

Lessons Learned from Zika and Tips for Ensuring Ongoing MCH INVOLVEMENT

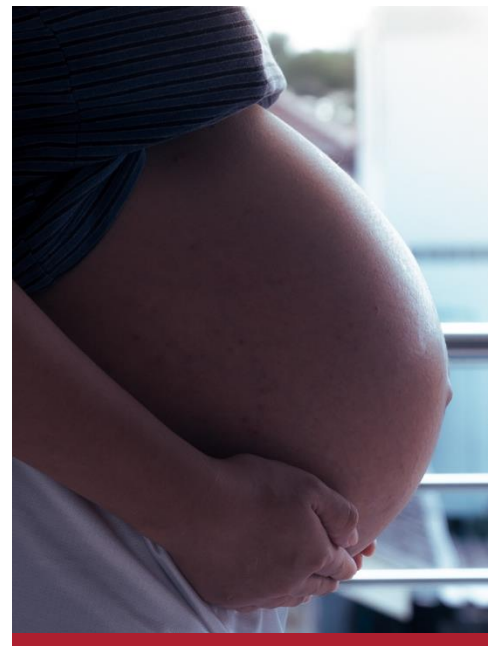


After the Centers for Disease Control and Prevention (CDC) launched its Zika emergency response efforts in 2016¹, states and territories actively responded to the threats and challenges posed by the Zika virus outbreak.

Many states turned to their Title V Maternal and Child Health (MCH) and Children and Youth with Special Health Care Needs (CYSHCN) programs to provide critical support to the emergency response efforts. In June 2019, the Association of Maternal & Child Health Programs (AMCHP) hosted a virtual focus group of seven Title V programs (California, Florida, Georgia, Minnesota, New York, Puerto Rico, and Virginia). The objectives were to reflect on lessons learned and the contributions Title V programs made in the response efforts.

A diverse group of states and territories were selected to represent the complex issues facing Title V programs from those with mosquitoes carrying Zika to those with travelers and other residents exposed to Zika outside the state.

This fact sheet synthesizes key take-aways on the value of Title V programs' active involvement in the response to the Zika outbreak as well as actions needed to ensure Title V programs play a central role in future emergency preparedness and response activities.



The Value of Title V in Emergency Preparedness and Response

Although state Title V programs were asked to participate in the Zika response efforts in a variety of ways, the motivation for bringing them on board was consistent:

Title V MCH and CYSHCN programs have expertise in working with the affected population of pregnant women and infants.

Title V MCH and CYSHCN programs have demonstrated expertise in addressing the unique needs of MCH and CYSHCN populations.

Thus, Title V MCH and CYSHCN programs are ideally suited to serve as liaisons between the MCH population and the broader response efforts geared toward the general population in a public health emergency. Title V programs can lend expertise to ensure that the needs of MCH populations are considered in emergency response efforts.



CYSHCN programs can be leveraged to provide service coordination for children and families affected by Zika or other emerging threats.

The vast majority of Title V CYSHCN programs provide and/or finance care coordination services for CYSHCN in their states.² Title V care coordination services and infrastructure can be leveraged during a public health emergency or threat to ensure that infants, children, and families have facilitated access to needed comprehensive services.

Connecting to Care:

In **Virginia**, the Title V program received referrals through the Zika Pregnancy and Infant Registry or the state Birth Defects Surveillance System. Infants received care coordination services through Title V's Care Connection for Children program and CYSHCN Child Development Centers.



State Title V programs can play an active role in educating health care providers and the public.

Title V programs know how to communicate with and disseminate messages to health care providers, MCH service providers, pregnant women, and families. They are also experienced in delivering provider training.

Messaging for MCH providers and the public:

In **California**, training on Zika was provided to Comprehensive Perinatal Services Program coordinators at annual meetings, local maternal, child and adolescent health directors at biannual meetings, and other perinatal health care providers through a webinar and in-person regional meetings. These trainings were accomplished through partnerships with local health departments and medical organizations. Other states worked with their state infectious disease and vector-borne disease programs to craft public education materials and messaging. Title V programs are exceptionally prepared to create this type of content because of their vast experience communicating with and educating pregnant women and families.

The Title V infrastructure serves as a foundation for emergency response efforts.

Although most funding for Zika response efforts and prevention came from the CDC, Title V funds sustained the critical systems that create the foundation of emergency response efforts for MCH populations and that provide family-centered, community-based care and services. For example, Title V funds may support birth defects surveillance systems, CYSHCN programs, public health department staff, and education for providers and MCH populations.

Collaboration with the Title V program provides access to networks of health care professionals who are experts in and have contact with MCH populations and their specific needs.

State Title V programs have extensive networks of provider systems and MCH public health professionals. Therefore, Title V is well positioned to act in emergencies that may have detrimental impacts on the MCH population. Moreover, they can engage the right partners in emergency preparedness efforts.

Systems and resources to support the needs of MCH populations:

In **Florida**, Title V is housed within multiple divisions in the Department of Health and works across sections to ensure the system of care in Florida for mothers and children is informed and capable of rapid response to emerging threats and trends. As an example, the Individuals with Disabilities Education Act (IDEA) Part C program, administered by the Division of Children’s Medical Services, promptly modified eligibility criteria to include infants who tested positive for probable and confirmed congenital Zika infection, as well as microcephaly.

In **Puerto Rico**, Title V led the way in establishing seven regional pediatric research centers to monitor and support children and families affected by Zika. Title V funds were used to purchase equipment and hire staff, which included medical abstractors, maternal fetal medicine specialists, pediatricians, and family engagement and support staff.



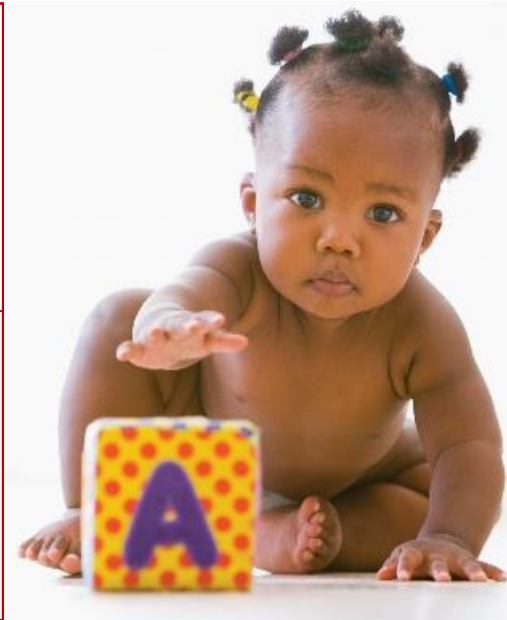
Title V can help address challenges learned from Zika to better prepare for future public health threats to women, children, and families.

- **The diagnostic criteria, known outcomes, and medical recommendations for Zika were continually being updated.** Frequent updates on Zika information and guidance were due to the emerging nature of this public health emergency. Strong communication networks are necessary in these types of public health crises in order to effectively relay information to local health departments and health care providers.
- **States that demonstrated a lower Zika risk had less impetus to scale up large public health infrastructure systems that could be beneficial should future emergency response efforts arise.** Without significant funding or a critical mass of cases, there might not be active systems-building in response to an emerging public threat like Zika. Still, Title V programs can promote an understanding of how other states’ lessons learned from Zika can be applied to help prepare for and respond to other public health emergencies and emerging threats, such as neonatal abstinence syndrome; cytomegalovirus (CMV); and natural disasters, such as hurricanes and wildfires.

- **It was challenging to track and support asymptomatic infants.** Infants with confirmed diagnoses were smoothly integrated into existing early intervention and referral systems through birth defects surveillance and CYSHCN programs. However, many states did not have processes in place to track infants exposed to Zika who were born without birth defects. Title V programs have developmental monitoring and screening initiatives to ensure all children are regularly assessed for healthy development.

Screening and follow-up for all:

Minnesota has a Title V priority need to “promote developmental screening and appropriate follow-up to support social-emotional and physical needs of children.” This priority need is one of the foundational ways the Minnesota Title V programs allows for and focuses on funding specifically for children with or at-risk for a special health care need. Title V funds can support local public health programs in following up with asymptomatic, Zika-exposed infants and children so that they receive ongoing developmental screening and referral to services.



Title V Tips for Ensuring Integration into Emergency Preparedness and Response Processes

- **Communicate the value of involving Title V in the public health emergency preparedness planning and response process.**
 - Identify the lead (or your peer) for the emergency response process in your state, introduce yourself, and begin a discussion about the unique needs of the MCH population in a public health emergency.
 - Demonstrate your expertise in responding to the needs of this population and the specific resources that Title V offers, which might otherwise be overlooked in emergency preparedness and response.
 - Foster new relationships and strengthen existing relationships with other sectors of the state health department, including epidemiology, infectious disease, and vector-borne diseases.
- **Create protocols to define the roles of the state, county, and local MCH programs in preparing for and responding to a public health emergency.** Doing so will eliminate ambiguity over each sector’s role.
- **Develop and maintain strong communication systems with local health departments and perinatal health care providers** so that rapidly evolving information can be efficiently disseminated.
- **Provide continuing education units/continuing medical education units to health care providers for attending trainings on Zika or other emerging threats.** Keep in mind that trainings and meetings on emerging threats may attract better attendance when they are bundled with other topics that providers may find more salient.

The Zika virus outbreak demonstrated a clear need for emergency preparedness and response systems to address the unique needs of MCH populations. In this way, the Zika outbreak highlighted the critical role that Title V can play, and the resources and systems that Title V programs can offer. In some states, the Zika response opened the door for Title V involvement in the incident command structure for public health emergencies. Lessons learned from the experiences of these states can facilitate the integration of MCH and emergency preparedness and response in the future and help center MCH populations before, during, and after public health emergencies going forward. For more AMCHP resources on Zika, visit

<http://www.amchp.org/programsandtopics/CYSHCN/projects/Pages/BirthDefectsDevelopmentalDisabilities.aspx>.

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References

¹Broussard, et al. (2018). Public health approach to addressing the needs of children affected by congenital Zika syndrome. *Pediatrics*, 141 (Supplement 2), S146-S153. Retrieved from: https://pediatrics.aappublications.org/content/141/Supplement_2/S146

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