



Preparing for the Future

Zika & Long-Term Implications for Systems of Care

The Centers for Disease Control and Prevention (CDC) established the U.S. Zika Pregnancy and Infant Registry (USZPIR) in 2016 to track the health outcomes of pregnant women and infants with confirmed and possible Zika infection in the United States. Data from the USZPIR shed light on birth defects potentially caused by congenital Zika infection as well as longer-term health conditions.

Data indicate about 1 in 7 (14%) infants born to mothers with confirmed or possible Zika infection had one or more health problems possibly caused by Zika. Lifetime medical and educational costs and emotional impact are likely to be substantial.

Zika's impact on children and families may last for years, sometimes in ways yet unforeseen. Those who work in and support services and systems of care for children and families should prepare now to ensure they are able to meet those future needs.



Introduction



In response to the Zika virus as an emerging public health threat to pregnant women and their infants, the Centers for Disease Control and Prevention (CDC) established the U.S. Zika Pregnancy and Infant Registry (USZPIR) in 2016. The USZPIR aims to track the health outcomes of pregnant women and infants with confirmed and possible Zika infection in the United States.

Data from the USZPIR has shed light on birth defects potentially caused by congenital Zika infection as well as longer-term health conditions that affected infants may experience.

In 2018, CDC published a report on more than 4,800 pregnant women in the U.S. territories who showed laboratory evidence of confirmed or possible Zika virus infection from 2016–2018. For these pregnancies, 1,450 infants were at least one year of age and had received some reported follow-up care. Of those infants, about 1 in 7 (14 percent) had one or more health problems possibly caused by Zika, which included birth defects and/or neurodevelopmental abnormalities.¹ In addition, emerging evidence suggests that some infants with congenital Zika infection who appear to have no apparent effects of infection at birth may have developmental delays over time.²

In every pregnancy, a woman starts out with a **3-5% chance** of having an infant with a birth defect.³ Pregnant women with confirmed or possible Zika infection are estimated to have a **30-fold greater risk of certain birth defects and neurodevelopmental problems.**^{4,5}

2016 - 2018

4800

pregnant women in the U.S. territories with confirmed or possible Zika virus infection

These findings attest to a long-term challenge: **Zika's impact on families and the systems of care that support them may last for years, sometimes in ways yet unforeseen.** The health and wellbeing of families requires a long-term response plan.⁶

Children with Zika-related birth defects and developmental problems will need ongoing monitoring and developmental screening and coordinated care in a medical home throughout their lives. This is in addition to resources needed for prevention and research. Although it may take years to fully understand the long-term impacts of congenital Zika virus, the lifetime medical and educational costs and the emotional impact on affected children and families are likely to be substantial.⁷

How, then, can we ensure that the systems of care and the workforce that support children and families are best prepared to meet those needs, and prepare for the next outbreak of Zika?

Identifying Needs for Recommended Care and Services for Children Affected by Zika

In April 2019, the Association of Maternal & Child Health Programs (AMCHP), in partnership with March of Dimes and CDC, brought together multidisciplinary leaders from state and local health department programs, MCH programs, community organizations, provider groups, university centers, and researchers, as well as family partners, and national and federal partners. The objective was to discuss the long-term needs of children affected by Zika and their families, including systems and programs to support them and their families.

This group of thought leaders identified the following key themes related to gaps in and opportunities to improve the systems of care to address the longer-term needs of those affected by Zika: **communication; data, research, screening, and surveillance; family support; policy; service delivery and coordination; technology; and workforce development.** Professionals who work in systems of care that support infants, children, and families are encouraged to assess their current programs and policies relative to these themes to ensure they are prepared to meet the needs of children and families impacted by Zika.



Long Term Needs for Families and Systems of Care

Adverse outcomes associated with congenital Zika infection include smaller than expected head size, called microcephaly (at birth and post-natal); problems with brain and eye development; problems with joint movement; issues with feeding, sitting, and sleeping; hearing loss; developmental delay; and seizures.⁸

Careful, ongoing monitoring and evaluation of children born to mothers with possible Zika infection during pregnancy is essential to ensure possible health problems are detected early and referral to needed services is timely.⁹

Building on existing initiatives can streamline efforts to address the long-term impacts for families and systems of care. The following long-term needs were identified at the individual/family and systems levels:

In April
2019

AMCHP, in partnership with March of Dimes and CDC, brought multidisciplinary thought leaders to discuss the needs for children affected by Zika



Areas of need	Individual/Family Needs	Systems Needs
Health and Development	May require specialty services, which include neurology, developmental pediatrics, nutrition, occupational therapy, speech and language pathology, audiology, ophthalmology, endocrinology, infectious disease, and genetics. They will require recommended developmental monitoring, screenings, and well-checks; improved access to specialty and sub-specialty care; above average contact with a medical home; and continuity of care.	Systems-level workforce needs include addressing shortages in sub-specialty providers; integrating better use of mid-level providers and other health care professionals; training for providers to be prepared to serve children with special needs, training to address family planning in the context of Zika; training on the impacts of Zika across the lifespan; learning how to incorporate monitoring and screening in routine visits, and having a specific, clear clinical definition of congenital Zika infection.
Family Supports and Services	Includes transportation, financial support, in-home support, respite, self-advocacy, education on services and rights, peer support and family-led organizations (e.g., Family-to-Family Health Information Centers), community-based care, protection from stigma and blame, and maintaining desired confidentiality.	The workforce will need to listen to families and adapt based on their needs. They will need to engage family-led organizations and build on existing supports (e.g., family navigator and positive parenting). They will need to ensure a “whole family” approach, which includes in-home care, education on resources, local supports that know how to address Zika-related needs, and community supports that address social determinants of health.
Care coordination¹⁰	For complex and non-complex needs, this includes regular care, specialty care, case management, referrals and follow-up, family supports, and family navigation.	Ensure capability for optimal care coordination across the lifespan. Communications should be coordinated across systems and programs and with families. Family organizations should be partners in systems efforts to ensure that families can access and map out care coordination. Ongoing surveillance of care coordination is necessary to ensure needs are identified and met.
Communication	Health communications and information must be culturally competent, linguistically appropriate, and accessible.	Health communication training is needed to ensure health care and service providers can address cultural and language barriers. Continue broad messaging for providers and families to keep Zika protocols in the forefront.
Education	Ongoing education services and supports include school readiness, Individuals with Disabilities Education Act (IDEA) Part C and B, special education services, supports to address absenteeism, and vocational services. Families will need family-led communication and advocacy supports.	Educational systems will need to identify, diagnose, and track educational needs. Better systems are needed to communicate with families, health care providers, family-led and community-based programs. Other systems that support children (beyond early childhood) are also needed. Zika may not be included in eligibility requirements for IDEA Part C in all states.
Surveillance, Data, Research	Families must be able to understand and monitor the health and development needs of their child, including developmental delays, school readiness, developmental milestones, and educational transitions.	Leverage existing data systems to support long-term surveillance, registry, and disease reporting to better understand the lifelong impacts of Zika. Longitudinal research, retrospective analysis, multi-level data collection, and better linkages of data and accessibility to providers will help inform surveillance and research.
Mental Health/ Psychosocial	Mental health for children should be addressed in the medical home and needs to be age appropriate. Families need ongoing support to address parental/caregiver mental health and prevent stigma and blame.	Strengthen and enhance mental health screening and services, use of appropriate screens, and screening and supports for parents and caregivers across the lifespan.
Financial & Eligibility Supports	Include sustained health care coverage for children, as well as legal and financial supports for families.	Access to coverage and payment for medical care and specialty care should be easily available to families, without burdensome prior authorization or barriers. Improve insurance infrastructure by maximizing private pay reimbursement, including insurance reimbursement for home visiting for Zika-exposed infants.
Transition	Across the lifespan, this includes access to health and specialty/sub-specialty care, transition throughout education and educational services (e.g., IDEA Part C to Part B), vocational rehabilitation services, guardianship, self-advocacy, and independent living.	Address the full spectrum of transition (health care, ¹¹ early childhood systems, education, adult workforce and employment). Families and youth should be engaged in transition planning. The adult system of care must be ready to address ongoing needs.
Other	May include legal representation and advocacy, a safety net of resources and services, and better use of technology (e.g., mobile health services, easily accessible records, telehealth, finding and connecting to providers and family supports).	Building flexible and responsive systems that prioritize identifying needs early for all developmental disabilities and delays will improve systems’ capabilities to address Zika. Flexibility in policy making is needed as we learn more about the long-term effects. Growing capacity in telehealth can help address needs.

Opportunities for Improvement: A Call to Action

Key themes emerged from the thought leaders' discussion regarding gaps and opportunities to improve the systems of care to address the needs of those affected by Zika:



Communication

Messaging and engagement to provide clear, consistent information and support trusting relationships with families



Service Delivery & Coordination

Easy to use systems for families and better provider care



Data, Research, Screening and Surveillance

Providing enhanced, better options for moving research to practice and determining long-term needs



Technology

Leveraging opportunities to connect systems and people



Family Support

Whole family support starts with learning from families



Workforce Development

Ensuring that the public health, primary care, and specialty care workforces are prepared to address Zika and its associated long-term needs



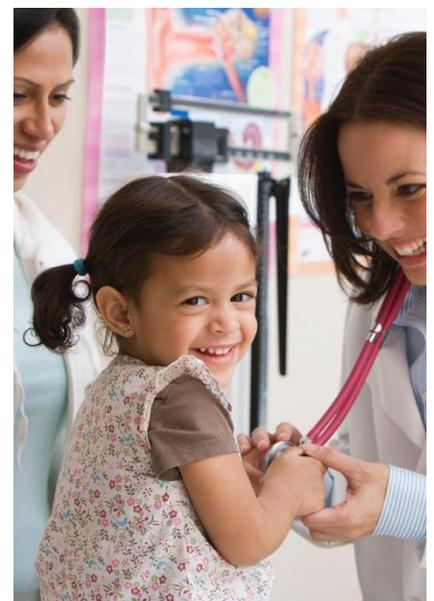
Policy

Ensuring sustained health care coverage, service continuity, and care standards

To ensure the needs of families impacted by Zika are met, staff and partners in state MCH programs, public health surveillance programs, primary and specialty care, education, Medicaid, insurance, family organizations, faith-based organizations, community organizations and family advocates should assess current systems of care and engage multidisciplinary partners to strengthen those systems.

Stakeholders can consider the following for each theme:

- How effective are our current systems, policies, and procedures in this area? Can existing systems be leveraged or expanded to strengthen efforts to help families affected by Zika?
- How could they be enhanced in our state? Are there certain recommendations that resonate with our state and populations?
- Does our organization have the authority to drive changes and improvements in this area? If not, who does, and how could/should we partner with them?





Communication

Messaging and engagement to provide clear, consistent information and support trusting relationships with families

- Ensure messaging prevents stigma and blame for families and ensures confidentiality of child and family
- Reframe messaging around Zika to include all possible health effects (not just microcephaly)
- Deliver ongoing messaging to keep Zika on people's minds
- Provide health communication training to providers and families
- Enhance communications and engagement with undocumented families
- Map communication flow and planning during a nonemergency (e.g. checklist or calling tree)
- Maintain communications and relationships across systems by leveraging professional partnerships
- Develop relationships with nongovernment organizations/nonpartisan/nonprofit organizations to centralize efforts
- Improve communication systems and use of the emergency preparedness Health Alert Network (HAN)



Data, Research, Screening, and Surveillance

Providing enhanced, better options for moving research to practice and determining long-term needs

- Enhance Electronic Health Records (EHR) to ensure surveillance happens at every level and that records are accessible to providers
- Maintain and enhance surveillance, registry, and data systems for long-term surveillance
- Emphasize existing recommendations for developmental monitoring and screening (not just developmental screening)
- Enhance data-sharing across systems of care (through central repository of programs, initiatives, workforce, and knowledge base)
- Establish evaluation across all systems and services based on human-centered design
- Fully utilize qualitative data, such as data from family stories and surveys
- Establish a research agenda for Zika, which addresses health inequities, and is informed by ongoing practice



Family Support

Whole family support starts with learning from families

- Engage family partners across all levels of the system to learn what did and did not work in caring for and supporting infants, children, and families
- Provide ongoing caregiver and family support services (transportation, respite, mental health, etc.)
- Work with adult care providers
- Include and support all family members, including mothers, fathers, siblings, and other caregivers
- Partner with family-led organizations to empower families to be self-advocates and utilize necessary systems



Policy

Ensuring sustained health care coverage, service continuity and care standards

- Promote policies that guarantee sustained private and public health care coverage for Zika-affected children and families
- Maximize Medicaid and private payer reimbursement of essential services, such as ongoing care coordination and incentives to encourage use of services (e.g., transportation or phone cards)
- Provide education on Zika for change makers (e.g., advocates and policymakers)
- Train staff and family members to be spokespersons for Zika's impact on children and families and the need for sustained coverage and care
- Establish policies on standards of care for Zika-affected children
- Develop policy and legislation to support coordination between various systems, including MCH, Medicaid, education, and social services
- Establish state and/or agency policies to ensure continuity of public health services during emergencies, workforce transitions, and/or other contingencies



Service Delivery & Coordination

Easy to use systems for families and better provider care

- Make systems easy to navigate for families: streamline care and bring services to families
- Include family organizational partners to advise on all systems change from the beginning
- Improve access and connection to specialists to address the unique needs of those affected by Zika
- Improve infrastructure for surveillance throughout life to ensure needs are identified and met
- Establish a universal model or definition of basic care coordination that meets national standards¹²
- Define a care package for those affected by Zika (health, development, educational, and social support)
- Establish a single point of entry for a multidisciplinary system
- Ensure early referral to intervention services
- Link child/youth systems with adult systems
- Strengthen and enhance screening and services, case management, and complex care coordination
- Evaluate mental health and wellbeing across the lifespan
- Establish community-based partnerships to operationalize systems coordination



Technology

Leveraging opportunities to connect systems and people

- Enhance the EHR system and data coordination
- Establish triggers or flags for referrals in EHRs to improve care coordination
- Develop or review telehealth licensing policy through the lens of Zika-related care and needs
- Leverage technology to share information across data systems (e.g., merge EHRs and health information exchanges, streamline reporting, and improve integration within health department programs) and with families (social media, jump drives, etc.)
- Use telementoring (such as the [ECHO model](#)) as an educational and/or care coordination tool
- Increase use of telehealth and telemedicine to bring the patient to the provider



Workforce Development

Ensuring that the public health, primary care, and specialty care workforces are prepared to address Zika and its associated long-term needs

- Improve communication across systems, within states and regions
- Strengthen linkages with emergency preparedness and MCH
- Improve ways to share best and promising practices (e.g., evidence-informed repository for Zika)
- Improve cultural competency and cultural brokering
- Provide ongoing training on Zika for the existing workforce
- Provide training on how to communicate about Zika and elevate family stories
- Reduce barriers for professionals to serve in shortage areas
- Integrate Zika into standards of care
- Improve recruitment of future workforce (e.g., establish a public health framework for education, a pipeline of providers at institutions of higher education)
- Expand and better resource school nursing/medical services, including allied health services



Conclusion

Robust public health and primary care infrastructures are needed to continue to understand the impacts of Zika and inform practice to support the needs of children and families. These health and social support systems must have the flexibility to accommodate change over time as more becomes known about the long-term impacts of Zika for children and families. In particular, national, federal, state, local, community, and family partners should prioritize the areas of **(1) communication; (2) data, research, screening, and surveillance; (3) family support; (4) policy; (5) service delivery and coordination; (6) technology; and (7) workforce development** to identify ways to improve systems.

States need to assess their current infrastructure, leverage current programs and promising practices, and collaborate with partners now, in order to address gaps and opportunities to improve the systems of care. In this way, states can better address the needs of those affected by Zika, and also improve the overall systems and programs that serve all children.

Acknowledgments:

Funding has been provided by the Centers for Disease Control and Prevention by way of March of Dimes. The views expressed in this report do not necessarily reflect the official policies of the Department of Health and Human Services or March of Dimes, nor does the mention of trade names, commercial practices or organizations imply endorsement by March of Dimes or the U.S. government. AMCHP would also like to thank the thought leaders who contributed their expertise and perspectives to develop the recommendations in this document. A list of participants is available [online here](#).

References:

- ¹ Zika in babies in US territories: Monitoring early health and development. (n.d.). Retrieved June 21, 2019, from <https://www.cdc.gov/vitalsigns/zika-territories/index.html>.
- ² Mulkey, et al. (April, 2019). *Neurodevelopmental decline in “normal” appearing Zika-exposed infants*. Presented at 2019 Pediatric Academic Societies Meeting, Baltimore, MD.
- ³ Zika virus and pregnancy (February 28, 2019). Retrieved June 21, 2019, from <https://mothertobaby.org/fact-sheets/zika-virus-pregnancy/>.
- ⁴ Rice, M.E., Galang, R.R., Roth, N.M., et al. (2018). Vital signs: Zika-associated birth defects and neurodevelopmental abnormalities possibly associated with congenital Zika virus infection – U.S. territories and freely associated states, 2018. *Morbidity and Mortality Weekly Report*, 67(31), 858-867. <http://dx.doi.org/10.15585/mmwr.mm6731e1>
- ⁵ Delaney, A., Mai, C., Smoots, A., et al. (2018). Population-based surveillance of birth defects potentially related to Zika virus infection – 15 states and U.S. territories, 2016. *Morbidity and Mortality Weekly Report*, 67(3), 91-96. [http://dx.doi.org/10.15585/mmwr.mm6703a2external icon](http://dx.doi.org/10.15585/mmwr.mm6703a2external%20icon)
- ⁶ Zika virus outbreak global response. (n.d.). Retrieved June 21, 2019, from <https://www.who.int/emergencies/zika-virus/response/en/>.
- ⁷ Broussard, C.S. et al., (2018). Public health approach to addressing the needs of children affected by congenital Zika syndrome, *Pediatrics*, 141, 2, https://pediatrics.aappublications.org/content/141/Supplement_2/S146
- ⁸ Microcephaly and other birth defects. (n.d.) Retrieved June 21, 2019, from https://www.cdc.gov/zika/healtheffects/birth_defects.html.
- ⁹ Caring for infants & children. (n.d.). Retrieved June 21, 2019, from <https://www.cdc.gov/pregnancy/zika/testing-follow-up/infants-children.html>.
- ¹⁰ Association of Maternal & Child Health Programs and National Academy for State Health Policy. (2017). Care coordination standards (as part of the medical home and integrated with community-based services) in: *Standards for Systems of Care for Children and Youth with Special Health Care Needs Version 2.0*. Washington, DC: Association of Maternal & Child Health Programs. <http://bit.ly/2sRNRDj>.
- ¹¹ Side-by-side version: Six core elements of health care transition 2.0. (2014). Retrieved June 21, 2019, from <https://www.gottransition.org/resourceGet.cfm?id=206>
- ¹² Association of Maternal & Child Health Programs and National Academy for State Health Policy. (2017). Care coordination standards (as part of the medical home and integrated with community-based services) in: *Standards for Systems of Care for Children and Youth with Special Health Care Needs Version 2.0*. Washington, DC: Association of Maternal & Child Health Programs. <http://bit.ly/2sRNRDj>.