Connecting Children with Spina Bifida and Encephalocele to Health and Social Services

Background
- Spina Bifida and encephalocele are major birth defects of the brain and spine. The Birth Defects Epidemiology and Surveillance Branch (BDES) refers children with select birth defects, including spina bifida and encephalocele to social workers from Specialized Health and Social Services (SHSS) on a quarterly basis.
- SHSS social workers connect families to health and social services. They also provide ongoing case management if needed.
- Since April 2019 social workers reached 67% of the 138 families of children with spina bifida or encephalocele. Seven percent of families declined help or a data collection form was not fully completed.

Percent of Total Referrals Made by Social Workers

<table>
<thead>
<tr>
<th>Category</th>
<th>Programs in Referral Category</th>
<th>% of Referrals Made</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental</td>
<td>Community First Choice, Early Childhood Intervention (ECI), Skilled nursing care, Children with Special Health Care Needs (CSHCN)</td>
<td>31%</td>
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<td>Head Start, Personal care service, Driscoll high-risk clinic</td>
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<tr>
<td>Financial Help</td>
<td>Health Insurance Premium Payment Program (HIPP), Supplemental Security Income (SSI), Supplemental Nutrition Assistance Program (SNAP), Temporary Assistance for Needy Families (TANF)</td>
<td>28%</td>
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<tr>
<td></td>
<td>Medicaid Waiver Program, Women, Infants, and Children (WIC), Child Support</td>
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<tr>
<td>Family Support</td>
<td>Immigration/legal assistance, Parent training and information centers</td>
<td>27%</td>
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<td></td>
<td>Counseling services, Texas Parent to Parent</td>
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<tr>
<td>Medical/Dental</td>
<td>Specialty care, Physical/speech/occupational therapy, Medical transportation</td>
<td>11%</td>
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<td>Dental, Audiologist, Pediatrician</td>
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<td>Educational</td>
<td>English as a Second Language (ESL), Parenting classes</td>
<td>3%</td>
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<td></td>
<td>School programs</td>
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Contact Information
Birth Defects Epidemiology and Surveillance Branch
Mail Code 1964
PO Box 149347
Austin, Texas 78714-9347

512-776-7232
BirthDefects@dshs.texas.gov
dhs.texas.gov/birthdefects

Programs with Most Referrals From Social Workers
- Texas Parent to Parent (64 referrals)
- Medicaid Waiver Program (35 referrals)
- CSHCN (33 referrals)
- SSI (24 referrals)
- Personal care service (24 referrals)
Time of Birth Defect Diagnosis
Social workers asked 92 families when their child’s birth defect was diagnosed:
• 62% reported their child was diagnosed during the mother’s pregnancy
• 27% reported their child was diagnosed at birth/delivery
• 9% reported their child was diagnosed after delivery/discharge from facility
• 1% did not know or remember when their child was diagnosed
• 1% stated their child was misdiagnosed or did not have a birth defect

Barriers Reported by Families
• Of the 92 families reached, 61% reported they were not experiencing any barriers.
• Among the 36 families who reported one or more barriers, the most common barriers reported were:
  o 44% Finances
  o 22% Issues navigating services
  o 22% Other/free response
    • Restrictions due to COVID-19 pandemic
    • Lack of social support
    • Limited resources