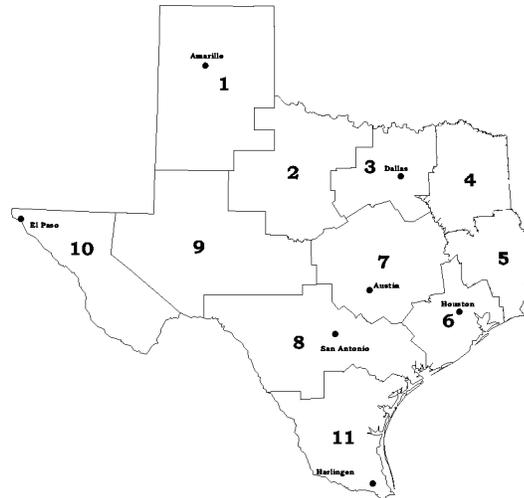# Methods

Scope of this Report

This report presents information on selected birth defects among deliveries during 2000 through 2009 to women who were residents of Texas at the time of delivery. The analyses are based on completed records in the Texas Birth Defects Registry as of January 9, 2012.

Case Definition

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. During 2000-2009, the registry covered the entire state of Texas.
- The infant or fetus must have a structural birth defect or developmental disability 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 syndrome.

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. Much of year 2000 surveillance activities were completed at the time this case definition went into effect. As a result, the 2000 data in this report include only a very small number of fetal deaths before 20 weeks gestation.

Data Collection

The Texas Birth Defects Registry uses active surveillance. This means it does not require reporting by hospitals or medical professionals. Instead, trained program staff members regularly visit medical facilities where they have the authority to review logs, hospital discharge lists, and other records. From this review, a list of potential cases is created. Starting with deliveries during 2009, we began also using Texas fetal death certificates with a congenital anomaly as the underlying cause of death (codes Q00.0 through Q99.9, International Classification of Diseases, Tenth Revision (ICD-10)) to identify potential cases. Program staff then review medical charts for each potential case identified. If the infant or fetus has a birth defect covered by the registry, detailed demographic and diagnostic information is abstracted. That information is entered into the computer and submitted for processing into the registry. Quality control procedures for finding cases, abstracting information, and coding birth defects help ensure completeness and accuracy.

Records in the birth defects registry were matched to birth certificates and fetal death certificates filed with the Vital Statistics Unit of the Texas Department of State Health Services. When a record in the birth defects registry matched a birth or fetal death certificate, and information was not missing from the matching certificate, the analysis for this report used demographic data from the birth or fetal death certificate for the following: date of delivery, mother's date of birth, mother's race/ethnicity, and mother's county of residence at the time of delivery. Information on the sex of the infant or fetus was handled a bit differently. We used the sex reported on the matching birth or fetal death certificate unless information abstracted from medical records indicated the sex was ambiguous, in which case we used the information from medical records. When a registry record did not match a birth or fetal death certificate, or when information was missing from the certificate, then this report used demographic data abstracted from medical records.

Regardless of the source of demographic information for this report, all diagnostic information was abstracted from medical records.

Data Analysis

Results are presented for 48 selected defects among deliveries during 2000 through 2009, regardless of whether the defect occurred alone or together with others. Appendix B lists the BPA codes used to define these defects, and Appendix C provides a glossary of birth defects and related terms.

Because an infant or fetus often has more than one defect, and not all monitored defects are included in these analyses, it is not meaningful to sum all diagnostic categories in the tables to obtain the total number of children with birth defects. In the data tables, totals are shown in the line labeled, "Infants and fetuses with any monitored birth defect."

Tables include the number of cases found, the estimated prevalence per 10,000 live births, and the 95% confidence interval for the prevalence. A case is an infant or fetus with the specified birth defect. Birth prevalence was calculated as follows:

$$\frac{\text{Number of cases}}{\text{Total number of live births}} \times 10{,}000$$

The denominators used in calculating prevalence are shown in Appendix A.

The prevalence is an estimate of the true prevalence, which can never be known with certainty. The 95% confidence interval contains the true prevalence of a birth defect 95% of the time. A wide interval indicates the uncertainty stemming from small numbers. This report displays 95% confidence intervals based on the Poisson distribution when there are 100 or fewer cases, and based on the normal distribution when there are more than 100 cases.

We used Poisson regression to identify birth defects with statistically significant differences in prevalence between maternal age groups, maternal race/ethnic groups, and between males and females. These birth defects are marked with an asterisk in Tables 3, 4, and 5.

Another simpler approach to determine whether the prevalence of a particular birth defect differs between groups, for example, between males and females, is to examine the 95% confidence intervals for the prevalences. If the 95% confidence interval for the prevalence among males does not overlap with the 95% confidence interval for females, we consider the prevalences to be statistically significantly different. However, this method is more conservative and has less power than Poisson regression, and will identify fewer significant differences between groups than Poisson regression.

Limitations of these Data

These data are subject to several limitations. First of all, the registry only includes birth defects diagnosed within one year after delivery (except for fetal alcohol syndrome), so birth defects detected after the first birthday and diagnoses that are refined after the first birthday are not in the registry. Second, we miss diagnoses that are made outside of Texas or in Texas facilities that our staff does not access at this time, such as prenatal diagnostic facilities and private physicians' offices. Third, data are collected from medical records and as such are subject to differences in clinical practice.

Acknowledgements

The Department of State Health Services continues to work on behalf of children and families affected by birth defects in Texas, and recognizes the critical contributions of families who have participated in research that one day will eliminate these conditions. We further acknowledge the dedicated efforts of the birth defects surveillance staff, who collect information on birth defects across the state.