Texas Plan for System of Services for Children with Congenital Zika Syndrome

Family of Child with Congenital Zika Syndrome

- DSHS Birth Defects Epidemiology and Surveillance Branch
- CSHCN Systems Development Group
- DSHS Regional and Local Health Services

DSHS Specialized Health and Social Services Case Management

- Community Based Services and Family Supports
- Health Care Benefits
- Medical Home Supports
- ECI Services
- Other Services

Texas Birth Defects Registry

Texas Parent to Parent

Ongoing Family Follow-up and Program Communication

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Families may enter the system on their own or through referral from various sources including but not limited to 2-1-1, hospitals, health care providers, and other service providers. If families enter via Children with Special Health Care Needs (CSHCN) Systems Development Group or Department of State Health Services (DSHS) Regional and Local Health Services, those programs will ensure that referrals are funneled up to other programs depicted in this flow chart.

The mission of the Texas Birth Defects Epidemiology and Surveillance (BDES) Branch is to identify and describe the patterns and outcomes of children with birth defects in Texas and to collaborate with others in research, prevention, and family outreach services. The Branch has two major components: the Texas Birth Defects Registry and the Texas Center for Birth Defects Research and Prevention. For more information visit https://www.dshs.texas.gov/birthdefects/

The Texas Birth Defects Registry (TBDR) is a data system containing all ascertained cases of structural and chromosomal anomalies diagnosed through infancy in babies born to mothers who are Texas residents. Children with microcephaly and birth defects that are linked to Zika virus will be identified through rapid ascertainment and referred to regional social workers for assessment and linkage to services.

The CSHCN Systems Development Group (Systems Development) is under Title V Maternal and Child Health in the Department of State Health Services. Systems Development works to strengthen community-based services to improve systems of care for CSHCN. Staff work closely with other state programs and community organizations to make progress on Title V Maternal and Child Health Block Grant National and State Performance Measures for CSHCN.

As the only designated affiliate for Family Voices, a national network recognized by the federal Maternal and Child Health Bureau as the national technical assistance center for family partnerships, and the only statewide CSHCN Services Program Community-Based Contractor, DSHS Specialized Health and Social Services Case Managers will refer families directly to Texas Parent to Parent. For more information visit http://txp2p.org/

The mission of DSHS Division for Regional and Local Health Services is to serve the needs of Local Public Health Agencies, DSHS Health Service Regions, and local communities in building and maintaining capacity to provide essential public health services responsive to local needs. For more information visit https://dshs.texas.gov/rls/default.shtm

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The Texas Department of State Health Services (DSHS) Specialized Health and Social Services (SHSS) staff in the DSHS Health Service Regions (HSRs) will provide case management services initially to all families of a child with Congenital Zika Syndrome who enter the system. DSHS SHSS Case Managers report to DSHS Regional and Local Health Services (RLHS). In cases where the family is already connected to services that provide case management, coordination between the DSHS SHSS Case Manager and established case management provider is expected. Referrals to case management services may be made directly to the DSHS SHSS staff or through the Health and Human Services Commission (HHSC) Case Management program. If the referral is received by the latter, the program links the client to the SHSS staff in the appropriate HSR.

Case Management includes determining the child and family’s needs through a family needs assessment, developing an individualized service plan that outlines how DSHS SHSS Case Management will assist the family in obtaining needed services and supports, and following up regularly with the family.

Services that follow are recommendations for referral based on family needs; Case Managers are not expected to determine eligibility for or provide the services. Referral to a program or service does not guarantee that a family/their child will be eligible to receive services, nor does it guarantee that services are available in every HSR when requested.

Community Based Services and Family Supports may include but are not limited to Children with Special Health Care Needs (CSHCN) Case Management and Family Supports and Community Resources contractors, who provide case management and/or services such as in-home and facility-based respite, specialized programming, education and events for families of CSHCN, and referral to local resources. Visit [http://dshs.texas.gov/cshcn/Community-Based-Contractors.shtm](http://dshs.texas.gov/cshcn/Community-Based-Contractors.shtm) for a complete listing of CSHCN contractors and their service areas.

Health Care Benefits may include but are not limited to Medicaid (including STAR Kids), Children’s Health Insurance Program (CHIP), and CSHCN Health Care Benefits. Eligibility requirements must be met to receive services, and determinations are made by HHSC and agencies overseeing the administration of other health care benefits programs.

Medical Home Supports may include but are not limited to assistance in finding a primary care provider, connection to Local Intellectual/Developmental Disabilities (I/DD) Authorities, Federally Qualified Health Centers (FQHCs), Texas Home Visiting Program, and Aging and Disability Resource Centers (ADRCs).

Early Childhood Intervention (ECI) provides services and supports to families with children from birth to 36 months of age. Children are eligible for services if they have developmental delay(s), hearing or vision impairments as defined by the Texas Education Agency (TEA), or who have a qualifying medical diagnosis. Services are designed to enhance infant and toddler development and to build the capacity of families to meet their children’s needs. ECI contracts with providers throughout the state of Texas to deliver services. For a list of contracted providers, visit [https://dmzweb.dars.state.tx.us/prd/citysearch](https://dmzweb.dars.state.tx.us/prd/citysearch)

Other Services may include but are not limited to Social Security; Women, Infants, and Children (WIC); Supplemental Nutrition Assistance Program (SNAP); Temporary Assistance for Needy Families (TANF); Blind Children’s Vocational Discovery and Development Program; long term services and supports such as Medicaid waiver programs; and other federal programs. Case Managers are encouraged to share information about Navigate Life Texas.
DSHS Birth Defects Epidemiology and Surveillance (BDES) Branch: BDES does not currently conduct referral or follow-up with families or other programs. Proposed referral and follow-up includes the following:
• Extract new, rapidly ascertained cases of Zika-related birth defects from the TBDR on a monthly basis and determine vital status of each case; exclude deceased case infants
• Refer cases with infants’ diagnostic and family contact information to DSHS regional social workers via CSHCN Systems Development Group in the region where the family resides
• Conduct follow-up through evaluation questions that are provided to and completed by regional social work staff and returned to BDES on a monthly basis.

CSHCN Systems Development Group (Systems Development): Currently families are referred with no follow-up and there is minimal communication with other programs. Potential new efforts include:
• Immediate referral to DSHS Specialized Health and Social Services Program Manager in the Health Service Region (HSR) in which the family resides and follow-up within one month to ensure that the HSR connected with the family. If the family has not been connected to the HSR, Systems Development will assist in connecting if needed/requested by the HSR.
• Follow up with the family within three months of initial contact. Re-establish connection to HSR as needed.

DSHS Specialized Health and Social Services (SHSS) Regional Case Management: Case Management staff provide follow-up services to families as outlined in the family’s Individualized Service Plan to ensure they have made connections to available resources. Current communication with Systems Development is made either through HHSC Case Management or directly from the HSR to Systems Development on a case-by-case basis. Immediate referral will be made to TxP2P. If the family has not been connected to TxP2P, RLHS will assist in connecting if needed/requested by TxP2P.

Early Childhood Intervention (ECI): When children are referred to ECI, the family is contacted and if they agree to ECI services, ECI determines eligibility. ECI case management services will connect them to all available resources. If the parent provides “informed” consent, ECI can provide information to referral sources. Consent must be specific to the program ECI is providing information to, and be specific about the kind of information being shared.

Families who decline services typically do not provide ECI with consent to share information with the referral source. At that point, ECI can refer them back to the DSHS SHSS Regional Case Management or CSHCN Systems Development to potentially access resources through these agencies.

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This document was prepared by a workgroup of staff from the Texas Department of State Health Services (DSHS) and Health and Human Services Commission (HHSC). Programs represented on the workgroup included:

- DSHS Deputy Commissioner’s Office
- DSHS Disease Control and Prevention
  - Birth Defects Epidemiology and Surveillance
- DSHS Family and Community Health
  - Title V Maternal and Child Health
  - Specialized Health Services
  - Women, Infants, and Children
- DSHS Regional and Local Health
  - Specialized Health and Social Services
- HHSC Case Management
- HHSC Early Childhood Intervention
- HHSC Medicaid

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