SOCIAL INNOVATION **IN HEALTH** INITIATIVE

ZIKA KIDS *Los niños del zika*

CONTINENT	South America
COUNTRY	Colombia
HEALTH FOCUS	Comprehensive health, quality and access to services
AREAS OF INTEREST	Congenital Zika Syndrome (CZS), Comprehensive medical care, social perspective of health, social empowerment
HEALTH SYSTEM FOCUS	Access and quality of health, psychosocial care for CZS patients and their families
	CESI CPS TORE For research on diseases of poverty Sida



ZIKA KIDS

This innovation project was developed in response to the effects of the Zika epidemic in Colombia in 2015 and 2016; the focus is on the 356 babies born with congenital defects as a result of Zika infection. The initiative aims to provide comprehensive, quality medical care to these children from 0 to 2 years old to guarantee their access to health care and promote support networks and social empowerment for mothers.

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LOS NIÑOS DEL ZIKA

Este proyecto de innovación se desarrolló en respuesta a los efectos de la epidemia de Zika en Colombia en 2015 y 2016; la atención se centra en los 356 bebés que nacen con defectos congénitos como resultado de la infección por Zika. La iniciativa tiene como objetivo brindar una atención médica integral y de calidad a estos niños de 0 a 2 años para garantizar su acceso a la atención médica y promover redes de apoyo y empoderamiento social de las madres.

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This case study forms part of the Social Innovation in Health Initiative Case Collection. This case study was prepared by CIDEIM. Research was conducted in 2019-2020. This account reflects the stage of the social innovation at that time.

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For more information on SIHI and to read other cases in the SIHI Case Collection, visit <u>www.socialinnovationinhealth.org</u>. The SIHI network is supported by TDR, the Special Programme for Research and Training in Tropical Disease, co-sponsored by UNDP, UNICEF, the World Bank and WHO. TDR is able to conduct its work thanks to the commitment and support from a variety of funders. For the full list of TDR donors, please see: https://www.who.int/tdr/about/funding/en/. TDR receives additional funding from Sida, the Swedish International Development Cooperation Agency, to support SIHI.

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ABBREVIATIONS

Bayley Scales of Infant Development
Centers for Disease Control and Prevention
Congenital Disorder
Abbreviated Developmental Scale, third edition
Healthcare Provider
National Institute of Health of Colombia
Healthcare Provider
Health Benefits Plan
Congenital Zika Syndrome
Central Nervous System
Zika Virus

CASEINTRODUCTION

Image 1. Angels on Wheels Family Foundation



Source: Martha Milena Bautista Gómez. 2020

This innovation project emerged from the research project entitled "Nursing infants with prenatal exposure to ZIKV" developed by The National Institute of Health of Colombia (NIH), the institution in charge of addressing the Zika emergency through the Sub-Division of Scientific and Technological Research

Image 2. Angels on Wheels Foundation Members



Source: Martha Milena Bautista Gómez. 2019

and the Maternal and Perinatal Health Research Group. This project completed follow-ups of 140 cases of children with prenatal exposure without congenital syndrome and 47 cases of children with microcephaly caused by Zika in the cities of Barranquilla and Neiva (NIH, 2018).

Map 1. Colombia (Location cities of Barranquilla and Neiva)



Early in the project, the NIH researchers met with the families and infants born with congenital defects due to Zika, and learned about their experiences and circumstances. The researchers learned about the grieving processes the families went through because of their children's disabilities and the clinical neglect of these children. For this reason, along with medical-scientific purposes, various actions were put into motion to ensure access to care for the children and to provide emotional support to the mothers. These actions led to a social innovation, implemented via three main components:

Visiting medical teams provided comprehensive medical care to infants,

which enabled them to identify the clinical manifestations associated with Zika and so to define medical procedures required.

Inter-institutional management was fundamental in guaranteeing access to and the quality of health care for paediatric patients and in developing a public policy "Recommendations for the care and follow-up of paediatric patients with prenatal exposure to the Zika virus."

Two foundations aimed at providing psychosocial support were established: God's Miracles, the children of Zika (Milagros de Dios, los niños del Zika) in Neiva; and Angels on Wheels (Ángeles sobre Ruedas in Barranquilla.

1. INNOVATION PROFILE AT A GLANCE

Project details	
Project name	Zika's kids
Year of foundation:	2017
Name of the founder	Dr. Marcela Mercado Reyes
Nationality of the founding partners	Colombian
Organization(s) involved	National Institute of Health of Colombia
Organizational Structure	National Institute of Health of Colombia (Public Entity affiliated with the Ministry of Health and Social Protection) - Scientific and Technological Research Sub-Division, Maternal and Perinatal Health Research Group
Project Team size	11 health workers (Initial phase), 6 health workers (Current phase)
Value of the innovation	
Value proposition	Improve the quality of life and health of children with prenatal exposure to ZIKV by providing specialized medical care, ensuring access to health, and providing psychosocial support to families
Beneficiaries	Paediatric patients with prenatal exposure to ZIKV and their mothers
Key components	Comprehensive medical care Inter-institutional management Social health approach
Operational details	
Main income sources	National Institute of Health of Colombia (NIH)
Yearly expenditure	\$57,972 USD
Scalability and transferability	
Operational coverage	140 children without congenital defects and 47 children with CZS were followed up by visiting medical teams and received health care and support through the foundations. The 16,241 Colombian children with prenatal exposure to Zika are beneficiaries of the public policy changes realized by the project.
Local commitment	Departmental health secretaries, academic institutions, scientific societies, healthcare providers.
Scalability	The innovation succeeded in scaling the paediatric patient care recommendations and the need for follow up of patients both with and without CZS at the public policy level, through Resolutions 3280 and 5857 of 2018.
Sustainability	Political sustainability via public policy ensures access to health for children with prenatal exposure to Zika. Social sustainability is achieved through the two foundations for mothers of children affected by Zika.

2. CHALLENGE

The innovation originated during the Zika epidemic in Colombia between 2015 and 2016, the second largest affected region after Brazil. Zika affected a large part of the country, especially in tropical areas. In total, 101,825 people in Colombia contracted the disease during this period. They included 18,117 pregnant women, with 16,241 children born alive with prenatal exposure to Zika, and 356 children with congenital defects related to the Zika virus, such as microcephaly and other central nervous system (CNS) congenital disorders (CD) (NIH, 2018).

From a clinical perspective, the main challenges were lack of knowledge about the natural history of the disease, its clinical manifestations, and its impact on in utero and early infant and child development. Many of the clinical manifestations in children, such as seizure episodes and difficulties in basic sleeping and feeding patterns, were not well understood nor controlled.

While most children with microcephaly received medical care through the Colombian health system (with the exception of Venezuelan migrants without papers), specialized medical care procedures were not defined, and preferential health attention was not given according to severity of the illness. Therefore, parents had to follow the regular process of receiving care, which presents access barriers for specialized services and an authorizing process for each specialized medical service. The psychosocial aspects of the process were a particular challenge. The innovation project developed in response to mothers' grieving about their children's disabilities and their complexities. One of the mothers stated:

It is not easy. The truth is that it is not easy to be told: "Oh no, your child is a retard" when you are sometimes afraid to go out in public because people are going to label you... so sometimes you just hide in your own sadness and you say 'Okay, why me?', if I haven't done anything wrong, why was I given this? (Interview, Daniela, community member, November 20, 2019)

Each family's situation was unique, with home or socioeconomic circumstances at times generating other problems, as one member of the innovation team explained:

I remember things like a lady from Neiva who sells eggs and her income is \$2000 pesos, \$3000 pesos per day [\$0.54 USD - \$0.81 USD/day] and she had no way to survive. It's something very complex, and it's not only the baby that has it bad; she has three other children... Then we started to see that many mothers were abandoned; their partners left them after seeing and not wanting to face the problem... So we (the team) began to have a closer relationship with these mothers. (Interview, Valeria, innovation team, November 18, 2019)

3. INNOVATION IN INTERVENTION AND IMPLEMENTATION

Image 3. Visiting medical teams



Source: Martha Milena Bautista Gómez.

The innovation project originated in 2017 when mothers started giving birth to children with prenatal exposure to ZIKV.

Image 4. Foundation Angels on Wheels



Source: Martha Milena Bautista Gómez. 2020

The initiative expanded and developed through the following components:

Table 1. So	cial innovati	ion in health	n: Children	of Zika

COMPONENTS	STRATEGIES	RESULTS
Comprehensive medical care	Visiting medical teamsAnalysis of case studies	 Natural history of the disease List of recommendations for paediatric patient care
Inter-institutional management	 Collaborative work (scientific societies, healthcare provider, Regional Secretaries of Health, etc) Public policy advocacy 	 Resolution 3280 from 2018: care package for a comprehensive maternal and perinatal health care Resolution 5857 from 2018: benefit plans
Social perspective on health	Emotional supportSocial empowermentCommunity action	 Foundations with the mothers of children affected by Zika

3.1 COMPREHENSIVE HEALTHCARE

Since 2017, visiting medical teams have provided multidisciplinary health services for children in the first two years of life. The visiting medical teams included field visits with a group of health professionals from the NIH, who provided medical attention for one week to children with microcephaly associated with ZIKV.

The main activity carried out during the visits was a clinical assessment involving the following disciplines: paediatrics, neuropediatric, ophthalmology, dentistry and genetics, with the relevant assessments developed by specialists

from scientific societies and several partner universities. Specialists carried out child development assessments based on the collection of neuroimaging studies and formulated specialized tests and medical procedures, some of which were performed directly by the NIH:

The visiting medical teams were carried out with the NIH's own resources, with the latest technology for this type of follow-up, which implied the purchase of specialized equipment, one of which is not available in the country, as is the case of the indirect retinoscopy examination using Retcam equipment, an examination that has been defined worldwide as the gold standard for evaluating eye damage produced by the ZIKV .(NIH, 2018:3)

As a result of the medical care provided by the visiting medical teams, many of the children's behaviors and manifestations were explained, and mothers were taught about the disease, appropriate care, and how to control symptoms, as described below:

The child starts crying and crying and it was not clear why... it was irritability due to a lack of sleep... so that was one of the paths we were discovering to uncover the natural history of the disease. And the second one that was more shocking was that because the child cried all the time, the most important thing to note was the difficulties of crying because they were hungry, but they could not easily control their movement to be able to take their bottle...with these discoveries you improve the quality of life of the child, of the family. (Interview, Diana, innovation team, November 18, 2019)

As a result of the medical attention carried out by the visiting medical teams, important findings on the impact of the disease were identified. Many of the children with microcephaly due to Zika presented the following related conditions: epilepsy; sleep disorders; visual disturbances; hearing impairment; swallowing problems; and low weight.

One of the most important achievements was the development of the Recommendations List for the Monitoring and Care of Paediatric Patients with Prenatal Exposure to ZIKV, published in December 2018, as a result of analysing the case studies provided by the visiting medical teams (NIH, 2018).

The list of recommendations defines the medical objectives, procedures, followup and goals, for which each one of the child's developmental stages is established: follow-up by specialists in paediatrics and anthropometry; the vaccination schedule; feeding guidelines; and interventions with physical, occupational and speech therapy.

3.2 INTERINSTITUTIONAL MANAGEMENT

A very important part of the process was the networking led by the NIH, which linked different organizations and sectors. managed resources. and established alliances with various actors within the health, academic, and scientific sectors along with public and private institutions. This cross-sectoral stakeholder collaboration ensured that children with microcephaly had access to medical care according to the NIH recommendation list and achieving the scale up of the recommendations to the public policy level. The regulation of care and health access of current and future patients with prenatal exposure to ZIKV was carried out in the following way:

 Resolution 3280 of 2018, which defines the comprehensive health care route for the maternal perinatal population, the paediatric patients with prenatal exposure to ZIKV were included as patients most at risk. This facilitates access to specialists and processes of follow-up and intensified surveillance.

 Resolution 5857 of 2018, which defines the benefit plans. This included a list of recommendations for patients with prenatal exposure to ZIKV and defined the provisions on authorized drugs, procedures and medical devices.

Being officially regulated was not sufficient to ensure that the processes and procedures were carried out in practice. It was necessary for the NIH to follow-up on the compliance of the institutions in the provision of health services established by law, and to intervene in cases of non-compliance. In order to do this, a matrix of services requested by and provided to each patient was made. Based on this list, the follow-up procedure was defined with the objective of ensuring that patients received the necessary therapy.

This process implied cross-collaboration between local health institutions and health provider institutions streamlined bureaucratic processes. Various institutions were able to appoint an officer to facilitate the care coordination of children with microcephaly and carry out the medical procedures indicated by the NIH for each patient.

Despite this process, authorizing medicines and procedures continues to be a major challenge, as one mother, Name, explained:

The child has also been attending the visiting medical teams for 3 years. He has been given good care, they have helped me a lot when the healthcare provider does not want to authorize orders, they process all that and collaborate with us in that matter... many healthcare providers deny us many things they need and we have to be put into legal protection... and even when the legal protection come out in our favour, the providers still don't comply. (Group interview, community, November 20, 2019)

3.3 SOCIAL PERSPECTIVE ON HEALTH

Gradually, the visiting medical teams came to be welcomed, not only because of the medical care they provided the children, but because of the emotional support they offered when they provided valuable listening moments to the mothers.

The emotional support that the NIH research team provided to the families has been a permanent innovation. At crucial moments, team members were able to strengthen their bonds with the families, including at the initial stage of assimilation of the children's disability, and when some of the mothers were abandoned by their partners. Members of the visiting medical teams gradually became a familiar comfort:

For the visiting medical teams, aside from the fact that all the specialists attend, activities are done so that you feel like part of a family. We shared about how we were doing, how the children were doing, how their process was going on at home...We talked as if we were a family. She [the founder of the foundation] is always looking out for you, not only during the health brigade, she gets you in touch with Dr. Marcela over WhatsApp. (Interview, Mariana, community, November 20, 2019).

From these interactions, processes of social empowerment began to be generated. Initially, the NIH researchers trained women on health rights and legal procedures to develop their own management capacity. At the same time, strong bonds developed between the mothers as they shared their experiences and feelings. They developed a support network that led to the creation of the *Foundation Miracles of God - the Zika Kids* in Neiva, and *Foundation Angels on Wheels* in Barranquilla in 2018. This process was narrated by one of the leaders as follows:

Also, by the hand of Dr. Marcela, thank God an angel fell on us, because Dr. Marcela is an angel who fell on us. She also gave us her initiative to see what would help us... the foundation focuses on that, that people know that these children exist, that Zika exists, and that the disability is not a monster. I was told

4. ORGANIZATION AND PEOPLE

The NIH was open to incorporate new approaches that innovative were necessary to provide comprehensive solutions beyond public health. inter-institutional supporting management processes and a social approach. The organization endorsed the innovation and gave it necessary support, and because the NIH was institutionally committed to helping children with microcephaly and their families, this enhanced the impact of the innovation.

The innovation was led by NIH Research Director Dr. Marcela Mercado, who, motivated by awareness of the reality faced by children with microcephaly and their families, managed all the contact networks that she had from her role and institutional affiliation, using them to support children affected by Zika. A multidisciplinary and inter-institutional team was formed to work with Dr.

when I was going to have my child that he was a monster.(Interview, Daniela, community, November 20, 2019)

Each foundation is under the direction of a lead mother. The main activities are the exchange of medicines and implements when there are delays in processing by the health provider institution, obtaining medical equipment for the children, learning about and controlling symptoms, mechanisms to defend their rights, and economic support as needed, given the vulnerable conditions of many families. The foundations also offer a meeting and celebration space for special occasions for the children .

Mercado, whose members who were willing to participate in the project out of scientific and social commitment.

There was a gender connection between patients and researchers. The medical team was constituted only of women and the affected population were mainly the mothers of the children of Zika, in some cases supported by other women like aunts and grandmothers, and, in a few cases the father; even, in the local authorities, women were predominant.

With each of **the** visiting medical teams and the strengthening of the links between health professionals and patients, NIH's project commitments increased. This meant more work and dedication for the project professionals to their initial responsibilities, which would result in the transformation of a strictly medical-scientific project into a social innovation.

5. RESULTS AND IMPACT

5.1. NATURAL HISTORY OF THE DISEASE

In the scientific field, one of the most important results of the innovation was the development of the natural history of the condition, as the result of the processes of surveillance, research and monitoring of patients, from which the processes of prevention, treatment and the provisions of the health system were designed. These scientific findings were documented in the following articles:

Table 2. NIH scientific articles on the Zika epidemic

Year	Scientific articles
2020	Zika virus detection in amniotic fluid and Zika-associated birth defects
	https://doi.org/10.1016/j.ajog.2020.01.009
2020	Etiology of Microcephaly and Central Nervous System Defects during the
	Zika Epidemic in Colombia
	https://doi.org/10.1016/j.jpeds.2020.02.023
2019	Genomic epidemiology supports multiple introductions and cryptic
	transmission of Zika virus in Colombia.
	https://doi.org/10.1186/s12879-019-4566-2
2018	Dengue, chikungunya and zika virus coinfection: results of the national
	surveillance during the zika epidemic in Colombia
	https://doi.org/10.1017/S095026881800359X
2018	Estimating the numbers of pregnant women infected with Zika virus
	and infants with congenital microcephaly in Colombia, 2015-2017
	https://drive.google.com/file/d/1-VDZc9RO4zAD91-
	P5ECepn2rtOR9VURx/view?usp=sharing
2017	Ocular Histopathologic Features of Congenital Zika Syndrome
	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5710450/
2017	Serial Head and Brain Imaging of 17 Fetuses with Confirmed
	Zika Virus Infection in Colombia, South America
	https://pubmed.ncbi.nlm.nih.gov/28594771/
2017	Severe Neurologic Disorders in 2 Fetuses with Zika Virus Infection, Colombia
	http://dx.doi.org/10.3201/eid2306.161702
2017	Zika Virus Disease in Children in Colombia, August 2015 to May 2016
	https://onlinelibrary.wiley.com/doi/epdf/10.1111/ppe.12391
2016	Zika Virus Disease in Colombia — Preliminary Report
	https://www.nejm.org/doi/full/10.1056/nejmoa1604037
2016	Clinical and histopathological features of fatal cases with dengue and
	chikungunya virus co-infection in Colombia, 2014 to 2015
	https://www.eurosurveillance.org/content/10.2807/1560-7917.ES.2016.21.22.30244

Source: Authors. 2019

5.2. PUBLIC POLICY ADVOCACY

The innovation had high impact on the Colombian health system. The innovation team identified the following main results:

- Definition of processes and procedures to contain the epidemic in terms of the development of surveillance and monitoring protocols, which can be applied also in the management of other epidemics
- Review of the processes and procedures of the policy on perinatal and early childhood care in Colombia, which led to rethinking some of the established guidelines
- Scaling of the list of public policy recommendations, which established the care routes within the health system for pregnant mothers and children with microcephaly derived from ZIKV and defining the technical and operational guidelines for this

5.3. RESILIENCE OF MOTHERS OF CHILDREN INFECTED BY ZIKA

One of the most surprising results was the empowerment process promoted by NIH and carried out by the mothers, as a result of which they progressed from initial mourning to a learning process about the implications of their children's disability, and then undertook a struggle to achieve a better quality of life for their children, taking it on as a project for life.

The challenge is in the psychosocial care and development of productive projects for the mothers, as well as in guaranteeing inclusive schooling for the children. Women dream about creating a school that will become a rehabilitation centre, as one of the mothers explained:

In the future, I know that the Angels on Wheels Foundation is going to grow into a school where there are children's educators, teachers... that in the school Angels on Wheels Foundation will not charge you for your studies, that at least they give you and ask you for something minimal..., because I know that it is going to happen with God's help, it is going to be a rehabilitation center. (Interview, Daniela, community, November 2019)

6. SUSTAINABILITY, SCALABILITY AND REPLICABILITY

The main mechanism that guarantees the sustainability of the innovation and its maximum possible scalability was the inclusion of the recommendations at the public policy level. This guarantees access to health care and quality of care for pregnant mothers and paediatric patients aged 0 and 2 with prenatal exposure to ZIKV, regardless of political-

administrative changes, and even regardless of the sustainability of the innovation. However, it is important to continue the process of medical monitoring of the children during their growth and development after two years.

The creation of the foundations is a key element to guarantee the social

sustainability of the innovation. This is an organizational method through which psychosocial support network is expected to continue, with members likely venturing into other fields to improve the quality of life of children with disabilities and their families. However, the foundations mentioned above are still relatively new and their continuity depends largely on the leadership of the mothers and their ability to link different institutions and manage resources to sustain them.

The innovation is a very useful experience to replicate in the control of other epidemics and diseases within the Colombian health system, and in Zika control in other affected countries. Colombia has stood out as a world leader in Zika virus infection research, presenting its successes in several

7. LESSONS LEARNED

A significant lesson learned was the multidimensional understanding of Zika disease, linking the clinical, social and management dimensions to ensure access to health. This multidimensional approach showed the importance of cross-institutional and multidisciplinary perspectives, consolidating a network through synergy between different stakeholders and areas of health. This process in the future will be necessary in order to strengthen other areas of knowledge, provide broader frameworks for analysis and understanding of the disease, and propose different forms of intervention.

The connection between research, public policy generation and quality and access to health is an important learning experience for innovation. There is often international academic events of public policy generation through research practice. This has guaranteed quality of care and access to care to ensure patient health.

The components and strategies developed in terms of follow-up to comprehensive health care, crossinstitutional management, and social impact can be replicated in the treatment of other diseases and/or epidemics similar to Zika, in different places. This provides the mechanisms to understand the natural history of unknown diseases, while ensuring quality and access in patient health and scaling to the public policy level.

a gap between research and policy; many research findings are not taken into account by political decision makers. This research never lost its medical-scientific purposes, but it concurrently worked in the interests of patients; although it is often assumed that research serves the population in the long term, this innovation has shown that it is possible to build scientific knowledge while ensuring real immediate effects on the lives of people affected by the disease.

Another key lesson of the innovation is the importance of contact between researchers and health professionals to ensure awareness of the experiences of patients and families. The innovation demonstrated that social awareness, empathy and commitment are effective elements for project impact.

CASE INSIGHTS

The innovation is the result of the commitment of the leader of the innovation project, who put her cultural capital at the service of the creation of solutions to improve the quality of life and health of Zika-affected children and their families. The innovation involved a team deeply committed both personally and professionally, and an institution that endorsed and supported it.

The innovation derived from research which linked the need for quality clinical care, management to ensure access to health, and social perspective on health to provide psychosocial support to families. This in turn lead to public policy generation.

This innovation has assured political sustainability given the scaling of the recommendation list included in public policy, which benefits all current and future patients with prenatal exposure to the Zika virus. Social sustainability through the foundations means that the beneficiary population will continue to improve their quality of life as a result of the social empowerment of their mothers, even if the innovation does not continue to provide medical care on a continuing basis.

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