

Supporting Children with Special Healthcare Needs Planning Resource

Updated August 12, 2016

<p>Purpose</p>	<ul style="list-style-type: none"> The intent of this planning resource is to enhance healthcare coalition and healthcare system preparedness and response to a domestic Zika virus disease outbreak by highlighting some of the existing federal and national services and programs for supporting children with special health care needs. This planning resource will be best utilized in tandem with appropriate risk communication and education for providers and the public regarding prevention and ongoing care strategies. Healthcare systems and coalitions are not required to use this resource, but are encouraged to consider how available resources may be affected by an increase in demand for social supports and services.
<p>Background Information for HHS leadership and state/local health officials</p>	<ul style="list-style-type: none"> 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.”¹ 15.1 % of U.S. children (birth to age 17) have special health care needs per the National Survey of Children with Special Health Care Needs conducted by HRSA in 2009/10.² The Division of Services for Children with Special Health Needs (DSCSHN)³ specifically focuses on this population and works to fund multiple National Resource Centers.⁴ [HRSA] National Center on Birth Defects and Developmental Disabilities (NCBDDD) conducts surveillance, research and prevention to promote the health of babies, children and adults.⁵ [CDC] The categories for this planning resource reflect the 6 core outcomes that are the framework for a comprehensive, family-centered, community-based, coordinated system of care for CSHCN and their families.

¹ <http://mchb.hrsa.gov/cshcn0910/population/cp.html>

² <http://childhealthdata.org/browse/survey/results?q=1792&r=1>

³ <http://www.nihcm.org/pdf/HRSAMCHB-DSCSHN.pdf>

⁴ <http://learning.mchb.hrsa.gov/about/factsheets/dschcnfacts.PDF>

⁵ <http://www.cdc.gov/ncbddd/index.html>

Decision-Making

Family/professional partnership at all levels of decision-making

1. **National Center for Family Professional Partnerships** provide 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.⁶
2. **Family-to-Family Health Information Centers** (located in all 50 states and DC) promote optimal health for CSHCN and facilitate their access to an effective health delivery system by meeting the health information and support needs of their families and the professionals who serve them.⁷
3. Reproductive Environmental Health Network (**Mother to Baby/ Organization of Teratology Information Specialists**) funded by HRSA provides evidence-based information to mothers, healthcare professionals, and the general public about medications and other exposures during pregnancy and while breastfeeding.^{8*}
4. **Office of Special Education and Rehabilitative Services** funds parent training and information centers to assist America's families of children with disabilities. The Centers will provide parents with detail and assistance on laws, policies and research based education practices for children with disabilities. They will also fund parent training and technical assistance.⁹
5. **Systems of Care** is a cooperative agreement that funds programs to improve mental health outcomes for children and youth (birth to 21 years of age) with serious emotional disturbances and their families.¹⁰ [SAMHSA]
6. **Legacy for Children™** 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.¹¹ [CDC]

⁶ <http://www.fv-ncfpp.org/>

⁷ <http://www.familyvoices.org/page?id=0034>

*Program applies to supports and services related to supporting children with special health care needs birth to age 3.

⁸ <http://fetal-exposure.org/otis-factsheets/>

⁹ <http://www.parentcenterhub.org/find-your-center/>

¹⁰ <http://www.samhsa.gov/grants/grant-announcements/sm-15-009>

¹¹ <http://www.cdc.gov/ncbddd/childdevelopment/legacy.html>

<p>Coordinated Care Access to coordinated comprehensive care within a medical home</p>	<ol style="list-style-type: none"> 1. National Center for Medical Home Implementation is a 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.¹² 2. Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program 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 who are physically, socially and emotionally healthy and ready to learn. HRSA, in close partnership with Administration for Children and Families (ACF), 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 effective. These programs improve maternal and child health, prevent child abuse and neglect, encourage positive parenting, and promote child development and school readiness.¹³ [HRSA/ACF] 3. Project LAUNCH (Linking Actions for Unmet Needs in Children’s Health) is to 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.¹⁴ [SAMHSA/ACF/HRSA/CDC]
<p>Financing Access to adequate private and/or public insurance</p>	<ol style="list-style-type: none"> 1. Medicaid 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. They may also approve applications for 1115 Demonstration waivers in response to a declared public health emergency related to Zika virus.¹⁵ Section 1115 of the Social Security Act gives the Secretary of Health and Human Services authority to approve experimental, pilot, or demonstration projects that promote the objectives of the Medicaid and CHIP programs. [CMS/states] 2. Children’s Health Insurance Program (CHIP) serves uninsured children up to age 19 in families with incomes too high to qualify for Medicaid (varies by state).¹⁶ 3. Supplemental Security Income (SSI) monthly payments for children with disabilities – a child can qualify if he or she has a physical or mental condition, or combination of conditions, that meets Social Security’s definition of disability for children, and if his or her income and resources fall within the eligibility limits (SSI payments vary by state).¹⁷ [SSA] 4. Catalyst Center is a national center dedicated to improving health care coverage and financing for children and youth with special health care needs (CYSHCN).¹⁸ [HRSA]

¹² <https://medicalhomeinfo.aap.org/Pages/default.aspx>

¹³ <http://mchb.hrsa.gov/programs/homevisiting/index.html>

*Program applies to supports and services related to supporting children with special health care needs birth to age 3.

¹⁴ <http://www.healthysafechildren.org/grantee/project-launch>

¹⁵ <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/eligibility/eligibility.html>

¹⁶ <https://www.medicaid.gov/chip/chip-program-information.html>

¹⁷ <https://www.ssa.gov/pubs/EN-05-10026.pdf>

¹⁸ <http://www.hdwg.org/catalyst/>

Screening

Early and continuous screening for special health needs

1. **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.¹⁹ [HRSA] *
2. Universal Newborn Hearing Screening – **Early Hearing and Detection Intervention** (EHDI)²⁰ 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. [HRSA]*
3. **National Center for Children’s Vision & Eye Health**²¹ promotes a comprehensive system of vision care and eye health for all young children.²² [HRSA]
4. Developmental Screening through **Bright Futures** is a national health promotion and prevention initiative that provides theory-based and evidence-driven guidance for all preventive care screenings and well-child visits.²³ [American Academy of Pediatrics (AAP) /HRSA]
5. “**Learn the Signs. Act Early**” program 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.²⁴ In addition, CDC funds 45 Act Early State Ambassadors who work to improve early identification within their state or territory.²⁵ [CDC]
6. **Birth to Five: Watch Me Thrive!** is a 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. 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.²⁶ [HHS]
7. **Physical Developmental Delays: What to Look For** is 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 not have a diagnosis. 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.²⁷ [CDC/AAP]
8. **Early and Periodic Screening, Diagnostic, and Treatment** (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, and developmental, and specialty services.²⁸

¹⁹ <http://learning.mchb.hrsa.gov/programs/newbornscreening/index.html>

²⁰ <http://www.asha.org/Advocacy/federal/Early-Hearing-Detection-and-Intervention/>

²¹ <http://nationalcenter.preventblindness.org/>

²² <http://nationalcenter.preventblindness.org/goals>

Integration of Services

Organization of community services for easy use

1. The **Healthy Start** 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 2.²⁹ [HRSA]*
2. **Title V Maternal and Child Health Services Block Grant Program** distributes funds to 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.³⁰ [HRSA]
3. **Head Start** and **Early Head Start** support 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. Head Start services are responsive to each child and family's ethnic, cultural, and linguistic heritage. Head Start began as a program for preschoolers. 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. Early Head Start programs are available to the family until the child turns 3 years old and is ready to transition into Head Start or another pre-K program. Early Head Start helps families care for their infants and toddlers through early, continuous, intensive, and comprehensive services.³¹ [ACF]
4. **Early Childhood Intervention (ECI)** Part C is a program for infants and toddlers from birth to age 2, and Part B is a program for children ages 3 to 21 years of age; both programs provide a broad array of services to children with special needs that provides a broad array of services to children with special needs.³² [Dept of Ed]*
5. **Child Care and Development Fund (CCDF)** is a 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.³³

²³ <https://brightfutures.aap.org/about/Pages/About.aspx>

²⁴ <http://www.cdc.gov/ncbddd/actearly/index.html>

²⁵ <http://www.cdc.gov/ncbddd/actearly/parents/states.html>

²⁶ <http://www.acf.hhs.gov/programs/ecd/child-health-development/watch-me-thrive>

²⁷ <http://motordelay.aap.org/>

²⁸ <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html>

*Program applies to supports and services related to supporting children with special health care needs birth to age 3.

²⁹ http://www.nationalhealthystart.org/healthy_start_initiative

³⁰ <http://mchb.hrsa.gov/programs/titlevgrants/index.html>

³¹ <http://www.acf.hhs.gov/programs/ohs/about/head-start>

³² <http://www2.ed.gov/programs/osepeip/index.html>

³³ <http://www.acf.hhs.gov/programs/occ/resource/ccdf-reauthorization-faq>

<p>Transition Youth transition to adult health care, work, and independent</p>	<ol style="list-style-type: none"> 1. Got Transition / Center for Health Care Transition Improvement aims to improve the transition from pediatric to adult health care.³⁴ [HRSA] 2. Administration on Intellectual and Developmental Disabilities (AIDD) ensures individuals with developmental disabilities and their families are fully able to participate in and contribute to all aspects of community life.³⁵ [ACL] 3. Social Security Disability Insurance (SSDI) pays benefits to adults who have a disability that began before they became 22 years old. This is paid on a parent’s Social Security earnings record.³⁶ [SSA]
<p>Other Nonprofit / Private Resources</p>	<ol style="list-style-type: none"> 1. American Academy of Pediatrics (National, International, State) provides resources and information for children’s health care providers through various modalities, as well as accurate information for parents and caregivers.³⁷ 2. March of Dimes aims to end premature birth by offering information and comfort to families, as well as funding research and working on preventions.³⁸ 3. Help Me Grow is a system that builds collaboration across sectors, including child health care, early care and education, and family support. Through comprehensive physician and community outreach and centralized information and referral centers, families are linked with needed programs and services.³⁹
<p>Potential Issues</p>	<ol style="list-style-type: none"> 1. Increases in the number of CSHCN due to Zika could burden already existing programs. 2. Families and health care providers may be unaware of some of the programs available or that they relate to children affected by Zika virus infection. 3. Families without legal immigration documentation may be hesitant to enroll in government programs or their eligibility may be unclear. 4. There might be greater consequences if a CSHCN became infected with Zika AND developed Guillain-Barre syndrome. 5. There are no diagnostic tests cleared for the detection of the Zika virus. FDA has granted Emergency Use Authorization (EUA) for the CDC’s MAC-ELISA test and the CDC Trioplex PCR assay.

³⁴<http://www.gottransition.org/>

³⁵<http://www.acl.gov/Programs/AIDD/Index.aspx>

³⁶<https://www.ssa.gov/pubs/EN-05-10026.pdf>

³⁷<https://www.healthychildren.org/English/Pages/default.aspx>

³⁸<http://www.marchofdimes.org/>

³⁹<http://helpmegrwnational.org/>