## The Guardian

# Zika epidemic sheds light on Brazil's 'invisible children'

Exclusive: families of thousands of babies born with neurodevelopmental disorders may get help for first time.

Brazil's "invisible children", the thousands of babies born with neurodevelopmental disorders, have been brought out of the shadows by the <u>Zika virus</u> epidemic and their families may get help for the first time.

Almost 4,000 babies were born in <u>Brazil</u> with microcephaly as a result of Zika virus infection – a brain malformation that left them with small and misshapen heads and poor developmental prospects.

But nobody knows how many babies have been born in Brazil with other developmental disorders. They are invisible all over the world, where it is estimated there are 250 million children with developmental delay or disability. The numbers are thought to be probably twice as high in the developing world as they are in the more prosperous countries of North America and Europe.

"Zika affected probably a relatively small amount of children – a few thousand. The epidemic came and went and hasn't come back," said David Edwards, a professor of paediatrics and neonatal medicine at King's College London.

It was a tragedy for each of them and their families, he said, but the numbers "pale into insignificance compared with the large number of children who are affected by neurodevelopmental disorders."

The two most common causes of death and disability in newborn babies are birth asphyxia and prematurity. Well-equipped modern hospitals in the western world can prevent much of the death and damage from these causes. But women in poor countries may have far to go to reach a maternity unit and can have very long labours. A colleague of Edwards working in Uganda told him: "We think 12 hours is a long labour. They think 12 days is a long labour"

Many women in developing countries are malnourished, which increases the risk to mother and baby. Genetic factors causing such disorders as Down's syndrome and fragile X play a part in all countries.

"Brazil has invested heavily in child health [areas] such as immunisation, where we are very strong," said Maria Elisabeth Lopes Moreira, professor of neonatal growth and nutrition at the Oswaldo Cruz Foundation in Brazil. "I think that there is a lack of data on the development of children and this is part of the problem. We don't know exactly the numbers. They need support in the very early days of life. We really need some investment in these children."

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Some of them, from the poorest families, have parents who work and older siblings are charged with looking after them. "We have children taking care of children," she said. "It is too difficult for them."

She and Edwards were part of an expert group brought together to discuss childhood neurodevelopmental disorders in Brazil by the UK's <u>Academy of Medical Sciences</u> and the <u>Academia Brasileira de Ciências</u> at a workshop in Rio de Janeiro. <u>The group's report</u> calls for more to be done for the invisible children not only in Brazil but around the world.

In Brazil, they identified a need for more diagnosis and assessment, as well as the collection of better data on how many children with neurodevelopmental disorders there are. Children's doctors need to be trained to diagnose babies and healthcare workers need to be able to offer support to families.

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The Zika crisis in Brazil and the fear it might <u>spread around the world</u> through mosquitoes and even, potentially, sexual transmission brought resources and expertise into a neglected area and has now shone a light on other damaged babies, says the report. "The identification and inclusion of 'invisible children' into the public health system has been an important consequence of the crisis," it says.

The experts say they believe that Brazil, which has a strong tradition of public health interventions – vaccination coverage is 95%, for instance – is well placed to become a model for other countries to imitate.