

Connecting Children with Critical Congenital Heart Defects to Social Services and Identifying Barriers to Accessing Healthcare

Overview

The Birth Defects Epidemiology and Surveillance Branch (BDES) conducted a survey for mothers of young children in the Texas Birth Defects Registry with critical congenital heart defects (CCHDs). The goal of the survey was to understand the child’s healthcare and barriers to accessing healthcare. At the end of the survey mothers were asked if they would like to be contacted by a social worker for case management.

The survey participation rate was 46% (461/1005). Among the 461 survey participants:

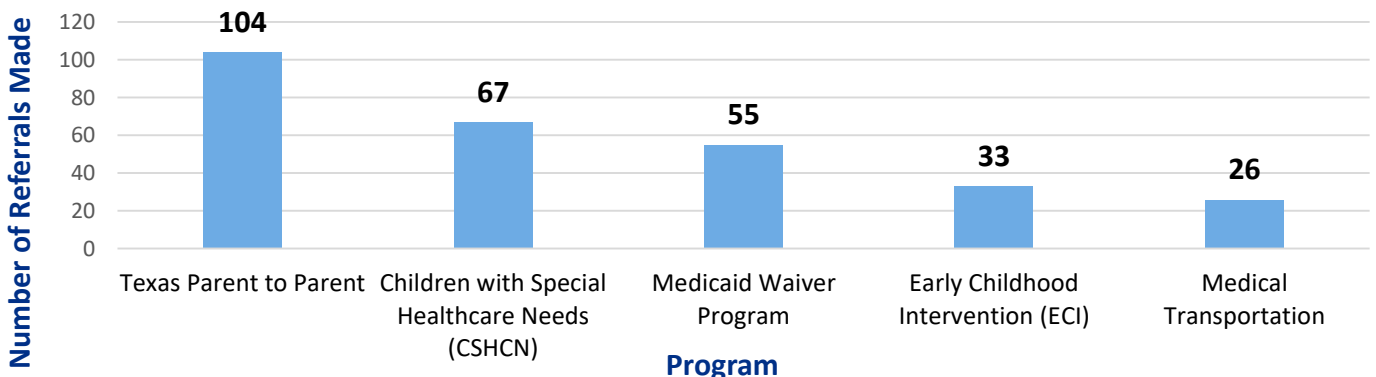
- 84% took the survey in English, 16% in Spanish
- 53% identified as Hispanic or Latino, 31% Non-Hispanic White, 9% Non-Hispanic Black or African American
- 40% reported completing a high school diploma/GED or less
- 40% requested to be contacted by a social worker

Referrals to Social Service Programs

Social workers from Specialized Health and Social Services (SHSS) reached 70% (129/183) of mothers who requested to be contacted and made 470 referrals to the following programs:

Referral Category	Programs in Referral Category	Referrals Made by Social Workers
Medical/Dental	Pediatrician, Specialty care, dental, physical/speech/occupational therapy, audiologist, medical transportation	14% (64/470)
Financial Assistance	Medicaid Waiver Program, Health Insurance Premium Payment (HIPP) Program, Supplemental Security Income (SSI), Supplemental Nutrition Assistance Program (SNAP), Temporary Assistance for Needy Families (TANF), Women, Infants, and Children (WIC), Child Support	26% (123/470)
Developmental	Community First Choice, Early Childhood Intervention (ECI), Personal care service, skilled nursing care, Head Start, Children with Special Health Care Needs (CSHCN), Driskoll High Risk Clinic	30% (139/470)
Educational	English as a Second Language, Parenting classes, School programs	4% (18/470)
Family Support	Counseling services, Immigration/Legal assistance, Parent training and Information Centers, Texas Parent to Parent, SHARE program	27% (126/470)

Programs with Greatest Number of Referrals Made by Social Workers



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Time of Child's Diagnosis

Mothers reached by social workers were asked if their child's birth defect was diagnosed during her pregnancy, at birth, or after delivery/discharge from facility.

- 53% of mothers reported their child was diagnosed during her pregnancy
- 28% of mothers reported their child was diagnosed at birth/delivery

CDC Developmental Milestones

About half (52%) of mothers reported their child is meeting the CDC developmental milestones for their age group (i.e. keeping up physically, or with their learning).

Barriers to Accessing Healthcare

Forty-two percent of mothers reported facing at least one barrier to accessing healthcare for their child. Mothers were able to report multiple barriers. The top barriers reported were:

- 48% - Finances
- 26% - Other barrier not specified
 - Other barriers cited by mothers included: COVID-19 and lapses in insurance coverage
- 24% - Transportation
- 24% - Language barriers

Future Plans for Referral Initiative

BDES has completed conducting surveys with mothers of children with CCHDs. BDES is evaluating whether to add children with CCHDs to the cohorts referred to social work on a quarterly on-going basis.

Contact Information

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Access to the Early Childhood Intervention (ECI) Program
Among Children with Critical Congenital Heart Defects
Reached by Social Workers (n=129)

