appreciating educational environments as ultimately an educational environment that facilitates the development of communication, social, and self-determination skills which enhance daily participation in other arenas of life.<sup>17</sup> Georgia was able to establish mutually meaningful friendships with peers who appreciated her unique style of communication, one of which continued after graduation and off school grounds.<sup>16</sup> Children should not be deprived of participation in educational environments, neither on the basis of their (presumed) deficient repository of skills, nor due to claims that schools cannot offer anything of value for children with severe disabilities.

As the WHO, United Nations agencies, non-governmental organizations, and national governments mount responses against the Zika virus and its vector, it is important that attention continue to be directed to those who will bear the legacy of this PHEIC long after the current epidemic recedes.

---

## The Zika Crisis: Focusing on Children with Disability.

---

Marina Atalla & Peter Rosenbaum  
Op-Ed, *cont'd*

### References

1. World Health Organization. WHO Director-General summarizes the outcome of the Emergency Committee regarding clusters of microcephaly and Guillain-Barré syndrome [internet]. Geneva: World Health Organization; 2016, Feb 1. Available from <http://www.who.int/mediacentre/news/statements/2016/emergency-committee-zika-microcephaly/en/>.
2. World Health Organization. Zika strategic response plan: Revised for July 2016-December 2017. Geneva: World Health Organization; 2016, July 15. Available from <http://apps.who.int/iris/bitstream/10665/246091/1/WHO-ZIKV-SRF-16.3-eng.pdf?ua=1&ua=1&ua=1>
3. Rosenbaum P, Gorter JW. The 'F-words' in childhood disability: I swear this is how we should think!. *Child: care, health and development*. 2012 Jul 1;38(4):457-63.
4. Musso D, Gubler DJ. Zika virus: following the path of dengue and chikungunya?. *The Lancet*. 2015 Jul 18;386(9990):243-4.
5. Eisenstein M. Disease: Poverty and pathogens. *Nature*. 2016 Mar 17;531(7594):S61-3.
6. Lindoso JA, Lindoso AA. Neglected tropical diseases in Brazil. *Revista do Instituto de Medicina Tropical de São Paulo*. 2009 Oct;51(5):247-53.
7. Leaming W & McClain M. A mother's battle: Surviving microcephaly in Brazil. *The Washington Post* [newspaper on the Internet]. 2016 July 23. Available from: [https://www.washingtonpost.com/video/world/a-mothers-battle-surviving-microcephaly-in-brazil/2016/07/23/e4798a1e-50f2-11e6-bf27-405106836f96\\_video.html](https://www.washingtonpost.com/video/world/a-mothers-battle-surviving-microcephaly-in-brazil/2016/07/23/e4798a1e-50f2-11e6-bf27-405106836f96_video.html).
8. Cotovio V & Walsh NP. Zika's ground zero: Generation of babies born with microcephaly face uncertain future. *CNN* [newspaper on the Internet]. 2016 June 6. Available from: <http://www.cnn.com/2016/06/06/americas/brazil-zika-babies-uncertain-future/>.
9. Garcia-Navarro L. Moms and infants are abandoned in Brazil amid surge in microcephaly. *National Public Radio*. 2016, Feb 18. Available from <http://www.npr.org/sections/goatsandsoda/2016/02/18/467056166/moms-and-infants-are-abandoned-in-brazil-amid-surge-in-microcephaly>.
10. UNICEF. Promoting the rights of children with disabilities. *Innocenti Digest*. 2007;13:1-68.
11. World Health Organization & World Bank. *World report on disability* [internet]. Geneva: World Health Organization Press; 2011. Available from: [http://www.who.int/disabilities/world\\_report/2011/en/](http://www.who.int/disabilities/world_report/2011/en/).
12. Csáky C. Keeping children out of harmful institutions: Why we should be investing in family-based care [internet]. London: Save the Children; 2009 Nov. Available from: [http://www.savethechildren.org.uk/sites/default/files/docs/Keeping\\_Children\\_Out\\_of\\_Harmful\\_Institutions\\_Final\\_20.11.09\\_1.pdf](http://www.savethechildren.org.uk/sites/default/files/docs/Keeping_Children_Out_of_Harmful_Institutions_Final_20.11.09_1.pdf).
13. World Health Organization & United Nations Children's Fund. *Early childhood development and disability: Discussion paper* [internet]. Geneva: World Health Organization; 2012. Available from: [http://www.who.int/disabilities/media/news/2012/13\\_09/en/index.html](http://www.who.int/disabilities/media/news/2012/13_09/en/index.html).
14. United Nations Human Rights Office of the High Commissioner. Committee on the rights of persons with disabilities considers initial report of Brazil [internet]. Vienna: United Nations; 2015 Aug 26. Available from: <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16348&LangID=E>.
15. World Health Organization. Zika strategic response plan, revised for July 2016-December 2017 [internet]. Geneva: World Health Organization; 2016 July 26. Available from: <http://apps.who.int/iris/bitstream/10665/246091/1/WHO-ZIKV-SRF-16.3-eng.pdf>.
16. Evans IM, Meyer LH. Having friends and Rett syndrome: How social relationships create meaningful contexts for limited skills. *Disability and Rehabilitation*. 2001 Jan 1;23(3-4):167-76.
17. Kurth JA, Lyon KJ, Shogren KA. Supporting students with severe disabilities in inclusive schools: A descriptive account from schools implementing inclusive practices. *Research and Practice for Persons with Severe Disabilities*. 2015 Jul 10:1540796915594160.