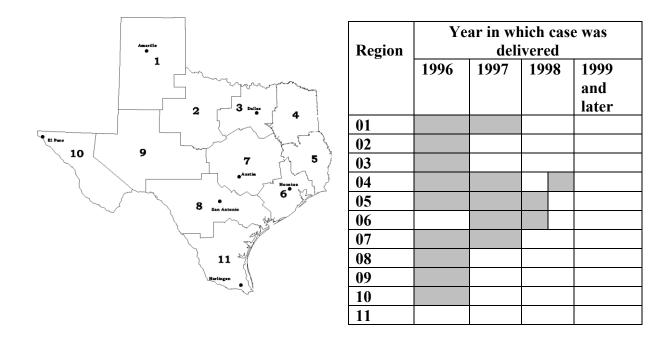


TEXAS BIRTH DEFECTS REGISTRY COVERAGE AND CHANGES

BIRTH DEFECTS EPIDEMIOLOGY AND SURVEILLANCE BRANCH TEXAS DEPARTMENT OF STATE HEALTH SERVICES

Registry Geographic Coverage:

The Texas Birth Defects Registry (TBDR) is a population-based active surveillance registry which collects statewide data on pregnancies affected by birth defects. It is run by the Birth Defects Epidemiology and Surveillance Branch (BDES) of the Texas Department of State Health Services. The Texas Birth Defects Registry began data collection in the Lower Rio Grande Valley (Public Health Region 11) and the Greater Houston/Galveston area (Region 6), and gradually expanded to encompass the entire state of Texas starting with deliveries on January 1, 1999. The Texas Birth Defects Registry ascertained cases from the Public Health Regions (shown on the map below) for the time periods not shaded in the table below:



Data Collection:

BDES continually strives to improve Registry operations, refining our case definitions, birth defect codes, and data collection procedures as needed. When possible, changes have been applied to previous, relevant cases in the Registry (e.g. updating codes for all cases with that birth defect).



Current Case Definition (adopted 4/5/2001):

A case is an infant or fetus with a birth defect. To be included as a case in the Texas Birth Defects Registry, all of the following criteria must be met:

- The mother's residence at the time of delivery must be in an area covered by the registry (see above). This area includes the entire State of Texas starting with deliveries on January 1, 1999.
- The infant or fetus must have a structural or chromosomal birth defect monitored by the registry.
- The defect must be diagnosed prenatally or within one year after delivery. This is extended to six years of age for special cases, currently only for fetal alcohol spectrum disorders.

The current case definition includes all pregnancy outcomes (live births, spontaneous fetal deaths, and induced pregnancy terminations) at all lengths of gestation. Prior to April 5, 2001, when the current case definition was adopted, the registry did not collect information on birth defects among fetal deaths before 20 weeks gestation.

Maternal Medical Records:

Due to increasing workload and finite resources a decision was made to stop abstracting maternal medical records on 9/1/2010, which primarily impacts live born cases delivered from 2008 to present. Maternal medical records are still abstracted for non-live born cases because the maternal chart is the only record available. Because only maternal delivery medical records were abstracted, the Registry probably under-ascertains maternal exposures and some of the maternal illnesses, conditions, and complications and prenatal procedures.

Data Migration into New Collection Systems:

Registry growth dictated changes in our data collection systems and data elements collected. Some data in legacy systems were formatted and collected differently. Data that were not parallel in old and new data systems may not have been migrated thus creating null fields. In addition we stopped collecting some fields, resulting in null values for cases collected thereafter. Impacted variables are indicated in Form D of the "<u>Policy and Procedures for Requesting Data</u>" and should be analyzed with care. To date there have been two system migrations:

- 1. Migration from the FoxPro database to the IAS database, implemented 2/1/2002; primarily impacts cases delivered before (versus after) 2001.
- 2. Migration from the IAS database to the Maven system, implemented 7/27/2012; primarily impacts cases delivered before (versus after) 2012.