

# 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.



*Spina bifida and encephalocele are neural tube defects usually apparent at birth.*

## Percent of Total Referrals Made by Social Workers

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

### Contact Information

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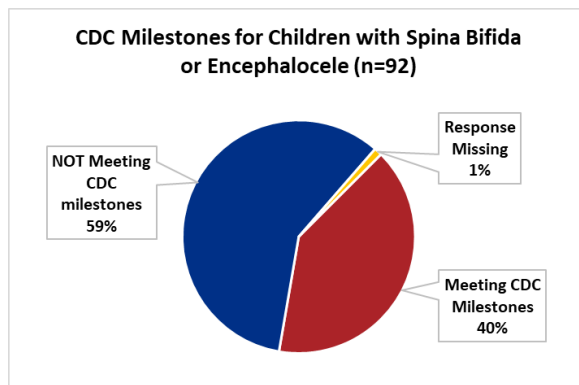
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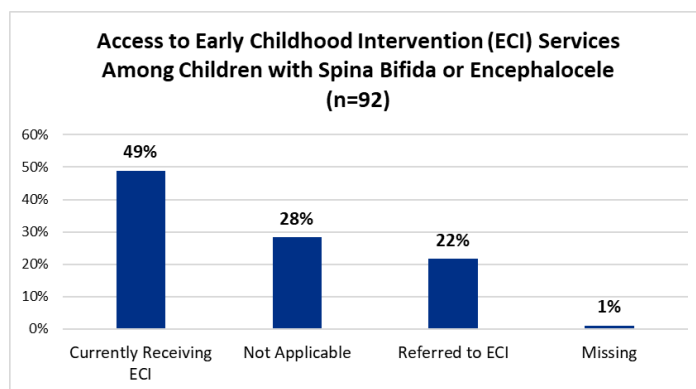
### Programs with Most Referrals From Social Workers

- Texas Parent to Parent (64 referrals)
- Medicaid Waiver Program (35 referrals)
- CSHCN (33 referrals)
- SSI (24 referrals)
- Personal care service (24 referrals)

## CDC Developmental Milestones



## Access to Early Childhood Intervention



## 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:
  - 44% Finances
  - 22% Issues navigating services
  - 22% Other/free response
    - Restrictions due to COVID-19 pandemic
    - Lack of social support
    - Limited resources

