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Case Management Partnership with Regional Specialized Health and Social Services: A Closer Look at Down Syndrome

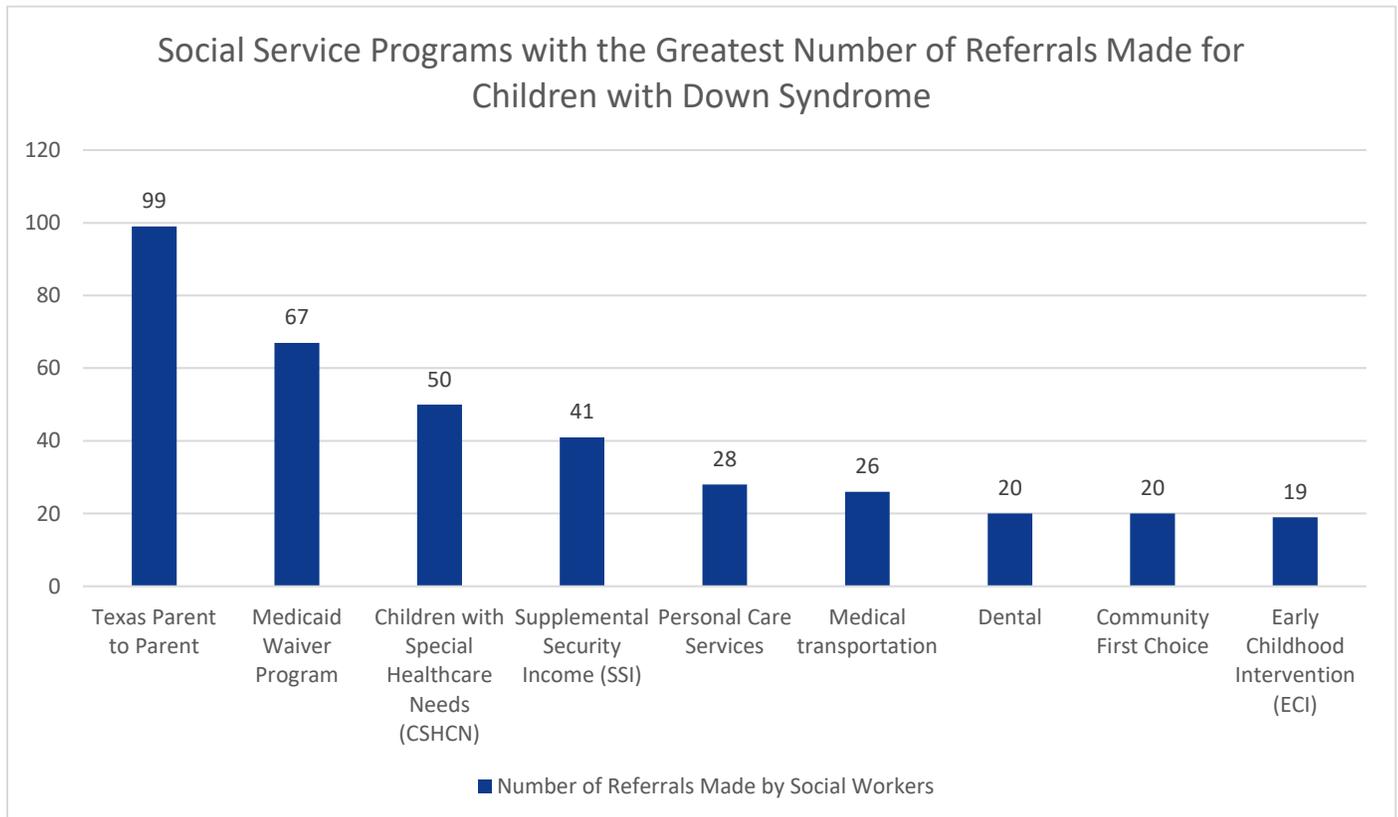
The Birth Defects Epidemiology and Surveillance (BDES) Branch and Regional Specialized Health and Social Services (SHSS) at the Texas Department of State Health Services (DSHS) collaborate to connect families of children in the Texas Birth Defects Registry (TBDR) to state and federal social service programs and help identify barriers to receiving services. BDES refers children in the TBDR with one or more of the following birth defects to SHSS: spina bifida, encephalocele, cleft lip, cleft palate, and/or Down syndrome. This report summarizes the referrals of 127 children with Down syndrome reached by SHSS since July 2019.

Regional SHSS social workers completed evaluation forms for 69% (127/184) of the families referred by the Branch. The remaining 31% (57/184) of families could not be reached, no longer lived in Texas, or an evaluation form was not completed for the family. Social workers connected families to various medical, financial, developmental, educational, and family support programs through referral to services including:

- More than 150 referrals to financial assistance programs including 67 referrals to the Medicaid waiver program and 41 referrals to Supplemental Security Income (SSI).
- Over 140 referrals to developmental programs, including 50 referrals to Children with Special Healthcare Needs (CSHCN), and 19 referrals to Early Childhood Intervention (ECI) services.

- More than 130 referrals to family support programs like English as a Second Language classes, counseling services, and Texas Parent to Parent.
- Over 60 referrals to medical programs such as medical transportation, dentists, and physical, speech, or occupational therapy.

Figure 1 below shows programs that families were most commonly referred to. The greatest number of referrals were made to Texas Parent to Parent, a program that provides support, information, and education for families of children who have disabilities or chronic illness.



When families were asked about services that they were already accessing the most common responses were: pediatrician (126), specialty care (107), physical/speech/occupational therapy (107), and ECI (88).

Social workers also collected information about the child’s healthcare and barriers to care to gain a better understanding of the challenges faced by families of children in the Registry with Down Syndrome. Some of these findings include:

- When families were asked when their child’s birth defect was diagnosed:
 - 50% (63/127) of families indicated their child was diagnosed during the mother’s Pregnancy
 - 38% (48/127) indicated their child was diagnosed at birth/delivery

- 9% (12/127) said their child was diagnosed after delivery/discharge
 - 2.3% (3/127) said they did not know or did not remember.
 - One family indicated their child was mis-diagnosed or does not have a birth defect.
- When families were asked if they felt their child was meeting the Centers for Disease Control and Prevention (CDC) developmental milestones (i.e. keeping up physically, or with learning) for their age group, 67% (84/126) of families said their child was not meeting the CDC developmental milestones.
 - When families were asked if they were experiencing any barriers to accessing medical care:
 - 58% (73/126) of families indicated that they were not experiencing any barriers at this time and 21% (27/126) reported multiple barriers.
 - The families reporting multiple barriers were asked to select the greatest barrier. Of the 27 families, 26% cited finances (7/27), 22% cited other (6/27), and 19% cited language barriers (5/27).
 - Some families that cited “other barriers” mentioned delaying or avoiding medical care due to the COVID-19 pandemic.



The collaboration with SHSS and BDES helps ensure that Texas families of children with birth defects have access to invaluable services and programs. BDES continues to partner with SHSS to refer children in the Registry to services and identify barriers to care. For more information on the initiative, contact Dayana Betancourt at dayana.betancourt@dshs.texas.gov.

Related Resources:

CDC’s Developmental Milestones:

cdc.gov/ncbddd/actearly/milestones/index.html

Children with Special Healthcare Needs: A Resource Guide:

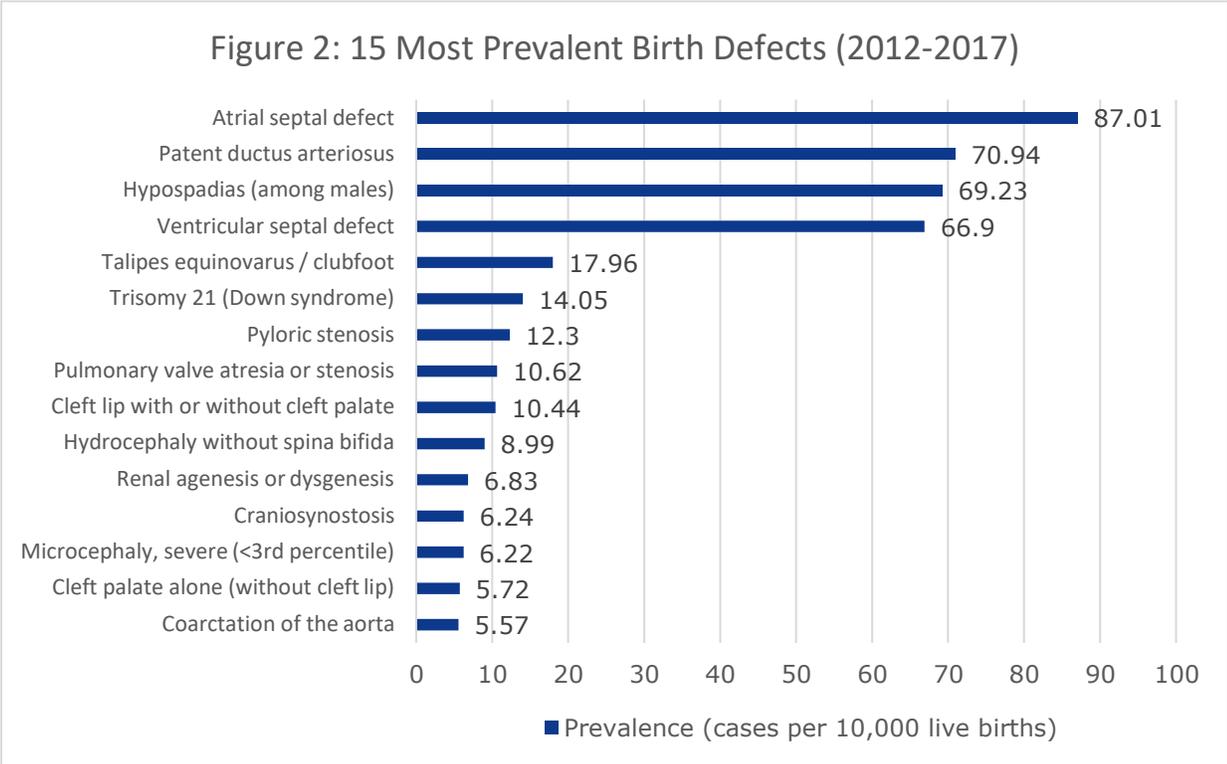
dshs.state.tx.us/birthdefects/CSHCN-General-Resource-Brochure.pdf

These family outreach activities were supported in part by the Centers for Disease Control and Prevention (CDC) grant CDCRFA-DD16-1601, “Birth Defects Surveillance in Texas: Methodological Enhancement and Impactful Data Utilization,” and Title V, Children with Special Health Care Needs, and Texas Parent-to-Parent Family Support Group.

Updated Birth Defects Prevalence Data from the Texas Birth Defects Registry, 2012-2017

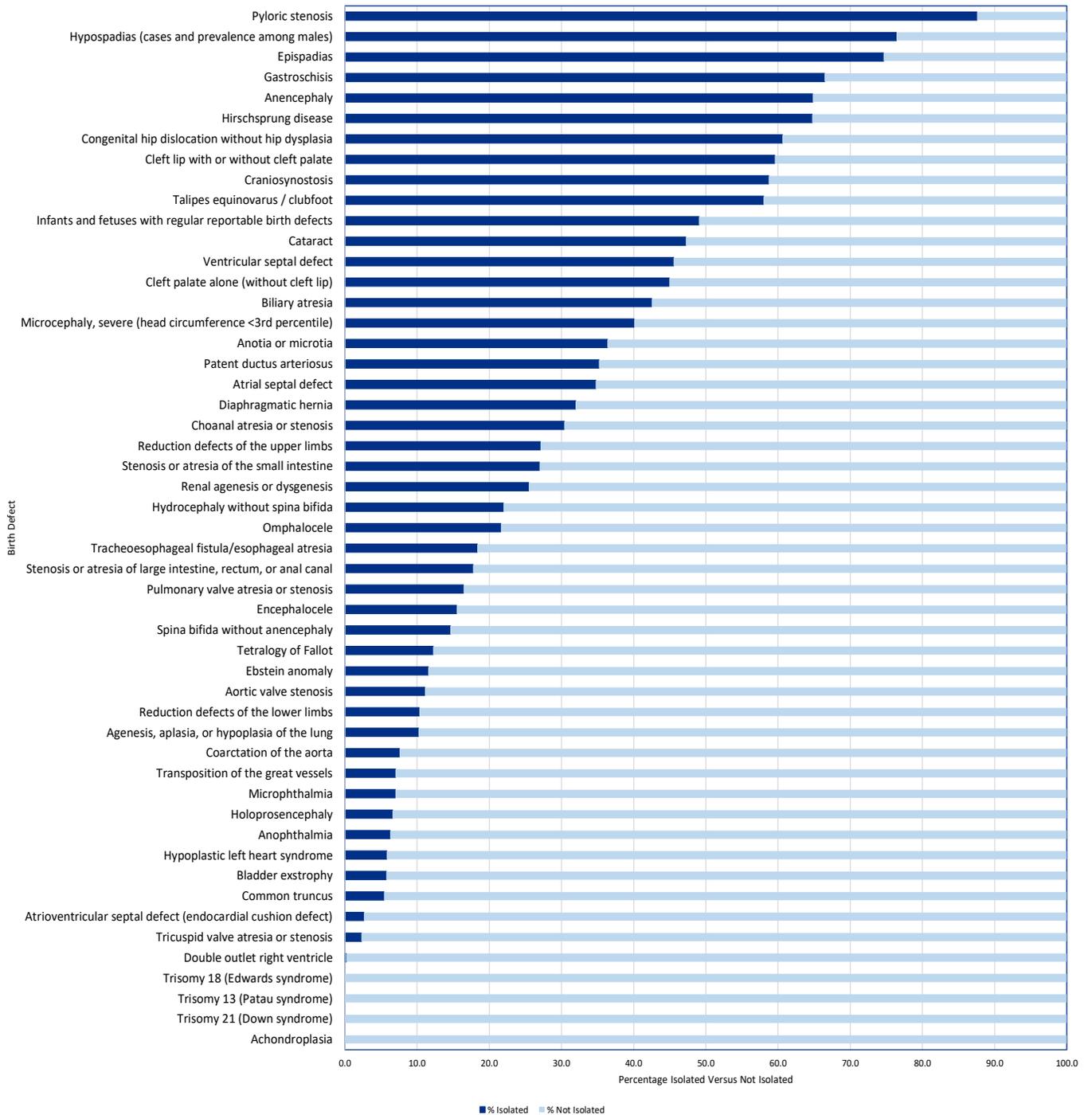
The two charts below show data from the most recently compiled annual report of the Texas Birth Defects Registry (TBDR), highlighting delivery years 2012 through 2017. During this 6-year period, about 6% of all births in Texas were affected by one or more major birth defects. An average of approximately 25,000 new case infants were added annually.

Figure 2 shows the 15 most prevalent birth defects from 2012 to 2017. Three of the top four most prevalent birth defects were heart defects (atrial septal defect, patent ductus arteriosus, and ventricular septal defect). Hypospadias, a condition in boys in which the urethral opening is misplaced, was the third most prevalent defect. Among more commonly known birth defects, Down syndrome was found to occur among 1 in 712 deliveries (or births), cleft lip 1 in 958, and cleft palate 1 in 1750 births.



Many individuals with birth defects have more than one birth defect. In the TBDR, 51% of the cases have more than one (i.e. non-isolated cases), and 49% of cases are isolated, that is, the child/fetus has only one major birth defect. Figure 3 shows which birth defects are more likely to be isolated rather than associated with another birth defect. The birth defect with the highest percentage of isolated cases is pyloric stenosis, a narrowing of the tube where the stomach exits, at 87.6%, followed by hypospadias at 76.4%. Chromosomal disorders are not considered isolated birth defects, since chromosomal disorders result in multiple birth defects in an individual. Examples of these are Trisomy 13, Trisomy 18 and Trisomy 21 (more commonly known as Down syndrome), which are also shown in Figure 3 on the next page.

Figure 3: Percent of Isolated Commonly Reported Birth Defects in Texas, 2012-2017



The Texas Birth Defects Registry Report of Birth Defects Among 1999-2017 Deliveries can be found online at dshs.texas.gov/birthdefects/Data/reports.shtm.

For a glossary of birth defect terms, visit dshs.texas.gov/birthdefects/glossary.shtm.

Critical Congenital Heart Defect Mortality

Critical Congenital Heart Diseases (CCHD) are twelve congenital heart defects that require surgery or other procedures in the first year of life. According to the Centers for Disease Control and Prevention, roughly 7,200 babies in the United States are born with a CCHD each year. One in every 4 babies born with a heart defect has a critical congenital heart defect¹. Historically in Texas, approximately 800 babies are born each year with a CCHD.



Advances in screening and medical intervention have contributed to improved clinical outcomes. Notably, state-wide policies mandating CCHD screening using pulse-oximetry have been associated with a reduction of death rates due to CCHD². In Texas, mandatory CCHD screening was implemented in September 2014. While mortality rates have decreased over time, racial and socioeconomic disparities have been reported^{4,5}.

We analyzed data from the Texas Birth Defects Registry to better understand the impact of newborn CCHD screening and socioeconomic factors on CCHD case fatality rates (CFR, a percentage, calculated as deaths/cases x 100). Using the years 2012-2016 to capture recent data before and after CCHD screening policy implementation, we determined prevalence and CFR for all CCHDs and compared pre- and post- screening time periods (Table 1). Information related to socioeconomic status including maternal education level and insurance payer status were obtained from birth certificate data.

During 2012-2016, the prevalence of any CCHD for all pregnancy outcomes in Texas was 20.78 per 10,000 births, which is similar to rates reported by other US jurisdictions^{6,7}. The most prevalent CCHDs were Coarctation of the Aorta (CoA) (5.55 per 10,000 births), Tetralogy of Fallot (5.19 per 10,000 births), and dextro-Transposition of the Great Arteries (d-TGA) (2.82 per 10,000 births). The overall infant CFR for all CCHDs during this time period was 17.5% (95% Confidence Interval, or CI, 16.4-18.7). Among individual CCHDs, the defect with the highest infant CFR was Hypoplastic Left Heart Syndrome (HLHS) (37.0%, 95% CI 32.7-41.3). CCHDs with the lowest infant CFR were d-TGA (11.4%, 95% CI 8.7-14.0) and CoA (11.7%, 95% CI 9.8-13.6). There was no significant difference in infant CFR seen when comparing 2012- 2013 data (pre-screening era: 17.9% (95% CI 16.0-19.7)) to 2015-2016 data (post-screening era: 17.1% (95% CI 15.3-18.9)) (Data not shown).

We then performed additional analysis on the CCHDs with the highest and lowest overall CFR to explore the impact of socioeconomic factors on CFRs in the infant and neonatal time periods (Table 2). It is notable that the interventional course for these three conditions are quite different from one another⁸. HLHS requires multiple surgeries and hospitalizations over the course of a baby's first 2-3 years of life, as well as life-long medical management and monitoring. d-TGA usually requires only a single surgery in the first month of life in addition to medical management and monitoring. Coarctation of the aorta may have a range of disease severity. Some phenotypes never become clinically significant or are not detected until later in life; some may be treated non-surgically such as with balloon

angioplasty; some will require surgery. In the setting of varying degrees of medical resources needed, socioeconomic factors may play an important role in outcomes.

Among babies born with HLHS, there was a significantly higher neonatal and infant CFR among those with “self-pay” status when compared to those with private insurance. No significant differences in CFR were seen across payer status for d-TGA and CoA. Among babies with HLHS, there was a higher neonatal CFR when maternal education was reported as “less than high school” when compared to maternal education “greater than high school”. No significant differences in CFR were seen across maternal education levels for d-TGA and CoA.

Our analysis found that prevalence for all CCHDs in Texas 2012-2016 were consistent with rates reported elsewhere in the United States. There was no significant difference observed in CFR in the “pre-screening” time period compared to the “post-screening” time period. While this suggests that mandated screening has not impacted CFR, this may be because some hospitals had initiated screening prior to the official policy change. Socioeconomic factors appear to influence CFR among CCHD types requiring the greatest degree of medical intervention. The CCHD with the highest CFR was HLHS; the CCHDs with the lowest CFRs were d-TGA and CoA. Among babies born with HLHS, self-pay status and maternal education level appear to be associated with CFR. These trends were not identified for d-TGA and CoA. These findings represent an initial understanding of the impact of CCHD screening and socioeconomic factors on CCHD fatality. Further analysis, including CFR analyses that adjust for important covariates such as birthweight, gestational age, or severity of defect, may further clarify these relationships.

For more information, please contact: Varun Shetty at varun.shetty@dshs.texas.gov

Table 1: Critical Congenital Heart Defect Prevalence and Infant Case Fatality Rate, Texas Birth Defects Registry 2012-2016.

Critical Congenital Heart Disease	Prevalence (cases per 10,000 live births)	95% CI	Infant CFR (deaths/cases x 100)	95% CI
Common truncus	0.70	0.58 - 0.82	31.2	23.4 - 38.9
dextro-Transposition of the great arteries	2.82	2.58 - 3.05	11.4	8.7 - 14.0
Tetralogy of Fallot	5.19	4.87 - 5.51	13.7	11.6 - 15.8
Pulmonary valve atresia	1.14	0.99 - 1.29	29.9	23.9 - 35.9
Tricuspid valve atresia	0.79	0.66 - 0.91	16.1	10.3 - 21.9
Ebstein anomaly	0.74	0.62 - 0.86	20.5	14.0 - 27.1
Hypoplastic left heart syndrome	2.48	2.26 - 2.70	37.0	32.7 - 41.3
Coarctation of aorta	5.55	5.22 - 5.88	11.7	9.8 - 13.6
Total anomalous pulmonary venous return	1.71	1.52 - 1.89	24.7	20.1 - 29.3
Single ventricle	0.81	0.68 - 0.93	28.9	21.9 - 36.0
Interrupted Aortic Arch	0.76	0.64 - 0.88	21.3	14.8 - 27.9
Double outlet right ventricle	2.52	2.30 - 2.74	27.2	23.3 - 31.1
Pulse oximetry screening era				
Pre-screening era (2012-2013)	20.66	19.65 - 21.68	17.9	16.0 - 19.7
Post-screening era (2015-2016)	20.55	19.56 - 21.54	17.1	15.3 - 18.9

Table 2: **Neonatal and Infant Deaths and Case Fatality Rates for Select CCHDs by Insurance Payer Status and Maternal Education, Texas Birth Defects Registry 2012-2016**

	Hypoplastic Left Heart Syndrome			Dextro-Transposition of the Great Arteries			Coarctation of the Aorta		
	Deaths	Neonatal CFR	95% CI	Deaths	Neonatal CFR	95% CI	Deaths	Neonatal CFR	95% CI
Insurance Payer Status									
Medicaid	52	22.0	16.7 - 27.3	20	7.6	4.4 - 10.8	26	5.2	3.3 - 7.1
Private Insurance	26	13.8	8.8 - 18.7	12	5.4	2.4 - 8.3	22	5.0	3.0 - 7.0
Self-Pay	12	38.7	21.6 - 55.9	1	3.1	0.0 - 9.2	9	10.7	4.1 - 17.3
Other	7	23.3	8.2 - 38.5	3	10.0	0.0 - 20.7	5	8.6	1.4 - 15.8
Maternal Education									
< High School	31	27.9	19.6 - 36.3	6	5.4	1.2 - 9.5	18	7.9	4.4 - 11.4
High School	38	26.4	19.2 - 33.6	16	9.9	5.3 - 14.5	16	5.7	3.0 - 8.4
> High School	28	12.0	7.8 - 16.2	14	5.1	2.5 - 7.6	27	4.7	3.0 - 6.4
	Deaths	Infant CFR	95% CI	Deaths	Infant CFR	95% CI	Deaths	Infant CFR	95% CI
Insurance Payer Status									
Medicaid	99	41.9	35.7 - 48.2	35	13.3	9.2 - 17.3	65	13.0	10.1 - 15.9
Private Insurance	52	27.5	21.1 - 33.9	20	9.0	5.2 - 12.7	40	9.1	6.4 - 11.8
Self-Pay	16	51.6	34.0 - 69.2	2	6.3	0.0 - 14.6	12	14.3	6.8 - 21.8
Other	14	46.7	28.8 - 64.5	6	20.0	5.7 - 34.3	11	19.0	8.9 - 29.1
Maternal Education									
< High School	46	41.4	32.3 - 50.6	14	12.5	6.4 - 18.6	38	16.7	11.8 - 21.5
High School	63	43.8	35.6 - 51.9	25	15.4	9.9 - 21.0	31	11.0	7.3 - 14.6
> High School	71	30.5	24.6 - 36.4	23	8.3	5.1 - 11.6	57	9.9	7.5 - 12.3

Notes: Neonatal Period=0-27 days; Infant Period=0-364 days; Education/Payer Status data: birth certificates

*For more information on Critical Congenital Heart Defects, visit:
cdc.gov/ncbddd/heartdefects/cchd-facts.html*

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September 12-18 is Folic Acid Awareness Week

Folic acid is an essential B-vitamin; therefore, everyone needs it to stay in good health. Folic acid helps build DNA and your body uses it for cell growth and reproduction, fundamental building block processing and genetic material production. In 1998, the U.S. Food and Drug Administration started fortifying cereal grain products with folic acid to reduce the risk for neural tube defects (NTDs), serious birth defects of the brain and spine.

Getting enough folic acid every day, before and during early pregnancy, is an important way to reduce the risk of NTDs. These birth defects occur in the first weeks of fetal development, often before a woman even knows she is pregnant. Because about 50 percent of pregnancies in the United States are unplanned, it's important to take folic acid

every day, even if you're not planning to get pregnant. Taking 400 micrograms (mcg) of folic acid daily has been shown to reduce the risk of having an NTD by up to 70 percent.

All women of reproductive age should get 400 mcg of folic acid daily. This can be accomplished through consuming multivitamins, fortified foods (for example, in fortified breads, corn masa, or cereal products), or a combination of the two. When planning to become pregnant, women who have already had a pregnancy affected by an NTD should consult with their healthcare provider. CDC recommends that these women consume 4,000 mcg of folic acid each day one month before becoming pregnant and through the first three months of pregnancy.

To learn more about Folic Acid, visit: [cdc.gov/ncbddd/folicacid/index.html](https://www.cdc.gov/ncbddd/folicacid/index.html).

‘Best for You. Best for Baby.’

January is National Birth Defects Prevention Month

The National Birth Defects Prevention Month campaign theme, “Best for You. Best for Baby.” aims to bring awareness to birth defects and five critical tips to reduce the chances of having a baby with a birth defect.

- 1. Be sure to take 400 micrograms (mcg) of folic acid every day.**
 - Folic acid is very important because it can help prevent some major birth defects of the baby’s brain and spine when taken before and during early pregnancy.

- 2. Book a visit with your healthcare provider before stopping or starting any medicine.**
 - There are often benefits to continuing treatment throughout pregnancy. Discussing a treatment plan before a pregnancy allows a woman and her health care provider to weigh the pros and cons of all options to keep mom and baby as healthy as possible.

- 3. Become up-to-date with all vaccines, including the flu shot.**
 - Having the right vaccinations, like the flu and Tdap vaccines, at the right time during pregnancy can help keep a woman and her baby healthy.

- 4. Before you get pregnant, try to reach a healthy weight.**
 - Obesity increases the risk for several serious birth defects and other pregnancy complications.

- 5. Boost your health by avoiding harmful substances during pregnancy, such as alcohol, tobacco, and other drugs.**
 - There is no known safe amount of alcohol during pregnancy and its exposure can cause major birth defects.
 - Smoking during pregnancy can cause dangerous chemicals to damage the placenta and/or reach baby’s bloodstream.
 - The opioid addiction epidemic has led to a sharp increase in Neonatal Abstinence Syndrome (NAS), premature birth and drug withdrawal in developing babies.

Not all birth defects can be prevented. But you can increase your chances of having a healthy baby by managing health conditions and by adopting healthy behaviors before and during pregnancy. Taking care of yourself and doing what’s best for you is also best for your baby!

Visit [cdc.gov/ncbddd/birthdefects/prevention-month.html](https://www.cdc.gov/ncbddd/birthdefects/prevention-month.html) to learn more about National Birth Defects Prevention month, and ways to reduce the risk of birth defects.

Source acknowledgement: National Birth Defect Prevention Network

Remote Access to Hospital Records Allows Rapid Response to COVID-19

Due to the rapid acceleration of COVID-19 cases in Texas between May and June 2020, the Texas Department of State Health Services (DSHS) partnered with the Centers for Disease Control and Prevention (CDC) to characterize recent COVID-19 hospitalizations across the state. This project was intended to guide public health action. DSHS selected the Texas Birth Defects Epidemiology and Surveillance (BDES) Branch to collect data for this project. The Branch, a Title V-funded program, is well-positioned within DSHS to collect data from hospitals due to surveillance staff's medical records abstraction expertise and ability to access hospital records via remote access, that is, the ability to connect to hospital records from another location.

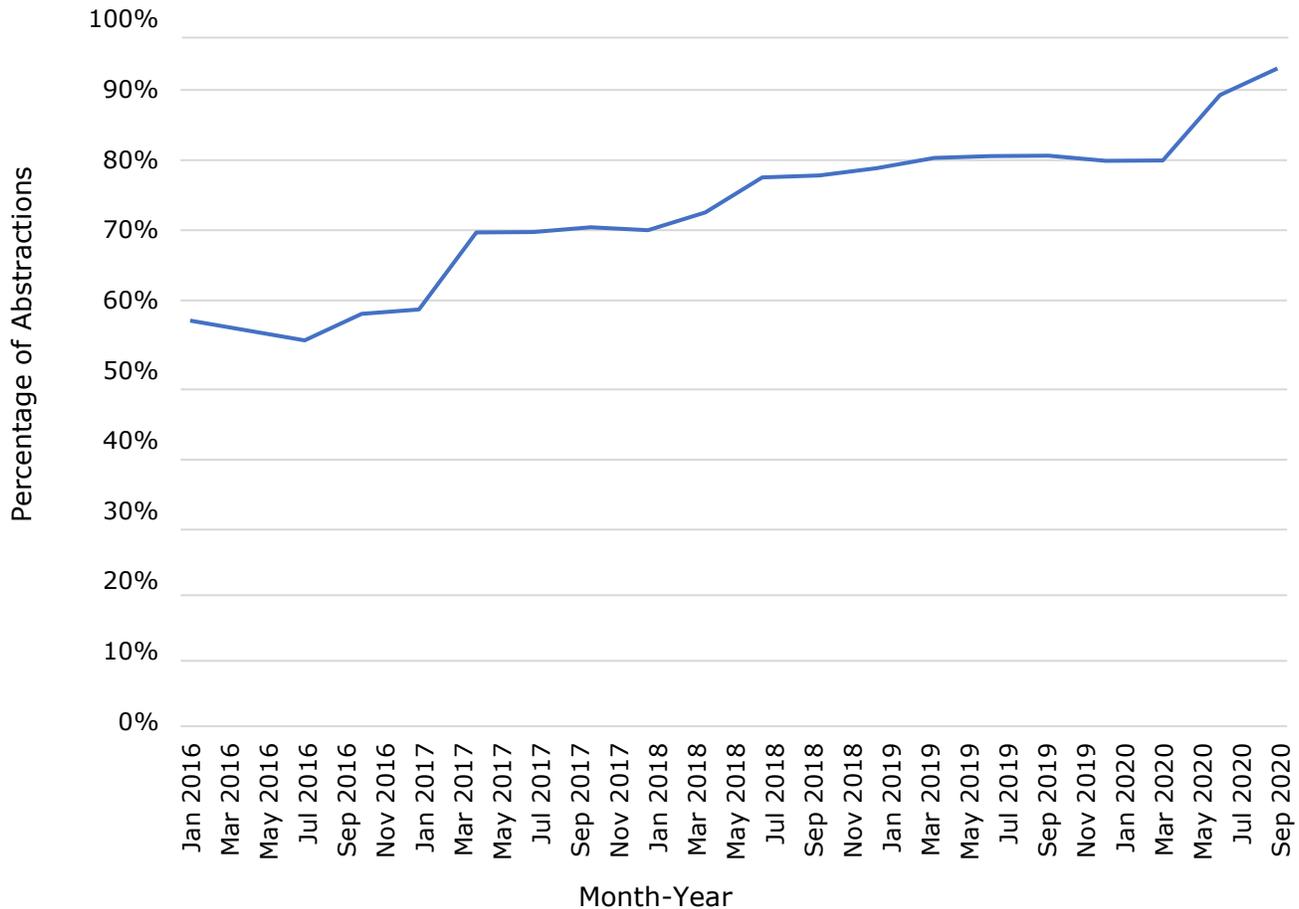
BDES regional surveillance staff have significant experience with remote access to hospital medical record systems. Remote access to hospital medical record systems is beneficial to both the Branch and hospitals by reducing the amount of time and costs associated with travel to collect data, while freeing valuable hospital space and resources. Most importantly, during the COVID-19 outbreak, allowing BDES staff to remotely access electronic medical records ensures the continuity of timely vital public health services while ensuring the safety of hospital employees, patients, and Branch staff.

Figure 4, on the following page, shows the percentage of abstractions completed via remote access, which increased from 57% to 93% from January 2016 to October 2020. This includes a relatively sharp increase between April and October 2020 when more hospitals allowed Branch staff to access medical records remotely due to the COVID-19 pandemic. During this four-year period, the percentage of hospitals providing remote access increased from 38% to 82%.

When BDES requested COVID-19 hospitalization data in July 2020, Texas hospitals quickly provided staff with discharge lists and electronic health records with COVID-19 diagnosis. In several weeks, regional surveillance staff abstracted over 730 records from 30 medical facilities across the state, including information on demographics, occupation, co-morbidities, length of hospital stay, outcomes/final patient discharge status, and treatments. Regional surveillance staff entered the information collected into the CDC Epi Info system, a tool designed for public health surveillance and research. CDC analysts completed data analysis for the project and expect to publish the results soon.

The execution of the COVID-19 abstraction project was successful due to regional surveillance staff's expertise in medical record abstraction, their ability to access medical records remotely from Texas hospitals, the rapid response by the Branch in planning and implementing the project, and the cooperation of Texas hospitals.

Figure 4: Percentage of Abstractions from Hospitals with Remote Access



Recent Publications from BDES Branch Staff and Collaborators

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Calendar 2020

January:

National Birth Defects Prevention Month

February:

American Heart Month

February:

International Prenatal Infection Prevention Month

February 14:

Congenital Heart Defect Awareness Day

Spring 2020:

March of Dimes March for Babies (check with MOD for specific dates and locations)

March:

National Nutrition Month

March:

National Developmental Disabilities Awareness Month

March 3:

World Birth Defects Day

April:

Alcohol Awareness Month

April:

National Autism Awareness Month

April:

National Minority Health Month

April:

STD Awareness Month

April 5-11:

National Public Health Week

June:

National Congenital Cytomegalovirus Awareness Month

June 21-22:

34th Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research, San Diego, CA

June 26-30:

61st Annual Meeting of the Teratology Society, Pittsburgh, PA

July:

National Cleft and Craniofacial Awareness & Prevention Month

July 30:

Gastroschisis Awareness Day

September:

Newborn Screening Awareness Month

September:

National Infant Mortality Awareness Month

September 12-18:

Folic Acid Awareness Week

October:

National Spina Bifida Awareness Month

October:

National Down Syndrome Awareness Month

October:

47th Annual Meeting of the International

Clearinghouse for Birth Defects Surveillance and Research (meeting dates pending)

November:

Prematurity Awareness Month (March of Dimes)

November:

Prematurity Awareness Month (March of Dimes)

About the Monitor

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Please visit the BDES website for updated information and to sign up for Branch updates:
dshs.texas.gov/birthdefects/.

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