

Resource Guide for States and Communities Caring for Infants and Children Affected by Zika Virus

INTRODUCTION

This resource is focused on the comprehensive health needs of infants and children affected by Zika Virus (ZIKV). It is intended as a planning resource for states and communities as they develop a coordinated response to meet the immediate and long term needs of infants and children affected by ZIKV, and their families. The resource guide applies a system of care approach and builds on existing Federal and State services and programs for supporting children with special health care needs (CSHCN). This information will assist states and communities in effectively leveraging and integrating existing programs and assessing programmatic flexibilities to augment their systems of care to address ZIKV.

Readers should be aware that the Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO) have published guidelines regarding screening, assessment, and management of newborns and infants with in utero ZIKV exposure. The Department of Health and Human Services also has developed resources regarding care for non-pregnant women and men of reproductive age, and for pregnant women in the context of ZIKV. This resource guide references these guidelines and other expert sources. This resource guide should be viewed as a companion emergency preparedness and public health document, and will be updated as the evidence, guidelines, and information on ZIKV evolves.

Information on ZIKV and infection is constantly evolving, therefore if you are a clinician treating a patient, please check the CDC Zika site for the most current information and clinical guidance. <http://www.cdc.gov/zika/>

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OVERVIEW OF ZIKV, INFECTION, AND OUTCOMES

ZIKV outbreaks have been reported in Africa, the South Pacific, and most recently the Americas. The virus usually is transmitted through the bite of an infected *Aedes* species mosquito. ZIKV also may be transmitted between sexual partners, from mother to fetus, and likely through blood transfusion. Many people infected with ZIKV will not have symptoms or will have only mild symptoms. Symptoms of Zika can include, fever, rash, joint pain, conjunctivitis (red eyes), muscle pain, and headache. These symptoms can last for several days to a week. There have also been increased reports of [Guillain-Barré syndrome](#), an uncommon sickness of the nervous system, in areas affected by Zika.¹ At present there is no vaccine to prevent or treat ZIKV infection.²

Zika infection during pregnancy can cause serious birth defects, especially affecting the neurological system. Some infants with congenital ZIKV infection may have severe microcephaly, seizures, irritability, limb contractures, hearing and visual abnormalities, and feeding difficulties. However, neurological abnormalities may occur without microcephaly; the abnormalities may become evident after birth through imaging studies and other diagnostic assessments. Developmental delays, hearing and visual impairments, epilepsy, and growth delays and other effects may become apparent in the first few months to years of life. At present, the long term effects of prenatal exposure to ZIKV are unknown. As with other chronic conditions, infection by ZIKV will require careful and consistent follow up and management. This needs to occur within the context of the family, community, cultural, and broader medical-social environment. Support for physical, behavioral, developmental, emotional, and mental health needs is critical for the population of Zika-exposed infants, children, and their families to achieve optimal health status.

On February 1, 2016, the WHO declared the clustering of microcephaly cases, Guillain-Barré syndrome, and other neurological conditions in some areas affected by ZIKV transmission, a Public Health Emergency of International Concern.³ On May 9, 2016, the CDC declared ZIKV disease and ZIKV congenital infection as [Nationally Notifiable Conditions](#); healthcare providers must notify their local/State health departments according to the laws or regulations for reportable diseases in their jurisdiction.⁴

What is the potential impact of ZIKV Infection?

In a recent report published in the *Journal of the American Medical Association – Pediatrics*, the CDC estimated that 5,900-10,300 pregnant women might be infected in Puerto Rico in 2016, in the absence of effective interventions.⁵ Among these women, CDC estimated that 100-270 infections might lead to microcephaly in infants born between mid-2016 and mid-2017. Recent evidence from Brazil highlights that microcephaly is only one of the multiple effects on a developing fetus and infant.

“Combined findings from clinical, laboratory, imaging, and pathological examinations provide a more complete picture of the severe damage and developmental abnormalities caused by ZIKV infection than has been previously reported. The term *congenital Zika syndrome* is preferable to refer to these cases, as microcephaly is just one of the clinical signs of this congenital malformation disorder.”⁶

The precise number of infants who will develop congenital Zika syndrome is unknown at this time. These estimates underscore the importance of the urgent actions being taken to prevent ZIKV infection during pregnancy, and the need to plan for medical and supportive services for families affected by ZIKV.

ZIKV infection, acquired through travel and local transmission, has been reported in the Continental United States.⁷ Cases of congenital infection with resultant birth defects continue to be reported to the CDC pregnancy registry. According to CDC and National Institutes of Health (NIH) estimates, the lifetime cost of care for an infant with congenital Zika infection to both the family and health-care systems is anywhere between \$1 million and \$10 million.⁸ A surge in the number of children with special health care needs as the result of this public health emergency will further stress the already underfunded and understaffed public health and healthcare systems.

CDC Interim Guidance

The CDC continues to revise its guidance, including updating recommendations for the initial evaluation and testing of infants with confirmed or possible congenital exposure to ZIKV infection, and establishing recommendations for the outpatient management and follow-up of infants with laboratory evidence of congenital ZIKV infection, with or without apparent associated birth defects. The guidance also emphasizes that families and caregivers will need ongoing psychosocial support and assistance with coordination of care.

Interim Guidance for the Evaluation and Management of Infants with Possible Congenital ZIKV Infection – United States, August 2016 (MMWR, August 19, 2016)

http://www.cdc.gov/mmwr/volumes/65/wr/mm6533e2.htm?s_cid=mm6533e2_w

Resources and Guidance for Healthcare Providers Caring for Infants Affected by ZIKV:

<http://www.cdc.gov/zika/hc-providers/infants-children.html>

<http://www.cdc.gov/zika/hc-providers/infants-children/resources-hc-providers-caring-for-infants.html>

Resources and Guidance for Pregnant Women and their Families:

<http://www.cdc.gov/zika/pregnancy/protect-yourself.html>

Refer to the CDC for information on how state, tribal, local, and territorial health departments and healthcare providers can participate in the US Zika Pregnancy Registry
<http://www.cdc.gov/zika/hc-providers/registry.html>

Resources and Guidance for Families Caring for Infants Affected by ZIKV:
<http://www.cdc.gov/zika/parents/index.html>
<http://www.cdc.gov/zika/parents/families-of-newborns-affected-zika.html>

WHO Interim Guidance

The WHO continues to update its interim guidance on the screening, clinical assessment, neuroimaging, and laboratory investigations of neonates and infants born to women residing in areas of ZIKV transmission. The recommendations provide guidance on the screening, clinical assessment, neuroimaging, laboratory investigation, and follow-up of children born to women living in areas of ZIKV transmission. The WHO Guidance summarizes the evidence base and rationale in support of the recommendations and expands the scope to address complications beyond microcephaly and what is now referred to as the congenital ZIKV syndrome.

For healthcare providers: <http://www.who.int/csr/resources/publications/zika/assessment-infants/en/>

Medicaid Guidance

The Center for Medicaid and CHIP Services (CMCS) released an information bulletin informing Medicaid agencies and interested stakeholders about how Medicaid services and authorities can help states and territories prevent, detect, and respond to the Zika virus. The Children's Health Insurance Program (CHIP) serves uninsured children up to age 19 in families with incomes too high to qualify for Medicaid. CHIP is administered by states, according to federal requirements. The program is funded jointly by states and the federal government.

CMCS Information Bulletin, June 2016: [*Medicaid Benefits Available for the Prevention, Detection and Response to the Zika Virus*](#)

SYSTEMS OF CARE AS A PUBLIC HEALTH APPROACH FOR COMPREHENSIVE CARE FOR INFANTS AND CHILDREN EXPOSED TO ZIKV

Children with Special Health Care Needs

Children with special health care needs (CSHCN) are defined as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by

children generally.”⁹ In 2011–2012, approximately 20 percent of U.S. children under the age of 18 years of age had a special health care need, representing almost 15 million children.¹⁰ Children exposed to ZIKV prenatally meet the definition of children with special healthcare needs, regardless of whether they are symptomatic at birth. Acute and long term follow up care for identified and at-risk children affected by ZIKV is consistent with HRSA’s Maternal and Child Health Bureau (MCHB) comprehensive systems approach to care for CSHCN.

System Of Care

In 1987, the Surgeon General called for “family-centered, community-based, coordinated care for CSHCN and their families”.¹¹ The six core constructs of this system are: 1) families of CSHCN are partners in decision making at all levels of the system; 2) CSHCN receive coordinated, ongoing, comprehensive care within a medical home; 3) families of CSHCN have adequate financing of care; 4) children are screened early and continuously for special health care needs; 5) services for CSHCN are well-organized for ease of use; and 6) youth with special health needs receive services necessary to make transitions to all aspects of adult life. The evidence base for this approach is extensive in improving health outcomes and assuring family engagement.¹²

The needs of infants and children affected by ZIKV are complex; families, health care providers and public health professionals should work together to support a system of care that assures that community-based, comprehensive high quality health and social services are available to these children. This must address the medical needs of these children, as well as regularly screen children who may not be symptomatic at birth, coordinate care through a medical home, finance care needed by children and families, link to community based services, partner with families, and eventually address transition to adult services.

The MCHB principles of family centered care (FCC) should be addressed in a comprehensive response to ZIKV infection. Specific to this response are activities that characterize FCC: “acknowledge the family as the constant in a child’s life, build on family strengths, support the child in participating, honor diversity, recognize the importance of community-based services, promote an individual and developmental approach, encourage family-to-family/peer support, develop family-centered policies and practices, and celebrate successes.”¹³

A comprehensive system of care as described above provides for effective service delivery systems for CSHCN. It organizes services into a coordinated network, integrates care planning and management across multiple levels, and builds meaningful partnerships with families.¹⁴ System of care planning and response includes state and local public health officials, health care professionals, community and educational providers, and most importantly families. It should build on existing infrastructure at the federal, state and community levels. The attached matrix provides an overview of multiple federal agencies and their role in supporting state and local systems for CSHCN.

Public Health Approach to Support a System of Care

The core functions of the public health model are the methodological framework to support a system of care.

(a) Assessment: monitoring and surveillance of the needs of infants and children affected by ZIKV; gap analysis and resource allocation;

(b) Policy development: family engagement; state plan; dissemination/communication;

(c) Assurance: medical homes; workforce development and training; shared resource of programs and services; evaluation and quality improvement.

PUBLIC HEALTH FRAMEWORK¹⁵			
CORE PUBLIC HEALTH FUNCTIONS	Resources for Communities	Resources for Population Health	Resources for Clinical Care
ASSESSMENT	<ul style="list-style-type: none"> Surveillance: collect, monitor, and report data for program improvement and effectiveness, and resource planning at the community level. 	<ul style="list-style-type: none"> Surveillance: collect, monitor, and report data for program improvement and effectiveness, and resource planning at the population level. 	<ul style="list-style-type: none"> Develop data systems for follow-up for children affected with Zika in clinical settings. Develop quality metrics for monitoring care quality and coordination.
POLICY DEVELOPMENT	<ul style="list-style-type: none"> Convene state and local partners to identify priority needs and goals. Participate in community needs assessments for exposure to ZIKV. Facilitate feedback loop between front-line providers and policymakers at the federal, state, and local levels. 	<ul style="list-style-type: none"> Develop policies to address access barriers (financial, transportation, cultural, etc). Develop policies to ensure family engagement. Establish processes (e.g. coordinating body) to assure service coordination and systems integration and reduce duplication and fragmentation of services. 	<ul style="list-style-type: none"> Develop standards and disseminate best practice guidelines. Support quality improvement and collaborative innovations in clinical care to address Zika-related health problems.
ASSURANCE	<ul style="list-style-type: none"> Establish community health teams. Assure a prepared public health and health care workforce. Develop shared resource of programs and services. 	<ul style="list-style-type: none"> Develop programs and provide technical assistance and training to community and health providers on family engagement and care coordination. Inform, engage, and empower families about Zika related health issues. 	<ul style="list-style-type: none"> Establish tele-health network to connect primary care providers with specialists. Link individuals (care coordination) to health, educational, and community services.

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- ¹ <http://www.cdc.gov/zika/about/overview.html>
- ² <http://www.cdc.gov/zika/prevention/index.html>
- ³ <http://www.who.int/emergencies/zika-virus/en/>
- ⁴ <https://wwwn.cdc.gov/nndss/data-collection.html>
- ⁵ <http://jamanetwork.com/journals/jamapediatrics/article-abstract/2545827>
- ⁶ <http://jamanetwork.com/journals/jamaneurology/article-abstract/2557231>
- ⁷ <http://www.cdc.gov/zika/geo/united-states.html>
- ⁸ <https://blogs.cdc.gov/cdcdirector/2016/09/02/cdc-and-nih-officials-how-not-to-fight-the-zika-virus/>
- ⁹ <http://mchb.hrsa.gov/cshcn05/>
- ¹⁰ <http://mchb.hrsa.gov/chusa14/dl/population-characteristics.pdf>
- ¹¹ <https://profiles.nlm.nih.gov/ps/access/NNBCFP.pdf#xml=https://profiles.nlm.nih.gov:443/pdfhighlight?uid=NNBCFP&query=%281987%20family%20centered%20community%20based%29>
- ¹² Ngui (2006); Scal (2005); Baruffi (2005); Smaldone (2005); Young (2005); Fiks et. al. (2012); Fiks et al. (2010); Jassen et al. (2007); Wilson et al. (2010); Smalley et al. (2014)
- Scal, P. & Ireland, M. (2005). Addressing transition to adult health care for adolescents with special health care needs. *Pediatric*, 115(6), 1607-1612.
- Baruffi, G., Miyashiro, L., Prince, C. B., & Heu, P. (2005). Factors associated with ease of using community-based systems of care for CSHCN in Hawai'i. *Maternal and Child Health Journal*, 9(Suppl. 2), S99-S108.
- Smaldone, A., Honig, J., & Byrne, M. W. (2005). Delayed and foregone care for children with special health care needs in New York State. *Maternal and Child Health Journal*, 9(Suppl. 2), S75-S86.
- Young, M. C., Drayton, V. L. C., Menon, R., Walker, L. R., Parker, C. M., Cooper, S. B., et al. (2005). CSHCN in Texas: Meeting the need for specialist care. *Maternal and Child Health Journal*, 9(Suppl. 2), S49-S57.
- Fiks, A. G., Localio, A. R., Alessandrini, E. A., Asch, D. A., & Guevara, J. P. (2010). Shared decision-making in pediatrics: A national perspective. *Pediatrics*, 126(2), 306–314.
- Fiks, A. G., Mayne, S., Localio, A. R., Alessandrini, E. A., & Guevara, J. P. (2012). Shared decision-making and health care expenditures among children with special health care needs. *Pediatrics*, 129(1), 99–107.
- Janssen, C., Ommen, O., Neugebauer, E., Lefering, R., & Pfaff, H. (2007). How to improve satisfaction with hospital stay of severely injured patients. *Langenbeck's Archives of Surgery*, 392, 747–760.
- Wilson, S. R., Strub, P., Buist, A. S., Knowles, S. B., Lavori, P. W., Lapidus, J., et al. (2010). Shared treatment decision making improves adherence and outcomes in poorly controlled asthma. *American Journal of Respiratory and Critical Care Medicine*, 181, 566–577.
- Smalley, L.P., Kenney, M.K., Denboba, D.D., & Strickland, B. (2013). Family perceptions of shared decision-making with health care providers: Results of the National Survey of Children with Special Health Care Needs, 2009-2010. *Maternal and Child Health Journal*.
- ¹³ [http://www.academicpedsnl.net/article/S1876-2859\(10\)00359-1/fulltext?mobileUi=0](http://www.academicpedsnl.net/article/S1876-2859(10)00359-1/fulltext?mobileUi=0)
- ¹⁴ Perrin JM, Romm D, Bloom SR, Homer CJ, Kuhlthau KA, Cooley C, Duncan P, Roberts R, Sloyer P, Wells N, Newacheck P. A Family-Centered, Community-Based System of Services for Children and Youth With Special Health Care Needs. *Arch Pediatr Adolesc Med*. 2007;161(10):933-936. doi:10.1001/archpedi.161.10.933
- ¹⁵ Adapted from http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2012/Feb/1580_VanLandeghem_new_opportunities_integrating_hlt_care_02.pdf

The intent of this planning resource is to support states and communities as they prepare to address the needs of children affected by Zika exposure by highlighting several key existing federal services and programs for supporting children. Prenatal Zika virus infection may cause multiple congenital anomalies including: microcephaly and other serious brain and nervous system malformations; visual and audiological impairments; orthopedic malformations; impaired growth; motor and cognitive delays; and possible other unrecognized physical and developmental effects.

OVERVIEW OF FEDERAL/STATE PROGRAMS SERVING CHILDREN AFFECTED BY ZIKA

Federal Office	Reach/Target Population Description	Services
PUBLIC HEALTH RESOURCES		
Assistant Secretary for Preparedness and Response [ASPR]	Leads HHS in preparing the nation to respond to and recover from adverse health effects of emergencies, supporting communities' ability to withstand adversity, strengthening health and response systems, and enhancing national health security.	Response and recovery from the health impacts of disasters This matrix highlights some of the existing federal and national services and programs for supporting children with special healthcare needs. It includes guidance and links to helpful resources for use in planning for Zika virus or other hazards. https://asprtracie.hhs.gov/documents/supportingcshcnmatrix.pdf
Centers for Disease Control and Prevention [CDC] http://www.cdc.gov/zika/index.html Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion (DRH/NCCDPHP)	To improve pregnancy health and care and improve fetal, newborn, and infant health To save babies by studying and addressing the causes of birth defects; help children reach their potential by understanding developmental disabilities; reduce	Surveillance <ul style="list-style-type: none"> • US Zika Pregnancy Registry • Zika Active Pregnancy Surveillance System • Birth defects surveillance systems • Pregnancy Risk Assessment Monitoring System Educational Resources for families: http://www.cdc.gov/zika/parents/families-of-newborns-affected-zika.html In development--Fact sheets on: 1) resources for parents expecting a baby with microcephaly, 2) resources for new parents of a baby with microcephaly, 3) resources for parents of a baby born with

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<p>National Center on Birth Defects and Developmental Disabilities (NCBDDD)</p>	<p>complications of blood disorders; and improve the health of people living with disabilities.</p>	<p>congenital Zika virus infection without problems apparent at birth,4) working on resources for providers who work with families that have children exposed to virus (in collaboration with ACF and OSEP).</p> <p>Webpage for healthcare providers: http://www.cdc.gov/zika/hc-providers/infants-children/resources-hc-providers-caring-for-infants.html</p> <p>In development—web-based Interactive algorithm for healthcare navigating guidance evaluation, testing and outpatient management.</p>
<p>Maternal and Child Health Programs [HRSA]</p> <p>Title V Maternal and Child Health Services Block Grant Program</p> <p>http://mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program</p> <p>Maternal, Infant, and Early Childhood Home Visiting</p>	<p>Supports grantees from 59 states and jurisdictions to provide access to comprehensive prenatal and postnatal care for women, as well as family-centered, community based-systems of coordinated care for children with special healthcare needs.</p> <p>Supports pregnant women and families. It helps at-risk parents of children from birth to kindergarten access resources and hone the skills they need to raise children</p>	<p>Services include providing and promoting family-centered, community-based, coordinated care (including care coordination services) for CSHCN and facilitating the development of community-based systems of services for such children and their families.</p> <p>FL Title V program is working with Part C to examine eligibility criteria for developmental delay as it relates to Zika.</p> <p>Funds States, territories and tribal entities to develop and implement voluntary, evidence-based home visiting programs using models that are proven to improve child health and to be cost</p>

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http://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting	who are physically, socially and emotionally healthy and ready to learn.	effective. These programs improve maternal and child health, prevent child abuse and neglect, encourage positive parenting, and promote child development and school readiness. MCHB and ACF are working with their Home Visiting grantees to get information about Zika to pregnant women and families receiving home visiting services.
HEALTH CARE FINANCING		
Medicaid [CMS] https://www.medicaid.gov/medicaid-chip-program-information/by-topics/eligibility/eligibility.html	<p>Provides health coverage for individuals meeting eligibility criteria based on income and/or other non-financial criteria (varies by state). CMS may expand benefits coverage and special enrollments periods.</p> <p>Early and Periodic Screening, Diagnostic, and Treatment benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid</p>	<p>CMCS Information Bulletin, June 2016: Medicaid Benefits Available for the Prevention, Detection and Response to the Zika Virus</p> <p>1135 waiver authority: When the HHS Secretary declares a public health emergency, the Secretary is authorized to take certain actions in addition to her regular authorities under section 1135 of the Social Security Act. She may waive or modify certain Medicare, Medicaid, Children’s Health Insurance Program (CHIP) and Health Insurance Portability and Accountability Act (HIPAA) requirements as necessary.</p>
Children’s Health Insurance Program (CHIP) https://www.medicaid.gov/chip/chip-program-information.html	Serves uninsured children up to age 19 in families with incomes too high to qualify for Medicaid.	
Supplemental Security Income (SSI)	Monthly payments for children with disabilities – a child can qualify if he or she has a physical or mental	Pays SSI benefits to children under age 18 who have disabilities

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<p>[SSA]</p> <p>https://www.ssa.gov/ssi/text-child-ussi.htm</p> <p>https://www.ssa.gov/disabilityssi/apply-child.html</p>	<p>impairment, or combination of impairments, that meets Social Security’s definition of disability for children, and if he or she has limited income and resources (SSI payments vary by state).</p>	
<p>Catalyst Center [HRSA]</p> <p>http://cahpp.org/project/the-catalyst-center/</p>	<p>National center dedicated to improving health care coverage and financing for children and youth with special health care needs (CYSHCN).</p>	
EDUCATION AND CHILD DEVELOPMENT		
<p>Part B of the Individuals with Disabilities Education Act (IDEA) [Dept of Education, OSEP]</p> <p>Part C of the Individuals with Disabilities Education Act (IDEA) [Dept of Education, OSEP]</p>	<p>Provides formula grants to States to provide a free appropriate public education and make available special education and related services for eligible children with disabilities age 3 through 21</p> <p>Awards formula grants to assist States in providing early intervention services to eligible infants and toddlers with disabilities, age birth through 2, and their families.</p> <p>Infants and toddlers with disabilities are children who are</p>	<p>Identification, referral, and evaluation for special education and related services</p> <p>States establish their own criteria for what constitutes a developmental delay and identify which diagnosed conditions qualify an infant or toddler for services.</p> <p>Some States have included exposure to Zika as an established</p>

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http://www2.ed.gov/programs/osepeip/index.html	experiencing developmental delays or have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.	condition, meaning that these children automatically qualify for services. Fourteen States have microcephaly as an established condition. Some States have indicated that if a child is exposed to Zika, but is asymptomatic, they will monitor the child or provide service coordination for a minimum of the first year.
Early Head Start and Head Start [ACF] http://www.acf.hhs.gov/ohs/about/head-start	Supports the comprehensive development and school readiness of low-income children from birth to age 5. In addition to education services, programs provide children and their families with health, nutrition, social, and other services. Three- and 4-year-olds made up the majority of the children served by Head Start. Early Head Start serves pregnant women, infants, and toddlers.	For enrolled children, services include ensuring medical home, insurance enrollment, and up-to-date on EPSDT. EHS/HS supports and facilitates ongoing care and extended follow up. Programs assist parents, as needed, in obtaining any prescribed medications, aids or equipment for medical and oral health conditions. Programs collaborate with parents to promote children’s health and well-being by providing medical, oral, nutrition and mental health education support services that are understandable to individuals, including individuals with low health literacy.
Child Care and Development Fund (CCDF) [ACF] https://childcareta.acf.hhs.gov/ccdf-reauthorization	Federal and state partnership administered to promote family economic self-sufficiency and to help low income children succeed in school and life through affordable, high-quality early care and afterschool programs. Children from birth through age 12 in vulnerable families have access, through CCDF subsidies, to child care settings that meet their needs, from full-day early care to afterschool care for school-age children.	States and Territories have the flexibility to define “vulnerable populations” which would allow States to offer priority for services, waive work requirements and co-payments, and on a case-by-case basis, waive income requirements for families. This flexibility could, at State/Territory option, be used to expand access to families affected by the Zika virus. Note: This is existing flexibility that ACF is proposing to codify in a new final rule.
NUTRITION		
Supplemental Food	Provides federal grants to states for healthy supplemental	As an adjunct to good health care, WIC’s role is to ensure that

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<p>Program for Women, Infants and Children (WIC) [USDA]</p> <p>http://www.fns.usda.gov/wic/women-infants-and-children-wic</p>	<p>foods, nutrition education including breastfeeding promotion and support, and health care referrals for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, as well as for infants and children up to age five who are found to be at nutritional risk.</p>	<p>women, infants and children program participants with special health needs are referred for appropriate care. In addition, state and local agencies may coordinate efforts to provide health-related information, such as Zika prevention, to WIC participants and to the parents and caregivers of WIC-enrolled children.</p>
<p>DEVELOPMENTAL DISABILITIES</p>		
<p>Administration on Intellectual and Developmental Disabilities (AIDD) [ACL]</p> <p>http://www.acl.gov/Programs/AIDD/Index.aspx</p>	<p>Ensures individuals with developmental disabilities and their families are fully able to participate in and contribute to all aspects of community life. Provides following grants to states/territories: (1) State Councils on Developmental Disabilities, (2) Protection and Advocacy Systems, and (3) University Centers for Excellence in Developmental Disabilities.</p>	<p>System advocacy, training, technical assistance, child development and evaluation services, individual legal advocacy</p>
<p>University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) [ACL]</p> <p>http://www.acl.gov/programs/aidd/Programs/UCEDD/index.asp</p>	<p>UCEDDs are a nationwide network centers, representing an expansive national resource for addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families.</p> <p>Four core functions frame the UCEDD program:</p> <ul style="list-style-type: none"> • Interdisciplinary pre-service preparation and continuing education • Research, including basic or applied research, evaluation, 	<p>Some UCEDDs include feeding clinics and nutrition programs.</p>

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Federal Office	Reach/Target Population Description	Services
x	and public policy analysis <ul style="list-style-type: none"> •Information dissemination •Community services, including direct services, training, technical assistance, and model demonstrations 	
TRANSITION SERVICES		
Got Transition / Center for Health Care Transition Improvement [HRSA] http://www.gottransition.org/	Improve the transition from pediatric to adult health care.	
MENTAL HEALTH SERVICES		
Systems of Care [SAMHSA] http://www.samhsa.gov/grants/grant-announcements/sm-15-009	Supports the development and capacity to implement, expand and sustain comprehensive, coordinated home and community-based services and supports for children and youth with serious emotional disturbances and their families.	Diagnostic and evaluation services; outpatient treatment; emergency services (24 hours a day, 7 days a week); case management; intensive home-based services; day treatment; respite care; therapeutic foster care; and services to help young people make the transition to adulthood. The Case management/wraparound service team, in collaboration with family and youth, manages an individualized service plan for each child. A few sites are implementing a few practices that include outreach, education and awareness. <ul style="list-style-type: none"> • Texas Panhandle-Plains Partnership for Children and Families: Each department at the center has a Safety Officer, and chooses pertinent matters to focus on each month. During the months of July and August, the Zika virus was prioritized. The department

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		has been using Behavioral Health Resources on Zika that were acquired from the SAMHSA website. These are used to inform, educate and provide handouts to individual/families using their services, as well as their staff/team, and collaborative partners.
SCREENING		
Newborn Screening [HRSA] http://mchb.hrsa.gov/maternal-child-health-initiatives/mchb-programs	Newborn Screening and genetic public health infrastructure initiatives help support State newborn screening and genetics programs, integrate these programs with other community services and medical homes, and strengthen existing programs. All States and Washington, DC have newborn screening programs, which help integrate genetics into public health and population health by supporting state newborn screening programs, genetic education programs and health information technology initiatives that work to link families, consumers and providers.	
Early Hearing and Detection Intervention (EHDI) [HRSA] http://www.asha.org/Advocacy/federal/Early-Hearing-Detection-and-Intervention/	Universal Newborn Hearing Screening refers to the practice of screening every newborn for hearing loss prior to hospital discharge. All 50 states and the District of Columbia have EHDI laws or voluntary compliance programs that screen hearing. Currently, the program provides funding to 59 states/territories.	<p>The purpose of this program is to focus efforts to improve the loss to documentation/loss to follow-up by utilizing specific interventions such as quality improvement methodology to achieve measurable improvement in the numbers of newborns/infants diagnosed as deaf or hard of hearing who receive appropriate and timely follow-up.</p> <p>The Puerto Rico Early Hearing Detection and Intervention program is working on providing guidance to pregnant women and mothers regarding the health impact of being affected with Zika as well as preventive measures (e.g., consistent use of mosquito nets).</p>
Bright Futures [American Academy]	Developmental screening is a national health promotion and prevention initiative that provides theory-based and	

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<p>of Pediatrics (AAP) /HRSA]</p> <p>https://brightfutures.aap.org/about/Pages/About.aspx</p>	<p>evidence-driven guidance for all preventive care screenings and well-child visits.</p>	
<p>“Learn the Signs. Act Early” [CDC]</p> <p>http://www.cdc.gov/ncbddd/actearly/index.html</p> <p>http://www.cdc.gov/ncbddd/actearly/index.html</p>	<p>Aims to improve early identification of children with developmental disabilities including autism by promoting developmental monitoring and screening so children and their families can get the services and supports they need as soon as possible. The Health Education campaign promotes awareness of healthy developmental milestones, the importance of tracking each child’s development and the importance of acting early if there are concerns. In addition, CDC funds 45 Act Early State Ambassadors who work to improve early identification within their state or territory.</p>	
<p>Birth to 5: Watch Me Thrive! [HHS]</p> <p>http://www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive</p>	<p>Coordinated federal effort to encourage healthy child development, universal developmental and behavioral screening for children and support for the families and providers who care for them.</p>	<p>This initiative has published a list of research-based developmental screening tools appropriate for use across a wide range of services, tailored user guides that addresses the importance of developmental monitoring and screening, how to talk to parents, where to go for help, and how to select the most appropriate screening tool for the population being served. In addition, there are selected federal resources for families and providers.</p>
<p>Physical Developmental Delays: What to Look For [CDC/AAP]</p>	<p>A tool developed in collaboration to help parents detect motor developmental delays in their children. It is designed for parents of children five years and younger who are concerned about their child’s physical development, but do</p>	<p>This tool provides parents with information about developmental delays, including by age and activity, as well as tips on how to talk to their child’s pediatrician.</p>

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http://motordelay.aap.org/	not have a diagnosis.	
NATIONAL TECHNICAL ASSISTANCE AND OUTREACH		
<p>Division of Services for Children with Special Health Needs (DSCSHN) [HRSA]</p> <p>Reproductive Environmental Health Network (Mother to Baby/ Organization of Teratology Information Specialists) http://mothertobaby.org/</p> <p>National Center for Children’s Vision & Eye Health [HRSA]</p>	<p>Provides evidence-based information to mothers, healthcare professionals, and the general public about medications and other exposures during pregnancy and while breastfeeding.</p> <p>Promotes a comprehensive system of vision care and eye health for all young children.</p>	<p>This program supports regional Teratology Information Services that provide one-on-one risk assessments and counseling to individuals of reproductive age and to providers on known and potential reproductive risks.</p> <p>Has available a free fact sheet on Zika Virus Disease and Your Eyes</p>

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<p>National Center for Hearing Assessment and Management (NCHAM) [HRSA]</p>	<p>Provide to state/territory EHDI programs training and technical assistance for planning, policy development, implementing innovations and quality improvement methodology to reduce their loss to follow-up rate/loss to documentation (e.g., the number of infants who do not receive timely and appropriate screening follow-up and coordinated interventions).</p>	<p>NCHAM via its website and social media accounts have been providing information as it pertains to Zika</p>
<p>The Coordinating Center on Epilepsy, housed at the American Academy of Pediatrics [HRSA] https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Coordinating-Center-on-Epilepsy/</p>	<p>Provides support and technical assistance to grantees receiving funding through the Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy. The Center will coordinate with the NCMHI to share guidance with grantees specific to neurological issues related to the care of children with possible congenital Zika syndrome as well as children with possible Zika infection.</p>	
<p>State Public Health Coordinating Center for Autism [HRSA] http://www.amchp.org/programsandtopics/CYSHCN/projects/spaharc/LearningModule/Pages/EarlyContinuosScreening.aspx</p>	<p>As part of a cooperative agreement with the Association of Maternal and Child Health Programs (AMCHP), SPHARC (State Public Health Autism Resource Center) coordinates with the Innovation in Care Integration for Children and Youth with Autism Spectrum Disorders and Other Developmental Disabilities program to develop and implement a strategies and provide technical assistance for defining, supporting, and monitoring the role of state public health systems in assuring that children and youth with</p>	<p>SPHARC has developed a number of resources to help states develop and strengthen their systems of care for developmental screening.</p>

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<p>Rural Health Information Hub [HRSA] https://www.ruralhealthinfo.org/</p>	<p>autism receive early and timely identification, diagnosis, and intervention.</p> <p>The Rural Health Information Hub is funded by the Federal Office of Rural Health Policy to be a national clearinghouse on rural health issues. The site includes toolkits, models, and resources that communities can utilize to support healthcare and population health in rural communities.</p>	
<p>Parent Training and Information Centers [Dept of Ed, OSEP] http://www.parentcenterhub.org</p> <p>Early Childhood Technical Assistance Center (Dept of ED, OSEP) http://ectacenter.org/</p>	<p>Funds parent training and information centers (PTIs) in every state to assist families of children with disabilities. The PTIs provide information and training to parents on laws, policies and evidence-based practices for children with disabilities, and helps parents understand their rights under the Individuals with Disabilities Education Act.</p> <p>Improves State early intervention and early childhood special education service systems, increase the implementation of effective practices, and enhance the outcomes of these programs for young children and their families.</p>	<p>Parent training and information Technical assistance to families on navigating the early intervention and special education system</p> <p>Work at the State level to inform policy decisions that impact families of children with disabilities</p> <p>Direct technical assistance to IDEA Part C and Part B, section 619 programs</p> <p>Resource development and dissemination</p> <p>Could provide technical assistance to States on child find efforts for children exposed to the Zika virus.</p> <p>Could develop and disseminate information to Part C on Zika.</p>
<p>National Center for Early Childhood Health and Wellness (ACF/HRSA)</p>	<p>Advances best practices for linking health and early childhood education systems. The Center's work will include, but is not limited to, providing support on topics such as medical and dental home access; health promotion</p>	<p>Outreach to families and ECE providers</p>

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https://eclkc.ohs.acf.hhs.gov/hslc/tta-system/ohs-tta/ncechw.html	and disease prevention; emergency preparedness and environmental safety; trauma and toxic stress; developmental, behavioral, vision and hearing screening; and nutrition.	
Legacy for Children™ [CDC] http://www.cdc.gov/ncbddd/childdevelopment/legacy.html	Program is an evidence-based, parent-focused intervention approach aimed at improving child outcomes by fostering positive parenting among low-income mothers of infants and young children.	
National Child Traumatic Stress Initiative (NCTSI) [SAMHSA] http://www.samhsa.gov/child-trauma/about-nctsi	NCTSI raises awareness about the impact of trauma on children and adolescents as a behavioral health concern.	The Terrorism and Disaster Program (TDP) works to promote the behavioral health of children and families by strengthening our nation’s response capacities before, during, and after terrorism, disaster, and mass violence. Program goals include raising awareness of the scope and serious impact of disasters on the behavioral health of children, families, and communities; shaping public policy to promote effective behavioral health policy before, during, and after mass casualty events; and—through collaborative efforts—developing effective evidence-based programs for use immediately after mass casualty events and during the long-term recovery or adjustment phase. In addition, the Program has established partnerships toward the adoption of best practices (e.g., Psychological First Aid, Skills for Psychological Recovery) and is improving access to care through real-time training and consultation (e.g., PFA Mobile, PFA Online, SPR Online). Finally, the Program develops products for all child-serving systems and for parents on assisting children and families after mass casualty events.” http://www.nctsn.org/about-us/national-center

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COORDINATED CARE		
<p>Healthy Start [HRSA] http://mchb.hrsa.gov/maternal-child-health-initiatives/healthy-start</p> <p>The Pacific Infant Mortality CoIIN Data Capacity Learning Network</p> <p>Infant Mortality Collaborative Improvement and Innovation Network (IM CoIIN)</p>	<p>Program funds 100 community-based programs which improve access to care, link families to a medical home, provide health promotion and prevention, and advance service coordination and systems integration for pregnant women and children up to age 2.</p> <p>A regional collaborative comprised of the six U.S. affiliated Pacific Islands (USAPI) focused on improving access to quality birth and death certificate data in the Pacific Basin. Jurisdiction teams are led by Jurisdiction MCH Directors, and comprise health department, vital statistics, hospital personnel, and others. The Learning Network is supported by a network of federal, international, non-governmental, and academic partner organizations that are invested in improving data capacity in the Pacific region.</p> <p>The IM CoIIN is comprised of teams in all 50 states and territories focused on reducing infant mortality and improving birth outcomes in six shared priority areas, including pre- and inter-conception care, early- and pre-term birth, and risk appropriate perinatal care. The IM CoIIN is an established network of state health department-led multidisciplinary (and multi-organizational) teams that foster information/resource sharing and collaborative learning.</p>	<p>MCHB utilizes existing communication channels and leverages grantee and partner networks both nationally and locally to promote Zika awareness and preventative measures through webinars, regional meetings, and the National Healthy Start Convention.</p> <p>Information about cases of Zika was shared with DHSPS through this network, and CDC guidance has likewise been shared with members of the Learning Network. Most recently, information about a confirmed case of Zika in a pregnant woman was shared by RMI. Regular communications with jurisdiction IM CoIIN teams and partner organizations is ongoing.</p> <p>Plan to work with the network to conduct outreach to the leaders, managers, data leads, and front line staff who work directly with women before, during and after pregnancy.</p>

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<p>Division of Workforce Development [HRSA MCHB]</p> <p>Healthy Tomorrows Partnership for Children</p>	<p>Promotes the development and advancement of healthy communities through partnerships with organizations that work to change conditions in the community and environment to improve health. Currently, Healthy Tomorrows funds 41 projects across 22 states.</p>	<p>Hawaii: The HTPC program is providing information on Zika to patients and is discussing-consulting with state agencies and community partners.</p> <p>Tennessee: The HTPC program is developing an approach to share information with staff and families through the use of EHR, in-clinic communication, and community-based activities to provide outreach and education, and to track patients.</p> <p>Ohio: The HTPC program is sharing information on the Zika virus through electronic and social media and on local news.</p>
<p>Health Center Program [HRSA]</p> <p>http://www.bphc.hrsa.gov/</p> <p>http://findahealthcenter.hrsa.gov/index.html</p>	<p>Provide comprehensive primary care services without regard for patients' ability to pay and charge for services on a sliding fee scale. There are nearly 1,400 health centers operating over 9,800 sites to provide care to more than 24.3 million people in every U.S. state, D.C., Puerto Rico, the Virgin Islands and the Pacific Basin.</p>	<p><u>Required Services:</u></p> <ul style="list-style-type: none"> General primary care Diagnostic laboratory and radiology Screenings Well child care Pharmaceutical services <p><u>Enabling Services:</u></p> <ul style="list-style-type: none"> Case management Eligibility assistance Health education Outreach

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<p>National Center for Medical Home Implementation [AAP/HRSA]</p> <p>https://medicalhomeinfo.aap.org/Pages/default.aspx</p>	<p>National technical assistance center focused on ensuring all children and youth, particularly those with special health care needs, receive care within, and have access to, a medical home.</p>	<p>HRSA and ASPR awarded a \$350,000 supplement to this program to provide technical assistance and education, including tele-mentoring, to clinicians providing care for children who are or may be impacted by Zika at HRSA-supported health centers and elsewhere within the United States (including U.S. territories and jurisdictions).</p>
<p>Project LAUNCH (Linking Actions for Unmet Needs in Children's Health) [SAMHSA/ACF/HRSA/CDC]</p> <p>http://www.healthysafechildren.org/grantee/project-launch</p>	<p>Provide the wellness of young children from birth to age 8 by addressing all domains of development. Project LAUNCH seeks to improve coordination across systems, build infrastructure and increase access to high quality prevention and promotion services for children and their families.</p>	<ul style="list-style-type: none"> • Mental health consultation in early care and education • Screening and assessment • Family strengthening and parent skills training • Enhanced home visiting with a focus on social and emotional well-being • Integration of behavioral health into primary care <p>Project LAUNCH staff are working with the Departments of Health (many are housed within the Dept of Health) to distribute information about Zika, and in the case of Puerto Rico, to address issues that have emerged. In PR this includes providing social emotional support to mothers of infants suspected of exposure to Zika, and helping them to cope with anxiety. We know work is underway in AL and FL as well.</p>
<p>Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy [HRSA]</p>	<p>Provides grants to promote the delivery of quality health care for children and youth with epilepsy. Grantees focus on efforts to implement telehealth/telemedicine, youth transition and to provide outreach and education regarding epilepsy to pertinent stakeholders. Grants in OH (1); PA (2); MI (2), MA (1); TX(1).</p>	<p>Grantees will work closely with the Coordinating Center to share guidance and approached to addressing neurological issues related to the care of children with possible congenital Zika syndrome as well as children with possible Zika infection.</p>

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Innovation in Care Integration for Children and Youth with Autism Spectrum Disorders and Other Developmental Disabilities Program [HRSA]	Supports innovative, evidence-informed strategies to provide integrated care for children and youth with autism spectrum disorders (ASD) and other developmental disabilities (DD) at the state level, including developing and strengthening systems of care for developmental screening. (Grantees: DE, RI, WA, WI)	These grants have a particular emphasis on children with ASD/DD living in medically underserved (e.g. those living in poverty, within a rural geographic location, and/or people who experience health disparities) communities with a focus on strategic approaches to telehealth, family engagement and shared plan of care in serving this population.
WORKFORCE DEVELOPMENT		
The Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) http://mchb.hrsa.gov/training/projects.asp?program=9	Improves the health of children who have, or are at risk for, neurodevelopmental or related disabilities by preparing trainees from a wide variety of professional disciplines to assume leadership roles and to ensure high levels of clinical competence	Promotes education, early detection, and intervention in autism spectrum disorders and other developmental disabilities. LEND programs reduce barriers to screening and diagnosis; promote evidence based interventions for individuals with developmental disabilities, and train professionals to utilize valid screening tools to diagnose and rule out autism and other developmental disabilities.
FAMILY PARTNERSHIPS AND ENGAGEMENT		
Division of Services for Children with Special Health Needs (DSCSHN) [HRSA]		

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<p>Family-to-Family Health Information Centers http://www.familyvoices.org/page?id=0034</p> <p>National Center for Family Professional Partnerships http://www.familyvoices.org/</p>	<p>Promotes optimal health for CSHCN and facilitate their access to and effective health delivery system by meeting the health information and support needs of their families and the professionals who serve them. (located in all 50 states and DC)</p> <p>Provides leadership in helping families of CSHCN/disabilities and professionals partner to improve care by strengthening the role of families as partners in the delivery of care.</p>	<p>The centers partner with other relevant organizations (such as State Title V and Medicaid agencies, Children’s hospitals, child-focused programs, primary care organizations, parent/family-led organizations, and other Federal agencies and HRSA programs) to coordinate and disseminate Zika-related information to families and providers.</p>