

Scientific Analysis of the Current State and Needs of the Maternal and Child Health Population in Texas



Division for Family & Community Health Services

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Chapter 1. Introduction

The Office of Program Decision Support (OPDS) was tasked with conducting a scientific analysis of the current state and needs of the maternal and child health population in Texas. The chapters that follow present the results of this work. The analysis was designed to have three complimentary components: 1) analysis of existing data; 2) community outreach surveys designed to assess what parents and people in the community think are their needs and strengths; and 3) qualitative data from focus groups and stakeholder meetings that build on the community outreach surveys.

OPDS was responsible for analyzing existing data, and for developing and analyzing the results of the community outreach surveys. The focus groups and stakeholder meetings were conducted by SUMA Social Marketing, Inc., and findings were included in their report that is also located in [Appendix D](#).

Analysis of Existing Data

The approach governing the analysis of existing data, and this scientific investigation, more generally, was grounded in four guiding principles. The first of these principles was that all analyses would be informed by, and **utilize, a Life Course Perspective**. The Life Course Perspective is grounded in the developmental sciences and recognizes that a child is not a product of the moment around him/her, but a product of this moment *and* the risk and resiliency that has been established over the course of development. From a public health point of view, this perspective helps guide the principle that intervening early is key to future health and that current health has been built through past behaviors.

The second guiding principle was that **children and youth with special health care needs (CYSHCN) have the same needs as the community, as do those with special needs**. CYSHCN live in the communities in which we all live. They are not removed from these communities and are impacted by them; further, they contribute to these communities. Therefore, we included the needs of these children and youth in our overall analysis. However, it is also clear that these youth have special needs; therefore, these needs are highlighted throughout the analysis.

The third principle was built on the understanding that a population as complex, diverse, and changing as the maternal and child population would **require complex analyses to understand their complex needs**. It is rare in any population that needs are not multi-faceted and complex. From both scientific and intervention perspectives, it is important to assess how these factors interact and mediate one another. This complex analysis will help differentiate what makes something a need or strength and build initiatives that support or tackles that factor in a way that considers the complexity of the situation. In order for this approach to be successful, it is also imperative that high quality data be used for all analyses. To this end, OPDS did a blanket scan of all available data and assessed the level to which the data was available (individual, census tract, zip-code, county, state), and the quality and generalizability of the data. Data were prioritized based on this scan, with datasets from random samples weighted to the population prioritized and only population data being ranked higher. Existing datasets would be linked when possible, allowing multiple levels of influence to be examined. All data sources used in the analysis, the quality of evidence for that source, and the level at which it was

available is shown in *Appendix A*. Please note that all confidence intervals (C.I.s) presented in this report are at the 95 percent confidence level.

The final guiding principle was that **all frequencies and percentages would be benchmarked to an existing target** whenever possible. Data out of context of what is and is not a problem or strength is just a number. In order to add context to the data, all prevalence rates, percentages and frequencies were benchmarked to a national target [i.e., Healthy People (HP) 2020 targets, March of Dime challenges, ASTHO challenges], a target set by state statute, or a target set by federal guidelines. When a target did not exist, all regional and county analyses were benchmarked to the state average or a key reference group.

Community Outreach Surveys

The second element of the scientific analysis was the development and utilization of two community outreach surveys (see *Appendix B and C*). The goal of these surveys was to directly ask parents and community members what they perceived as being the needs and strengths of their community and what needs to change to make it healthier. These surveys were not intended to replace or supplant any data analysis or results from a higher quality data source; rather, the surveys served to enhance these sources with an understanding of how needs and strengths are perceived within the community.

One of these surveys was general and targeted at all community members (*Appendix B*). This survey was developed by OPDS staff. OPDS began developing the survey by conducting a general scan of needs surveys that were conducted by other states, while also conducting individual and group interviews with subject matter experts in the Office of Title V and Family Health (OTVFH). From this scan and these interviews, a draft survey was developed that focused on perceptions of: 1) provider access; 2) availability of information about a variety of health needs; 3) community engagement; 4) concerns about community issues; and 5) concerns about community health, specifically. This survey was then reviewed and refined by both OPDS and OTVFH.

OTVFH solicited partners, direct care providers, regional teams and other stakeholder groups to widely distribute the survey and to also fill it out as parents and community members. The Title V Community Outreach Survey (in both English and Spanish) was open from July 7th until August 31st.

The other community outreach survey was specifically designed for parents of CYSHCN (*Appendix C*). This survey overlapped with the general population survey, but also specifically focused on individual needs in this population. The parents of CYSHCN are engaged and are an advocacy oriented population. Despite this, our understanding of their needs at a local level is very limited. This special survey was intended to fill this knowledge gap.

The survey was developed by OPDS and the CYSHCN program. OPDS first did an in-depth analysis of the National Survey of Children with Special Health Care Needs (NS-CSHCN) to assess which specific aspects of each performance measure the state was doing poorly. This analysis resulted in a survey focus on who has helped the parent with transition to adulthood issues and care coordination. For these topics, wording was borrowed from the NS-CSHCN for basic questions and supplemented with state-focused questions. In addition, the CYSHCN program and OPDS developed questions focused on assessing the

need for respite care, the level of emergency preparedness by the family, and health insurance needs. The survey also overlapped with the general community survey and asked parents to identify general concerns they have about their community and the health concerns in the community. Because this CYSHCN survey focused on individual needs, not community perception, the survey was reviewed by the Texas Department of State Health Services (DSHS) Institutional Review Board and exempt status was granted before the survey was distributed.

The CYSHCN Community Outreach (Parent) Survey (in both English and Spanish) was open August 1st through August 31st. The CYSHCN program solicited contractors, parent advocates and their clients to take and distribute the survey to all parents with a child with special needs.

Focus Groups and Stakeholder Meetings

The third element of the needs assessment was qualitative information gathered through focus groups and stakeholder meetings. The content and framework of the focus groups was designed to complement the community outreach surveys and the qualitative analyses. Three focus groups were held in each of the state's public health service regions with two focus groups dedicated to understanding the general needs in the community, and the third dedicated to parents of CYSHCN receiving benefits or supplementary services from the state. These focus groups were also complimented with specific meetings for stakeholders in the communities.

The focus groups and stakeholder meetings were conducted by SUMA Social Marketing, Inc. based in Austin, Texas. Table 1.1 outlines the location and the demographics of the focus groups dedicated to the general population. Men-only groups were conducted in two key areas of the state so that a focus on work, fatherhood, and environmental issues could be assessed. These two areas were specifically selected because they are stable communities that have been impacted by the oil and gas boom in Texas.

Location		Demographics		Language
Amarillo	Small urban/rural	Women 19-22	White/mixed	English
Brownsville	Small urban/rural	Women 19-22	Hispanic	Spanish
Fort Worth	Large Urban	Women 25-35	Black/Mixed	English
Houston	Large Urban	Women 25-35	Black	English
Killeen	Small urban/rural	Women 25-35	Mixed	English
Nacogdoches	Rural	Women 25-35	Black	English
San Angelo	Small urban/rural	Men 25-35	Mixed	English
San Antonio	Large Urban	Men 25-35	Hispanic/Mixed	Bilingual

The focus groups dedicated to CYSHCN were held in the different locations and their composition was standardized across all locations. The focus groups consisted of parents who had a child with a qualifying special health care need. Focus group membership was prioritized to include parents receiving medical benefits from the CYSHCN program first, then those receiving services from a CSHNC program community contractor, then those on the waiting list to receive health care benefits, and finally, those without any medical insurance or who were recruited through professional recruitment methods.

Location:	Geography	Language
Lubbock	urban/rural	English
San Antonio A	Large Urban	English
San Antonio B	Large Urban	English

Temple	Small urban/rural	English
Jasper	Small urban/rural	English
Houston A	Large Urban	English
Houston B	Large Urban	English
El Paso	Large Urban	Spanish
Laredo	Large Urban	Spanish
Dallas A	Large Urban	Spanish
Dallas B	Large Urban	English

Stakeholder meetings were also held in every health service region in the state. They were strategically held in cities with major medical centers and where providers receive training. These cities were El Paso, Laredo, San Antonio, Houston, Tyler, Waco, Lubbock, and Arlington. Arlington was chosen because it is halfway between Dallas and Fort Worth and is a common and convenient location for holding a meeting for stakeholders in both cities. The meetings were designed to encourage providers, community health workers, and other local stakeholders to provide input about the needs they perceive in their community. The stakeholder meetings were predominantly held in English, but the sessions in El Paso and Laredo were bilingual.

A comprehensive report by SUMA of the findings from the focus groups and stakeholder meetings is attached (see [Appendix D & E](#)).

Chapter 2. Texas Overview

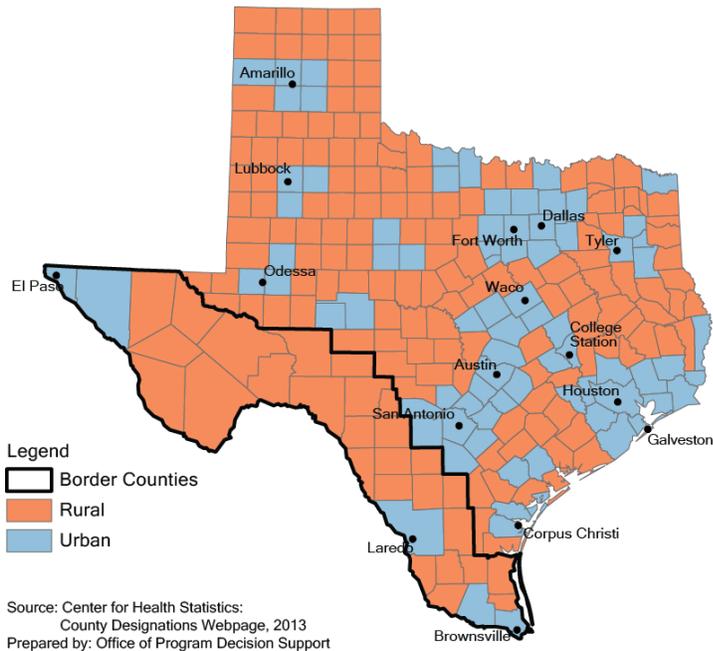
Texas is vast and varied, with regional differences in socioeconomic characteristics, mobility/migration patterns, language spoken at home, geography and population characteristics. The purpose of this chapter is to provide an overview of these variations and relate them to the challenges that exist for health care availability and access. Together with health care coverage and access to care, an overview of these factors is presented here to show the challenges that exist for meeting the health needs of mothers and children and their families.

Geography

To say that Texas is “big” is an understatement. The land area of Texas is approximately 262,000 square miles, accounting for 7.4 percent of the total U.S. land area. The area is equal to the land area of all six New England states, Ohio, New York, Pennsylvania, and North Carolina combined. Texas has a larger land area than any single country completely contained in Europe including France and the Ukraine. The longest straight-line distance in Texas is 801 miles from the northwest corner of the Panhandle to the extreme southern tip of Texas on the Rio Grande below Brownsville. With the large north-south expanse of Texas, Dalhart, in the northwestern corner of the state, is closer to the state capitals of Kansas (430 miles), Colorado (310 miles), New Mexico (200 miles), Oklahoma (275 miles), and Wyoming (390 miles) than it is to Austin (470 miles), its own state capital. The greatest east-west distance is 773 miles from the extreme east-ward bend in the Sabine River in Newton County to the extreme western bulge of the Rio Grande just above El Paso. This east-west expanse is so large that El Paso, in the western corner of the state, is closer to San Diego, California (630 miles) than to Beaumont (740 miles), near the Louisiana state line; Beaumont, in turn, is closer to Jacksonville, Florida (680 miles) than it is to El Paso.

The geography of Texas is as varied as it is large. Texas is comprised of 254 counties that are classified as rural or urban (see Figure 2.1; [1]), with 88.5 percent of the population concentrated in urban areas [2]. The five largest metropolitan areas are centered around the cities of Houston, San Antonio, Dallas, Austin, and Fort Worth and encompass multiple counties.

Figure 2.1
2013 Rural, Urban, and Border County Designations in Texas

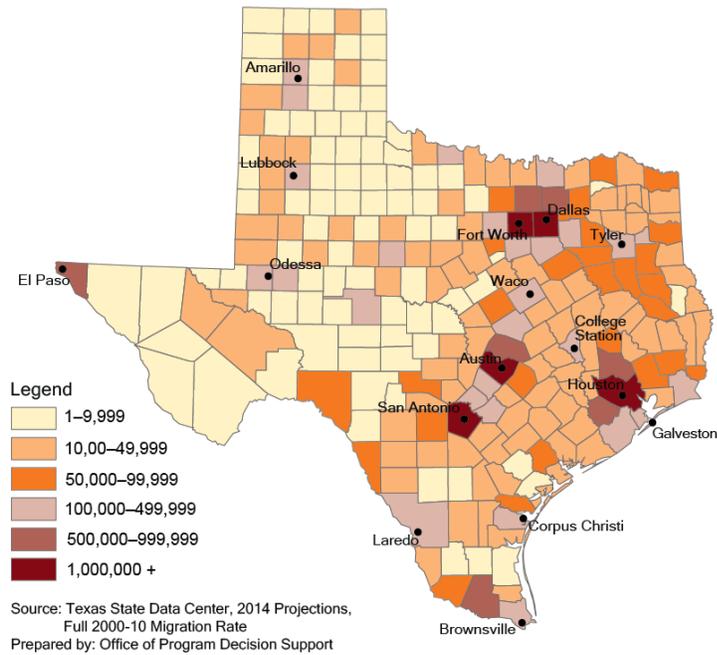


Given the vast and varied geography of Texas, the distance that some individuals travel to receive health care services can be a significant challenge to accessing and receiving those services.

Population

Just as the Texas geography is varied, so too is the distribution of its population (see Figure 2.2). Differences in race/ethnic composition, along with the high percentage of foreign-born residents, present particular cultural challenges when it comes to meeting maternal and child health needs.

Figure 2.2
Texas Population by County, 2014

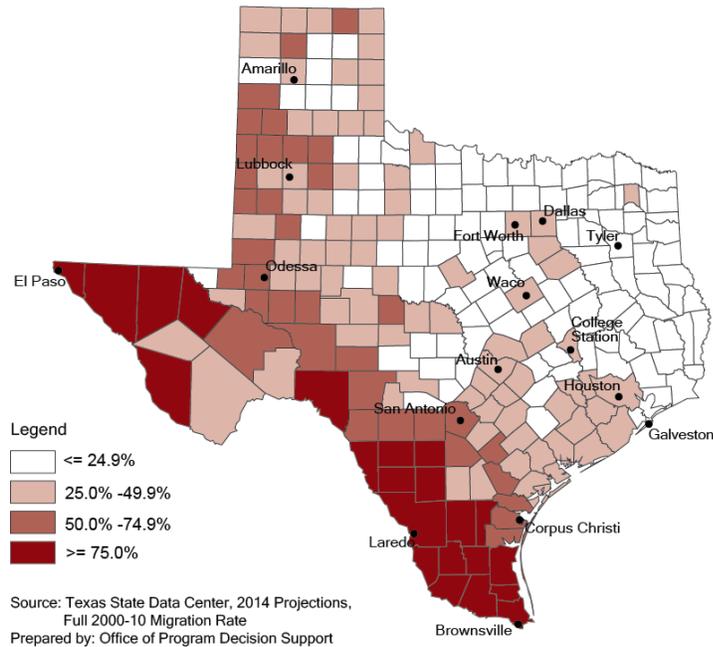


Texas has an estimated population of over 26 million [2] and, according to 2013 Census estimates, has been the second fastest growing state in the nation since 2010 [3]. Growth in Texas is attributable in equal parts to migration and births. According to U.S. Census annual estimates for the population, there has been a 5.2 percent increase in people living in Texas from 2010 to 2013 [3]. The Texas State Data Center predicts the population in Texas will exceed 31 million people [2] by 2050, even if migration patterns fall to zero.

Race/Ethnicity

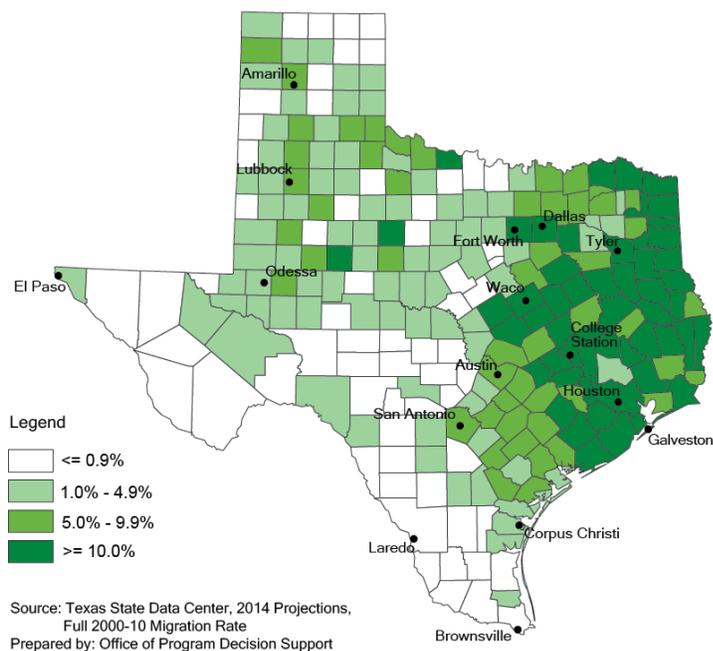
Texas has six major cities that are located in counties where the Hispanic population makes up more than 50 percent of the population in the county: San Antonio, Corpus Christi, Brownsville, Laredo, El Paso, and Odessa (see Figure 2.3). These counties are primarily concentrated in the southern and western regions along the border. In three of the counties—counties containing the cities of Brownsville, Laredo, and El Paso—Hispanics comprise more than 80 percent of the population in each county.

Figure 2.3
Percent of Population that are Hispanic, by County, 2014



The regional concentration of the Black population (see Figure 2.4) stands in contrast to the Hispanic population. The Black population along the border was estimated to be slightly above 26,000 in 2014. When El Paso is excluded, the total Black population is approximately 4,800, or less than one percent of the population in the remaining border counties.

Figure 2.4
Percent of Population that are Black, by County, 2014

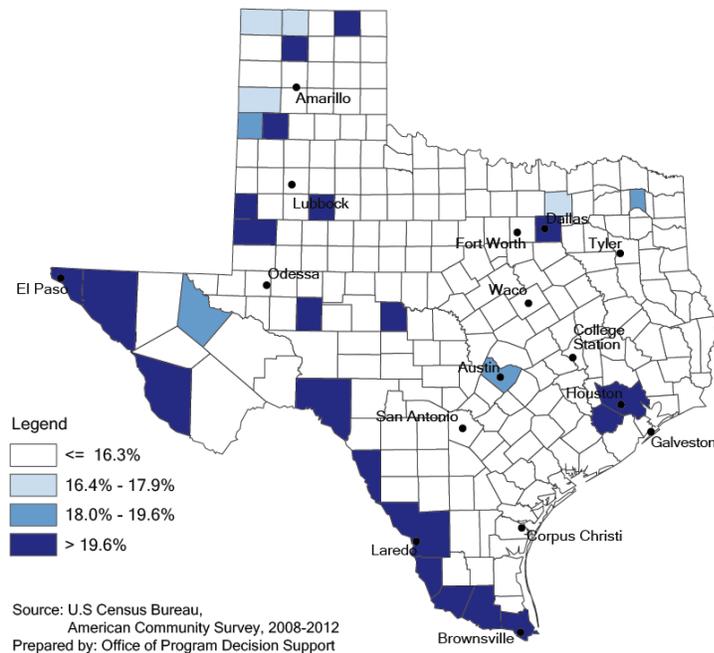


In the eastern and north gulf-coast regions of the state, the race/ethnic distribution is quite different. Blacks outnumber Hispanics in three metropolitan areas, Beaumont-Port Arthur, Longview, and Texarkana. There are two metropolitan areas in the state—the Dallas-Fort Worth-Arlington area and the Houston-Woodlands-Sugarland area—in which 74 percent of all metropolitan-dwelling Blacks live.

Foreign-Born

Texas has a higher percentage of foreign-born residents (16.3 percent) compared to the nationwide average (12.9 percent). Almost 70 percent of Texas foreign-born residents are not United States citizens. Over 70 percent of foreign-born residents in Texas are originally from Latin American countries—20 percentage points more than the nationwide average. It follows, then, that over 34 percent of Texans speak a language other than English at home. Within four of the metropolitan statistical areas (MSAs) in Texas—Laredo, McAllen-Edinburg-Mission, El Paso, and Brownsville-Harlingen—between 73 and 92 percent of persons speak a language other than English at home, with the vast majority speaking Spanish. Foreign-born residents are concentrated along the border (see Figure 2.5), but several of the non-border cities of Houston, Dallas, and Austin are also in counties with a high concentration of foreign-born residents.

Figure 2.5
Percent of Population Who Are Foreign Born, 2008-2012



Age

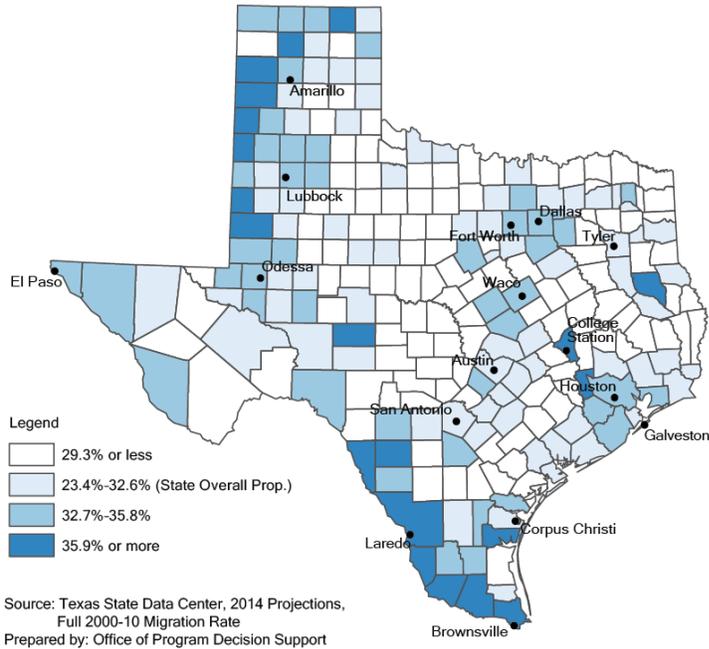
According to 2008-2012 American Community Survey, Texas is the second youngest state in the nation, with a median age of 33.6 years. The only state that is younger is Utah, where the median age is 29.3 years [4]. This trend has remained constant since the 2000 census.

Texas is second only to California in the number of births occurring in the state [3]. From 2010 to 2013, between 390,000 and 400,000 infants were born each year in Texas, accounting for approximately 10

percent of all births in the nation. (See Chapter 5 for more birth statistics.) Children younger than 18 years old account for 27 percent of the total Texas population. Texas is tied for second for the largest percent of the population of children younger than the age of 5 (7.7 percent), children 5 to 14 years (15.1 percent), and children 15 to 17 years old (4.5 percent; [4]).

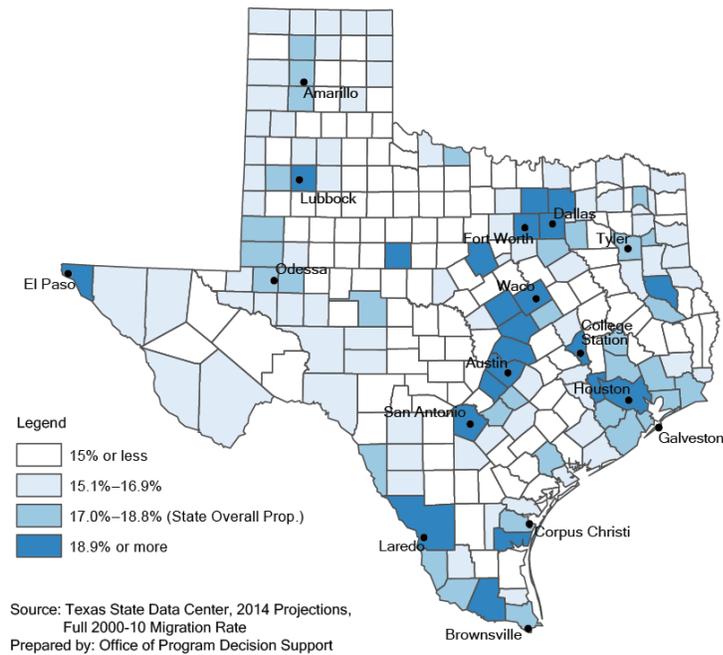
Texans younger than 22 years old account for 32.6 percent of the total population (see Figure 2.6; [2]). In 2014, the border region had the highest percentage of the population younger than the age of 22.

Figure 2.6
Percent of Population Younger than 22 Years, 2014



Women in Texas comprise half of the total population. However, women between 18 and 44 years of age account for 18.8 percent of the total population (see Figure 2.7). With the exception of Brownsville, Amarillo, and Odessa, women in their childbearing years were concentrated in and around larger cities in Texas in 2014.

Figure 2.7
Percent of Population 18-44 Years Old and Female, 2014



Socioeconomic Characteristics

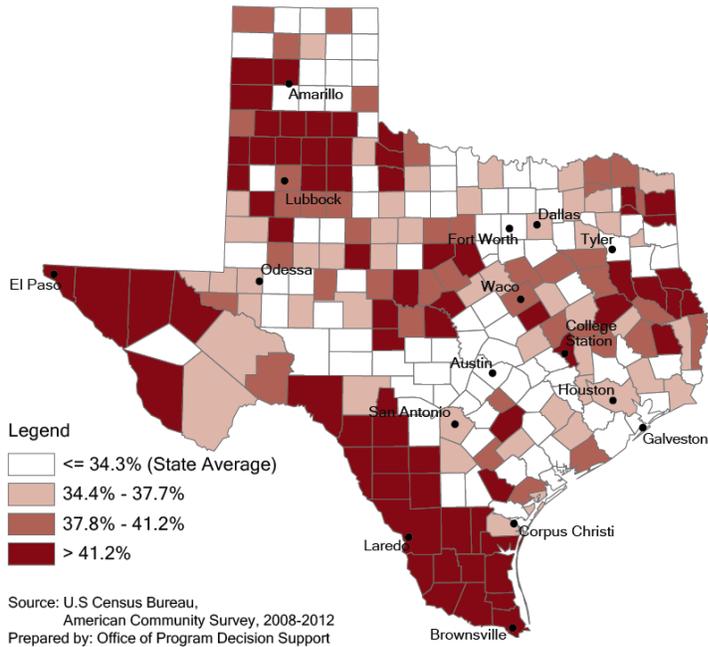
Socioeconomic characteristics, such as income and poverty, education, unemployment, and crime are added challenges for meeting the health needs of mothers, children, and families in Texas. The presence of many of these factors in the community in which the individual lives has been identified as important risks for the life course of the individual.

Income and Poverty

Income inequalities in Texas are geographically disparate, and are reflective of gender and race/ethnic differences. In 2008-2012, the median household income in Texas was \$51,563—lower than the national median income of \$53,046. To determine who lives in poverty, the U.S. Census Bureau uses a set of income thresholds that vary by family size and composition. If a family’s total income is less than the family’s threshold, then that family and every individual in it is considered to be in poverty. The same income thresholds are used throughout the U.S. and do not vary geographically.

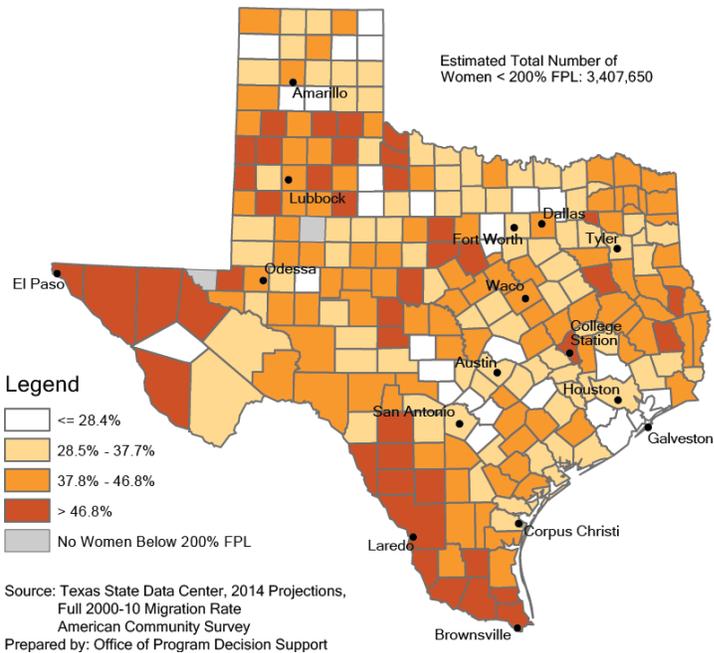
Texas has a higher poverty rate than the country as a whole. Specifically, Texas (38.5 percent) has higher rates of people living below 200 percent of the Federal Poverty Level (FPL) compared to the national average of 33.6 percent. Furthermore, Texas has higher rates of people living below 100 percent of FPL for every age group, gender, race/ethnicity, and employment status than the nation as a whole. The highest concentrations of poverty in 2008-2012 were in the border region (see Figure 2.8). The metropolitan areas located in the Texas-Mexico border region had the highest poverty rates among all metropolitan areas in the U.S. (i.e., El Paso, Laredo, and Brownsville).

Figure 2.8
 Percent of Adult Population with Income Below 200% of Federal Poverty Level, 2008-2012



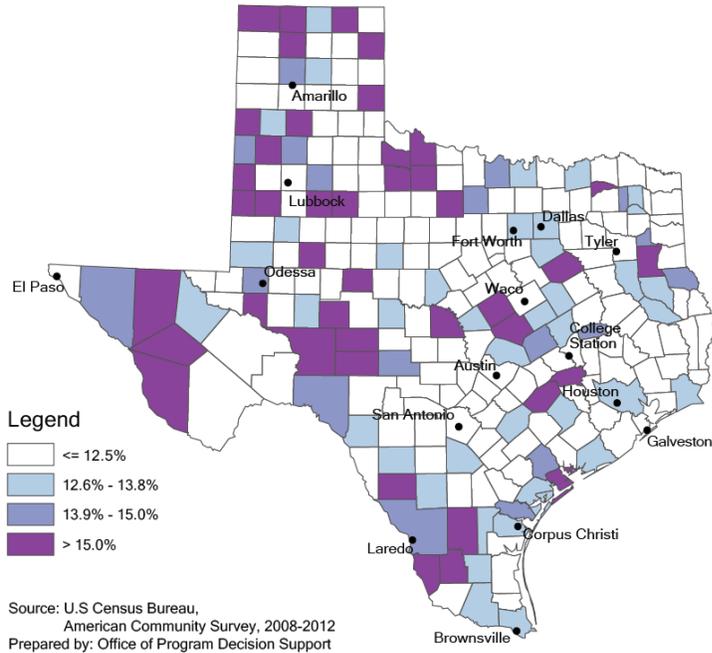
In 2008-2012, there were high percentages of women below 200 percent FPL in the rural areas of east Texas around Tyler, south of Fort Worth, and also between Lubbock and Amarillo in the panhandle (see Figure 2.9). The fastest growing major metropolitan areas—Austin, Houston, and San Antonio—did not have a high percentage of women below 200 percent FPL.

Figure 2.9
 Estimated Percent of Adult Female Population below 200% of Federal Poverty Level



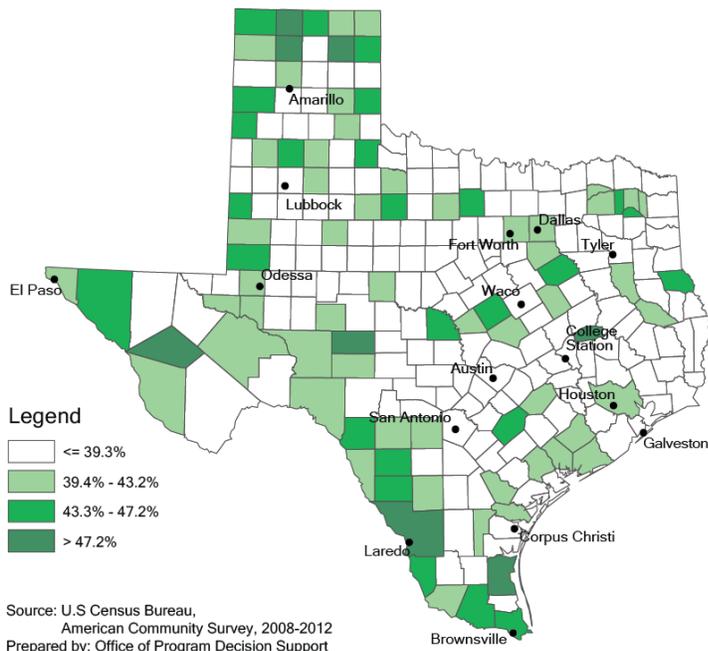
Additionally, Texas has a greater proportion of children younger than 5 years of age living below 100 percent FPL (12.5 percent) than any other state [4]. Children below the poverty level comprise 39.3 percent of the population younger than 18 years of age [4], which is also more than any of the other states.

Figure 2.10
Percent of Children Younger than 5 Years Old Below
100% Federal Poverty Level, 2008-2012



In 2008-2012, there were 42 counties where more than 15 percent of children younger than the age of 5 live below 100 percent FPL (see Figure 2.10). The highest concentrations of poverty were in the rural areas of far west Texas and areas north of Amarillo. There are also areas of the state with low concentrations of poverty. There were 153 counties where the percentage of children in poverty is at or below the state average of 12.5 percent. There are seven more counties where the percentage of children aged 18 and younger living in poverty in 2008-2012 was at or below the state average of 39.3 percent (see Figure 2.11).

Figure 2.11
 Percent of Children Younger than 18 Years Old Below
 100% Federal Poverty Level, 2008-2012



Education

Lower educational attainment is also associated with poverty, and consequently related to poor health outcomes. According to the U.S. Census Bureau’s American Community Survey five-year estimates, among those aged 25 and older, a greater percentage of men (19.8 percent) and women (18.7 percent) in Texas had less than a high school education in 2008-2012, compared to men (15.0 percent) and women (13.6 percent) in the U.S., as a whole [4]. Approximately a quarter of Texas residents have a high school diploma or equivalent, and a quarter have a bachelor’s degree or higher. The educational attainment in Texas is slightly lower than the rest of the U.S. However, this level of education attainment is not evenly distributed throughout the state.

There are four counties where the educational attainment of a bachelor’s degree or higher for individuals 25 years of age and older was 40 to 50 percent in 2008-2012, namely Denton and Collin counties outside of Dallas, Fort Bend county outside of Houston, and Travis county in Austin. Counties where less than 10 percent of the population aged 25 years and older had a bachelor’s degree or higher were clustered along the border.

Unemployment

While Texas has a higher percentage of people without a high school diploma, it has a lower rate of unemployment than the nation as a whole. In fact, the unemployment rate in 2008-2012 for those without a high school diploma was still lower in Texas (9.4 percent) compared to the national average (14.2 percent) [4]. The Texas unemployment rate continues to decrease in parallel as education increases. The unemployment rate in Texas is as low as 3.5 percent among those with a bachelor’s degree or higher.

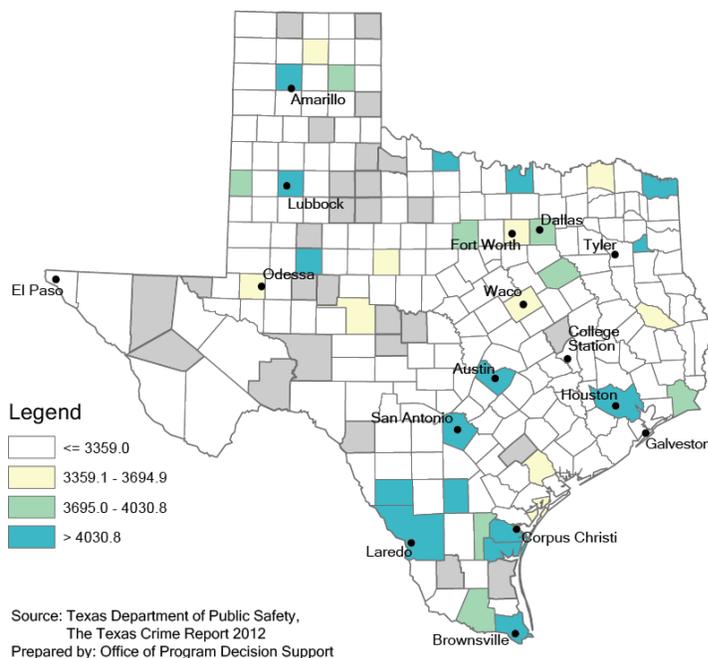
Whereas Texas (7.7 percent) has had a lower unemployment rate compared to the U.S. (9.3 percent), there are 93 counties that have had an unemployment rate higher than the state average. The same areas of the state with a low percentage of higher educational attainment (a bachelor’s degree or higher), especially along the border region and northeast of Galveston bordering Louisiana, have also had higher unemployment rates.

Crime

Crime impacts the physical and behavioral health and wellbeing of mothers, children, and their families. Neighborhood crime can be detrimental to the safety of children, creating unstable living environments. By tracking communities where crimes occur, it is possible to identify areas most at risk. There has been a three percent decrease in the crime rate from 2011 to 2012 [5] in the state.

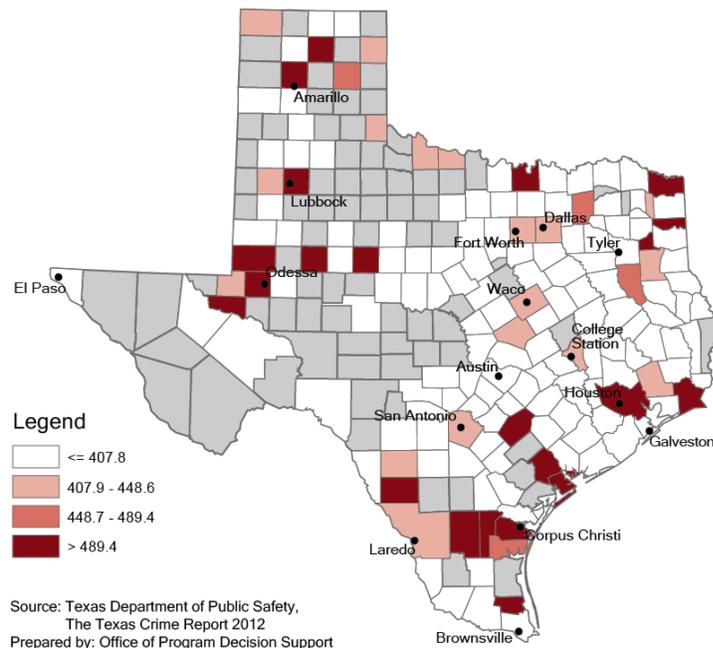
Texas crime statistics describe two major categories of crimes—property crime and violent crime. Property crime consists of burglary, larceny, and motor vehicle theft. These types of crime in 2012 were primarily localized in and surrounding larger cities in the south, and larger cities in the panhandle of Texas (see Figure 2.12).

Figure 2.12
Property Crime Rate per 100,000, Texas 2012



Violent crime includes murder, rape, robbery, and aggravated assault. These types of violent crime were primarily concentrated near the larger cities of the panhandle, in Odessa, Lubbock, and Amarillo (see Figure 2.13). Other areas with a high concentration of violent crime in 2012 were around Corpus Christi and the surrounding areas. Two counties had both the highest property and violent crime rates, namely Howard County (north of Odessa) and Harris County (Houston area).

Figure 2.13
Violent Crime Rate per 100,000, Texas 2012



Violence within Texas families has also been recognized as a growing threat to the safety of Texans. According to the Uniform Crime Report, there were 198,366 family violence incidents in Texas in 2012, an 11.5 percent increase when compared to 2011. Although the largest percentage of family violence involved other family members (46 percent), family violence also occurred among spouses/couples (38 percent) and within parent/child relationships (16 percent). Of the victims involved in family violence in 2012, 27 percent were males and 73 percent were females. The age group with the highest number of victims or offenders was between 20 to 24 years of age.

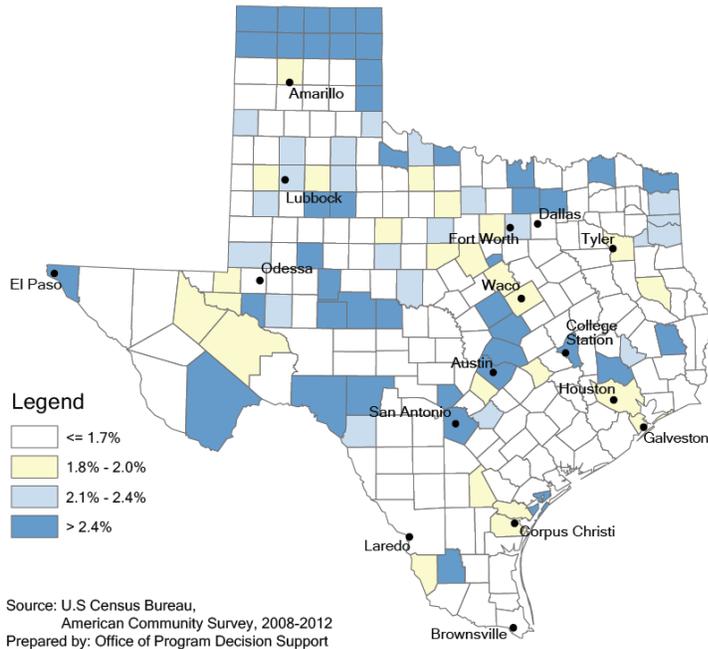
Mobility/Migration

Moving or relocating is one of life's most stressful events, and as such, it can impact individual health and wellbeing [6, 7]. Indeed, the Texas School Survey of Substance Use (TSSSU) shows that students in grades 7 to 12 living in their current school district for three years or less are more likely to use illicit drugs than those living in there more than three years. [8] (See Chapter 7 for further discussion of this health issue.)

Out-of-State Mobility/Migration

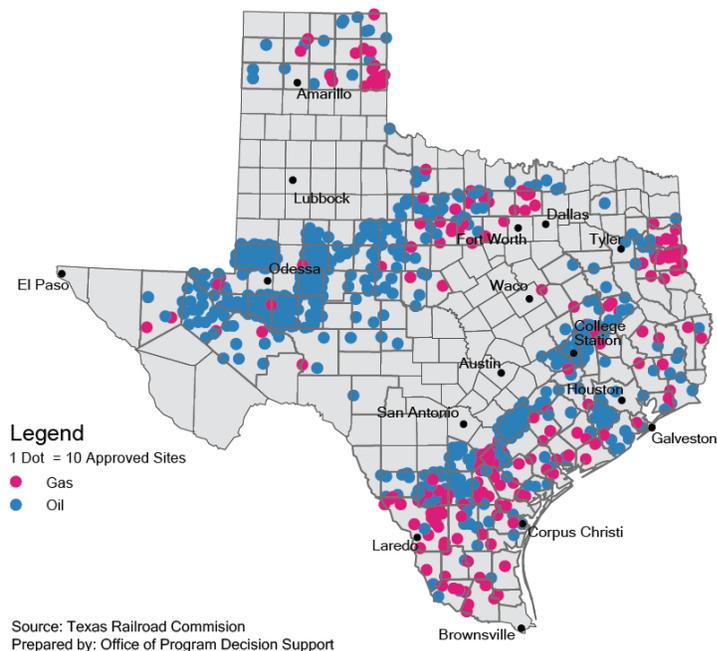
Texas is home to three of the ten fastest growing major metropolitan areas in the United States—San Antonio, Houston, and Austin [3]. In 2008-2012, more than 500,000 people moved to Texas from another state [4]. In two of the three fastest growing areas in Texas, Austin and Houston, more than 2.4 percent of their population consists of people who moved to the area from out of state. In addition to migration in urban areas, some rural areas have also seen high levels of out-of-state migration, particularly in the parts of the state bordering Oklahoma and the panhandle (see Figure 2.14). While relocation into Texas has been dramatic in several areas of Texas, the majority of counties have had little or no new residents from other states.

Figure 2.14
Percent of Population that Moved from Another State to Texas,
2008-2012



Several areas with high rates of migration into the state also have high densities of oil and gas sites [9]. The oil and gas industry is concentrated in three areas of the state (see Figure 2.15). Many of the counties with a large number of active oil or gas wells are also counties with high out of state migration. The strong oil and gas industry and resulting jobs may well be contributing to the migration of people into these areas.

Figure 2.15
Approved Oil and Gas Sites, June 2013-June 2014



In-State Mobility/Migration

Another aspect of mobility is the number of people who move within counties or between counties in Texas. While out-of-state migration may reflect job growth, mobility of populations within a county and between counties is more complicated.

The counties with universities and colleges in Texas have also been the places that have some of the highest rates of within-county relocations in the past year. For example, the cities of College Station, Austin, and Lubbock are home to three of the ten largest universities in Texas [10], which can partially explain the high rates of within-county relocations. After all, college students tend to move often within the same county to take advantage of lower rents.

Apart from college counties, however, within- and between-county mobility in Texas is associated with poverty. Poorer people tend to move more within the same county, whereas richer people tend to move more between counties. That is, within-county mobility during the past year is positively correlated with the poverty rate (below 100 percent FPL, $r = .28$) and the near-poverty rate (below 100 percent FPL, $r = .16$), such that census tracts with higher rates of poverty or near-poverty tend to also be census tracts with higher within-county mobility.

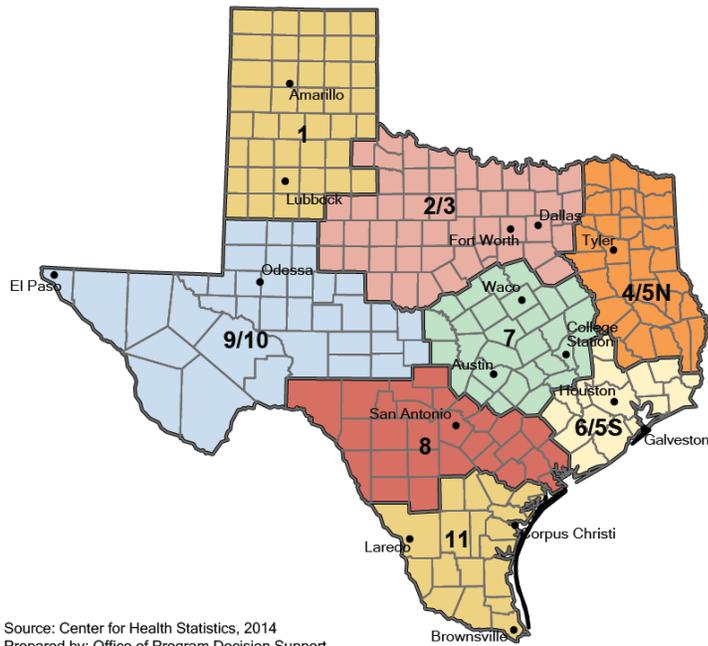
Between-county mobility and poverty have just the opposite relationship. Between-county mobility during the past year is negatively correlated with the poverty rate (below 100 percent FPL, $r = -.10$). This means that census tracts with higher poverty rates tend to also be census tracts with lower between-county mobility.

Health Care Coverage and Access

Fundamental to the health of Texas mothers, children, and families is the extent to which they have health insurance and access to health care. The major result from the Title V stakeholder meetings was that access to care was a major concern and was a concern for all populations. For children with special health care needs, lack of financial support or no insurance was a top reason parents said they could not receive care for their child. Understanding access issues and barriers will be paramount to addressing these identified needs.

Each of the 254 Texas counties is assigned to one of 11 public health regions (see Figure 2.16). However, for administrative purposes, there are eight Health Service Regions (HSRs). Region 1 (HSR 1) is administered from an office in Lubbock. Regions 2 and 3 (HSR 2/3) are administered from a regional office in Arlington. Region 4 and the northern part of Region 5 (HSR 4/5N) are administered from a regional office in Tyler. Region 6 and the southern part of Region 5 (HSR 6/5S) are administered from a regional office in Houston. Regions 9 and 10 (HSR 9/10) are administered from a regional office in El Paso. Of the counties in Region 5, three are in HSR 6/5S: Hardin, Jefferson, and Orange. The rest of the Region 5 counties are in HSR 4/5N [11].

Figure 2.16
Texas Health Service Regions



Source: Center for Health Statistics, 2014
Prepared by: Office of Program Decision Support

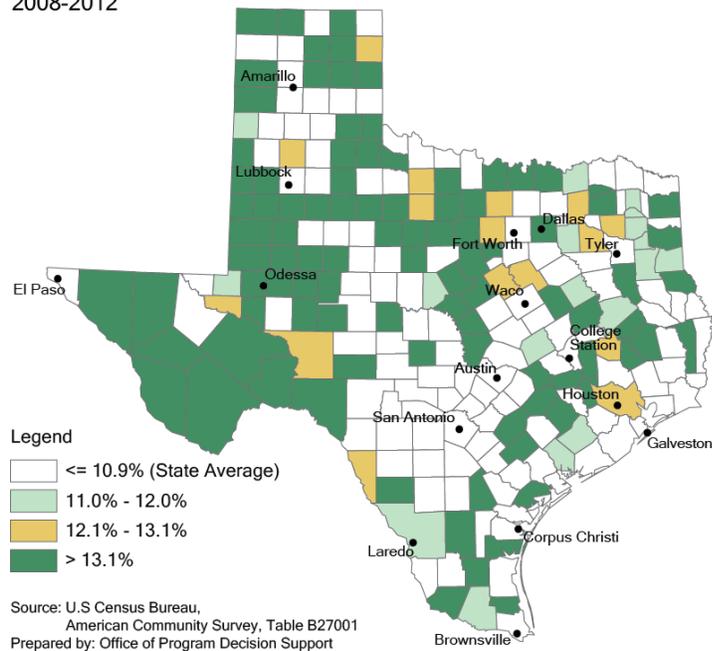
Health Insurance

At 23.0 percent, Texas led the nation in the percentage of the population without health insurance coverage in 2008-2012. The national average was 14.9 percent [4]. The high rate of uninsured individuals places a burden on both state and national public health services. The uninsured are less likely to have a regular source of medical care and are more likely to delay or forgo needed health care services, as evident from the results of the CYSHCN parent outreach survey. The highest uninsured populations in Texas include Hispanic women, Black women, and individuals along the Mexico-Texas border. These groups also have the highest poverty rates and the lowest levels of educational attainment.

In terms of race/ethnicity, according to the American Community Survey [4], there were higher rates of uninsured among Whites (13.3 percent), Blacks (20.7 percent), and Hispanics (35.9 percent) in Texas in 2008-2012 than among the same race/ethnic groups in the U.S. (Whites = 10.4 percent; Blacks = 17.5 percent; Hispanics = 30.1 percent).

In Texas, 14.5 percent of people at or above 200 percent FPL were also uninsured compared to 9.3 percent of the nation as a whole. Data show that vulnerable populations in Texas also have lower rates of health insurance coverage, including children and women in their childbearing years [4]. In Texas, 10.9 percent of children younger than age 6 are uninsured compared to only 6.6 percent nationwide, and 33.6 percent of Texas women aged 18 to 44 are uninsured compared to 21.3 percent in the nation.

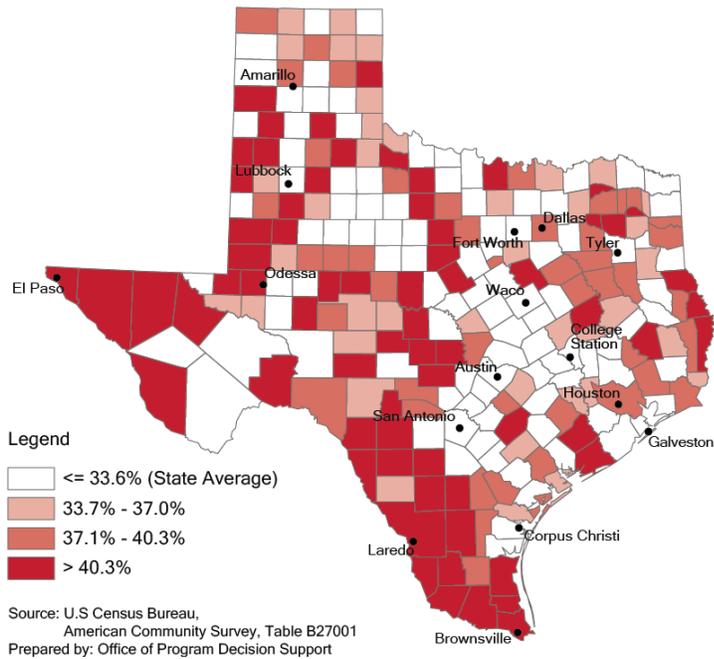
Figure 2.17
 Percent of Children Younger than 6 Years without Health Insurance,
 2008-2012



Children younger than 6 years of age without health insurance tend to be concentrated in west Texas right outside of El Paso and up into the panhandle (see Figure 2.17). In two-fifths of the counties in Texas, more than 13.1 percent of children younger than the age of 6 did not have health insurance coverage.

Among Texas women aged 18 to 44, 33.6 percent were without insurance in 2008-2012 (see Figure 2.18). Additionally, the border region and north into the lower part of the panhandle, have a greater percentage of women of childbearing age who were uninsured.

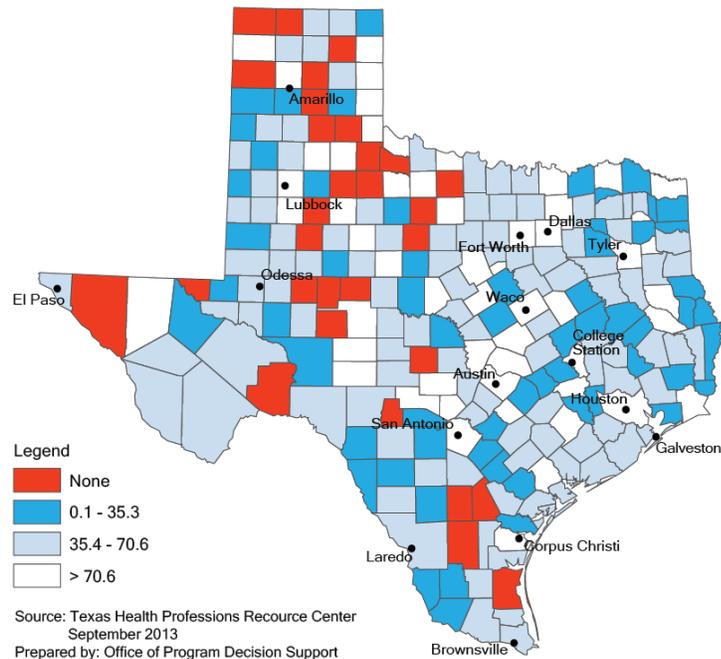
Figure 2.18
 Percent of Females (18-44 years) without Health Insurance, 2008-2012



Access to Health Care

Given the size of the state and the vast distances between points of care for health services in rural areas, access to care in Texas can be a challenge. Overall, for every 100,000 Texas residents, there were 70.6 primary care physicians in September 2013 (see Figure 2.19). There are 30 counties that did not have any primary care physicians. The total number of primary care physicians has increased, from 16,830 in 2009 (67.7 per 100,000) to 18,834 in 2013 (70.6 per 100,000).

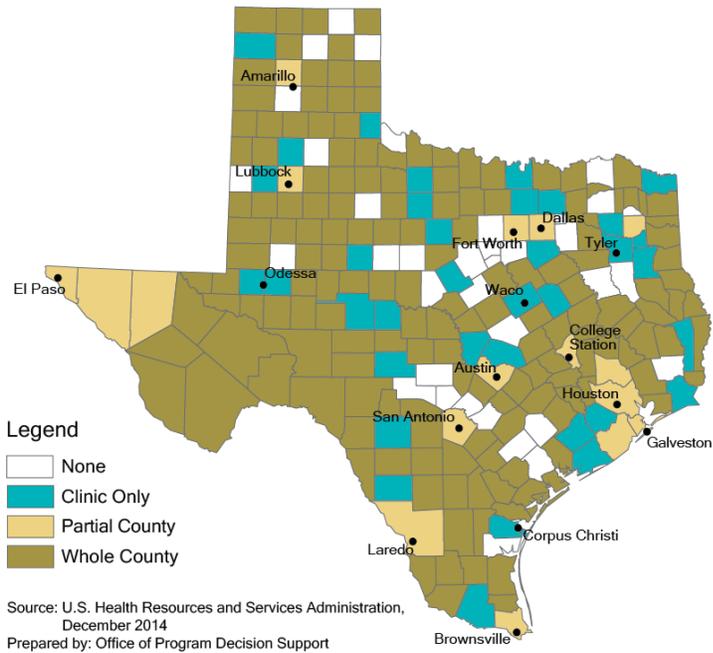
Figure 2.19
 Ratio of Primary Health Care Physicians to 100,000,
 Texas September 2013



The number of obstetricians (OB) and/or gynecologists (GYN) has increased from 2,314 in 2009 to 2,483 in 2013. However, for every 100,000 females in Texas, the number of OB/GYNs has decreased from 19 in 2009 and 2010 to 18.5 in 2013. A total of 149 counties did not have any OB and/or GYN in 2013 [12]. Furthermore, in 2013, 48 counties did not have a local dentist.

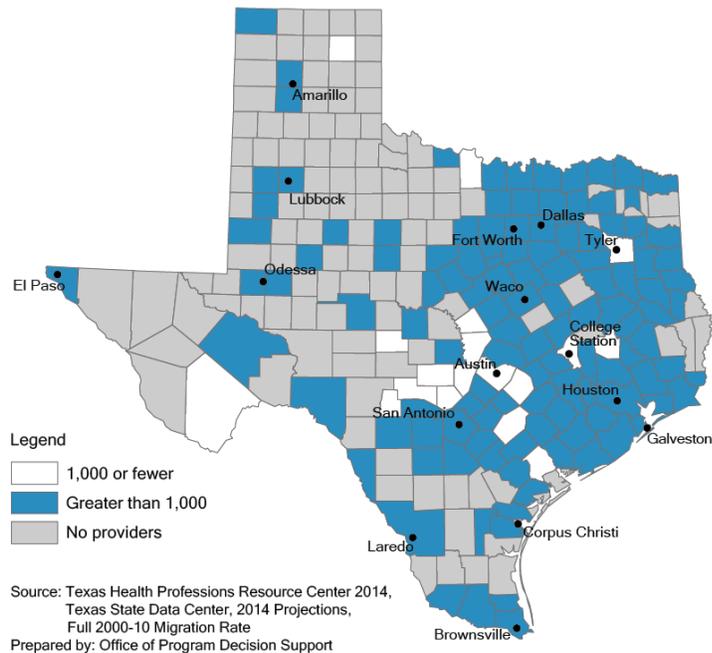
The geography and population in the state of Texas presents a unique challenge in terms of adequate access to health care services across the state. As a result, whole or partial counties, as defined by the Health Resources and Services Administration (HRSA), have been designated as health professional shortage areas (HPSAs) by having a shortage of primary medical care, dental, or mental health providers. Recruiting and retaining health care professionals is an ongoing challenge not only in rural areas but also in some urban areas. In rural areas, it is mostly due to population size, but in some urban areas, access is limited because many providers do not accept Medicaid or because patients are not enrolled in Medicaid and are unable to pay out-of-pocket. There are very few areas in the state that are not designated as a HPSA (see Figure 2.20; [13]).

Figure 2.20
 Primary Care, Health Professional Shortage Areas, December 2014



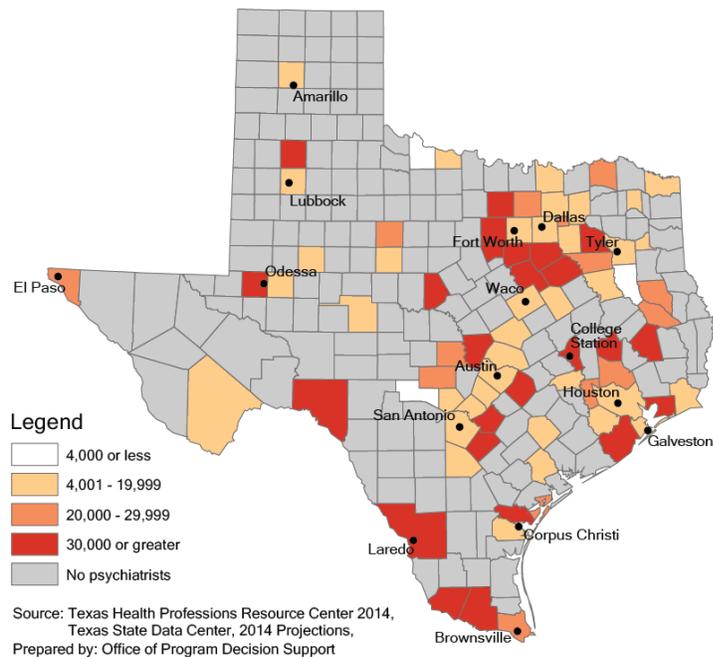
Parents who responded to the Title V community outreach survey indicated that finding a mental or behavioral health professional was very or extremely difficult, especially finding those that treat children. The National Association for School Psychologists recommends a provider to student ratio of 1:1,000 [14]. We do not have specific student enrollment for each county, but based on population, the only county with a high population meeting this ratio is Travis, where Austin is located (see Figure 2.21).

Figure 2.21
Ratio of Children to School Psychologist, 2014



The availability of psychiatrists (or lack thereof) is also concerning. Studies have indicated areas with more than 4,000 people in the population to every psychiatrist are likely to be impacted by a lack of mental health providers. There are only three counties in Texas meeting this ratio (see Figure 2.22). The cut offs for designating a county a mental health shortage area is 20,000 to 1 psychiatrist and 30,000 to 1 psychiatrist, depending on if the county has a high need for mental health services. Of the counties with a psychiatrist, most of the border counties would meet one of these two cut-offs and many counties surrounding major cities would meet these cut-offs.

Figure 2.22
Ratio of Population to Psychiatrist, 2014



While psychiatrist shortages point to a general shortage in the population, it must be noted that these shortages are even worse for finding psychiatrists who specialize in child psychiatry. It has been estimated that there are only about 8,300 practicing child and adolescent psychiatrists in the country. There are almost no child and adolescent psychiatrists in the state practicing outside of the major cities, [15].

Chapter 3. Pre-Pregnancy Health

This chapter focuses on general health issues in Texas. Because men are fathers and their health behaviors can influence the mother's behaviors [16] [17], select health risks for men will also be presented. There is certain terminology and population distinctions that must be kept in mind when reading this chapter. The focus is on both women's health in general and the health of women who gave birth. General women's health refers to all women between 18 and 44 years of age and who reside in Texas. The health of this group of women provides an overview of general preconception health in the state, as it is clear that health in this period has a lasting impact on health during a pregnancy [18]. The women who went on to give birth are a distinct group and are referred to as the maternal birth cohort.

This latter distinction is made because not all women in the 18-44 year old age range are "at-risk" of giving birth. According to Texas Behavioral Risk Factor Surveillance System (BRFSS) data, in 2009 and 2010, approximately 17 percent of women in this age range either had a tubal ligation or hysterectomy as a stated means to avoid getting pregnant, and 65 percent of women were actively avoiding becoming pregnant. Therefore, the health issues that women in the general population are facing may not necessarily reflect the health status of the women in the maternal birth cohort.

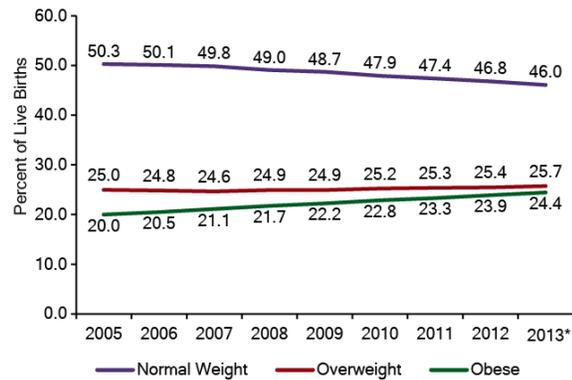
Obesity and Chronic Disease

The terms overweight and obesity will be used throughout this report. These categories are determined by an individual's body mass index (BMI), which is the person's weight divided by height squared. BMI is used to determine obesity and overweight because, for most people, it correlated with the person's level of body fat. The overweight and obese cut-offs differ based on the individual's age and is based on the general distribution of BMI in the population. For all age groups, individuals with a BMI in the 85th-95th percentile for their age are categorized as overweight. Those with BMI in the 95th percentile or higher are categorized as obese.

In Texas, 30.9 percent of adults are obese compared to 29.4 percent for the United States [19]. Texas has the 15th highest obesity rate in the United States. However, obesity is not equally distributed across all race/ethnic groups. Texas is tied with Michigan for the third highest obesity rate among Hispanics.

Women in the maternal birth cohort have a slightly lower rate of obesity than women in the general population. However, there has been a rise in women being obese before becoming pregnant in the maternal birth cohort. The percent of women with a BMI in the obese range among this group has increased 22 percent since 2005 (see Figure 3.1).

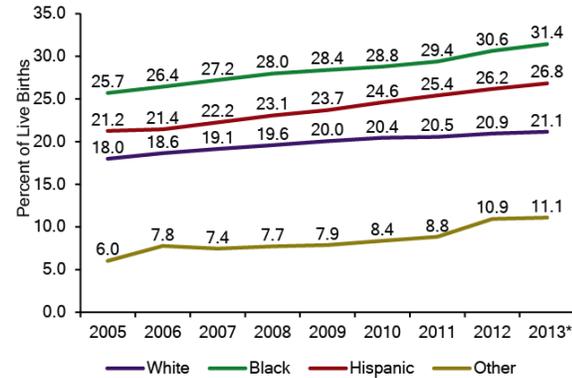
Figure 3.1
Distribution of Pre-Pregnancy Body Mass Index, Texas 2005-2013



*2013 Texas data are preliminary
Source: 2005-2013 Birth Files
Prepared by: Office of Program Decision Support

Black and Hispanic women in the maternal birth cohort have the highest pre-pregnancy obesity rate (see Figure 3.2). In 2013, the rate for Black women was 22 percent higher than the rate in 2005. The rate for Hispanic women rose 26 percent from 2005 to 2013. White women had a 17 percent rise in pre-pregnancy obesity since 2005. Women in the “other” race/ethnic category have the lowest pre-pregnancy obesity rate; however, this group has experienced the largest percent increase in obesity since 2005. The underlying causes of this increase are likely due to a host of factors, including changes in the demographics that make-up this group (see Chapter 4).

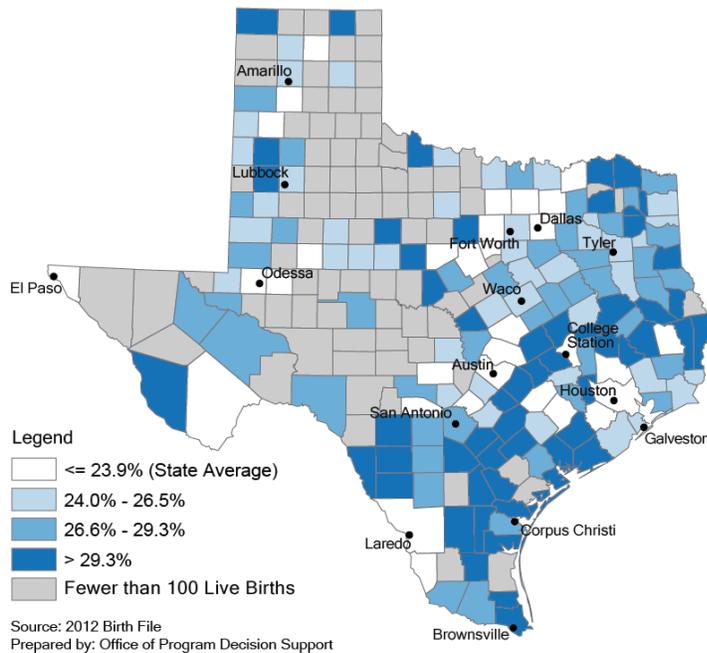
Figure 3.2
Pre-Pregnancy Obesity, Race/Ethnicity 2005-2013



*2013 Texas data are preliminary
Source: 2005-2013 Birth Files
Prepared by: Office of Program Decision Support

With few exceptions, higher concentrations of obese women in the maternal birth cohort live in rural and suburban areas (see Figure 3.3). These are the counties surrounding the major cities. However, within counties and cities, the concentration of obesity is also not evenly distributed through the county.

Figure 3.3
Percent of Births to an Obese Mother, 2012



One environmental factor that may be associated with obesity is access to nutritious food. In April 2011, the Division of Nutrition, Physical Activity and Obesity of the Centers for Disease Control and Prevention (CDC) released the modified retail food environment index (mRFEI) for all census tracts in the United States [20]. The mRFEI index measures the number of healthy and less healthy food retailers within census tracts as defined by food groups and type of retail stores (e.g., supermarkets, convenience stores, or fast food restaurants). The mRFEI is calculated for each census tract using a score based on the number of “healthy food retailers” and “less healthy” food retailers. This index defines healthy food retailers as supermarkets, larger grocery stores, supercenters, and produce stores within the census tract or a half mile from the tract boundary. Less healthy food retailers are fast food restaurants, small grocery stores, and convenience stores within the census tract or a half mile from the tract boundary. The mRFEI categorizes the environment into three types of food environments. Food deserts are areas that lack healthy retail outlets. Food swamps are areas with a large amount of retailers selling energy-dense snack foods. Healthy food environments have a relatively high number of health food retail outlets.

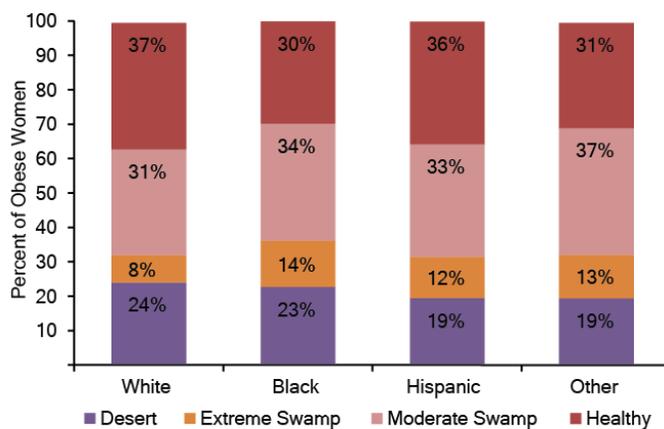
To explore variance in obesity rates among women in the maternal birth cohort, mother’s place of residence was geo-coded and linked to the modified retail food environment index (mRFEI) for 2000 census tracts. This index was developed by the CDC between 2009 and 2010. To be temporally concurrent with the measure, only 2010 birth data were linked to the index. There was a significant, but surprising, difference in the way that pre-pregnancy obesity was distributed across the categories.

Within the entire birth cohort, there were a greater number of White and Hispanic women in food deserts, regardless of BMI than was statistically expected. Black women had a higher than expected concentration in extreme food swamps. Additionally, with the exception of Hispanic women, women in

the birth cohort living in food deserts were significantly younger than women living in healthy food environments.

When assessing the entire distribution of obese women across these food environments (see Figure 3.4), women in food deserts were at a higher risk of being obese than women living in a healthy food environment, controlling for age of the mother. Surprisingly, women living in extreme food swamps, were at a lower risk of being obese than women living in healthy food environments, even when controlling for maternal age. Overall, though, these relations were weak, meaning that these relations did little to explain variance between census tracts in pre-pregnancy obesity.

Figure 3.4
Distribution of Pre-Pregnancy Obesity Across Food Environments, 2012



Source: 2012 Birth File Linked Modified Retail Food Environment
Prepared by: Office of Program Decision Support

It is important to consider the results of the linked analysis of mRFEI index and pre-pregnancy obesity in the context of other data sources. The results of the Title V Focus Groups suggest that knowledge about obesity and eating healthier is not enough to change behavior. Most of the focus group members understood what eating healthy meant and could describe a healthy meal. Additionally, with few exceptions, most did the majority of their shopping at grocery stores. These participants described the barriers to healthy eating as time, fatigue, and cost. Both men and women cited a lack of time and energy to cook healthy meals and the convenience of fast food as to the reasons they did not eat healthy every day. While some of the focus group members said that “fast food was everywhere”, all understood that it was unhealthy and all knew a place where to purchase fresh food and vegetables. Many of the participants were clear that unhealthy food was cheaper than healthy food; therefore, they were likely to purchase it when budgets were tight. For the men and women in these groups, the barriers to healthy eating were about time, energy, and cost.

Obesity and chronic diseases that are associated with obesity are top health concerns within the state. Among the parents who responded to the Title V community outreach survey, 54.0 percent chose obesity as a top health concern and 39.9 percent chose chronic disease. Additionally, 40.5 percent chose lack of exercise and physical activity as a top five health concern in their community. Among the Title V Focus Groups, all groups listed obesity as a top health concern and cited its links to heart disease,

diabetes, and hypertension. There is wide awareness about the negative health effects of obesity on health in the state.

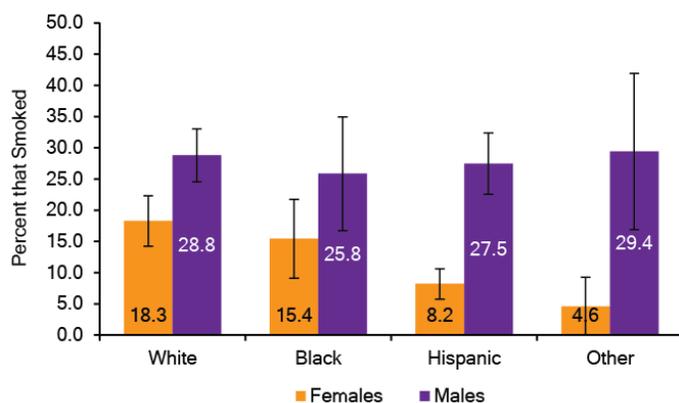
Smoking and Other Risk Behaviors

Smoking is a leading cause of disease, as well as a contributor to the poor outcomes of many diseases. Smoking increases the risk of several types of cancer such as throat, lung, mouth, nasal cavity, esophagus, stomach, pancreas, kidney, bladder, cervix and acute myeloid leukemia. Smokers also have a six-fold increased chance of a heart attack as compared to non-smokers [21]. As will be discussed in later chapters, parental smoking poses a significant risk for fetal, infant, and child health, as well. The risks of smoking are not confined to the smoker, making it an important behavior to target to improve the health of the communities. Although the prevalence of smoking has been on the decline for several years, efforts are still needed to reduce the rate even more.

Texas has the 15th lowest smoking rate in the United States according to the 2011 BRFSS data [19]. Among the 18-44 year old population, there are substantial differences between men and women and race/ethnicities (see Figure 3.5). Men (27.9 percent; C.I.: 25.0-30.9) have a significantly higher rate of being a current smoker than women (12.7 percent; C.I.: 10.6-14.8).

These sex differences are even larger when race/ethnicity is also considered. Hispanic women and women in the “other” race/ethnicity category have significantly lower smoking rates than men of any race/ethnicity or of White women.

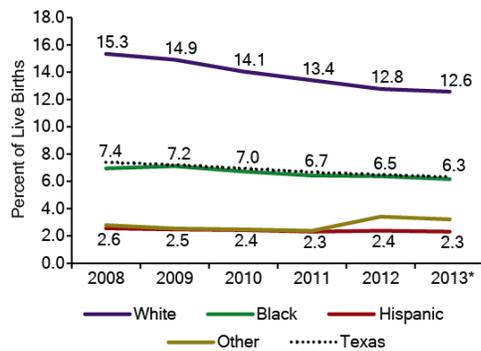
Figure 3.5
Smoking Rates by Sex and Ethnicity, BRFSS 2012



Source: 2012 Behavioral Risk Factors Surveillance System
Prepared by: Office of Program Decision Support

These low smoking rates carry over into the maternal birth cohort, as well. In Texas, the reported rate of smoking 3-months before pregnancy has decreased to 6.3 percent (see Figure 3.6). This rate is better than the HP2020 target of 14.6 percent. All race/ethnic groups in the state have exceeded the HP2020 target since 2010. As with smoking in the general population, Hispanic women and women in the “other” race/ethnicity category have significantly lower smoking rates than White and Black women.

Figure 3.6
Women who Smoked 3-Months Prior to Pregnancy,
Race/Ethnicity 2008-2013



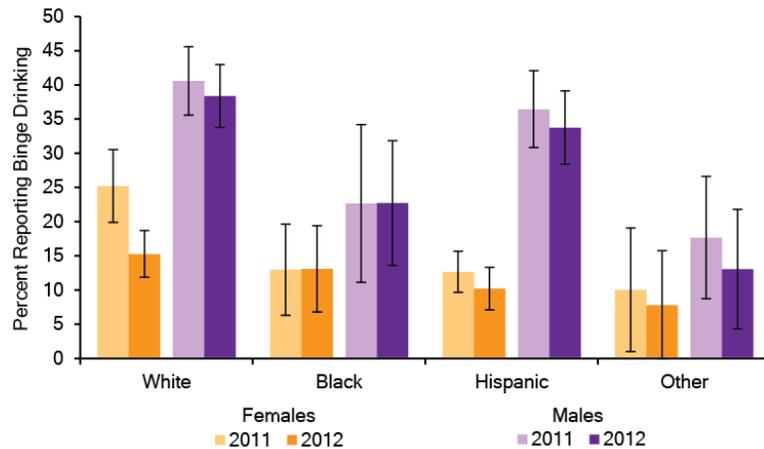
*2013 Texas data are preliminary
 Source: 2008-2013 Birth Files
 Prepared by: Office of Program Decision Support

In addition to smoking, women engage in other risk behaviors, such as alcohol and drug use. Prenatal exposure to alcohol is one of the leading preventable causes of birth defects and intellectual disabilities. Nonmedical drug use (e.g., recreational use) has been associated with poor prenatal weight gain, impaired fetal growth, and premature birth [22]. Use of alcohol or/and drugs is also harmful to health of the mother and can interfere with chances of becoming pregnant.

Alcohol is the most widely used substance in the adult population. Additionally, it is the most frequently mentioned substance used in combination with other illicit drugs [23]. Binge drinking (i.e., having 5 or more drinks for men or having 4 or more drinks for women on the same occasion on at least 1 day in the past 30 days) among young adults is also of concern. Combined 2010 and 2011 data from the National Survey of Drug Use and Health (NSDUH) found that 54.0 percent (C.I.: 51.6-56.4) of adult Texans aged 18 years and older reported past-month alcohol use and 26.4 percent (C.I.: 24.6-28.2) had engaged in binge drinking. This binge drinking rate is higher than the HP2020 target of 24.4 percent. Young adults aged 18-25 (39.2 percent; C.I.: 36.8-41.7) have a higher rate of binge drinking in the past month than adults aged 26 or older (23.9 percent; C.I.: 21.9-26.1).

The rates for drinking among women of childbearing age are lower than those of men in the same age range according to the 2011 and 2012 BRFSS data (see Figure 3.7). NSDUH also shows that about 53.6 percent (C.I.: 50.6-56.6) of women aged 18-44 had a drink in the past month and 25.2 percent (C.I.: 22.7-27.8) had engaged in binge drinking. In comparison, males aged 18-44 reported a significantly higher rate of past-month alcohol use (65.7 percent; C.I.: 62.4-68.9) and binge drinking (43.8 percent; C.I.: 40.6-47.0). While past-month drinking rates in Texas were lower than the national rate, Texas binge drinking rates were similar to the nation. Binge drinking among men aged 18-44 in Texas has continued to decrease since 2004-2005, yet women aged 18-44 has seen a 14 percent increase in binge drinking since 2004-2005.

Figure 3.7
Binge Drinking Rates by Sex and Ethnicity, BRFSS 2011, 2012



Source: 2011 & 2012 Behavioral Risk Factors Surveillance System
Prepared by: Office of Program Decision Support

Use of illicit drugs, such as marijuana, cocaine (including crack), hallucinogens, heroin, Ecstasy, and methamphetamine, or nonmedical use of prescription drugs, such as pain relievers, stimulants, and depressants, also causes serious consequences to the health and well-being of the user. From the 2010-2011 NSDUH, about 6.9 percent (C.I.: 6.1-7.8) of adult Texans aged 18 years and older reported past-month use of illicit drugs. This rate is better than the HP2020 target of 7.1 percent.

Marijuana is the most commonly used illegal drug among adults. About 5.3 percent (C.I.: 4.6-6.1) of adult Texans aged 18 or older had used marijuana in the past month and 9.0 percent (C.I.: 8.0-10.2) had used marijuana in the past year. However, both rates are lower than the national rates (6.9 percent; C.I.: 6.6-7.1 for past month use and 11.3 percent; C.I.: 11.0-11.6 for past year use in U.S., respectively). Among the 18-44 year old population in Texas, the rate of marijuana use among men was almost twice as high as that of women (9.7 percent; C.I.: 8.1-11.6 versus 5.3 percent; C.I.: 4.3-6.6 for past month use and 17.0 percent; C.I.: 14.6-19.6 versus 9.7 percent; C.I.: 8.2-11.6 for past year use, respectively). While the marijuana use pattern among women of child-bearing age has been stable over a three-year period, past-year marijuana use among men aged 18-44 has increased from 15.7 percent (C.I.: 13.6-18.1) to 17.0 percent (C.I.: 14.6-19.6).

Nonmedical use of prescription drugs is second only to marijuana as the state's most prevalent illicit drug and its prevalence has been increasing among teens (see Chapter 7) and young adults. Prescription drugs are often easy to access, inexpensive, and falsely believed to be safer than illicit drugs [24].

Nonmedical use is defined as use of prescription drugs without a prescription or to experience the feeling the drug causes. In the NSDUH, this use does not include misuse of over-the-counter medicines or legal use of prescription drugs. In Texas, approximately 3.1 percent (C.I.: 2.2-4.3) of women aged 18-44 reported nonmedical use of prescription drugs in the past month, and 7.0 percent (C.I.: 5.7-8.7) had engaged in nonmedical use of prescription drugs during the past year in 2010-2011. While men in the same age group reported a similar rate of use in the past month (3.3 percent; C.I.: 2.4-4.5) as women, they had a significantly higher rate (8.8 percent: C.I.: 7.3-10.7) of past-year use than women.

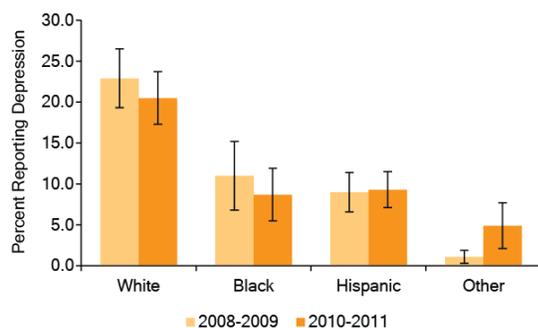
Mental Health

Mental illness is a public health problem that is also important to address. For women of child-bearing age, poor mental health may adversely affect a woman's quality of life, work productivity, and physical health, as well as have a negative impact on pregnancy, maternal functioning, and infant and child health and development [25]. The most common mental illnesses in adults are depression and anxiety. Both depression and anxiety disorders are more likely to affect women than men.

Depression is not only associated with substance use and the development of hypertension, heart disease, diabetes, and stroke, but is also a risk factor for suicide attempts [26]. A major depressive episode is defined as a period of at least 2 weeks when a person had a depressed mood or loss of interest or pleasure in daily activities, and had a majority of specified depression symptoms. A major depressive episode is not the same as having a diagnosis of depression. The 2010-2011 NSDUH data indicates that in Texas, 5.5 percent (C.I.: 4.8-6.4) of adults aged 18 or older had experienced at least one major depressive episode in the past 12 months, which is slightly higher than the HP2020 target of 5.8 percent. Also, 6.3 percent (C.I.: 5.3-7.4) of adults aged 18-25 and 2.2 percent (C.I.: 1.7-3.0) of adults aged 26 or older in Texas had serious thoughts of suicide during the past year.

Lifetime depression includes any individual who has been diagnosed with depression at any point in that person's life. The rate of lifetime depression for women is more than double that of men. Based on 2010-2011 NSDUH information, about 13.7 percent (C.I.: 11.8-15.7) of women aged 18-44 in Texas had ever been diagnosed with depression in her lifetime (see Figure 3.8), compared to 5.6 percent (C.I.: 4.2-7.3) of men aged 18-44. The rate of diagnosed depression differs by race/ethnic group. More than one in every five (20.5 percent; C.I.: 17.3-24.1) White women of child-bearing age had ever been diagnosed with depression, which is significantly different from Hispanic women (9.3 percent; C.I.: 7.1-12.1), Black women (8.7 percent; C.I.: 5.5-13.3), and all other race/ethnic groups (4.9 percent; C.I.: 2.1-11.2). Lifetime depression estimates from 2012 BRFSS are comparable to those in the NSDUH.

Figure 3.8
Percent of Females (18-44 years old) Ever Diagnosed with Depression, NSDUH



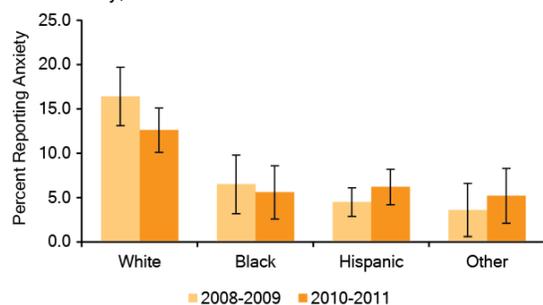
Source: 2008-2009 & 2010-2011 National Survey on Drug Use and Health
Prepared by: Office of Program Decision Support

Depression diagnoses also differed by employment status. The Texas BRFSS (2012) data for the 18-44 year old population indicated that employed men (7.6 percent; C.I.: 5.7-9.5) were significantly less likely to report lifetime depression than those not employed (16.6 percent; C.I.: 11.1-22.2). For employed women, 16.5 percent (C.I.: 13.3-19.6) had a lifetime depressive disorder compared to 18.4 percent (C.I.:

14.7-22.0) of women who were not employed. The data suggests that depression may be more likely to be associated with low social support and economic or structural inequality.

Anxiety and depression often occur together. Results of 2010-2011 NSDUH find that 8.7 percent (C.I.: 7.3-10.5) of Texas women aged 18-44 had ever been diagnosed with anxiety (see Figure 3.9), compared to 5.2 percent (C.I.: 3.7-7.1) of Texas men aged 18-44. Race/ethnic differences are also evident in lifetime prevalence for anxiety. Among the 18-44 year old women population in Texas, Whites reported a significantly higher rate of lifetime anxiety (12.6 percent; C.I.: 10.1-15.6) than Hispanics (6.2 percent; C.I.: 4.2-9.0), Blacks (5.6 percent; C.I.: 2.6-11.6), or all other race/ethnic groups (5.2 percent; C.I.: 2.1-12.0).

Figure 3.9
Percent of Females (18-44 years old) Ever Diagnosed with Anxiety, NSDUH



Source: 2008-2009 & 2010-2011 National Survey on Drug Use and Health
Prepared by: Office of Program Decision Support

Mental health conditions among women of child-bearing age have been critically alarming, making efforts to assess and identify risk factors associated with depression, anxiety, and poor mental health important. It is also crucial to have early diagnosis and treatment to reduce the disease burden of mental health disorders, as well as related chronic diseases. [27]

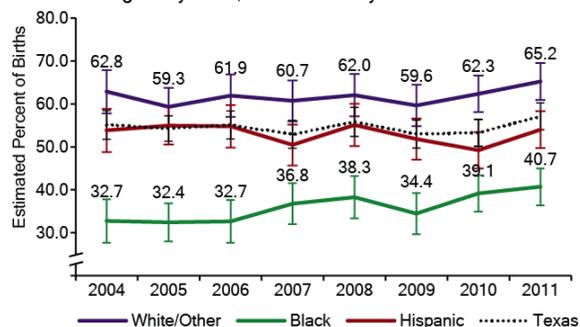
Planning and Pregnancy Spacing

The Texas BRFSS data (2009-2010) showed that an estimated 65 percent of women between 18 and 45 years old were not trying to become pregnant. This percentage jumped to 76 percent when women who were not sexually active or had same-sex partners are excluded. While this is an encouraging statistic, it should be considered in light of family planning choices women are making—5.6 percent of women are using methods with questionable efficacy and 18.3 percent are relying on male condoms as their sole source of contraception.

Part of having a healthy pregnancy is not just about whether the mother is healthy coming into the pregnancy, but also whether she and her partner planned the pregnancy. Women in Texas with an unintended pregnancy have significantly more health problems and pre-pregnancy risk behaviors than women with intended pregnancies. Analysis of Texas data from the Pregnancy Risk Assessment Monitoring System (PRAMS) for 2002-2010 has shown that women with unintended pregnancies were more likely to be physically inactive, to smoke, to binge drink, to be underweight, and to be anemic before they got pregnant. They were also less likely to be taking multi-vitamins [28]. As will be seen in later chapters, many of these risks continue into the pregnancy period, as well.

The rate of intended pregnancy has not significantly changed since 2004 according to our statewide PRAMS data (see Figure 3.10). Only about 50 percent of all pregnancies in Texas are intended. The differences in the intention rate among the race/ethnic groups are significant, though. For Black women, only about 40 percent of pregnancies were intended in 2011, which is significantly lower than the rates for White and Hispanic women.

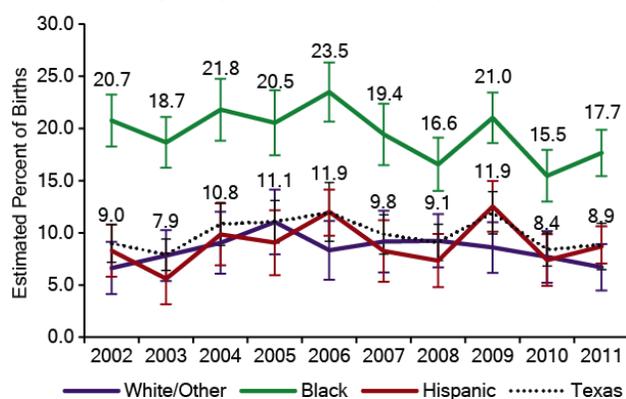
Figure 3.10
Intended Pregnancy Rate, Race/Ethnicity 2004-2011



Error Bars: 95% Confidence Interval
Source: 2004-2011 Texas PRAMS
Prepared by: Office of Program Decision Support

One of the most concerning categories of unintended pregnancies are the ones where the pregnancy was unwanted [29]. As with the general trend of unintended pregnancies, Black women have the highest rates of unwanted pregnancies (see Figure 3.11). For these women, between 15 and 20 percent of pregnancies from 2002 to 2011 were unwanted. This is significantly higher and almost double the rate of unwanted pregnancies for Hispanic and White women.

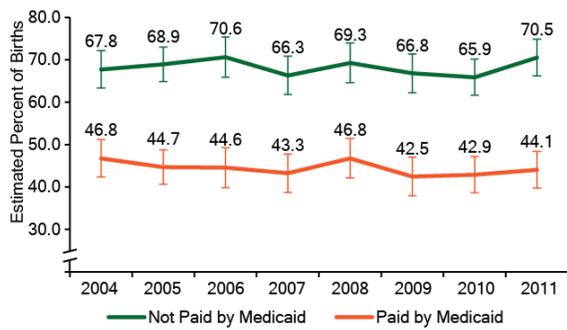
Figure 3.11
Unwanted Pregnancy Rate, Race/Ethnicity 2002-2011



Error Bars: 95% Confidence Interval
Source: 2002-2011 Texas PRAMS
Prepared by: Office of Program Decision Support

The rates of unintended pregnancies, and specifically, unwanted pregnancies, are highest among women whose birth is later paid for by Medicaid (see Figure 3.12). Consistent with the previous pregnancy intention trends, this rate has not shifted since 2002. Although these women had their births paid for by Medicaid, it is likely that they were not covered by Medicaid before becoming pregnant. Many may be reliant on low-cost safety net programs for health care and contraceptives.

Figure 3.12
 Intended Pregnancy Rate, Payer of Delivery 2004-2011

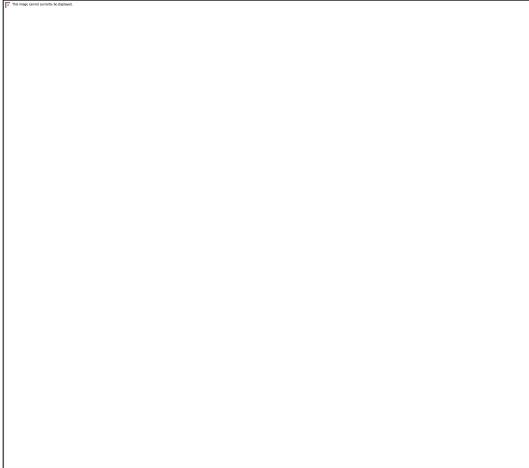


Error Bars: 95% Confidence Interval
 Source: 2004-2011 Texas PRAMS
 Prepared by: Office of Program Decision Support

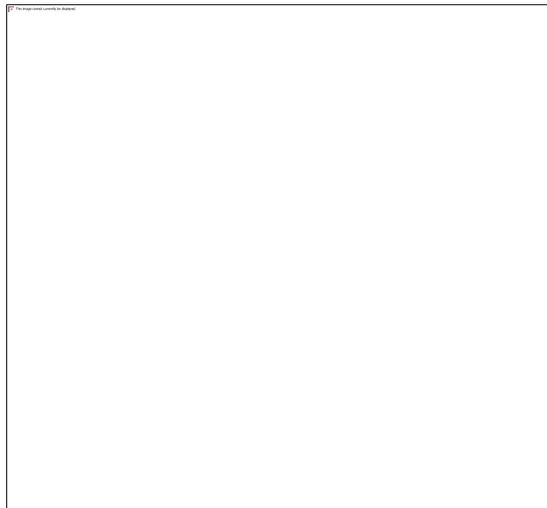
The PRAMS data on unintended pregnancies and BRFFS data on contraception use are all before 2012, which was a significant year for women’s health programs in Texas. In 2011, women’s health safety net programs were cut dramatically and state administered family planning programs were barred from contracting with agencies or providers who performed abortions. This funding was restored in 2013, however, there were still limits on whom the state could contract to provided family planning services. Because of these issues, the landscape and need for family planning services are likely different than reported here, especially for low-income women. As PRAMS data become available for 2012 and 2013, OPDS will be monitoring the unwanted and unintended pregnancy rates, especially in the populations that will go on to have their births paid for by Medicaid.

Part of planning for a healthy pregnancy is having healthy spacing between pregnancies [30] [31]. In Texas, approximately 62 percent of the birth cohort has already had a birth; therefore, pregnancy spacing impacts the majority of women in the birth cohort. There is clear evidence that a shorter inter-pregnancy interval—the time between delivery of the previous birth to conception of the current birth—is associated with several pregnancy risks and negative outcomes [30]. As will be shown in Chapters 4 and 5, women in Texas are not exceptions to these risks.

Since 2008, there have been changes in the distribution of inter-pregnancy intervals (see Figure 3.13). The percent of women with an inter-pregnancy interval of less than 7 months has decreased by 13 percent since 2008. However, the percent of women with intervals greater than 48 months has increased by 8 percent. These two inter-pregnancy intervals categories are noteworthy because they are associated with a variety of negative birth outcomes including low birth weight and preterm birth [30].



In 2012, Black women and Hispanic women had a higher percentage of births in these two categories than White women or women in the “other” category (see Figure 3.14). Additionally, women with the shortest inter-pregnancy intervals are significantly younger than all other groups. Women with the longest inter-pregnancy intervals are significantly older than women with other inter-pregnancy intervals. While the shortest and longest intervals are over-represented by these same two race/ethnic groups, the age differences strongly suggest that associated pregnancy risks and birth outcomes will be markedly different for each group.



There has been literature linking inter-pregnancy interval and pregnancy intention, showing that women with intervals shorter than 18 months are more likely to report that the birth was unintended. This finding is supported in the Texas data, as well. According to Texas PRAMS data in 2011, 57.9 percent of women with an interval of less than 18 months reported that the birth was unintended. This unintended pregnancy rate is significantly higher than the rate for women with any other interval length.

Like pregnancy intention generally, short inter-pregnancy intervals may also be an issue of access to health care. In the birth cohort, between 60 and 64 percent of births with intervals shorter than 7

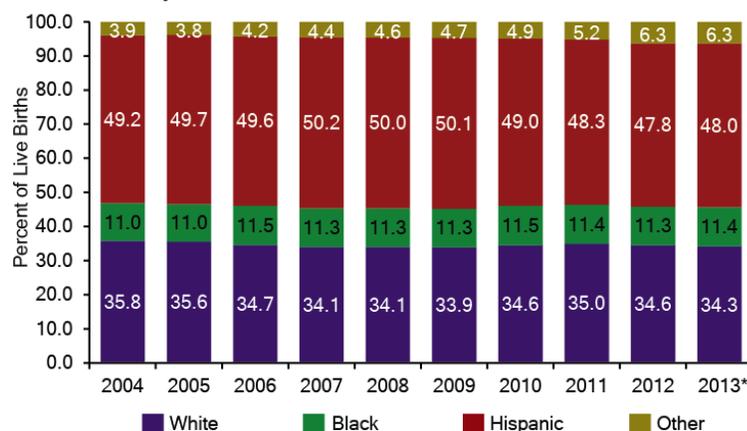
months were paid for by Medicaid. This finding is in contrast to the 45-47 percent of births paid for by Medicaid with inter-pregnancy intervals longer than 24 months. It is known in Texas through birth certificate Medicaid linking, that the birth certificate under-identifies the real numbers of births paid for by Medicaid by approximately 4-5 percentage points. Based on this trend of under-identification, the percent of births paid for by Medicaid in this shortest interval is likely higher.

Chapter 4. Pregnancy & Birth

Demographics of the Birth Cohort

Between 2004 and 2013, there has been a shift in the demographics of Texans giving birth (see Figure 4.1). The percent of births to Hispanic and White women has remained relatively stable, with a slight decrease for both groups over this time period. For Black women, the proportion of births has also remained stable, considering the slight increase in 2006, the year after the severe gulf coast hurricane season.

Figure 4.1
Race/Ethnicity of Women with a Live Birth, Texas 2004-2013



*2013 Texas data are preliminary
Source: 2004-2013 Birth Files
Prepared by: Office of Program Decision Support

“other” category. In 2004, there were 14,881 births to a woman in the “other” category and this increased to 24,195 in 2012. Considering the overall number of births in Texas this group seems small; however it is not small when put in other contexts. In 2012, the number of Texas women in the “other” category who gave birth was greater than the *total* number of births in 13 other states and the District of Columbia combined.

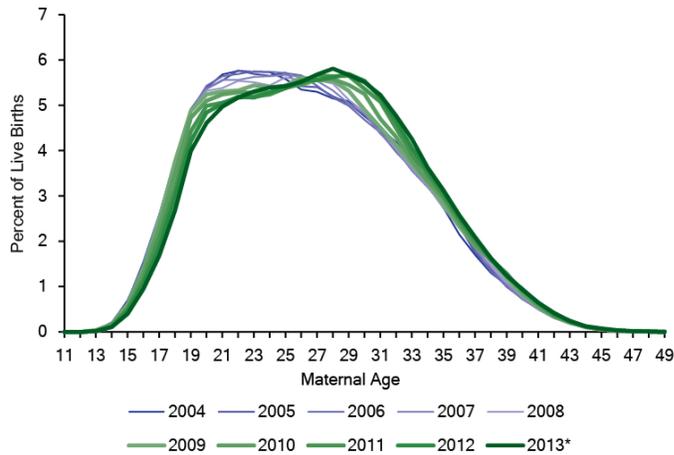
Within the “other” category there have been shifts, showing that who is classified into this group has changed over time. These changes cannot be due to the way the woman completed the birth certificate, as race/ethnic options have been stable; nor is it due to the way these groups were defined, since the same grouping definitions were used in all years of data. In 2004 and 2005, about 47 percent of the women in this category were either Vietnamese or Indian. In 2012, that proportion decreased to 39.5 percent, with the decrease being mainly among Vietnamese women. There are several groups that have increased their representation in this category, notably a rise in women of Middle Eastern descent; however, one of the largest increases has been among women who identify as mixed race. In 2004, mixed race women were about two percent of the women in the “other” category, and in 2012, this percentage increased to more than 10 percent. The heterogeneity in the “other” group is substantial and suggests that there will be important and meaningful differences in risk and birth outcomes within this group, as well.

Texas has also seen a major demographic shift in maternal age (see Figure 4.2). From 2004-2008, the age distribution of the maternal birth cohort did not change substantially. However, since 2009, the age

There has been a significant increase in the proportion of the maternal birth cohort that falls in the “other” category. In 2004, this group was 3.9 percent of all the births in the state, and this has grown to 6.3 percent in 2012 and 2013. This increase is not due to a shift in percentage because of fewer births in the White, Hispanic, and Black categories. Rather this shift is the result of an increase in the absolute number of births to women in the “other” category. In 2004, there were 14,881 births to a woman in the

distribution within the maternal birth cohort has seen major and significant declines in Texas. This shift is concentrated in two areas in the age distribution: the 11-19 year old age range, and the “peak” area of the age distribution.

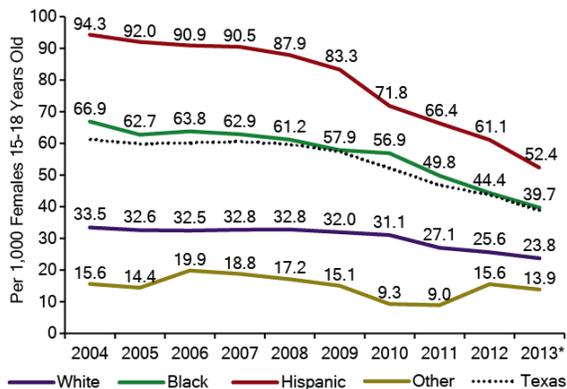
Figure 4.2
Distribution of Maternal Age, Texas 2004-2013



*2013 Texas data are preliminary
Source: 2004-2013 Birth Files
Prepared by: Office of Program Decision Support

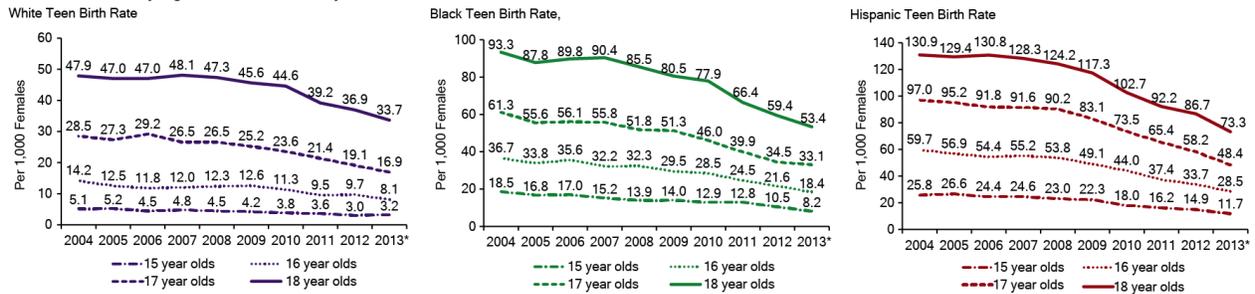
In 2004, 17-year olds represented 2.6 percent of all the births to a Texas resident. This percentage decreased to 1.7 percent in 2013. The shift in the age distribution of the maternal birth cohort corresponds to a significant and meaningful decrease in the teen birth rate in Texas. When the birth rate of teens is analyzed more closely, it is clear that all three major race/ethnic groups in the state have seen decreases in the birth rate (see Figure 4.3). Hispanic teens have seen the largest decreases. Across all race/ethnic groups, 18-year olds have seen the largest decreases in the teen birth rate (see Figure 4.4).

Figure 4.3
Teen (15-18 Years Old) Birth Rate, Race/Ethnicity 2004-2013



*2013 Texas data are preliminary
Source: 2004-2013 Birth Files
Prepared by: Office of Program Decision Support

Figure 4.4
Teen Birth Rate By Age and Race/Ethnicity, 2004-2013



*2013 Texas data are preliminary
Source: 2004-2013 Birth Files
Prepared by: Office of Program Decision Support

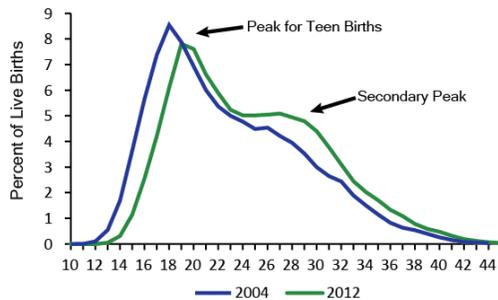
These birth rate decreases correspond to a decrease in the teen pregnancy rate as well, which not only includes live births, but also fetal deaths and abortions (data not presented). Simply stated, fewer teens living in Texas have been becoming pregnant.

While these decreases are exciting, this excitement is tempered when looking at the country as a whole. In 2012, Texas still had the third highest teen birth rate of all states and the District of Columbia. The current teen birth rate in Texas is approaching what the national average was in 2004 [32].

The second major shift in the distribution of maternal age is in the “peak age” of mothers. This peak corresponds to the ages that have the highest proportion of births. During 2004-2008, this peak occurred among those aged between 22-24 years. After the economic downturn in 2009, this peak age shifted significantly to mothers 27-29 years old. The same shift in the distribution was also evident among women in their thirties giving birth.

This type of shift could suggest that there are fewer women giving birth for the first time, as these women tend to be younger, or that women are having children for the first time at a later age. There has not been a notable decrease in the percent of women who are giving birth for the first time. Nulliparous women have consistently represented 38 percent of residence births since 2004. The maternal peak age shift is partially due to women having children for the first time at a later age.

Figure 4.5
Distribution of Maternal Age for Nulliparous Women, Texas 2004 & 2012



Source: 2004 & 2012 Birth Files
Prepared by: Office of Program Decision Support

The age distribution of first-time mothers is double peaked (see Figure 4.5). One of these peaks corresponds to women giving birth in their teens, and the other is a “secondary peak” in the 25-30 year age range. From 2004-2012, the initial peak has decreased, as would be expected with the decreasing teen birth rate. However, there has also been a rise in the secondary peak at the 25-30 year age range. Approximately 48 percent of all births were to a mother younger than 23 years of age in 2004. In 2012, this midpoint shifted an entire year to 24 years of age, which is a significant change.

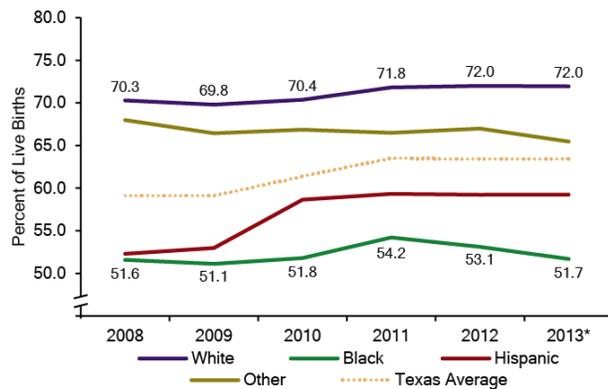
As will be discussed throughout this scientific analysis, these shifts in demographics are central to understanding the risks and health of the maternal birth cohort. As the race/ethnic and age composition of the maternal birth cohort changes, the types of risks and birth outcomes that exist within the cohort will also change.

Prenatal Care

A woman’s first point of interaction with the medical system during pregnancy is at her first prenatal care visit. The HP2020 target for on-time prenatal care access is that 77.8 percent of pregnant women will begin prenatal care in the first trimester of the pregnancy.

On-time prenatal care access has increased in Texas since 2008, however, only 64.5 percent of women had their first visit in the first trimester, which is far from meeting the HP2020 target (see Figure 4.6). The rates also differ between race/ethnic groups. White women have the highest rate of receiving care on time, whereas Black women have the lowest rate. Only slightly more than half of Black women begin prenatal care in the first trimester.

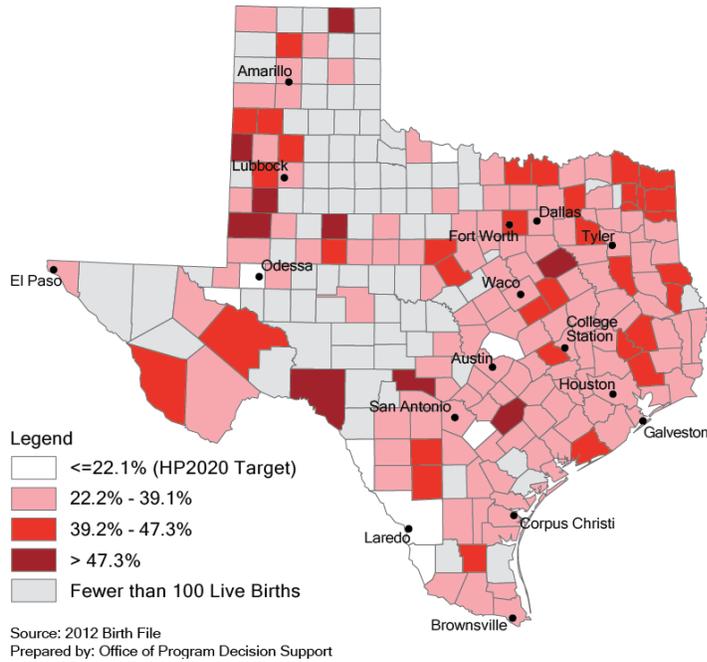
Figure 4.6
First Trimester Entry Into Prenatal Care by Race/Ethnicity,
Texas 2008-2013



*2013 Texas data are preliminary
Source: 2008-2013 Birth Files
Prepared by: Office of Program Decision Support

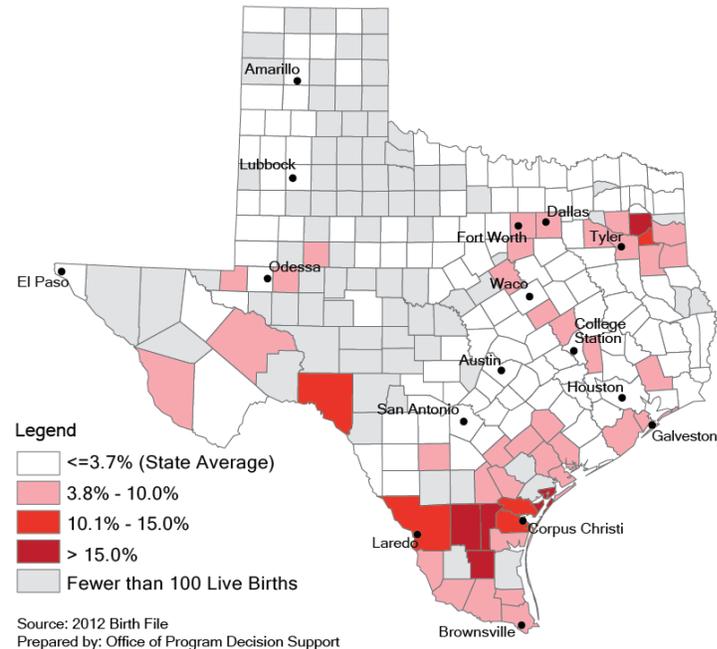
Texas’s low utilization of on-time prenatal care is a statewide problem (see Figure 4.7). Only three urban counties are meeting the HP2020 target.

Figure 4.7
Late Entry into Prenatal Care, 2012



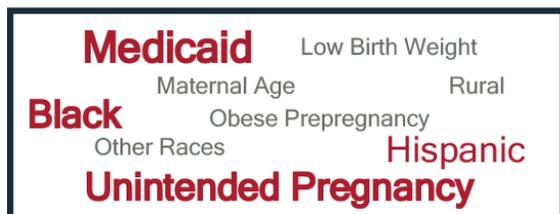
It is important to consider whether the communities with a high percentage of women not receiving prenatal care within the first trimester have a high proportion of women who never receive care, or if these women are simply receiving care late. There are pockets in the state where a substantial proportion of women never receive prenatal care or do not enter care during the first trimester (see Figure 4.8).

Figure 4.8
No Entry into Prenatal Care, 2012



In order to develop appropriate interventions to increase timely prenatal care access, it is important to understand the barriers that women face when receiving prenatal care. To better understand these issues, 2011 PRAMS data were analyzed to assess what characteristics predicted whether women entered prenatal care within the first trimester (see Figure 4.9).

Figure 4.9
PRAMS 2011: Factors Predicting not Receiving Prenatal Care in First Trimester



Red factors were associated with a significant increased risk, $p < .05$.
Bigger words had higher odds of the outcome
Grey factors were not significant predictors.
The model was assessed with all factors included.
Prepared by: Office of Program Decision Support

Black women and Hispanic women were significantly more likely to enter prenatal care late, regardless of whether their delivery was paid by Medicaid or not. A large predictor of whether the mother received prenatal care in the first trimester was if the pregnancy was intended, even after controlling for all other events. Women who have an unintended pregnancy are at an increased risk of not receiving care in the first trimester compared to women whose pregnancy was intended. Additionally, based on the 2012 birth file data, women with very short inter-pregnancy intervals

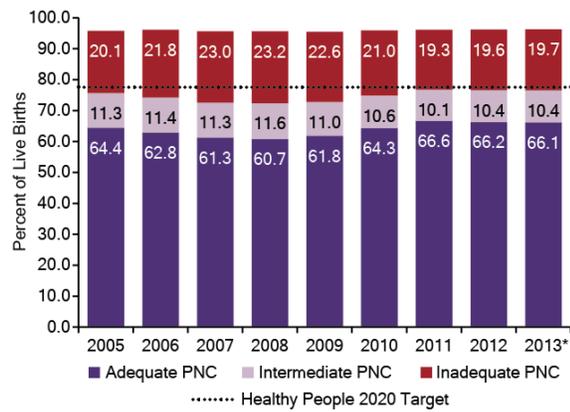
were also less likely to have received prenatal care during the first trimester. From the literature and from these data sources, many of these pregnancies were unintended. Women whose delivery was paid by Medicaid were significantly more likely to enter prenatal care late than non-Medicaid recipients. Based on PRAMS data, waiting for Medicaid eligibility determination was the most frequently cited reason for not receiving prenatal care as early as they wanted [33].

One of the issues with prenatal care access is whether women are not receiving care because they do not seek it or because they do not have access to it. While it is clear that access is a barrier, it is also clear from PRAMS data that the mother's behavior and perception regarding care-seeking may also be a barrier. There is a gap among Hispanic women and Black women about when they receive care and their perception about whether they received care as early as they wanted. In the 2011 Texas PRAMS data, 64.7 percent (C.I.: 59.4-70.0) of Black mothers received care in the first trimester; however, 75.7 percent (C.I.: 71.0-80.4) said they received care as early as they wanted. If women wanted care in the first trimester, but were unable to access it, these two percentages would be closer together. The disparity in these percentages for Black and Hispanic women suggests that many women were not seeking or wanting care in the first trimester. The barriers to on-time prenatal care are not just about access, but also about narrowing the gap between when they wanted care and when they should have been seeking/accessing care.

In addition to receiving care on time, it is also important that the utilization of care throughout pregnancy be adequate in its timing and frequency [34]. Measures of adequate prenatal care do not reflect quality but do reflect the frequency and timing of when that care is received. Adequate prenatal care using the Adequacy of Prenatal Care Utilization Index is defined as women who started care by the end of the fourth month of pregnancy and received more than 80 percent of the expected number of visits, given when the mother began care and when she delivered. Women receiving inadequate prenatal care began care after the end of the fourth month and received less than 50 percent of expected prenatal care visits or no prenatal care at all [34]. The HP2020 target for adequate prenatal

care utilization is 77.8 percent of births. Similar to on-time care, Texas is not meeting this target (see Figure 4.10). From 2005-2013, the overall percentage of women receiving adequate care is still low in the state. Black women have the lowest rate of receiving adequate prenatal care.

Figure 4.10
Adequacy of Prenatal Care, 2005-2013



PNC: Prenatal Care
 *2013 Texas data are preliminary
 Source: 2005-2013 Birth Files
 Prepared by: Office of Program Decision Support

The low rate of adequate prenatal care is two-fold. One piece is that women are beginning care late; the other is that even ones entering care on time are not utilizing at an adequate rate. Among women in the intermediate and inadequate categories, 39.7 percent started care on time, but received too few visits. As will be shown in Chapter 5, the level of prenatal care utilization during pregnancy is an important predictor and risk factor for several negative birth outcomes and risks during pregnancy.

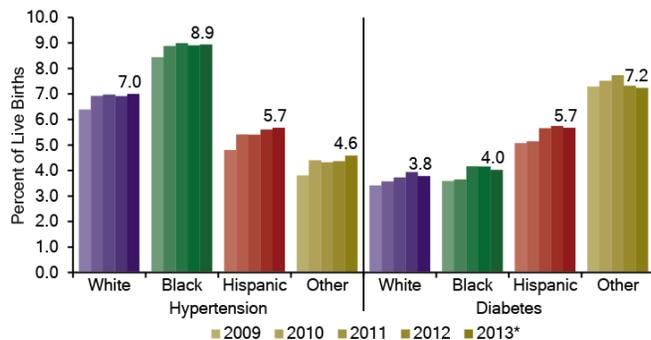
Diabetes and Hypertension

In 2013, at least 4.9 percent of all live births were to a mother identified as having diabetes that developed pre-pregnancy or over the course of the pregnancy (see Figure 4.11). However, it is also clear based on previous work linking birth and Medicaid files, that the prevalence of diabetes is higher than what is reported in the birth file. It has been recently estimated that 9 percent of women enrolled in Medicaid developed gestational diabetes during pregnancy and another 4.1 percent had pre-pregnancy diabetes [35]. The Medicaid population is more than 60 percent Hispanic, and this group is disproportionately affected by diabetes; hence, the prevalence in the general population may be lower than what has been found in the Medicaid population. While the report makes a distinction between gestational diabetes and pre-pregnancy diabetes, based on the birth data and other estimates, that label may not be true in all cases. It is clear that a fair percentage of women came into pregnancy with undiagnosed diabetes. Women with diabetes have an increased risk for a variety of complications, including fetal and infant death [36], so identifying them early is paramount to properly managing and caring for these women.

Much like diabetes, between five to six percent of all births are to a mother that was identified on the birth certificate as having some form of hypertension prior to pregnancy or as developing it over the course of the pregnancy (see Figure 4.11). While this rate represents a small proportion of the women

who have a live birth each year, about 11 percent of all the fetal and infant deaths are to a mother with some form of hypertension. Like diabetes, it is likely that this rate is underestimated from the birth file.

Figure 4.11
Pregnant Women with Hypertension and/or Diabetes,
Race/Ethnicity 2009-2013



*2013 Texas data are preliminary; data label is 2013 rate
Source: 2009-2013 Birth Files
Prepared by: Office of Program Decision Support

Rates of both hypertension and diabetes are slowly rising in Texas (see Figure 4.11). This rise may be due to better documentation in the birth file or it may be a real rise in the incidence of these two conditions. Given the rise in obesity among women in the birth cohort, this rise cannot simply be dismissed as better documentation. Additionally, analysis of Medicaid data and other sources, strongly suggests that this rise is not due to better reporting. However, one of the more striking trends in Texas is the race/ethnic differences between women with diabetes or hypertension and how they co-occur. Diabetes is prevalent among Hispanic women and women in the “other” race/ethnic category. Hypertension, in contrast, is prevalent among White and Black women.

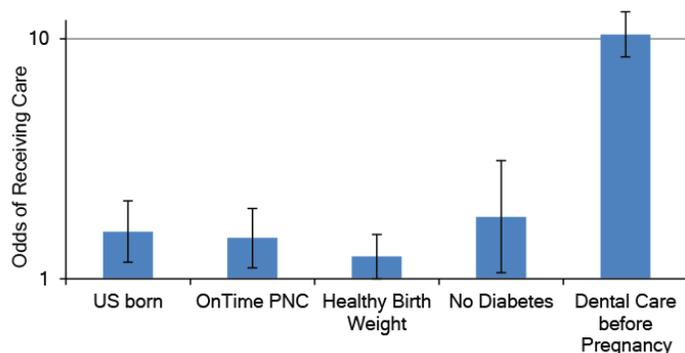
Despite these race/ethnic differences, it is clear that obesity is an important risk for both diagnoses. In 2013, 18.4 percent of obese women in the birth cohort had either hypertension, diabetes, or both, while 2.5 percent of all obese women had both. This rate is in contrast to the 6.6 percent of women with healthy pre-pregnancy BMI that were hypertensive, diabetic, or both, with less than 0.1 percent of these women having both.

Oral Health Care Utilization

There is growing awareness that a woman’s oral health during pregnancy can have an impact on fetus and birth outcomes [37]. Maintaining good oral health during pregnancy is important to the general health of both mothers and their babies, yet pregnant women seldom seek dental care during this period. During pregnancy, women experience complex physiological changes that can adversely affect their oral and overall health. There is a growing body of research showing a positive association between periodontal disease and adverse pregnancy outcomes [38]. There is also a growing body of evidence showing the causal biological mechanisms for how oral pathogens spread through the blood and amniotic fluid into the fetus, which then can provoke an inflammatory response and induce preterm birth [39]. Furthermore, periodontitis has been shown to be associated with high levels of cariogenic bacteria in mothers, which can lead to an increased risk of dental caries in infants.

Despite this evidence, it is clear that dental care utilization before and during pregnancy is low. Based on aggregated Texas PRAMS data from 2009 to 2011, only 29 percent (C.I.: 26.8-30.1) of pregnant women had a dental cleaning during pregnancy and 40.9 percent (C.I.: 39.1-42.7) had a cleaning one year before becoming pregnant. An in-depth analysis of the possible barriers to receiving dental care during pregnancy revealed that there was a strong and positive association between receiving care before becoming pregnant and having a dental check-up during pregnancy. However, after controlling for this association, other unique risk factors for not receiving dental care during pregnancy emerged (see Figure 4.12).

Figure 4.12
Factors Associated with an Increased Odds of Receiving Dental Care During Pregnancy



Model controlled for: race/ethnicity, socioeconomic status, education, maternal age, obesity status, smoking during pregnancy
 Source: Texas PRAMS, Combined 2009-2011
 Prepared by: Office of Program Decision Support

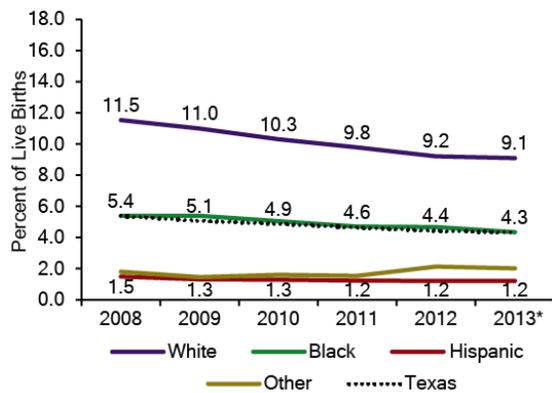
As would be expected, women who received prenatal care on time were more likely than women receiving prenatal care late to have dental care during pregnancy. There were also clear associations between a woman’s pre-pregnancy BMI and seeking dental care. Women with pre-pregnancy obesity had significantly lower odds of receiving dental care compared to women with healthy pre-pregnancy weight. Additionally, women with diabetes, even after controlling for obesity, had significantly lower odds of receiving dental care during pregnancy than non-diabetic women. This finding is of particular concern because diabetes, in and of itself, has negative effects on oral health.

The low utilization rates that were seen in 2009-2011 may not reflect the current utilization rates in Texas. Texas has been engaged in a recent push to increase access to oral health services for pregnant women. All safety net programs that provide prenatal care services offer therapeutic and preventative oral health benefits beginning in 2013. Additionally, the move in Texas to have all pregnant women receiving Medicaid to be served through a managed care organization means that many more women will have access to oral health services, as many of the large organization offer these benefits to their pregnant clients. As Texas PRAMS data becomes temporally aligned with these policy changes, we will be monitoring changes in the utilization and barriers to oral health care.

Smoking During Pregnancy

Texas is one of the better performing states when it comes to smoking during pregnancy. Part of the reason for the low smoking rate in the state is because over half of the maternal birth cohort is Hispanic. Regardless of pregnancy status, Hispanic women have some of the lowest smoking rates among all demographic groups (see Chapter 3). Consequently, Hispanic women also have the lowest rates of smoking during pregnancy nationally and within Texas. However, Texas still has room for improvement when it comes to smoking during pregnancy. In 2009, 29.7 percent of women who smoked 3 months prior to pregnancy did not smoke at all once becoming pregnant. In 2013, this rate of total abstinence from smoking among previous smokers had risen to 33.5 percent.

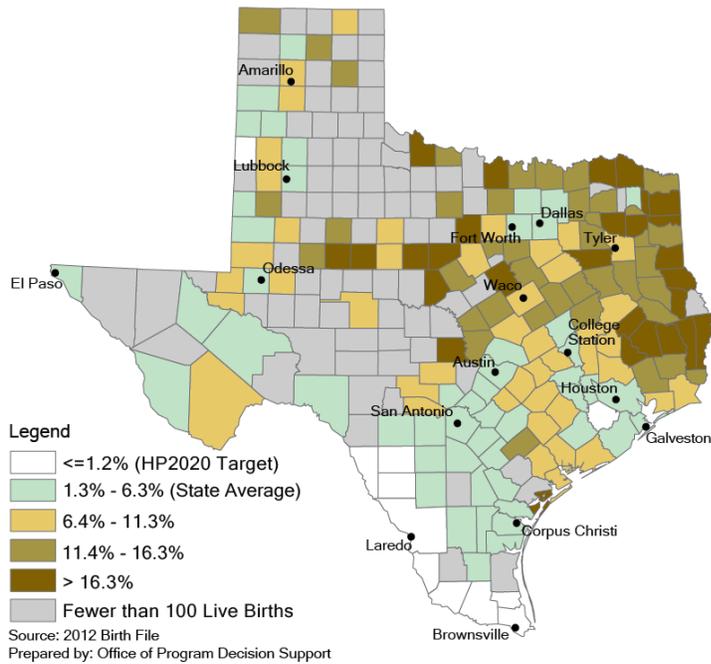
Figure 4.13
Women who Smoked During Pregnancy,
Race/Ethnicity 2008-2013



*2013 Texas data are preliminary
Source: 2008-2013 Birth Files
Prepared by: Office of Program Decision Support

Despite these gains and the low smoking rate, Texas still has 95.6 percent of pregnant women abstaining from smoking, which is below the HP2020 target of 98.6 percent (see Figure 4.13). Only Hispanic women are meeting the target. The three major race/ethnic groups in the state have all seen decreases in the smoking rate from 2008 to 2013. The smoking rate among White women is the highest, but has decreased 20.9 percent in the past six years.

Figure 4.14
Smoking During Pregnancy, 2012



The gains made in the overall percentages hide some stark regional differences in the smoking rates among pregnant women (see Figure 4.14). As would be expected, the border regions of the state have the lowest rate of smoking during pregnancy. The north and eastern regions of the state have the highest rates of smoking. In the regions with high smoking rates, the rates are high for both White and Black women, suggesting that the regional differences are a greater influence on smoking rates than the race/ethnic differences. Most of the major cities in the state have low smoking rates.

Figure 4.15
PRAMS 2011: Factors Predicting Smoking During Pregnancy



While complete abstinence from smoking while pregnant is important, it is also important that a woman quit during her pregnancy. According to Texas PRAMS data, three out of every five women who reported smoking before pregnancy were not smoking by the third trimester of pregnancy. This leads to the question of what factors predict whether or not a woman will continue to smoke during pregnancy. Race/ethnicity and Medicaid status were significant predictors of women smoking during pregnancy in our PRAMS data (see Figure 4.15). However, women who

reported that their pregnancy was unintended were also significantly more likely to smoke during pregnancy than were women whose pregnancy was intended. Women who did not enter prenatal care within their first trimester were significantly more likely to smoke than women who entered care on time.

Many of the women in the Focus Groups who smoked during pregnancy also cited a lack of support to quit smoking during pregnancy. While they received information about the dangers of smoking, they said they received little help to quit. Additionally, many counties with high rates of smoking while pregnant predictably have high smoking rates in general. Consistent with this generally high rate of smoking, women in the Focus Groups said that it was hard to quit smoking because smoking was everywhere. Even if they were successful quitting, staying away from partners and family members that still smoked was a challenge. These sentiments are also reflected in the literature on the role of fathers' behaviors on birth outcomes [16]. Mothers' and fathers' risky behaviors co-occur and a smoking mother is less likely to quit if the father smokes [17]. It is clear from focus group responses and from the literature, that a father's behavior is important for influencing the mother's risky behavior.

Stress and Maternal Risk During Pregnancy

The effects of stress during pregnancy on birth outcomes and inter-generational health has a long history of research in the developmental sciences going as far back as the mid-1900s. Throughout this research and its subsequent migration into the public health arena, there have been two common themes that resonate: (1) stress affects pregnancy, and (2) stressful events are not always experienced as stress.

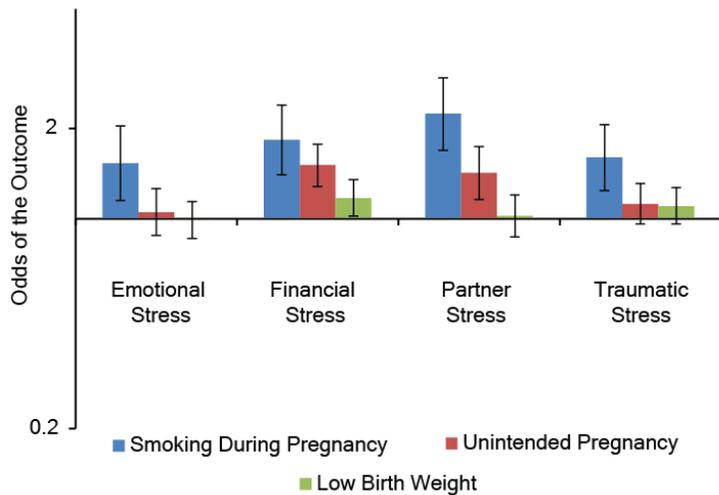
Newer research highlights the importance of not just understanding stressors that a woman experiences in both a psycho-social and physiological sense, but also events that buffer stressors. These buffers have been called "uplifts" and others have referred to them as "personal capital." These buffers can refer to such things as social support, joy from being pregnant, and other positive experiences, such as feeling the baby move. The current work on stress during pregnancy has emphasized that understanding the balance between these positive and negative events is important to understanding how stress directly affects pregnancy outcomes.

The literature that focuses solely on stressors has also shown that not all stress is equal, and the way that a stressful event affects a woman's behavior is also unequal. Data in Texas also shows this unequal effect. The PRAMS survey asks women about 12 common life stressors that they may have experienced during pregnancy. Both published research and the work that has been done in Texas has shown that these 12 stressors cluster into four major stress categories. Partner stress contains items where the couple fought or divorced; financial stress focuses on difficult paying bills; traumatic stress contains events such as the illness or death of a loved one; and emotional stress consists of issues of homelessness or jail of a loved one.

In the Texas PRAMS 2010 data, unintended pregnancy was associated with higher levels of partner and financial stress (see Figure 4.16). This result showed that pregnancy itself may magnify stressors. Analysis of the PRAMS data also showed that elevated stress of any kind, but especially of partner stress, was associated with increased odds of smoking during pregnancy. The association with financial stress is noteworthy because poverty was statistically accounted for in the analysis, showing that this association is not just one of poverty.

Figure 4.16

Type of Stress Associated with Smoking During Pregnancy, Unintended Pregnancy, and Low Birth Weight, 2010



Source: Texas PRAMS, 2010
Prepared by: Office of Program Decision Support

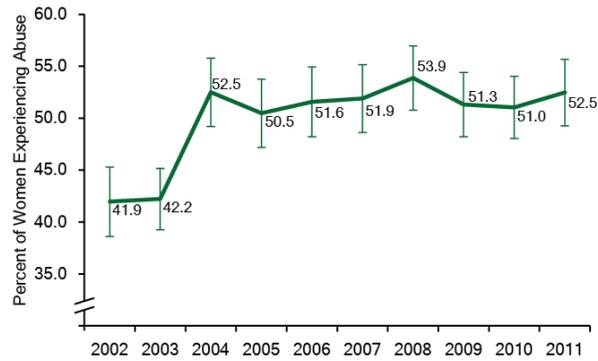
Taken together, these results begin to paint a picture of how stressful events can build and lead to high risk behaviors during pregnancy. Unintended pregnancies are associated with higher levels of partner and financial stress. Higher levels of financial and partner stress are associated with increased odds of smoking during pregnancy. Stress, in and of itself, can have physiological effects on the pregnancy, but it can also be associated with increased occurrence of high risk behaviors that, in-turn, have effects on the pregnancy.

Intimate Partner Violence

Intimate partner violence (IPV) refers to physical, sexual, psychological, or emotional abuse by a current or previous romantic partner or spouse. According to findings from the National Violence Against Women Survey, almost 25 percent of U.S. women reported that they were raped and/or physically assaulted by a current or former spouse/partner/date at some point in their lives. Abused women often may not report abuse the first time they are asked about it by a healthcare professional. Additionally, IPV may begin later in the pregnancy, so women should be screened more than once through the pregnancy.

Overall, PRAMS 2011 data estimate that 52.5 percent of women had this discussion. This rate of screening has significantly increased since 2002 according to PRAMS data (see Figure 4.17). In 2011, these discussions were more likely to happen among women in “high-risk” groups. While targeting “high risk” groups is important, these discussions are missing a large segment of the population experiencing IPV. When 2002-2011 PRAMS data were combined across all years, about half of the women that experienced IPV were not screened, the same was found for women who did not experience IPV. This finding suggests that the correct groups are not being targeted for screening.

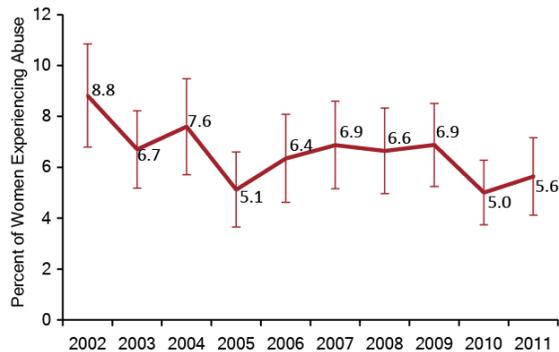
Figure 4.17
Trends in Women Reporting Discussions of Physical Abuse with Provider During Prenatal Care Visit, PRAMS 2002-2011



Source: 2002-2011 Texas PRAMS
Prepared by: Office of Program Decision Support

Data from the PRAMS survey estimated that 5.6 percent of pregnant women had experienced physical IPV either before or during pregnancy. While this rate has not changed significantly since 2002, the rates are trending towards decreasing in Texas (see Figure 4.18).

Figure 4.18
Trends in Women Reporting Experiencing Intimate Partner Violence Months Before or During Pregnancy, PRAMS 2002-2011



Source: 2002-2011 Texas PRAMS
Prepared by: Office of Program Decision Support

Physical violence has been associated with numerous perinatal risks including unintended pregnancy, late entry into prenatal care, preterm delivery, and low birth weight [40]. Texas PRAMS data generally show the same pattern. Women who experienced IPV smoked at rates that were twice as high as women who reported no experience with IPV. Women who experienced IPV began prenatal care after the first trimester at a higher rate than women who did not report experience with IPV. As will be seen in Chapter 5, the risk factors associated with IPV are also clear risk for threats to the child.

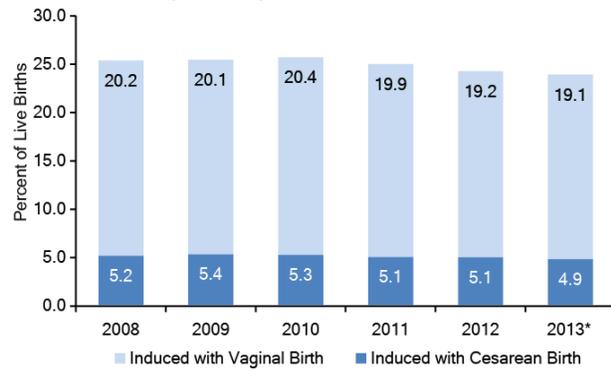
Delivery

There are two major factors that determine when a woman has her baby: (1) biological and environmental factors, and (2) decisions made by the woman's doctor. Doctors' decisions have been a point that public health officials have targeted to influence as a way to improve birth outcomes. One of the biggest decisions that a provider can make is to induce labor. Inductions are not always elective procedures, and a provider may induce a woman because the pregnancy is well past a due date and there is risk, or as a way to treat a mother or fetus in crisis. These situations are important points where

a doctor’s decision to induce labor can improve birth outcomes. The target within public health and the medical field has been to reduce elective inductions and cesarean sections scheduled before 39 weeks gestation.

In Texas, the total rate of labor inductions has declined since 2008, with noteworthy drops in 2011 and 2012 (see Figure 4.19). It is important to make clear that not all of these births were elective inductions. In 2012, 4.6 percent of all inductions were performed when the pregnancy was preterm or late gestation; 20.8 percent were early term (37-38 weeks gestation) and 74.6 percent were between 39 and 42 weeks gestation.

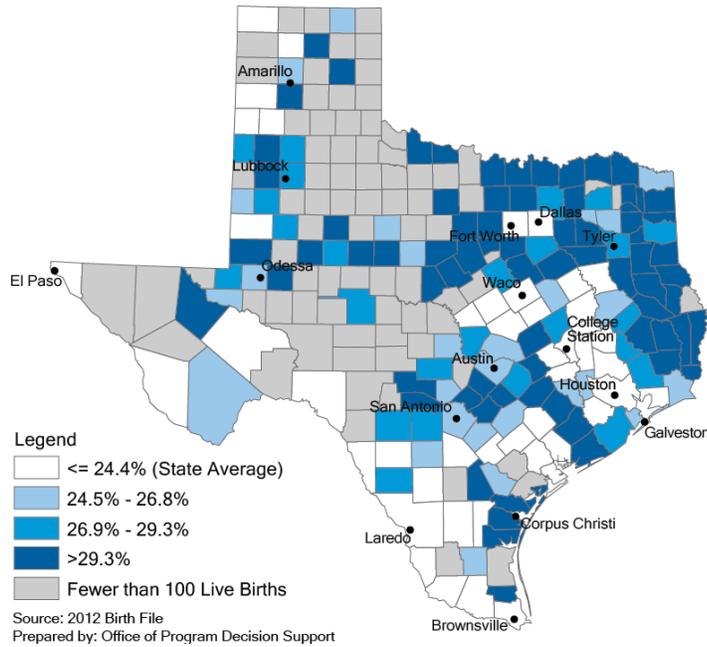
Figure 4.19
Induced Births by Delivery Route, Texas 2008-2013



*2013 Texas data are preliminary
Source: 2008-2013 Birth Files
Prepared by: Office of Program Decision Support

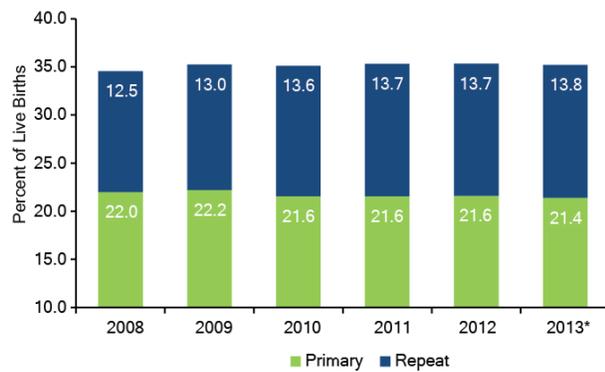
The distribution of labor inductions for singleton births across the state shows that women residing in rural counties have a significantly higher odds (O.R. = 1.3; C.I. = 1.28-1.34) of having labor induced than those living in urban counties (see Figure 4.20). This finding is consistent with the idea that doctors may induce labor in women living far away from hospitals as a way to manage expectant mothers and the delivery.

Figure 4.20
Percent of Singleton Births That Were Induced, 2012



The rate of cesarean section has also been showing modest declines since 2008, especially among women receiving a cesarean section for the first time (see Figure 4.21).

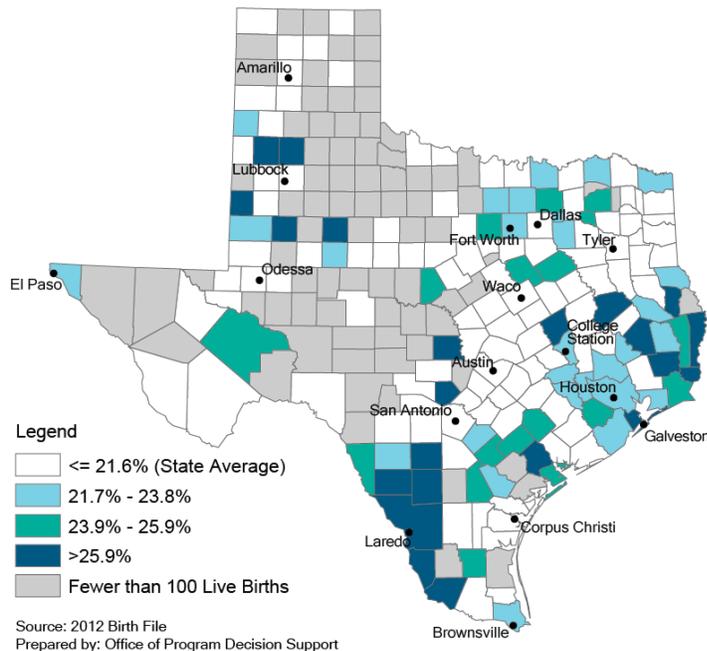
Figure 4.21
Primary and Repeat Cesarean Section Rate, Texas 2008-2013



*2013 Texas data are preliminary
Source: 2008-2013 Birth Files
Prepared by: Office of Program Decision Support

As with other birth outcomes, there are stark regional differences in the primary cesarean section rate. In particular, counties within and surrounding the Laredo metropolitan area have a particularly high rate of primary cesarean sections (see Figure 4.22).

Figure 4.22
Percent of Deliveries via Primary Cesarean Section
for Singleton Births, 2012



The number of inductions or cesarean sections that are elective is difficult to assess in the Texas birth file. Many of the exclusionary criteria that identify a delivery as not elective have been found to be unreliable. For example, in 2012, specifically, there were clusters of hospitals with extremely high rates of non-vertex presented infants and, as previously stated, the rate of maternal medical inductions are underreported on the birth certificate. The state is currently working to engage hospitals across the state to improve data quality on the birth certificate. These efforts will help to improve the data and subsequent public health response to problems affecting women in the state. Through the rest of the section, we will not be making distinctions between “elective” and “non-elective” deliveries, but will be making distinctions between “low-risk” and “not low-risk” deliveries. Low-risk deliveries are defined as deliveries where the fetus is between 37 and 41 weeks gestation and vertex. Additionally, the woman was nulliparous, had no history of diabetes, no history of hypertension, and had no indication of premature rupture of membranes. Gestational age in this analysis was the indicated clinical estimate (see Chapter 5 for a discussion of gestation age) on the birth certificate. Given the known problems with some of these variables, the analyses done with this low-risk distinction should be viewed with caution.

There is a striking difference in the primary cesarean section rate and the labor induction rate. These two rates do not co-vary in counties. The counties with high induction rates are not necessarily the counties with high primary cesarean section rate. When the data are restricted to the low-risk group, the relation between these rates at the individual level are weak (O.R. = 1.03; C.I. = 1.00-1.06) after controlling for race/ethnicity, Medicaid status, maternal age and obesity. There are published reports showing a strong relation between inductions and increased cesarean sections, but there are also other studies showing a weak and protective relation between inductions and cesarean sections. In 2009, the Agency for Health Care Research and Quality conducted a meta-analysis of studies assessing the relation

between labor inductions and cesarean sections. This meta-analysis found only weak relations between the two in the case-control studies reviewed and mixed results in the retrospective studies. In the Texas data, the nature of the relation between the two is highly dependent on the exclusion criteria used to define the low-risk group.

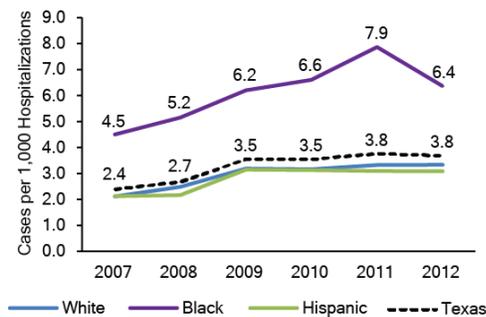
In the Texas data, what predicted a cesarean section among the low-risk group was, by far, obesity. Low-risk obese women had approximately a 200 percent increased odds (O.R. = 1.98; C.I. = 1.92-2.05) of having a cesarean section over non-obese women after controlling for age, race/ethnicity, Medicaid status, and induction of labor. Among low-risk women, 45 percent of obese women had a cesarean section, whereas only 28.2 percent of non-obese women did. Further, there is also evidence that obese women have their labor induced at a higher rate than non-obese women. Among the identified group of low-risk women, 35.2 percent of obese women were induced; whereas, only 29.4 percent of non-obese women were induced. Given that obese women make-up 31 percent of our “low-risk” group, it was calculated that cutting the cesarean section rate in half for “low-risk” obese women would lower the total cesarean section rate for the low-risk group as a whole by almost 4 percentage points.

Maternal Morbidity and Mortality

Severe maternal morbidity refers to severe injury or illness that occurs or is present when a woman delivers. While this definition is conceptually clear, it has proven difficult to operationalize. There have been several efforts to operationalize severity that have been met with a variety of successes and acceptance. In Texas, severe morbidity and the underlying diagnosis of that morbidity are defined in two ways. The data source for morbidity in the state is the Texas Hospital Discharge data, which are all-payer claims for the majority of hospitals in the state. Every discharge in the dataset is coded to have two variables of interest: illness severity and risk of mortality. These two variables identify cases of severe morbidity. The underlying diagnosis groups analyzed are derived from the coding procedures outlined in Callahan et al. (2008).

The rate of severe morbidity among pregnancy-related hospitalizations has remained steady for the state as a whole since 2009 (see Figure 4.23). However, there are stark race/ethnic differences, with Black women having severe morbidity rates almost twice as high as those of White or Hispanic women.

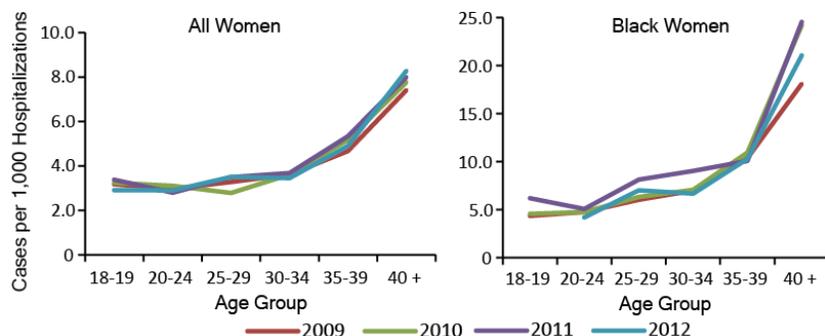
Figure 4.23
Texas 2007-2012 Severe Maternal Morbidity Rate by Race/Ethnicity



Source: 2007-2012 Texas Hospital Discharge Public Use Data:
Risk of Mortality High & Extreme for Identified Deliveries
Prepared by: Office of Program Decision Support, FCHS, DSHS, 2014

Rates of severe morbidity have an exponential relation with age, meaning that risks increase at a higher factor for older ages than for younger ages (see Figure 4.24). This exponential increase is across all race/ethnic groups, but is especially severe among Black women (see Figure 4.24). Black women older than 40 years have a rate of severe morbidity that is 3 to 4 times higher than the state average for this age range, whereas the rate of severe morbidity for 20-24 year old Black women is closer to the state average.

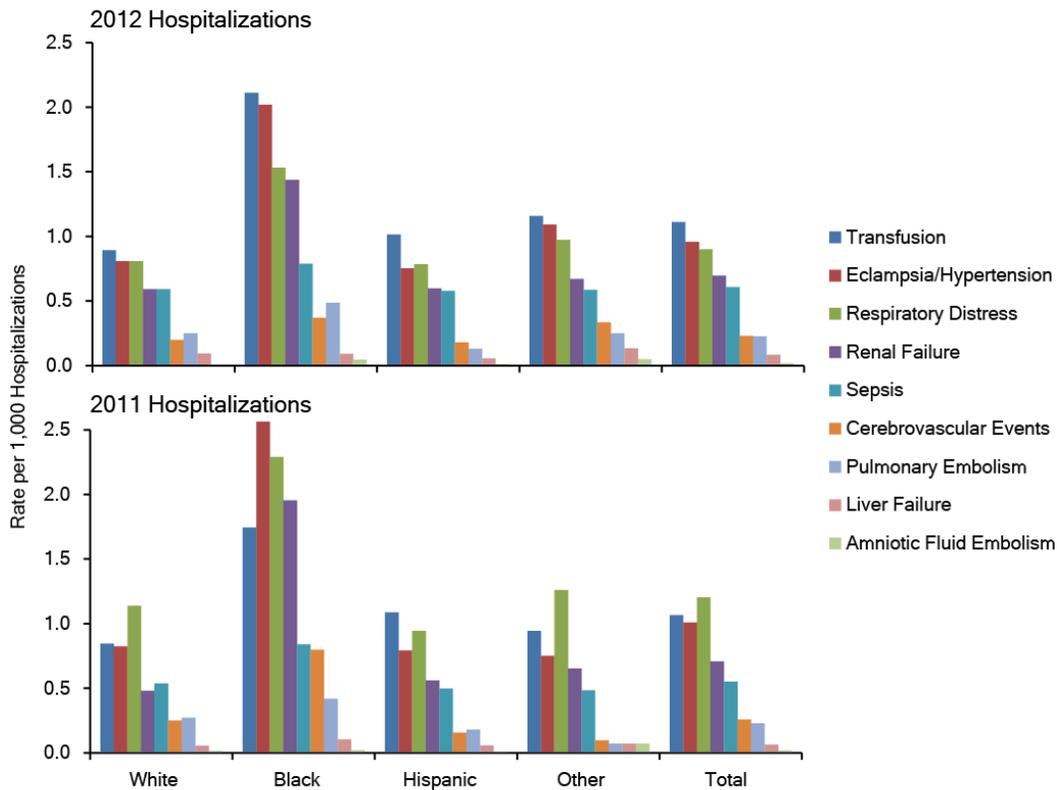
Figure 4.24
2009-2012 Distribution of Severe Morbidity by Age Group



Source: 2009-2012 Texas Hospital Discharge Public Use Data:
Risk of Mortality High & Extreme for Identified Deliveries
Prepared by: Office of Program Decision Support, FCHS, DSHS, 2014

Following the procedures outlined in Callaghan et al. (2008), morbidities were grouped into 9 causes. In addition, an accidental drug overdose group was included because a scan of the data indicated a large group of women with these codes. Additionally, the hypertension codes were expanded from the restricted code range used by Callaghan to all hypertension codes. It was found that the restricted code range underestimated the prevalence of hypertension and eclampsia in the Texas discharge data. Eighty-one percent of all severe morbidity cases could be classified by one of the 10 causes previously defined. It must be noted, that many cases were comorbid for several identified causes; thus, the percentages will not add up to 100. In 2011 and 2012, the three leading diagnoses associated with severe morbidity were hemorrhage (identified as a woman receiving a whole blood transfusion), eclampsia/hypertension, and respiratory distress (see Figure 4.25). These three diagnoses, as well as renal failure, had a rate of occurrence that was almost twice as high among Black women as that for all other race/ethnic groups.

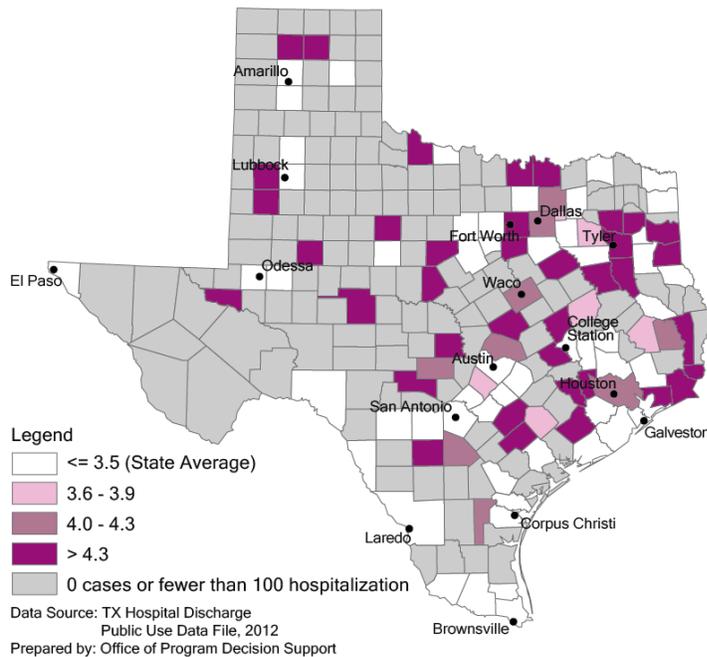
Figure 4.25
 2011 & 2012, Rates* of Different Severe Morbidity Diagnoses by Race/Ethnicity



*Rates are not mutually exclusive as the majority of women have more than one diagnosis
 Source: Texas Hospital Discharge Public Use Data
 Risk of Mortality High & Extreme for Identified Deliveries
 Prepared by: Office of Program Decision Support, FCHS, DSHS, 2014

A disadvantage of using the public use hospital discharge data is that the hospital file cannot be linked to the birth file. However, the woman’s county of residence is known and data can be linked at the community level (see Figure 4.26 for geographic distribution of rate). When assessing the association between community-level risks and severe morbidity, it is clear that these rates are more closely tied with maternal risks than fetal/infant risk. In particular, counties with high rates of access to prenatal care after the first trimester and high rates of obesity tend to have higher rates of severe morbidity. There is no evidence that rates of severe morbidity are related to the county-level rate of preterm birth or low birth weight.

Figure 4.26
Severe Maternal Morbidity Rate (per 1,000 Hospitalizations), 2012



Maternal mortality—the death of a woman who was pregnant or who had given birth within one year of her death—is a tragic event with far reaching consequences beyond the loss of the mother. Maternal death is rare, with mortality rates among currently and recently pregnant women generally lower than those of women in the same age range in the general public. However, there is evidence, albeit controversial, that the rate of deaths that are directly related to pregnancy is rising.

The issues of definition and accurate surveillance of maternal death are not insignificant and will be discussed before the prevalence of maternal death is discussed. One of the greatest issues with maternal mortality and morbidity surveillance is that it is difficult to accurately find and identify the cases. Even nationally, there have been widely discrepant discussions on how to identify these deaths in vital statistics records (Hoyert, 2007; Berg et al., 2010).

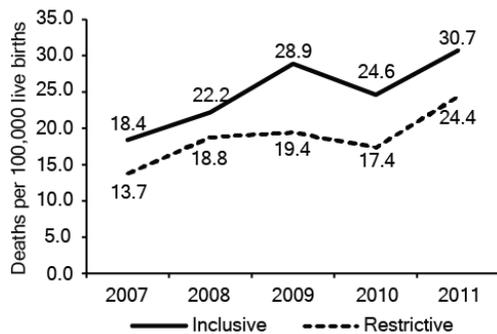
Deaths that are caused by pregnancy-related complications are classified on the death certificate using two pieces of information: 1) the cause of death written on the death certificate, and 2) the “pregnancy check box.” This check box identifies whether the woman was: 1) currently pregnant; 2) not pregnant currently, but pregnant within 42 days of death; or 3) not pregnant currently, but pregnant 42 days to 1 year prior to the time of death.

The cause of death, sometimes combined with the answer on the check box, should lead to an ICD-10 code being assigned to the death that is the official classification of the death. The different national and international rates that are reported stem from differing opinions about which ICD-10 codes should be used to classify Maternal Death and whether or not the pregnancy check box is a requirement for that classification.

The most inclusive definition encompasses ICD-10 codes O00-O999 (all obstetric codes; O-Codes) and A34 (sepsis). For this definition, the check box is not considered. This definition generally leads to a large number of deaths being classified as Maternal (pregnancy-related) Deaths. However, some have advocated that the ICD-10 codes are too broadly inclusive, because they do not separate deaths caused by a pregnancy and those causes only related to a pregnancy death. This group advocates a restrictive definition so that the ICD-10 codes included are O00-O959, O98-O999, (restricted obstetric codes) and A34 (sepsis). In addition, the pregnancy check box *must* have indicated that the woman was currently pregnant or at least pregnant within 1 year of the death.

Data on the maternal mortality rates in Texas from 2007 to 2011 using both definitions show very different rates (see Figure 4.27).

Figure 4.27
Maternal Mortality Rate in Texas 2007-2011: Differences between Vital Statistics Definitions Inclusive of All Obstetrics Codes and Restricted Based on the Pregnancy Checkbox

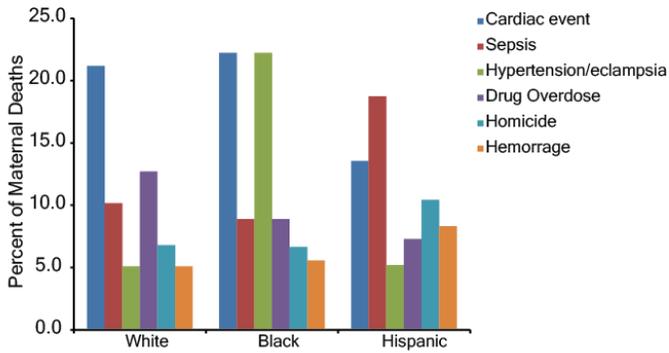


Source: Vital Statistics Death Files
 Prepared by: Office of Program Decision Support

A birth-death matching project that was conducted for the Maternal Mortality and Morbidity Task Force has shown that the pregnancy checkbox on the death certificate does not accurately identify recently pregnant women. In 2012, there were 225 women identified on the death certificate as being pregnant at time of death, pregnant within 42 days of death, or pregnant 43 days before death but within one year of death. The linked death cohort only had 145 women with an appropriate pregnancy check box designation. As with the pregnancy check box, an O-code cause of death did not confirm pregnancy status for many women. In the 2012 death file, there are 120 women with an O-Code cause of death. The identified cohort with confirmed pregnancy had only 80 women with an O-Code as a cause of death, also calling into question the use of O-Codes alone as a way to identify deaths.

This matching project has given insight into the leading causes of death among women who were recently pregnant or currently pregnant at the time of death. Once motor vehicle deaths and cancer deaths were excluded, the leading two causes of death in 2011 and 2012 were cardiac events and hypertension/eclampsia (see Figure 4.28). Black women were disproportionately affected by these two causes. Drug overdose was found to be the third leading cause of death and was the second most prevalent cause of death for White women.

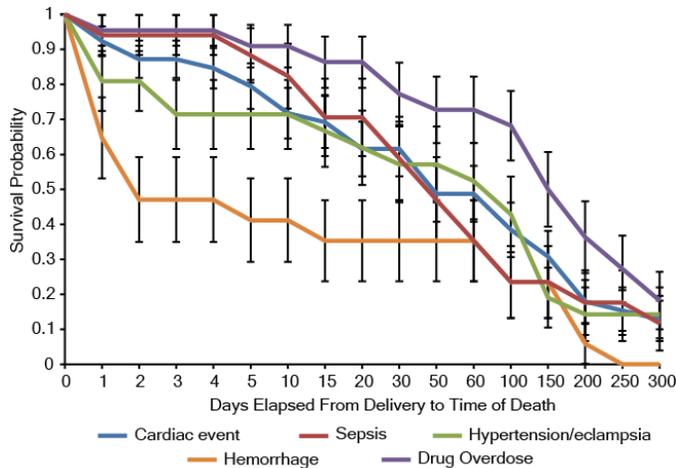
Figure 4.28
Maternal Death Cohort 2011 & 2012, Six Most Pervalent Causes of Death



Source: Vital Statistics Birth Matched Death Files
 Prepared by: Office of Program Decision Support

Additionally, it was found the survival rates for many causes of death to be long, showing that many women are surviving the delivery, but may be experiencing complications later (see Figure 4.29).

Figure 4.29
Maternal Death Cohort Survival Times From Delivery to Death



Source: Vital Statistics Birth Matched Death Files
 Prepared by: Office of Program Decision Support

As the Maternal Mortality and Morbidity Task Force moves forward with reviewing these deaths, it will become clearer how many of these deaths were related to the woman’s pregnancy.

Chapter 5. Birth & Infancy

When an infant is born, he or she has already been exposed to environmental, social, and genetic factors that increase health risks. The focus of the previous chapter has been to understand the risks that the mother carries into the pregnancy and may develop over the course of the pregnancy. This chapter will focus on understanding the infant's risk and how the maternal risks discussed previously are related to the infant's outcomes, both immediately after birth and within a year of birth.

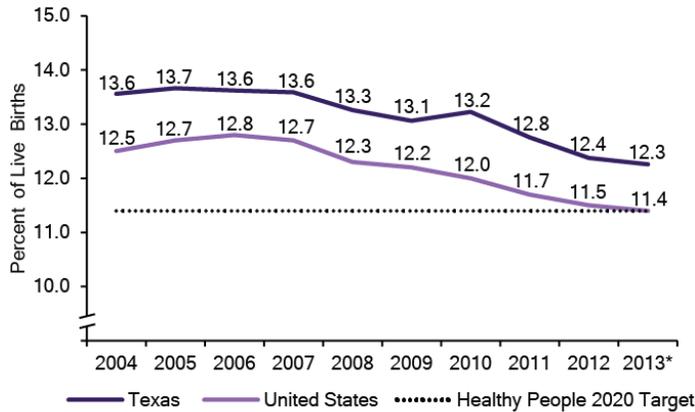
Preterm Birth Rate

Knowing the infant's gestational age throughout pregnancy and at birth is important for proper care and management of a pregnant mother and also with caring for the infant. However, with the exception of certain artificial reproductive techniques, gestational age can only be estimated. The two sources of gestational age on the birth certificate are an estimate based on last menstrual period and one based on a clinical determination. The clinical estimate may be based on last menstrual period, report from the mother, ultrasound or other estimates; the birth certificate does not identify how this estimate is being derived. The difference between these two estimates is not insignificant, as some benchmarks use clinical estimates and some use last menstrual period. The rates of preterm birth depending on the estimate used can vary greatly.

In 2012 Texas birth data, these two estimates were in perfect agreement only 62 percent of the time and have a kappa reliability score of .5, meaning that they have low agreement with each other. These two estimates are not interchangeable. Deciding which to use is also problematic because both estimates have well documented problems. The HP target for preterm birth uses a hybrid method to estimate gestational age. This method uses last menstrual period first, but if it is missing or out of range with the infant's birth weight, the clinical estimate is used [41]. All gestational ages in this chapter, except where noted, are calculated based on this method so that Texas progress can be compared to this important public health benchmark. However, The Joint Commission Perinatal Care quality measures are based on clinical estimations of gestation [42].

Preterm births are those that occur prior to 37^{0/7} weeks of gestation. The preterm birth rate in Texas has consistently been higher than the national average for the past ten years (see Figure 5.1). From 2010 to 2011, the preterm birth rate decreased by 3 percent and this decrease has carried over into 2012. However, Texas is still far from meeting the HP2020 target for preterm births [41]. Between 2009 and 2013, the preterm birth rate has decreased by 6 percent, which is still short of the Health Babies Challenge to reduce preterm births by 8 percent by 2014 issued by the Association of State and Territorial Health Officials [43].

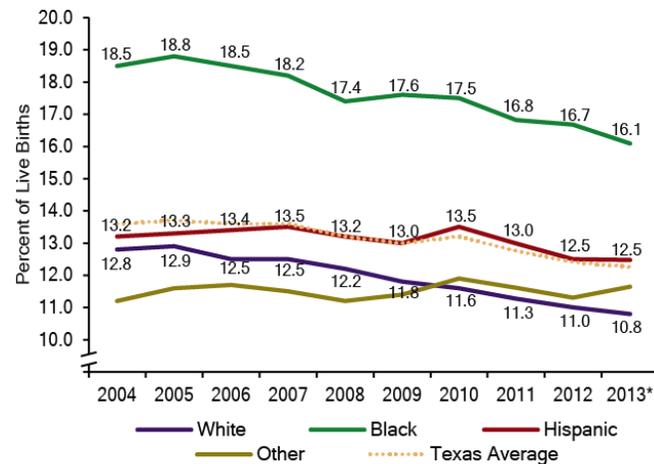
Figure 5.1
Preterm Births for Texas and the United States, 2004-2013



*2013 Texas data are preliminary
Source: 2004-2013 Birth Files
National Center for Health Statistics Vital Records Report
Prepared by: Office of Program Decision Support

There are substantial race/ethnic gaps in the preterm birth rate, with Black women having a high percentage of their infants being born preterm (see Figure 5.2). Encouragingly, the rate has decreased among all race/ethnic groups, with the largest gains being made with infants born to Black mothers. The preterm birth rate for infants born to Black women has decreased 8.5 percent since 2009.

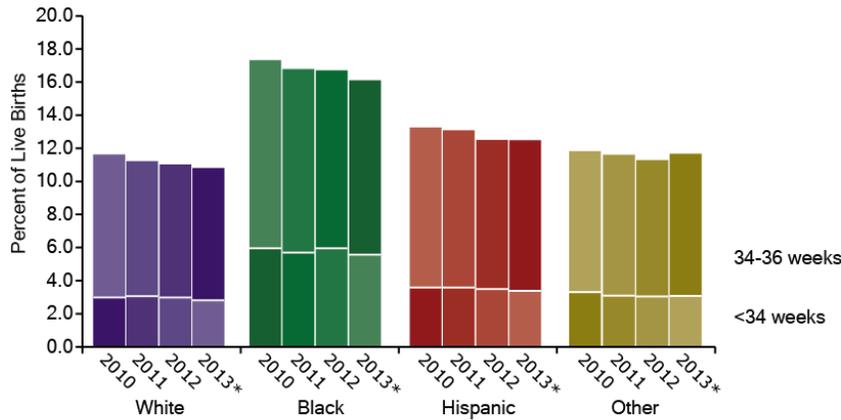
Figure 5.2
Preterm Births by Race/Ethnicity, Texas 2004-2013



*2013 Texas data are preliminary
Source: 2004-2013 Birth Files
Prepared by: Office of Program Decision Support

The preterm rate can be further divided into infants born at 34-36 weeks, and those born at less than 34 weeks gestation. The declines in preterm birth have mainly been driven by decreases in the percent of infants being born in the 34^{0/7}-36^{7/7} week gestation range (see Figure 5.3) [44].

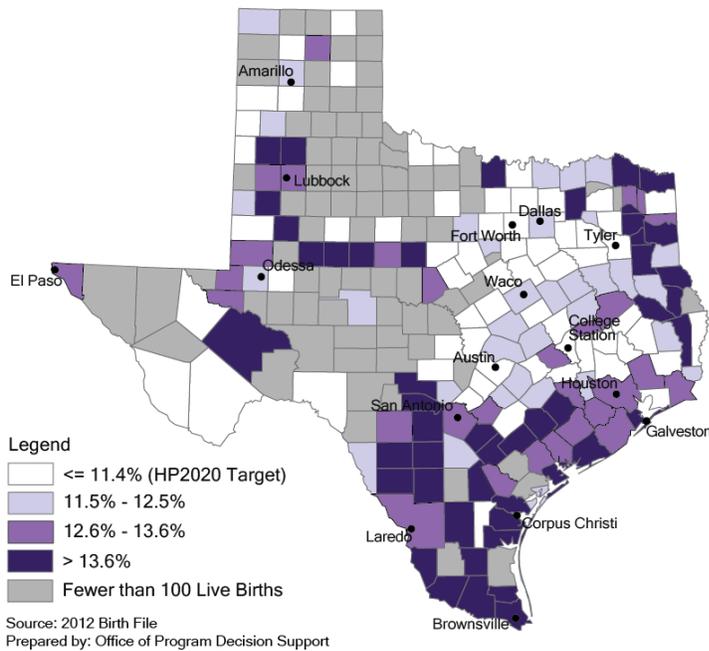
Figure 5.3
Preterm Births by Category, Race/Ethnicity 2010-2013



*2013 Texas data are preliminary
 Source: 2010-2013 Birth Files
 Prepared by: Office of Program Decision Support

As has been seen with maternal risk behavior and health, there are substantial regional differences in the distribution of preterm births (see Figure 5.4). The southern border and gulf coast regions and eastern Texas have high percentages of infants being born preterm.

Figure 5.4
Percent of Births that are Preterm, 2012

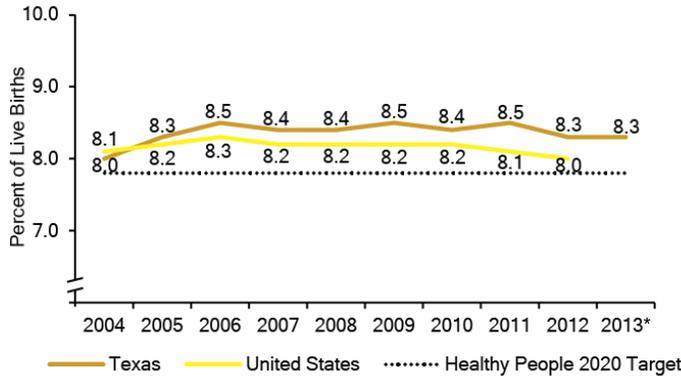


Low Birth Weight

Many birth outcome metrics and guidelines for care are defined by birth weight (e.g. [42] [45]). As with preterm birth, low birth weight is associated with a variety of poor outcomes and is an important marker for the health and well-being of infants, generally.

The percentage of babies born weighing less than 2500 grams (5 pounds 8 ounces) has not meaningfully changed since 2006 (see Figure 5.5). The low birth weight rate in Texas is above the national average and is not meeting the HP2020 target of less than 7.8 percent of live births weighing less than 2500 grams [46].

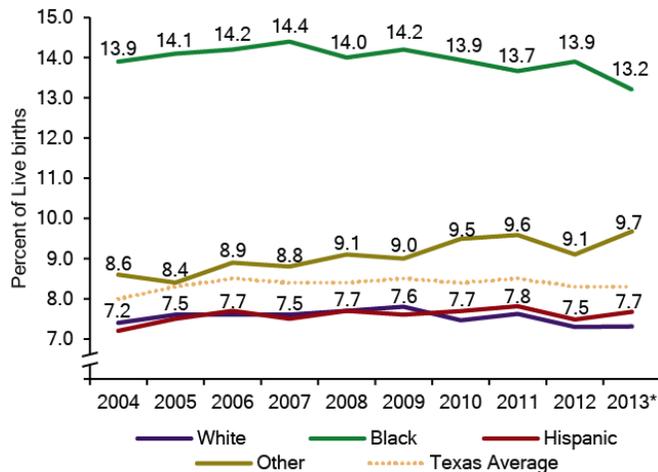
Figure 5.5
Low Birth Weight for Texas and the United States, 2004-2013



*2013 Texas data are preliminary
Source: 2004-2013 Birth Files
National Center for Health Statistics Vital Records Report
Prepared by: Office of Program Decision Support

Black mothers have a disproportionately high percentage of infants being born low birth weight (see Figure 5.6). Additionally, the low birth weight rate is high among mothers in the “other” race/ethnic category. Demographic shifts in the makeup of this group (see Chapter 3), especially the rise in mixed-race mothers, may be contributing to the slow, but steady increase in the rate since 2004.

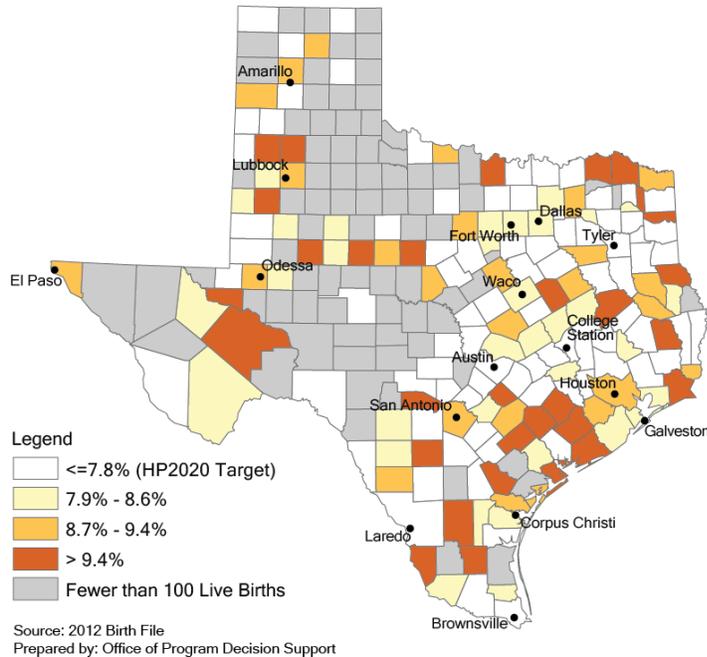
Figure 5.6
Low Birth Weight by Race/Ethnicity, Texas 2004-2013



*2013 Texas data are preliminary
Source: 2004-2013 Birth Files
Prepared by: Office of Program Decision Support

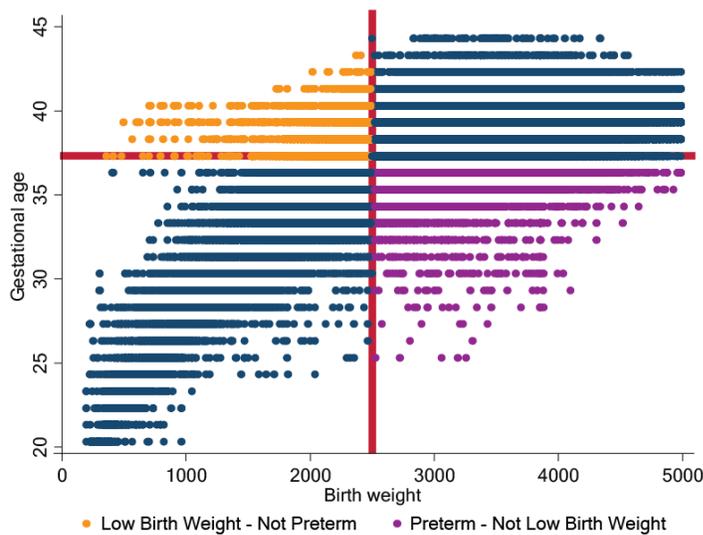
Throughout the state, there are individual counties that are meeting the HP2020 target, but they are not clustered geographically; meaning that there are no clear regional disparities in the low birth weight rate (see Figure 5.7). However, there are disparities between individual counties.

Figure 5.7
Percent of Births that are Low Birth Weight, 2012



Preterm births are decreasing in Texas but low birth weight is not, even though both rates should track more closely with each other. The clear regional patterns that are seen in preterm births are not present with low birth weight. Birth weight and gestational age are correlated in the Texas data ($r = .66$), meaning that shorter gestation ages are associated with lighter birth weights. Therefore, it is reasonable to expect that as one decreases, the other would also decrease, even if slightly. Analysis of the relation between birth weight and gestational age shows that there are a substantial number of babies that are low birth weight but preterm, and a very large number of infants that are preterm but not classified as low birth weight (see Figure 5.8). The part of the distribution that has the greatest variation between low birth weight and preterm is in the 34-36 week range, which is the preterm range that is declining in Texas.

Figure 5.8
Relation between Gestational Age and Birth Weight, 2012



Source: 2012 Birth Files, Extreme Individual Cases Removed
Prepared by: Office of Program Decision Support

To understand the differing factors that may be contributing to each birth outcome, the relationship between several maternal risk factors, low birth weight, and preterm birth were assessed using birth certificate data.

Figure 5.9
Maternal Characteristics Associated with Low Birth Weight & Preterm Birth, Texas 2012



Larger words had higher odds of the outcome
Brown and Purple factors were associated with a significant increased risk, $p < .05$.
Black factors were associated with a significant decreased risk, $p < .05$.
Grey factors were not significant predictors.
The model was assessed with all factors included and controlling for gestational age or birth weight, respectively.
Prepared by: Office of Program Decision Support

Generally, the risk factors that were found to be associated with low birth weight were also associated with preterm birth (see Figure 5.9). However, there were notable differences. Tobacco use and late prenatal care were associated with low birth weight, independent of the infant's gestational age.

Additionally, PRAMS data also reveal a variety of other maternal factors that are associated with low birth weight, even after statistically controlling for other factors. Notably, stress and a lack of oral health care utilization during pregnancy are predictors of low birth weight (see Chapter 4). When bivariate relations, not controlling for other factors, are examined, unwanted pregnancies are associated with a higher prevalence of low birth weight than wanted pregnancies, but not with preterm birth. Consistent with the birth certificate data, late prenatal care is also significantly more prevalent among women with

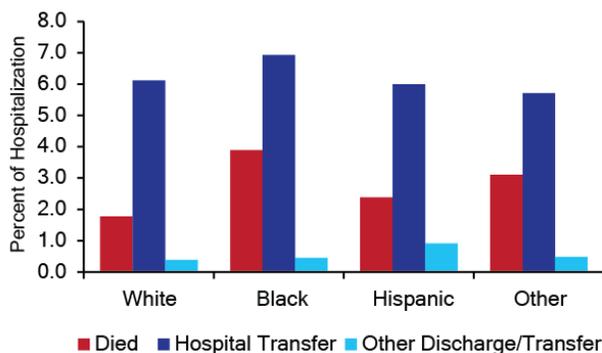
a low birth weight infant than women with a healthy weight infant. Women with a low birth weight infant are significantly more likely to say they received care later than they wanted. The unique relation these factors have with low birth weight may help explain some of the divergence between then multi-year trend in the low birth weight and preterm birth rates.

Further study and monitoring of these factors may help identify modifiable behavioral factors that are associated with one, but not the other. In the Texas data, both measures together explain about 17 percent of the variance in infants whose birth certificate indicated at least one complication during delivery (such as NICU stay, fetal intolerance of labor, antibiotic administration). Reducing both low birth weight and preterm births will be an important step towards having healthier and safer deliveries.

While it is important to study the divergence of these two trends, it is also important to consider the extreme risk carried by an infant who is born both preterm and low birth weight. Preterm infants that are low birth weight can be identified through hospital discharge data. Because of the way that ICD-9-CM defines these diagnosis codes, low birth weight cannot be differentiated from preterm birth. Additionally, hospital discharge data do not represent incidence because these data are not full population data in Texas and they represent hospitalizations, not individuals. Additionally, these preterm codes tend to correspond with clinical estimates of gestation, not the hybrid method defined in the HP2020 objective. However, these data do provide an understanding of the impact of both factors on an infant’s hospitalization and severity of illness.

Of the infant hospitalizations with any preterm/immaturity diagnosis code, regardless of birth weight, 90.8 percent of these hospitalizations resulted in a discharge to home, 2.5 percent resulted in the death of the infant, and 6.1 percent resulted in a transfer to another general hospital or children’s hospital. The remaining infant hospitalizations were discharged to a variety of other care facilities. The subset of the infants who were low birth weight (53 percent) showed evidence that their condition was more severe, as only 86.7 percent were discharged to home and 4.1 percent died during the hospitalization. These discharge patterns also showed race/ethnic differences, with hospitalizations of Black infants having a higher number of deaths than did the other race/ethnic groups (see Figure 5.10).

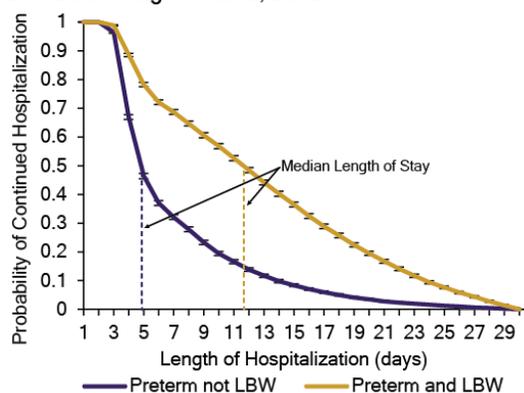
Figure 5.10
Rate of Different Discharge Outcomes For Births
with an Indication of being Preterm, by Race/Ethnicity 2012



Source: 2012 Texas Hospital Discharge Data
(ICD-9 644.2, 765.1-765.28)
Prepared by: Office of Program Decision Support

When assessing only the hospitalization that resulted in a discharge to home, there were also significant differences in how long the infant was in the hospital (see Figure 5.11). The median length of stay for all infant hospitalizations with any preterm/immaturity indication was 5-6 days. For hospitalizations where there was an indication that the infant was low birth weight and preterm, the median length of stay was 10-11 days. Hospitalizations of preterm but not low birth weight infants had significantly shorter length of stays at 3-4 days than those comorbid with low birth weight. It is clear from the hospital data that having both is a high risk to the infant, with significantly longer hospital stays and a significantly higher probability that the infant will die.

Figure 5.11
Length of Hospital Stay for Preterm and Preterm–Low Birth Weight Infants, 2012



Error Bars: 95% Confidence Interval
Source: 2012 Texas Hospital Discharge Data
(ICD-9 644.2, 765.1-765.28)
Prepared by: Office of Program Decision Support

Breast Milk

Breast milk is the best source of nutrition for infants, as it contains the essential nutrients and antibodies necessary to nourish and protect infants from disease. Formula-fed babies are at higher risk of numerous adverse outcomes, including necrotizing enterocolitis (a condition that affects the gastrointestinal tract of preterm infants), asthma, lower respiratory infections, obesity, and type 2 diabetes [47]. Breastfeeding has also been shown to be protective against SIDS, specifically, and infant mortality, more generally [48].

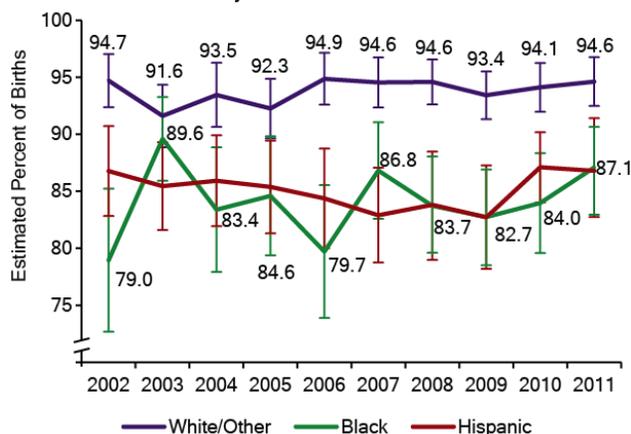
Breastfeeding also has numerous benefits for the mother; besides helping with postpartum weight loss, it helps to establish and strengthen the bond between mother and baby. Breastfeeding has been associated with a lower risk of type 2 diabetes, breast and ovarian cancers, and postpartum depression in mothers. Additionally, since breastfed infants are sick less often, women who breastfeed miss fewer days of work.

According to 2011 Texas PRAMS data, it is estimated that 85.8 percent (C.I.: 83.5-88.0) of women had initiated breastfeeding with her youngest infant in the hospital. This estimate is significantly higher than the breastfeeding rate reported by the National Immunization Survey of 78.4 percent (C.I.: 73.5-83.3). Texas is not significantly different from the HP2020 target for breast feeding initiation of 81.9 percent. Among the WIC population, 81.5 percent of clients surveyed in the 2010 Infant Feeding Practices Survey

reported ever breastfeeding, and in 2012, 84.8 percent reported ever breast feeding. The initiation rates in the WIC population have consistently been shown to be higher than the general population.

While PRAMS may be an overestimate of breastfeeding initiation, it is clear that there are significant race/ethnic differences in this rate (see Figure 5.12). Both Black and Hispanic mothers have significantly lower initiation rates than White mothers.

Figure 5.12
Percent of Women that Breastfed in Hospital,
PRAMS Race/Ethnicity 2002-2011



Error Bars: 95% Confidence Interval
Source: 2002-2011 Texas PRAMS
Prepared by: Office of Program Decision Support

While Texas has high initiation rates, exclusive breastfeeding is significantly lower. Research has shown that the benefits of breastfeeding are highest when the baby is exclusively fed breast milk for the first 6 months after birth. Only 20.1 percent of mothers receiving WIC reported exclusive breastfeeding at 3 months and that rate decreased to 6.3 percent at 6 months. The National Immunization Study reports higher rates within the general population. At 3 months, 38.9 percent (C.I.: 33.6-44.2) reported exclusive breastfeeding and 16.8 percent (C.I.: 12.8-20.4) reported exclusive breastfeeding at 6 months.

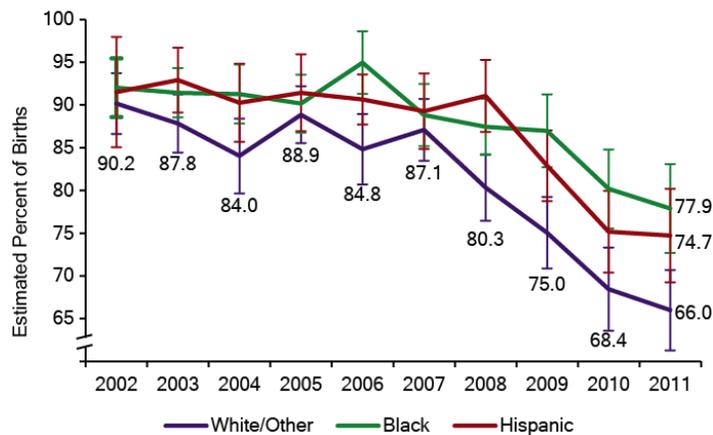
It has been shown that the woman’s experience in the hospital has an influence on her initiation of breastfeeding. In Texas, only 3.4 percent of births in 2011 occurred in a Baby Friendly Hospital according to the National Immunization Study. Initiating breastfeeding in the hospital is the first step towards exclusive breastfeeding.

Focus group work with lactation consultants and other hospital workers conducted in 2008 suggested that hospitals have substantial work to do with educating nursery nurses and administrators on the benefits of breastfeeding and exclusive breastfeeding and behaviors by staff that subtly discourage exclusive breastfeeding.

One administration policy that has been shown to hinder exclusive breastfeeding is the hospital providing complimentary formula to the parents in a gift bag. In regards to this policy, specifically, there has been significant improvement in the state—the percentage of women surveyed through PRAMS who reported receiving formula in a gift bag from the hospital (see Figure 5.13). There has been a

significant and steady decrease in the percentage of women receiving complimentary formula from the hospital. There are also race/ethnic differences in this rate, which may reflect cultural norms, women requesting formula, or subtle differences in hospital practice. Further study and monitoring will be needed to assess the influences of hospital policy and women requesting formula.

Figure 5.13
Percent of Women Receiving Formula in a Hospital Gift Bag,
Race/Ethnicity 2002-2011



Error Bars: 95% Confidence Interval
Source: 2002-2011 Texas PRAMS
Prepared by: Office of Program Decision Support

In addition to hospital and systems level risk, there are maternal and infant characteristics that are also significantly associated with low in-hospital breastfeeding according to the Texas birth certificate file. Two findings that are noteworthy from this analysis is the significantly lower odds of women with an inter-pregnancy interval of 6-months or less have of breastfeeding compared to women with pregnancy intervals between 24 and 48 months. This finding has been documented in the literature, as well. Additionally, women who deliver an infant that is post-term (more than 48 weeks gestation based on clinical estimates) are significantly less likely to breastfeed in the hospital than women with a full-term infant, or even women with a preterm infant.

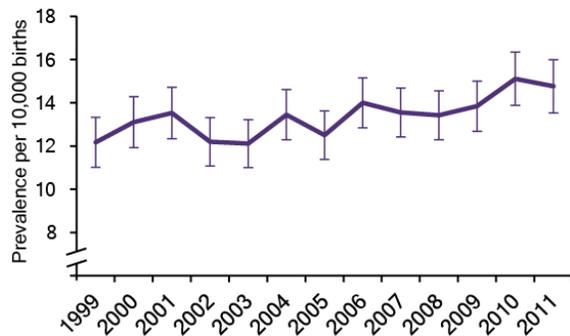
Congenital Abnormalities, Birth Defects, and Cerebral Palsy

Birth defects and congenital abnormalities not only have an impact on the infant mortality rate, but also on the health care delivery systems and the CYSHCN program. Birth defects have a mix of causes ranging from genetic predisposition, environmental factors, maternal illness and a combination of any of the three. In Texas, the Birth Defects Registry has tracked and collected data on all reportable birth defects since 1993. All other references to “birth” in this report refer only to pregnancies that resulted in a live birth. In this section, birth defects are not only situations that result in a live birth, but also those that result in fetal death and early termination of the pregnancy. In Texas, 2.92 percent of all reported birth defects from 1999-2011 did not result in a live birth, with some abnormalities having more than 65 percent of reported cases not resulting in a live birth.

Between 1999 and 2011, Texas has seen a steady and significant increase in the number of Down syndrome cases reported to the registry (see Figure 5.14) [49]. Given the rise in maternal age in the

birth cohort (see Chapter 3) and the strong relationship between maternal age and Down syndrome, this increase is not surprising. “Other congenital and genetic disorders” is the third leading diagnosis category for children enrolled in the CYSHCN program. Children with Down syndrome comprise almost half of this group; therefore, a rise in the number of infants born with this syndrome signals a growing need from the CYSHCN program.

Figure 5.14
Prevalence of Down Syndrome, 1999-2011
Texas Birth Defects Registry



Error Bars: 95% Confidence Interval
Source: Texas Birth Defects Registry
Prepared by: Office of Program Decision Support

Texas, unfortunately, has a history of clusters of spina bifida and other neural tube defects occurring. One of these clusters of spina bifida led to the establishment of the Birth Defects Registry. Spina bifida, specifically, is the 13th most prevalent diagnosis category for clients served through the CYSHCN program. These birth defects are considered largely, but not completely, preventable through a diet rich in folic acid or through pre-pregnancy folic acid supplementation. From 1996 to 1999, Texas saw a significant decrease in spina bifida; however, since 1999, the rate has not significantly changed [50]. The combined rate from 1999-2011 was 37.7 per 100,000 live births; above the HP2020 target of 30.8. In Texas, Hispanic women are at increased risk of neural tube deficits and the border region of the state has significantly higher prevalence of spina bifida than non-border regions [50].

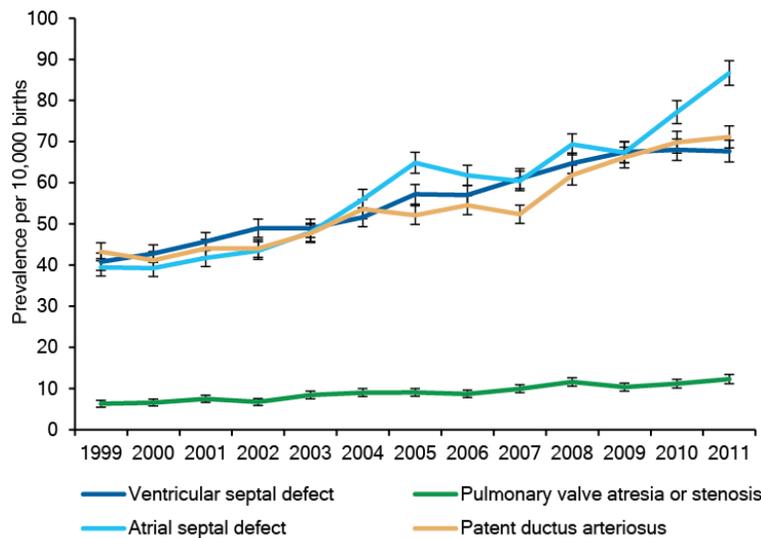
2011 Texas PRAMS data has shown that women along the border are well educated about the benefits of folic acid with 91.2 percent (C.I.: 85.7-96.7) reporting that they know about the link between folic acid and birth defects. This rate is significantly higher than reported knowledge in non-border regions (76.5 percent, C.I.: 73.6-79.4). However, despite this knowledge, folic acid and multivitamin use is low among this group of women, with only 45.9 percent (C.I.: 35.3-56.6) reporting supplementation pre-pregnancy.

Pre-pregnancy supplementation is also predicated, to some extent, on the idea that the pregnancy was intended. The rate of unintended pregnancy has been cited as a barrier to persuade women to take vitamins pre-pregnancy. In the 2011 Texas PRAMS data, 70.2 percent (C.I.: 65.6-74.8) of women with an unintended pregnancy did not take a supplement. This rate is significantly higher than the 45 percent (C.I.: 45.3-53.7) of women who reported the pregnancy was intended, but did not take a pre-pregnancy supplement.

A healthy diet is also a way for women to receive enough folic acid. Obesity can be used as a proxy for poor diet, and the Birth Defect Registry has found that the prevalence rates of spina bifida follow a dose-dependent like relationship with pre-pregnancy obesity status [51]. A healthy diet is a key component to reducing neural tube defects, such as spina bifida, given the high rates of unintended pregnancy and the low rate of supplementation among this group.

The Texas Birth Defects registry also shows a significant increase in the rates of some congenital heart defects since 1999 [49]. While some heart defects will resolve without intervention, others will require life-time monitoring and surgery. Heart defects are the sixth most prevalent diagnosis category for the CYSHCN program; therefore, changes in the prevalence of these birth defects will likely impact the CYSHCN program.

Figure 5.15
Prevalence of Select Heart Defects, 1999-2011
Texas Birth Defects Registry



Error Bars: 95% Confidence Interval
Source: Texas Birth Defects Registry
Prepared by: Office of Program Decision Support

Among heart defects, the increase has mainly been due to a rise in ventricular septal defects, atrial septal defects, pulmonary valve atresia or stenosis, and patent ductus arteriosus (see Figure 5.15). The significant rise in these defects has been attributed to a rise in early diagnosis and identification, rather than to a change in the true occurrence in the population. However, these defects have been linked to maternal characteristics that are also notably gaining in prevalence among the birth cohort. The Birth Defects Registry has reported that these heart abnormalities, in particular, have a higher prevalence among women with pre-pregnancy obesity [51]. Three of these abnormalities show a dose-dependent like relation with the mother’s level of obesity. Further, this rise in prevalence is magnified if the mother had an indication of diabetes. Additional study will be needed to assess whether the increase in obesity among the birth cohort can account for some of the increase in heart defects since 1999.

Cerebral Palsy (CP) is not a birth defect, but it is the most prevalent neuro-muscular disorder in children world-wide. Its origin is not clear. There are many events that may give rise to CP. These events can be from several sources, including placental problems and umbilical cord problems, and there is increasing evidence that the infant’s genetic predisposition or other prenatal factors may also play a role [52]. There are no specific surveillance systems in Texas that monitor or track the incidence of CP. However, its impact on programs is clear; CP was the leading diagnosis category for the CYSHCN program in 2013.

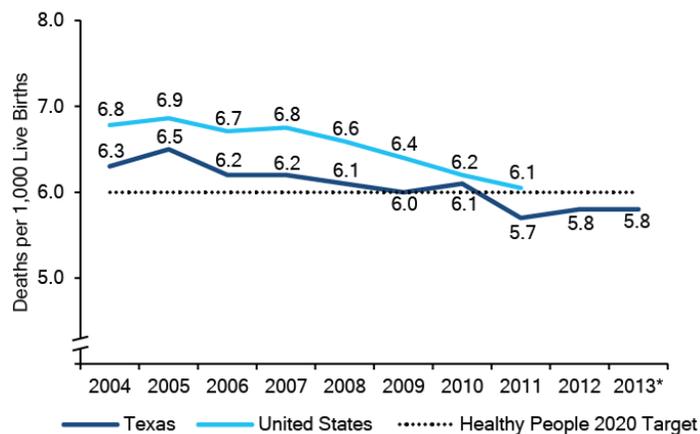
Research on risks associated with CP has found that preterm birth is very high among these children, with almost half of children with CP being born preterm. A recent meta-analysis that included data from six developed countries, including the U.S., found that among those children that were born full term (>36 weeks gestation), several other factors were also important risks, including low birth weight, labor induction, maternal hypertension, maternal pre-eclampsia, among others [53]. A California report linking hospital discharge data to birth records also found an increased risk for cerebral palsy if the woman did not receive prenatal care, even after controlling for other factors [54]. These risks and multi-year trends have been highlighted throughout this and the previous chapter. Prevention of these risks is not just paramount to the survival of the infant, but also to the long-term prognosis of the infant.

Infant Mortality

Infant death is one of the more tragic birth outcomes. Infant mortality does not just reflect the general health and risk of the individual infant, but of society in general. Infant mortality is a general marker of the health of the community. Therefore, addressing and understanding infant mortality requires not just a focus on the infant’s risk, but also on maternal risks, systems risk, and societal risks.

The infant mortality rate (IMR) in Texas has been better than the national rate for the past ten years (see Figure 5.16). However, it has only been since 2009 that the state has met the HP2020 target of 6.0 deaths per 1,000 live births. Preliminary 2013 data suggest that the low IMR has remained stable.

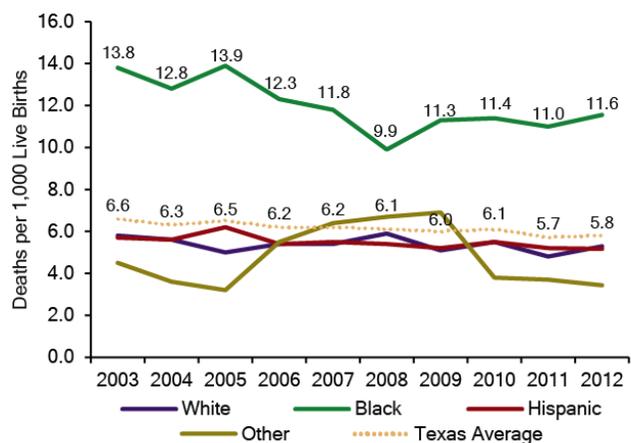
Figure 5.16
Infant Mortality Rate for Texas and the United States, 2004-2013



*2013 Texas data are preliminary
 Source: Texas 2004-2013 Birth Files and Death Files
 National Center for Health Statistics Vital Records Report
 Prepared by: Office of Program Decision Support

Despite the overall decrease in the IMR, the racial-ethnic disparity between Black mothers and all other race/ethnic groups in IMR has persisted (see Figure 5.17). The IMR for Black mothers is more than two times higher than those of White and Hispanic mothers.

Figure 5.17
Infant Mortality Rate by Race/Ethnicity, Texas 2003-2012

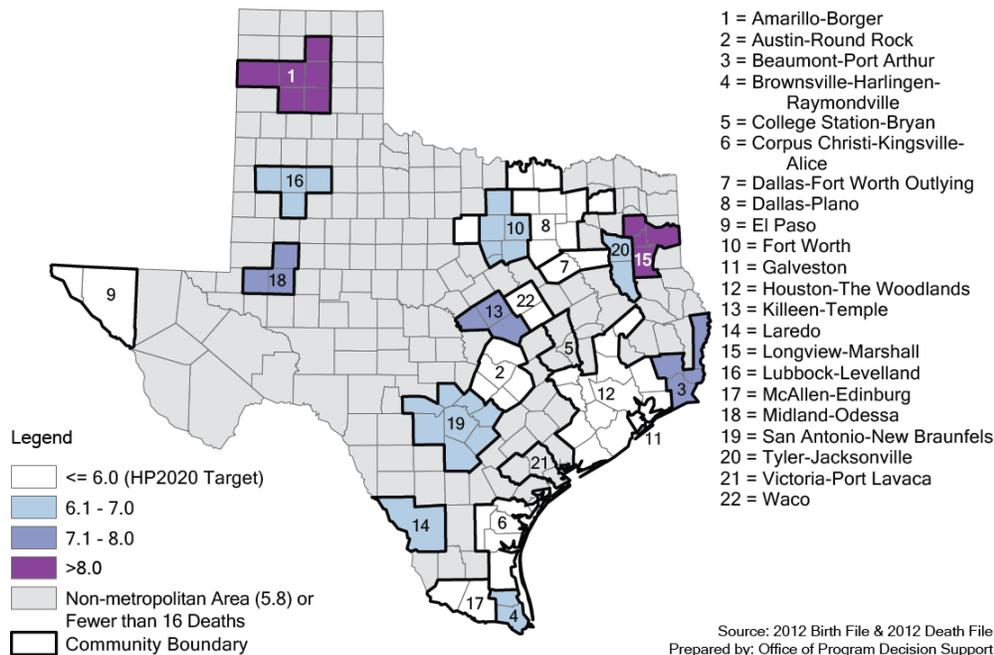


Source: 2003-2012 Birth Files and Death Files
Prepared by: Office of Program Decision Support

Infant mortality, even in Texas, is an event that is rare enough that county level analysis is not possible with a single year of data. In order to focus on current data, which is lost with combining years of data, the geographic analysis for mortality data uses communities defined through the Census Bureau to aggregate data across counties. In this report the term “communities” refers to core-based statistical areas (CBSA) as defined by the Census Bureau. CBSAs are micropolitan and metropolitan areas and are defined by a high degree of social and economic integration between the counties. This scientific analysis uses the 2013 CBSA definitions with two exceptions: 1) the traditional metropolitan area of Dallas-Fort Worth was divided into three areas: Fort Worth-Arlington, Dallas-Plano, and the remaining outlying counties of the metropolitan area; and 2) the county of Galveston was removed from the Houston-The Woodlands CBSA so that particular county could be analyzed separately. All remaining counties were aggregated into a single “non-metropolitan area” and the data for this remaining area is reported in the legend of all maps.

Across these communities, geographic disparities are evident within the state (see Figure 5.18). In 2012, nine of the twenty largest communities in the state with a calculated IMR were better than or meeting the HP2020 target including Houston-The Woodlands and Dallas-Plano areas, which are the two most populous areas in the state. Five communities had IMRs above 7.0 infants per 1,000 live births in 2012. While the state as a whole is moving towards a decrease in IMR, there are still communities that are lagging behind this state-level trend.

Figure 5.18.
 Infant Mortality Rate (per 1,000 Births) by Select Communities (CBSA), 2012

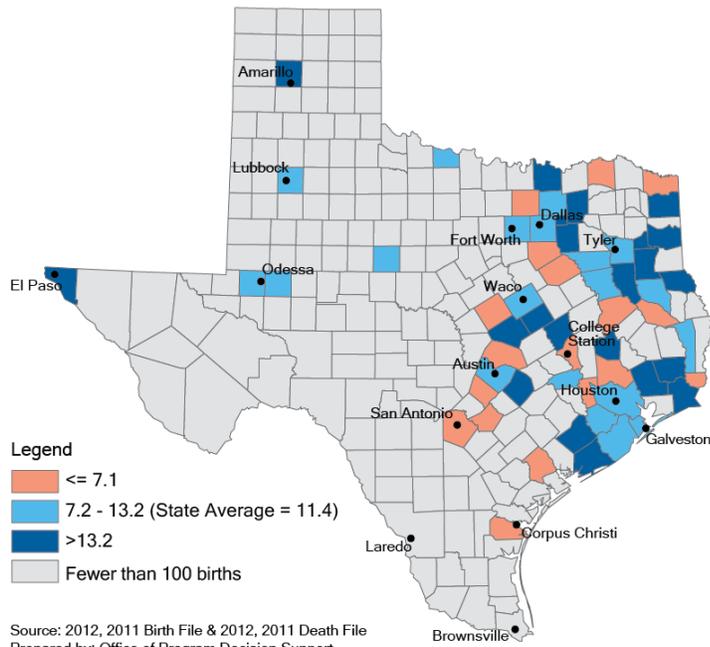


A trend in the IMR of particular concern is the persistently high IMR for Black women. The high rate for Black women is especially puzzling because the Houston-Woodlands and the greater Dallas-Fort Worth metropolitan areas are home to almost 75 percent of the state’s urban-dwelling Black population (see Chapter 2). Therefore, it is reasonable to expect that the overall decreases in IMR in these communities should also result in a decrease in the state IMR for Black women.

Black Infant-Mortality-Rate

In order to assess regional differences in IMR for Black women, 2011 and 2012 data were combined and the Black-IMR was calculated at the county level when there were more than 100 births to a Black woman in the county. This analysis revealed stark and substantial regional differences in Black-IMR (see Figure 5.19).

Figure 5.19
Black Infant Mortality Rate (per 1,000 Births), 2011 & 2012



A striking finding of this analysis is the great variance in the rate across the state and within communities. During 2011 and 2012, there were 10,007 infants of Black mothers (11.6 percent) born in counties with a collective Black-IMR of 5.1 deaths per 1,000 live births (range: 0.0-7.2). There were also 9,774 Black infants (11.3 percent) born in counties with a collective Black-IMR of 16.1 deaths per 1,000 live births (range: 13.2-22.5). Just as with IMR generally, there are substantial regional differences in the Black-IMR. This variability begs the question of what separates these high performing and low performing communities.

Perinatal Periods of Risk Analysis

To understand the disparities in IMR across the state, it is important to look closer at these rates. One way to take a more nuanced view of infant death is to also look at a restricted feto-infant mortality rate (r-FIMR). The Perinatal Periods of Risk (PPOR) approach has been advocated as a way to more specifically look at the r-FIMR and to understand the risks in the community [55]. This approach not only considers live births and infant deaths, but also fetal deaths. Therefore, r-FIMR assesses pregnancy outcomes, not just birth outcomes. The PPOR analysis restricts the types of fetal and infant deaths/births that are analyzed [56]. These restrictions help clearly define the population of deliveries and the types of events that are included, facilitating comparison across years even when fetal death reporting laws and policies shift. The PPOR approach adopted in this report only includes fetuses and infants who weigh more than 500 grams at delivery, or who were at or past 20 weeks of gestation at delivery. In Texas, there are 20-90 births each year where the infant was born before 20 weeks gestation; because these infants would not meet the fetal death cut-off, they were also excluded.

The key component of the PPOR approach is that it divides the r-FIMR into four major periods of risk. The period of risk within which the infant or fetal death falls, depends on its weight at delivery and gestational/birth age at death (see Figure 5.20).

Figure 5.20
Definitions of the Four Perinatal Periods of Risk from the Restricted Feto-Infant Mortality Rate

Maternal Health	Delivery weight less than 1500 grams
Maternal Care	Fetal Deaths with weight greater than 1500 grams
Newborn Care	Delivery weight greater than 1500 grams Death within 28 days of birth
Infant Health	Delivery weight greater than 1500 grams Death after 28 days of birth

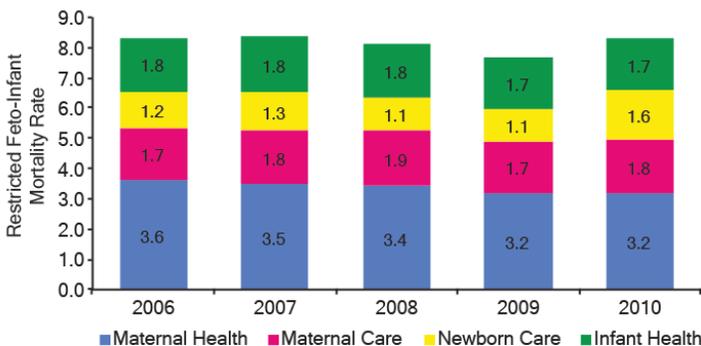
The first period of risk is the Maternal Health period and includes the death of a fetus or infant who weighed less than 1500 grams at delivery, regardless of gestational age. The second period of risk is the Maternal Care period and only includes fetal deaths in which the weight at delivery was 1500 grams or more. These two periods of risk are most associated with health issues of the mother that existed both before and during pregnancy, but they are also some of the most vulnerable infants. It has been shown that the quality and level of care at the hospital where these

infants are born is related to the survival of these infants. While maternal factors may lead to these events, the chance of these infants surviving is increased if they are being delivered in a hospital with a level -III or -IV neonatal intensive care unit [45].

The third period of risk, Newborn Care, includes infants (live births) that died within 28 days of birth. These deaths are most associated with factors related to access to neonatal care. The fourth period of risk is the Infant Health period. This portion of the r-FIMR includes infants who died after 28 days of birth. The risk factors associated with these deaths focus on the environmental health and safety of the infant.

Between 2006 and 2010 (the most recent birth-death linking and fetal death file), the r-FIMR remained relatively constant, as it did for the IMR during this same time period (see Figure 5.21). However, there was a steady decrease in the portion of the r-FIMR associated with Maternal Health Period of Risk.

Figure 5.21
Restricted Feto-Infant Mortality Rate:
Perinatal Periods of Risk, 2006-2010



Texas data from Birth, Death, and Fetal Death Vital Records
Prepared by: Office of Program Decision Support

As with the IMR, there are substantial geographic disparities in the r-FIMR across the 22 largest communities in the state. The period of risk with which each community struggles is different. Interventions that aim at reducing IMR and r-FIMR should consider the specific issues and period of risk that are a challenge for that community.

Maternal Health and Maternal Care Periods of Risk

Sixty percent of the state r-FIMR in 2010 was in the Maternal Health and Maternal Care periods of risk. These two periods of risk were associated with the mother’s general pre-pregnancy health, as well as her health and access to care while pregnant.

There are specific pockets of the state that are showing elevations in the r-FIMR associated with either Maternal Health or Maternal Care. In 2010, six of these communities showed rates that were more than five percent higher than the state average for the Maternal Health period of risk (see Figure 5.22), and eight communities showed elevated rates in the Maternal Care period of risk (see Figure 5.23).

Figure 5.22
Restricted Feto-Infant Mortality Rate: Maternal Health Periods of Risk, 2010

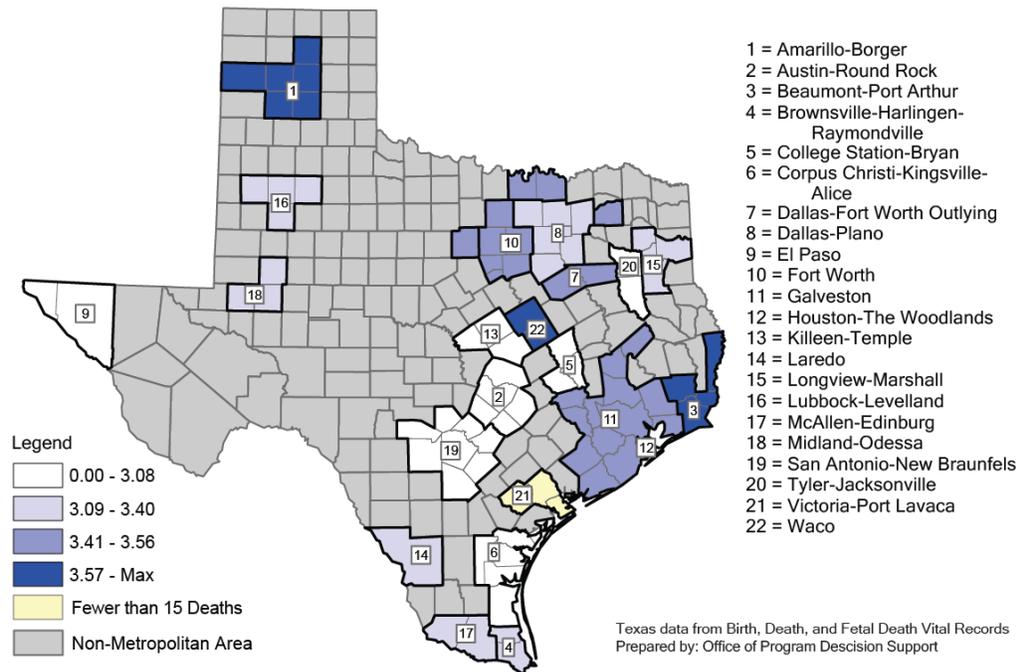
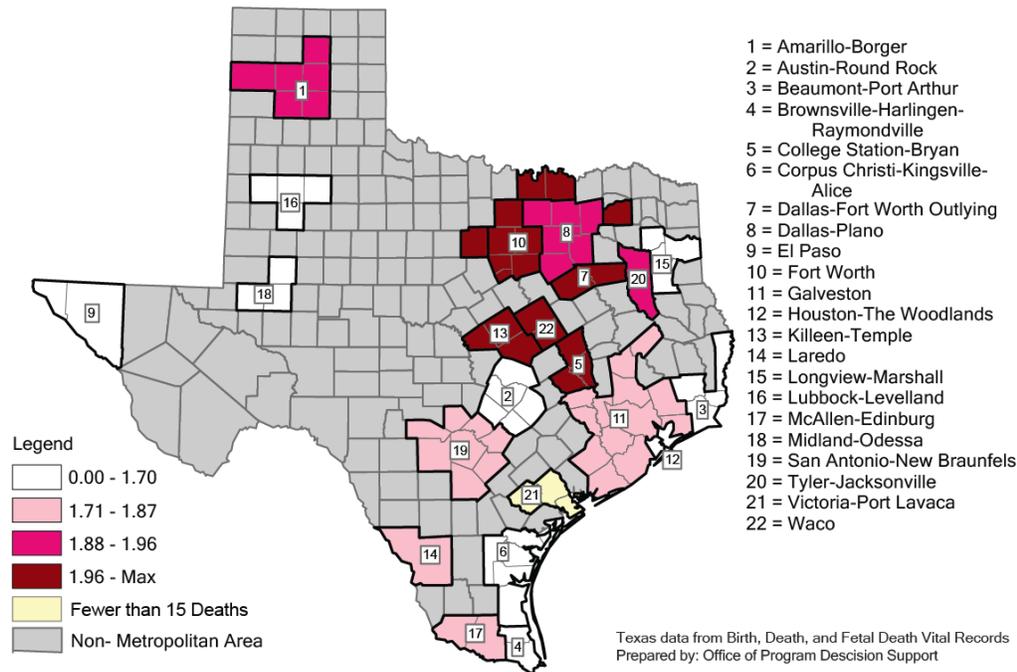


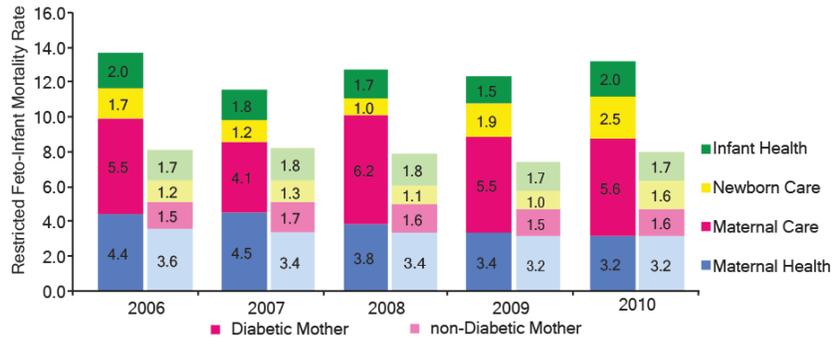
Figure 5.23
 Restricted Feto-Infant Mortality Rate: Maternal Care Periods of Risk, 2010



To assess the influence of select health issues on the r-FIMR in these two periods of risk, three of the most common conditions in pregnant mothers were analyzed to evaluate their relative contribution to this rate. The trends and disparities for each of these conditions are discussed in Chapter 4.

Women with diabetes have an increased risk for a variety of complications, including infant or fetal death. In 2010, the r-FIMR for women with diabetes was more than 60 percent higher than for women without diabetes. Breaking down the r-FIMR into the four periods of risk showed that the r-FIMR in the Maternal Care period of risk was 3.5 times higher than the r-FIMR of women not identified as diabetic in 2010 (see Figure 5.24). The concentration of the r-FIMR in this period of risk highlights the increased rate of fetal death that these women have versus non-diabetic women.

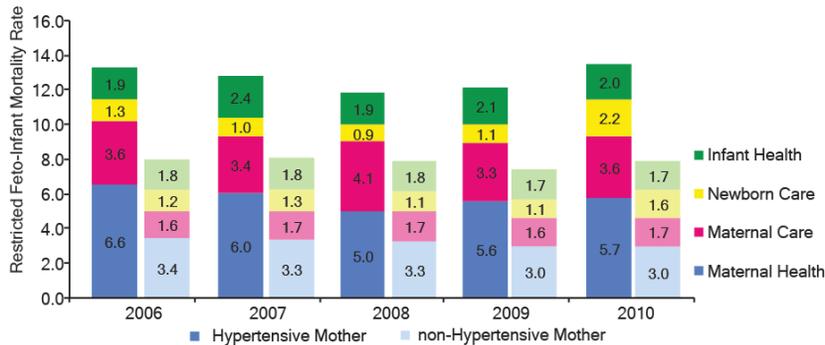
Figure 5.24
 Restricted Feto-Infant Mortality Rate for Diabetic and non-Diabetic Mothers,
 2006-2010 Deliveries



Texas data from Birth, Death, and Fetal Death Vital Records
 Prepared by: Office of Program Decision Support

Approximately 11 percent of all the feto-infant deaths were to a mother with some form of hypertension. Hypertensive mothers had an r-FIMR that was 1.7 times higher than that of women not identified as hypertensive. The r-FIMR for these women was concentrated in the Maternal Care and Maternal Health periods of risk (see Figure 5.25). Hypertensive women had an r-FIMR in the Maternal Health period that was almost two times higher than that of women not identified as hypertensive.

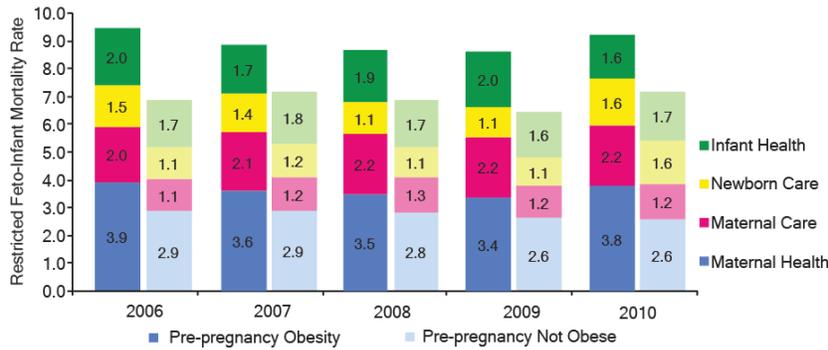
Figure 5.25
 Restricted Feto-Infant Mortality Rate for Hypertensive and non-Hypertensive Mothers, 2006-2010 Deliveries



Texas data from Birth, Death, and Fetal Death Vital Records
 Prepared by: Office of Program Decision Support

Obesity is a major risk factor for developing both hypertension and diabetes during pregnancy. The r-FIMR among these women was higher than the r-FIMR among non-obese women. The r-FIMRs in the Maternal Health and Maternal Care periods of risk were elevated for these women in comparison to non-obese mothers (see Figure 5.26). The clustering of the r-FIMR in these two periods of risk was expected because obesity is a risk factor for hypertension and diabetes, which are also associated with elevated r-FIMRs in these two periods of risk.

Figure 5.26
Restricted Feto-Infant Mortality Rate for Women with Pre-pregnancy Obesity
and Those Without, 2006-2010 Deliveries



Texas data from Birth, Death, and Fetal Death Vital Records
 Prepared by: Office of Program Decision Support

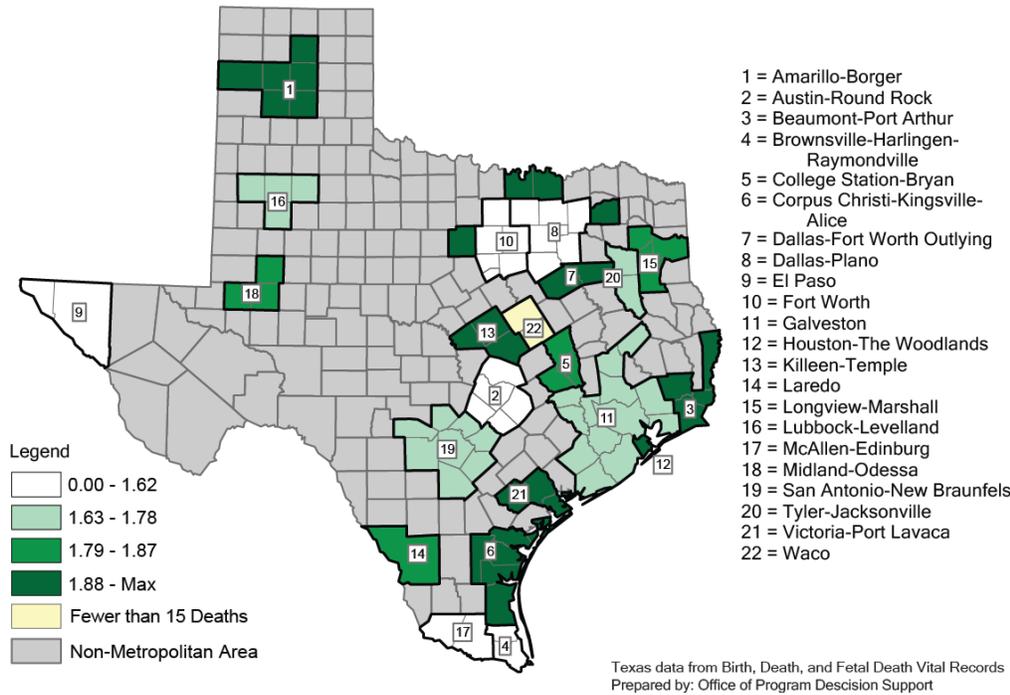
Given the co-occurring nature of hypertension, diabetes, and obesity, it is important to understand whether these risk factors are contributing to the same set of feto-infant deaths, or if they represent independent risk factors that can compound a woman’s risk for a feto-infant death when they co-occur. Even when assessed together and controlling for race/ethnicity and tobacco utilization during pregnancy, obesity, hypertension and diabetes were each a significant unique predictor of fetal death. Obesity and hypertension were significant unique predictors of infant death. These findings suggest that each of these three factors comes with its own unique risk, and having more than one of these factors will increase the risk of either a fetal or infant death.

Newborn Care and Infant Health

The r-FIMR attributed to the Newborn Care period of risk is the smallest of all four periods of risk in the state. Interventions in this period of risk are focused on hospital practices related to appropriate level of care for the infant and screening. Despite Texas as a whole doing quite well in this period of risk, there are pockets of the state with elevated rates of the r-FIMR related to newborn care.

The Infant Health period of risk includes infants that died 28 days or more after their birthdate. This period is most associated with environmental and/or safety issues, such as safe sleep environments, exposure to toxins, and disease protection through cocooning. In Texas, there were seven communities in 2010 with r-FIMRs that were 10 percent higher than the state average (see Figure 5.27).

Figure 5.27
 Restricted Feto-Infant Mortality Rate: Infant Health Periods of Risk, 2010

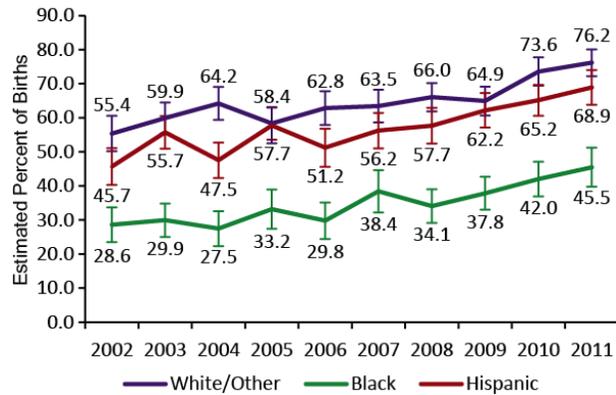


Unlike the other periods of risk that are dominated by congenital abnormalities and extreme prematurity as leading causes of death, the Infant Health period of risk is remarkable because Sudden Infant Death Syndrome (SIDS) or sudden unexplained infant deaths is the leading causes of death. It has been found in the Texas data that the effects of smoking during pregnancy are particularly profound during this period of risk.

Smoking during pregnancy elevates the infant’s risk for a variety of problems, including death [57]. Using the linked birth-death files in 2010, it was found that mothers who smoked during pregnancy had significantly higher odds of infant mortality—even after controlling for other health issues of the mother, Medicaid status, and race/ethnicity. Specifically, these women had more than a three-fold increase in the odds of their baby’s death being classified as SIDS, specifically, than women who did not smoke [58].

Placing an infant on his/her back is an important strategy to reduce sleep-related deaths [59]. PRAMS Texas data has shown that there has been a significant increase in the percent of infants being placed on his/her back to sleep since 2002. Despite this increase, there are still race/ethnic differences, with infants of Black mothers having significantly lower rates of being placed on his/her back (see Figure 5.28).

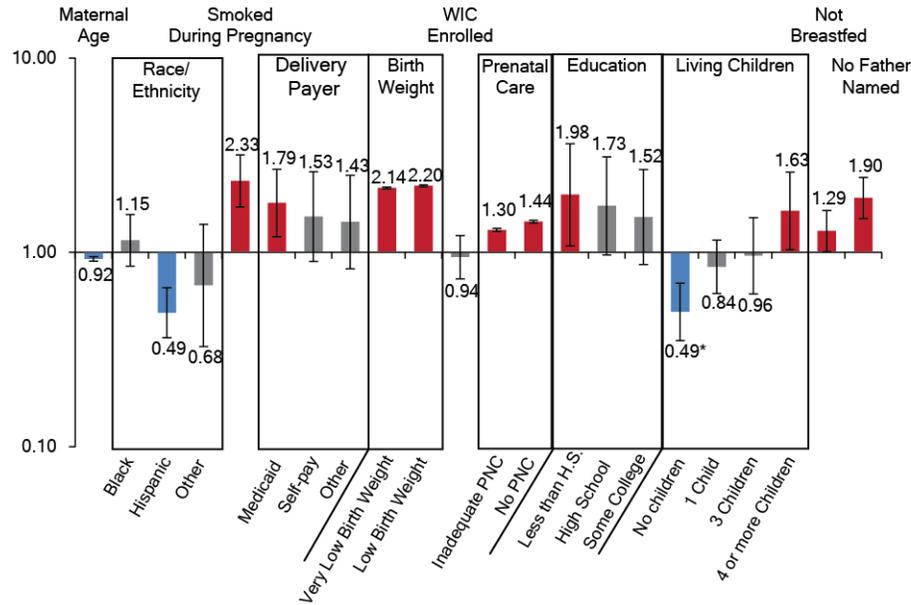
Figure 5.28
Percent of Infants Placed on Back to Sleep,
Race/Ethnicity 2002-2011



Error Bars: 95% Confidence Interval
 Source: 2002-2011 Texas PRAMS
 Prepared by: Office of Program Decision Support

Another concerning cause of death during this period of risk is homicide. Of all deaths investigated by the Department of Family and Protective Services (DFPS) between 2010 and 2012 and found to have substantiated abuse or neglect, 38 percent were deaths to infants. In 2014, DFPS and DSHS began a process to develop a plan to coordinate preventative and family support services administered by each agency in order to prevent child abuse and neglect fatalities. The plan was driven by an in-depth analysis that linked cases of substantiated abuse and neglect with death and birth certificate data. The results of these analyses showed that there are clear risks at birth that put the infant at a higher risk of dying from abuse or neglect (see Figure 5.29).

Figure 5.29
Risk Model for Abuse or Neglect Fatalities



Gray bars are non-significant effects
 Red bars are significant increases in risk
 Blue bars are significant decrease in risk
 *No children is a decreased risk for some types of abuse, but it is an increased risk for physical abuse
 Prepared by: Office of Program Decision Support, Nov. 2014

There are two major findings from this analysis. One finding is that the type of abuse is important for understanding key risks at birth. For example, smoking is significantly related to both physical abuse and sleep related deaths, but it is a much higher risk for sleep related abuse and neglect deaths. Not having other children at home is protective against neglect related deaths, but it is an increased risk for physical abuse deaths. The second major finding is that the general profile of risk that is seen for a child abuse death is a similar profile of risk that is seen in the Texas PRAMS data for intimate partner violence (see Chapter 4).

Chapter 6. Childhood

The early (1-5 years) and late (6 years to the onset of puberty) childhood periods are relatively protected periods of life for children. These periods have the lowest mortality and injury rates of the 18 year span covering childhood. However, this period does mark the emergence of several health risks that can set the child on a long-term path for later health problems.

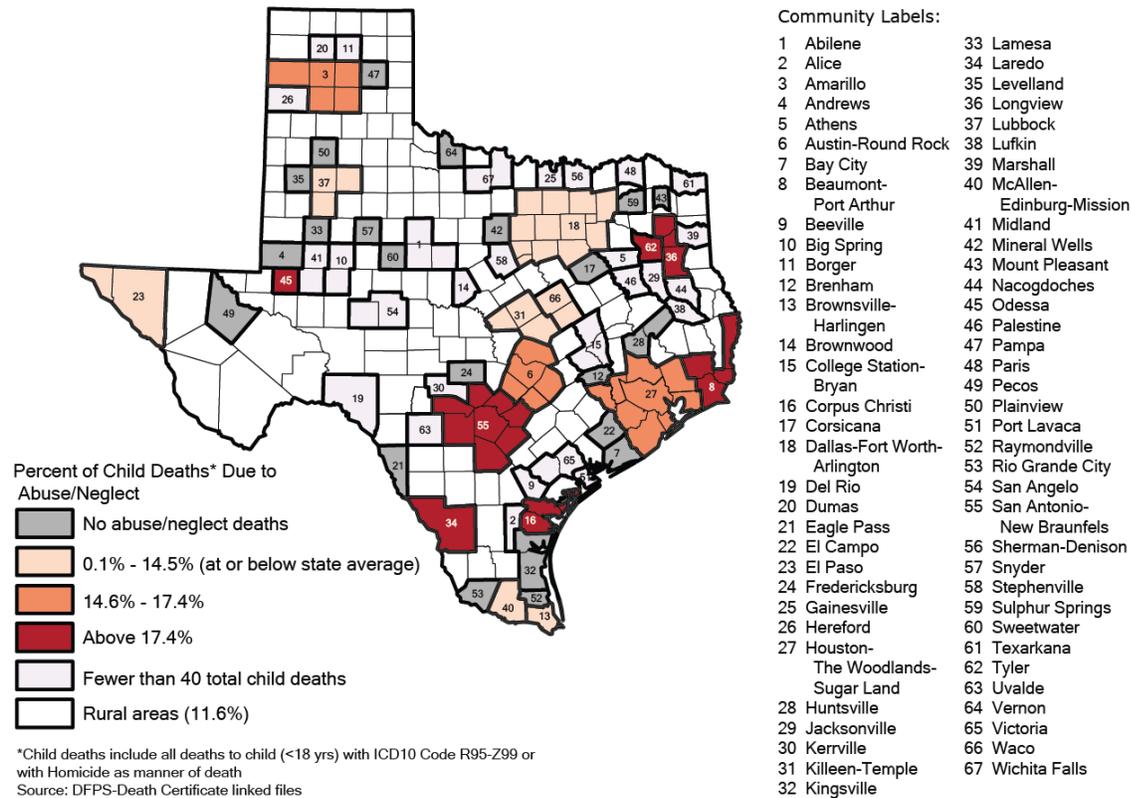
Fatalities

Despite the relative protection of this period, fatalities do occur. For non-natural deaths, the origins of these risks often come from the home environment. The three leading causes of non-natural deaths that will be covered in this chapter are motor vehicle crashes, drowning, and child abuse and neglect. The risks for child abuse and neglect and drowning are unique to this age range, so each will be covered next.

Child Abuse and Neglect

In Texas, child abuse and neglect fatalities account for 11 percent of all non-natural deaths among children 0-17 years of age. However, the early childhood period (1-5 years old) shows particular risk, with 22 percent of all non-natural fatalities being due to substantiated abuse or neglect (see Figure 6.1). These deaths can be grouped into three causes: physical abuse, drowning, or motor vehicle deaths.

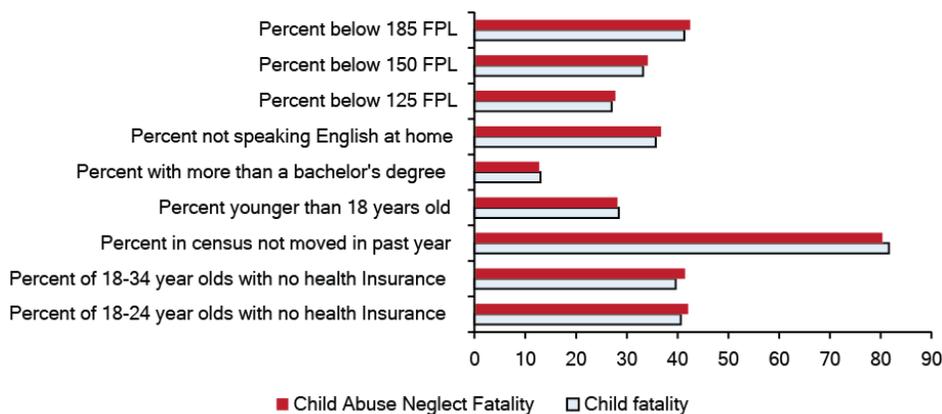
Figure 6.1
Percent of Child Deaths* that Were Abuse/Neglect by Community, 2010-2012



Fatalities are the most tragic outcome of abuse and neglect; however, these deaths are indicative of a larger problem. DFPS estimated that, in 2013, there were 9.2 confirmed abuse or neglect cases for every 1,000 children in the population [60]. Of the cases investigated by DFPS in 2013, 24 percent were substantiated cases of abuse or neglect. These cases are part of a bigger problem, in that 28.7 percent of the investigated cases indicated violence in the family, although violence towards the child may not have been substantiated. The prevalence of family violence underscores the need to address intimate partner violence as a viable strategy to reduce child abuse and neglect (see Chapters 4 and 5).

One of the needs for developing efficient interventions is identifying the communities in which these cases are occurring. The collaboration between DFPS and DSHS to analyze abuse and neglect child fatalities showed that, with two notable exceptions, the communities that are experiencing fatalities in general (excluding all motor vehicle deaths), carry the same risks as the communities that experience abuse and neglect fatalities (see Figure 6.2). These communities do not significantly differ on a variety of measures of community risk including the community’s concentration of poverty, number of people per room per household, percent of population younger than 18 years old, and percent of the population with a bachelor’s degree or higher. These communities did differ on measures of mobility, with more families moving in census tracts experiencing an abuse or neglect death than in communities experiencing child fatalities in general. Additionally, there was a higher percentage of uninsured adults (25-34 years of age) in census tracts who experienced an abuse or neglect death. The general overlap between these community risks shows that preventing abuse and neglect fatalities can fit within population-based strategies to reduce all child fatalities.

Figure 6.2
Community Differences for Child Fatalities and Child Abuse and Neglect Fatalities, Texas 2010-2012



*Child deaths include all deaths to child (<18 yrs) with ICD10 Code R95-Z99 or with Homicide as manner of death, but excluded Motor Vehicle Deaths
 Source: DFPS-Death Certificate linked files
 American Community Survey 2008-2012
 Prepared by: Office of Program Decision Support

The in-depth analysis of the child abuse and neglect fatalities also showed place-based needs that are centered on specific types of fatalities. Homicides, the majority of which are identified as physical abuse, are spread throughout the state. However, drowning and motor vehicle related abuse and

neglect fatalities are more prevalent in the Dallas/Fort Worth area than would be statistically expected. The border region, specifically the southern region, has higher than statistically expected numbers of motor vehicle related abuse and neglect fatalities. It is also notable that the majority of these motor vehicle fatalities (64%) are not vehicle-to-vehicle crashes; rather, these are pedestrian deaths and children being left in vehicles on a hot day.

Discussions of child abuse and neglect must also include children with birth defects and special health care needs. Across several studies, it has been shown that these children have a higher prevalence of abuse or neglect than children without special needs or birth defects. As part of an inter-agency project to assess the prevalence of abuse and neglect among those with birth defects, DFPS full case report files, the birth defects registry, and birth certificate records from 2002-2011 were linked [61]. This project found that children with cleft palate/lip (36 per 1,000), or Spina Bifida (38 per 1,000) had higher prevalence of abuse or neglect than did children not in the birth defects registry (22 per 1,000). Children with Down syndrome, cleft palate/lip, or Spina Bifida were at increased risk for confirmed medical neglect compared to children without an identified birth defect. Additionally, children with cleft palate/lip were at increased risk for physical neglect compared to these children.

The most extreme intervention for a family with an abuse or neglect history is removal from the family and termination of parental rights. Children with special health care needs are at particular risk for not finding a permanent home if this happens. There is a shortage of adoptive families for children who have been removed, and children with special needs are at an additional disadvantage of finding a permanent home. In 2014, 1,623 children with special needs were adopted; however, it is difficult to ascertain how many were eligible or still waiting for adoption [60].

Drowning

Drowning fatalities and motor vehicle fatalities alternate being the leading cause of accidental death for children between 1 and 5 years of age. Texas Child Fatality Review Team data show that almost all of the drowning fatalities for this age range occurred in a private swimming pool. The teams determined that almost all of these deaths could have been prevented. In 88 percent of the cases reviewed in 2011, there was no barrier present that could have prevented or deterred the child from entering the pool.

The teams also determined that poor or absent supervision was a contributing factor in 59 percent of the drowning fatalities in 2011. According to DFPS data, 31.8 percent of drowning fatalities in 2011 involved a confirmed case of abuse or neglect. These data underscore the need to address the wider issues of supervision around pools in the general population, not just in populations that are at risk for abuse or neglect.

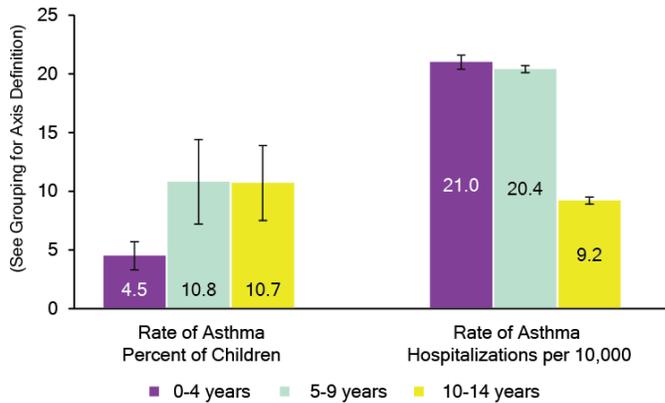
Asthma

It was estimated in 2012 that 9.3 percent of children are affected by asthma nationwide [62]. Recent work has shown that its prevalence rates are closely tied with poverty, although the genetic susceptibility of some children cannot be discounted [63].

In Texas, it is estimated in the Burden of Asthma Report that 9.1 percent of children 0-17 years old have asthma [64]. However, there are significant race/ethnic differences, with 19.2 percent of Black children

having asthma. Children 0-4 years of age have the lowest reported prevalence of asthma, but the highest hospitalization rate (21.0 per 10,000; see Figure 6.3). This low prevalence and high hospitalization rate likely correspond with the child’s initial diagnosis of asthma. Children between 5 and 9 years of age have a hospitalization rate of 20.1 per 10,000, but a prevalence rate similar to the state average. These data likely correspond to the time period when parents and children are learning to control the asthma.

Figure 6.3
Asthma Prevalence and Hospitalization Rates by Age,
Texas 2013



Source: Taken From: Texas Asthma Burden Report
Prepared by: Office of Program Decision Support

The hospitalization rate provides a picture of the extent to which asthma is controlled. The distribution of claim types among Medicaid recipients reveals race/ethnic differences. Hispanic children account for 53.9 percent of physician submitted Medicaid claims and 43.2 percent of all inpatient hospital claims. In contrast, Black children account for 17.3 percent of physician claims and 25.4 percent of inpatient claims. This disproportionate percentage of hospital claims shows that Black children are more likely to be in the hospital for their asthma than those of other races/ethnicities, and hence, further suggests that this group is less likely to have their asthma under control.

These hospitalizations also represent a burden on the medical system. Of asthma-related Medicaid claims, hospitalizations account for less than 1 percent of the number of claims for childhood asthma, but 24 percent of expenditures for children.

In addition to the burden on the medical system, asthma also takes its toll on the child’s education. According to the 2006-2010 BRFSS asthma call-back survey, 53.9 percent of children with asthma had missed school in the past year. Further, 43.2 percent reported having an active asthma management plan with their school. The issues surrounding the school and asthma are also significant to the medical community. The Baylor Asthma Care for Kids Educational Resource study of child asthma cases treated through the Baylor University medical system reported that in 67.4 percent of asthma-related emergency room visits, the child was engaged in a school activity prior to the emergency room visit. In contrast, the child was engaged in an activity at home in only 21.4 percent of the cases.

Obesity

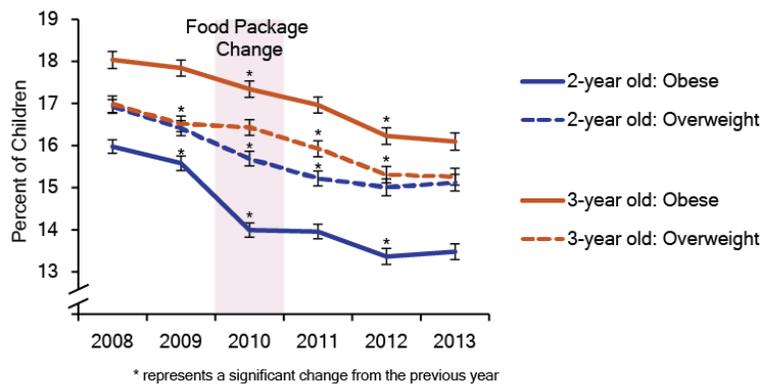
According to the National Health and Nutrition Examination survey, the national prevalence of obesity among 2-5 year old children (n = 871) has decreased from 13.9 percent in 2003-2004 to 8.4 percent in 2011-2012. This represents a significant 43 percent reduction in obesity [65]. The authors of the studies and others have pointed to the changes in the food package provided through the Food and Nutrition Service for Women Infants and Children (WIC) made in 2009 and 2010 as a driving force for this change. However, the results of this study have been called into question as to its generalizability and whether this change was seen in the WIC population.

The changes in obesity were analyzed in the Texas WIC population among toddlers from 2008-2013 (see Figure 6.4). These changes were assessed two ways, one looking at cross-sectional changes from year to year, and the second was to assess longitudinal change in BMI for children who were enrolled in WIC at 2 and 3-years old.

The percent of obese 2-year olds decreased from 16 percent in 2008 to 14 percent in 2010. This percentage of obese children decreased even more in 2013 to 13.5 percent. The change from 2008 to 2013 represents an 18.5 percent decrease in the obesity rate.

The changes for 3-year olds have also been significant, but more modest. The obesity rate decreased from 18 percent in 2008 to 17.3 percent in 2010 and to 16.1 percent in 2013. This change represents a 10.7 percent decrease in the obesity rate from 2008 to 2013.

Figure 6.4
Changes in Obesity and Overweight in 2 and 3 year old Children Enrolled in WIC



Source: WIC Certification Files 2008-2013
Prepared by: Office of Program Decision Support

These decreases in the obesity rate have also been associated with modest decreases in the overweight rate, and additionally, increases in the rate of toddlers who are normal weight.

The longitudinal change in BMI seen in the WIC population shows that individual BMI generally increases from the age of 2 to the age of 3. The extent of this BMI gain differs by race/ethnicity, with Hispanic children showing the biggest gains in BMI from the age of 2 to 3. A significant finding from this

analysis is that, despite these gains, children whose mother was enrolled in WIC in 2012-2013 still had lower BMI at the age of 3 than those enrolled in 2008-2009, before the food package change.

Within the state, WIC provides the only viable surveillance of obesity among toddlers. Tracking this rate and changes in this rate are important for assessing the overall health of children. There is an increasing number of studies showing that obesity among toddlers can lead to later health issues and long-term problems with weight.

One of the issues emerging in the literature on obesity prevention with young children is whether or not parents recognize that the child is obese or overweight and what parents view as healthy weight for their children. It has been shown that parents tend to underestimate their child's weight status [66]. Several studies have shown that this underestimation is also associated with a lack of concern for the child's weight and level of physical activity.

In the late childhood period, parental attitudes and perceptions have an impact on children's physical activity. Fourth grade students, on average, engage in more than 30 minutes of vigorous physical activity 3.3 days a week according to the Texas School Physical Activity Nutrition Survey (SPAN). One of the factors that has been found to influence this level of activity is the parents' perception of safety in the neighborhood [67]. Specifically, parents that view traffic in their neighborhood to be unsafe were significantly less likely to let their child play outside than parents who did not have concerns about traffic. Parents in the Title V Focus Group also expressed concern about neighborhood safety as a factor for letting their children play outside with these expressed fears being more about crime.

One theme about obesity that emerged out of both the Title V Focus Groups and the CYSHCN Focus Groups is parents feeling powerless to influence their young children's food choices. A sentiment expressed throughout all Focus Groups was lack of knowledge on how to get their children to eat healthier food, and that it was easier to let them eat unhealthy food that they liked. This sentiment was especially expressed by parents with a child with special health care needs, whose children may be less flexible about routine or choice. It is clear from the SPAN data and focus group results that parental perceptions, parenting needs, and views about obesity are all vital components of the obesity rate for young children.

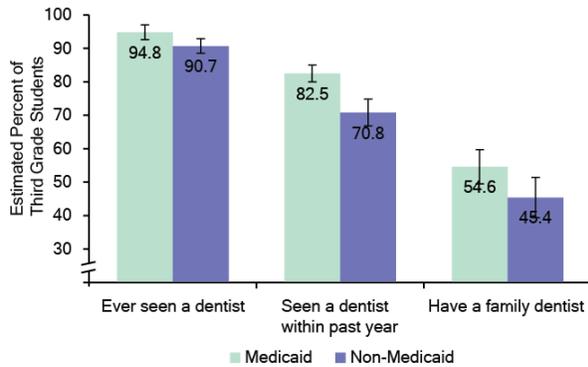
Oral Health

Every five years, DSHS conducts the Oral Health Basic Screening Survey (BSS) to assess the level of oral health service utilization and oral health status of third grade and Head Start students in the state. The BSS consists of a short survey that parents fill out concerning utilization of oral health services for their child. Additionally, there is also a limited oral exam of the child conducted by a trained dentist. The most recent BSS was conducted in 2012-2013, and included a representative sample of 3,143 Head Start students and 6,351 3rd grade students.

In Texas, the oral health utilization disparities between Medicaid enrolled children and those not enrolled in Medicaid are well documented [68]. Children enrolled in Medicaid in Texas have higher oral health care utilization than children not enrolled in Medicaid, including those children with private insurance. The results from the BSS also illustrate this disparity (see Figure 6.5). Among 3rd grade

students, 70.8 percent (C.I.: 66.8-74.8) of children not enrolled in Medicaid had seen a dentist in the past year. In contrast, 82.9 percent (C.I.: 80.0-85.0) of children receiving Medicaid had seen a dentist in the past year. Continuity of care is not just important for general medical care, but also for oral health care, and a component of this continuity is having a regular provider. Third grade students enrolled in Medicaid (54.6 percent; C.I.: 49.5-59.8) had a higher prevalence of having a family dentist than those not enrolled in Medicaid (45.4 percent; C.I.: 39.4-51.4).

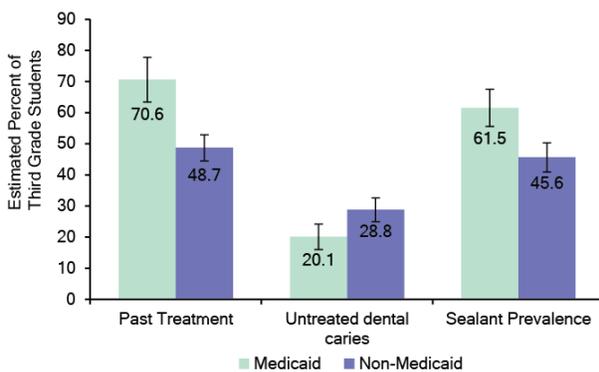
Figure 6.5
Access to Dental Services among Third Grade Students
by Medicaid Status, Texas 2012-2013



Source: Oral Health Basic Screening Survey, 2012-2013
Prepared by: Office of Program Decision Support

This higher level of access also translates into better oral health (see Figure 6.6). Medicaid enrolled third grade students had lower prevalence of untreated dental caries (20.1 percent; C.I.: 16.0-24.1) and a higher prevalence of sealants (61.5 percent; C.I.: 55.5-67.6) than students not enrolled in Medicaid (28.8 percent, C.I.: 25.0-32.7; 45.6 percent, C.I.: 40.9-50.4, respectively). However, third grade students, generally, have better oral health and sealant usage than what was seen in the 2008-2009 BSS.

Figure 6.6
Dental Outcomes for Third Grade Students
by Medicaid Status, Texas 2012-2013

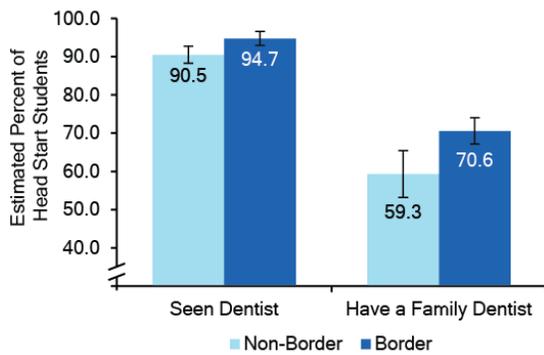


Source: Oral Health Basic Screening Survey, 2012-2013
Prepared by: Office of Program Decision Support

Head Start enrollment is dominated by children enrolled in Medicaid, as 80 percent of Head Start slots are earmarked for low-income families, and all Head Start students are required to have an oral health check-up within 6 months of enrollment. Therefore, there are very few differences between children

enrolled and not enrolled in Medicaid. However there are geographic differences in utilization and health outcomes (see Figure 6.7). Children living along the border have a significantly higher prevalence of ever seeing a dentist (94.7 percent; C.I.: 92.9-96.6) than those living outside the border region (90.5 percent; C.I.: 88.3-92.7). Additionally, children living in the border region have a higher prevalence of having a family dentist (70.6 percent; C.I.: 67.2-74.0) than those not living near the border (59.3 percent; C.I.: 53.2-65.4). This higher level of access does not necessarily translate into better outcomes, however. For all dental outcomes, except the need for urgent care, there is little difference between children living in these two areas of the state.

Figure 6.7
Dental Access for Head Start Students
by Border Status, Texas 2012-2013

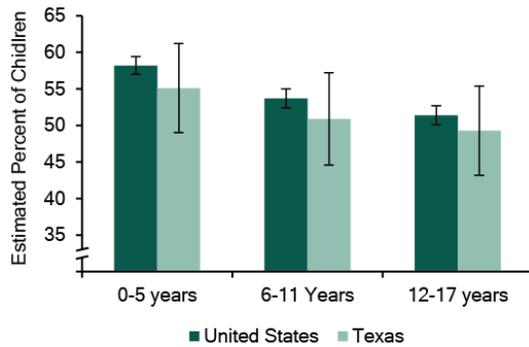


Source: Oral Health Basic Screening Survey, 2012-2013
Prepared by: Office of Program Decision Support

Medical Home

A good medical home has seven major components: 1) a personal physician; 2) physician directed medical practice; 3) a whole person orientation; 4) coordination of care; 5) care is high quality; 6) there is enhanced access to care; and 7) payments should be based on quality. For patients, the medical home should be accessible, family-centered, comprehensive, coordinated, and culturally effective. In Texas, 51.8 percent (C.I.: 48.2-55.4) of children received coordinated, ongoing, comprehensive care within a medical home (see Figure 6.8). This prevalence is lower, but not significantly so, from the national prevalence of 54.4 percent (C.I.: 53.7-55.1). Nationwide, the prevalence of Medical Home decreases with increasing age of the child. In Texas, this change is difficult to assess using the National Survey of Children’s Health because the margin of error is so large in the Texas sample.

Figure 6.8
Children Receiving Care in a Medical Home
by Age Group, 2011-2012



Source: National Survey of Children’s Health, 2011-2012
 Prepared by: Office of Program Decision Support

Estimates of CYSHCN are indicators of quality care in the general population, as they are heavy users of the medical system. In Texas, CYSHCN have low rates of medical home utilization. The NS-CSHCN estimates that only 40.1 percent (C.I.: 35.6-44.5) of CYSHCN received their care within a medical home. As will be discussed in Chapter 7, the utilization of medical home for these children is a strong predictor for later outcomes and transitions to adult care.

One way that Texas is failing in terms of medical home is with “coordinated care.” On the NS-CSHCN, this component of medical home is the most likely to be missing for children in Texas. The CYSHCN Community Outreach (parent) Survey also indicated that coordination of care is a challenge, with 71.6 percent of parents reporting that they coordinate their child’s care themselves. For these parents, that level of responsibility also means overcoming barriers to seeking care. For parents responding to the 2014 CSHCN Parent Survey, lack of transportation (57.3 percent), lack of a close medical provider (54.8 percent), and not having medical providers qualified to care for their child nearby (51.6 percent) were all barriers to receiving care. Despite these barriers, 77.0 percent of parents said they had a regular place to take their child when sick, and 81.4 percent said they take their child to a specialist or doctor’s office when the child is sick.

Chapter 7. Adolescents & Transition to Adulthood

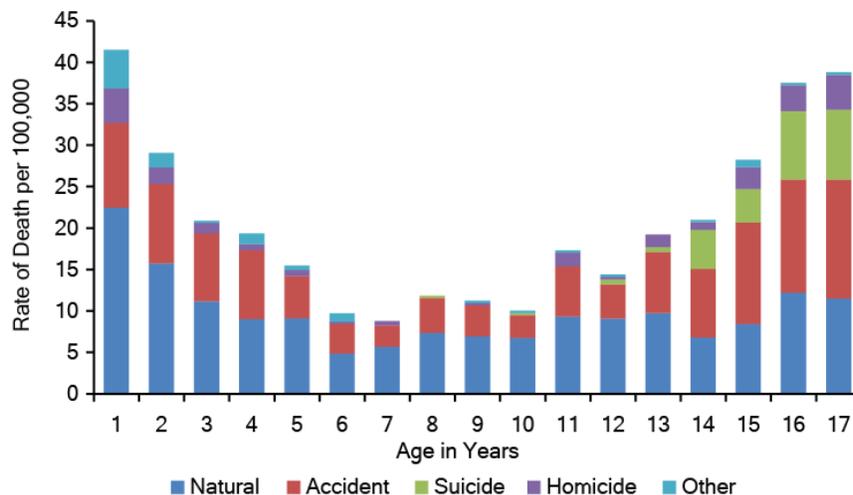
Adolescence is a period of a child's life with little consensus in the literature on when this time begins and when it ends. However, the importance of this period in development is clear. There are major transitional changes in physical and psychological development, including neurologic changes to the brain, which can lead to risky behaviors, sleep disruptions, changes in health, and profound changes in social-emotional processing.

Throughout this chapter, different age ranges for some of the topics and indicators will be presented. These differences are due to the variation in how data sources group the various ages defined as youth or adolescence. The age ranges will be presented in the titles of the figures and maps. An effort was made to have all age ranges include 15-17 year olds when the data was presented throughout the chapter.

Fatalities

The period of child development with the second highest risk for death is adolescence—after the infancy/early toddler period. Youth from 15-17 years of age are more likely to die from a non-natural cause of death, whereas infants and toddlers are most likely to die from a natural cause (see Figure 7.1). These non-natural causes of death are mainly accidents and suicides for youth in this age group.

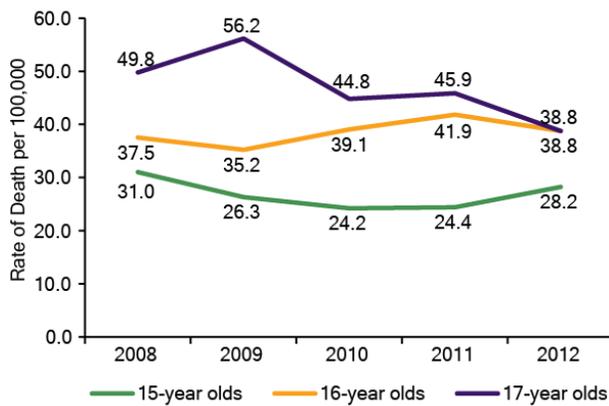
Figure 7.1
Mortality Rates by Manner of Death for Children 1-Year Old to 17-Years Old,
Texas 2012



Source: 2012 Texas death file, 2012 Population Estimates
Prepared by: Office of Program Decision Support

There are differences in the fatality rate within these age groups. From 2008 to 2012, the fatality rate among 17-year olds decreased 22.1 percent, the rate for 16-year olds remained stable, and the rate for 15-year olds only decreased 9 percent (see Figure 7.2).

Figure 7.2
Mortality Rates by Age for 15 – 17-Year Olds, Texas 2008-2012

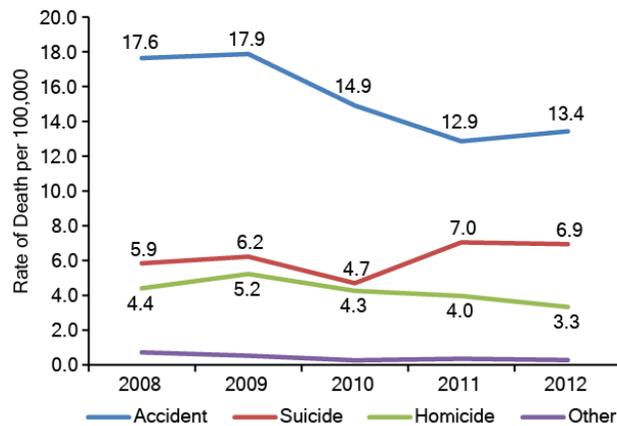


Source: 2012 Texas death file, 2012 Population projections,
2008-2011 Population estimates
Prepared by: Office of Program Decision Support

Motor Vehicle Crashes

The decline in the fatality rate for the 15-17 year old age group has been mainly driven by a decrease in accidental deaths (see Figure 7.3).

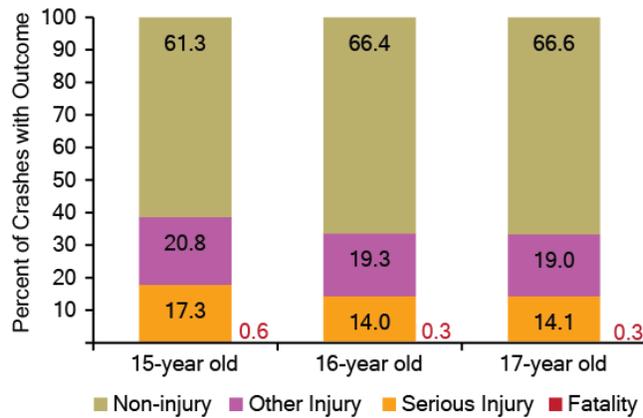
Figure 7.3
Mortality Rates by Manner for 15 – 17-Year Olds, Texas 2008-2012



Source: 2012 Texas death file, 2012 Population projections,
2008-2011 Population estimates
Prepared by: Office of Program Decision Support

The leading cause of accidental death for this age group is motor vehicle crashes. Among 15-17 year olds, the rate of motor vehicle fatalities has declined 30.7 percent since 2008. Local Texas Child Fatality Review Teams examined 171 of the 267 motor vehicle deaths in 2011. The Teams found that in 32 percent of the deaths, the victim was the driver of the car. In all but one of these 267 cases, the driver was between 15-17 years old. Data from the Texas Department of Transportation (TXDOT) indicated that a fatality resulted in 3 out of 1,000 crashes for drivers aged 16 and 17 (.3 percent, respectively, in Figure 7.4).

Figure 7.4
Outcomes of Crashes Involving a Driver Aged 15-17,
Texas 2013



Source: TX Dept. of Transportation, Motor Vehicle Data Report
 Prepared by: Office of Program Decision Support

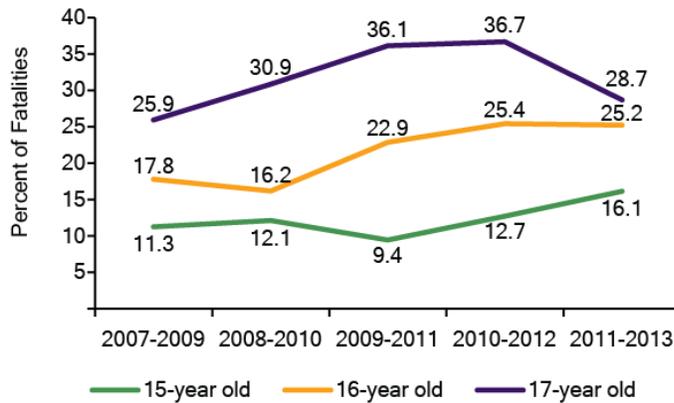
In 2013, TXDOT reported that youth 15-17 years old were unrestrained in 56.8 percent of the motor vehicle fatalities. TXDOT further reported that an additional 11.1 percent of the crashes with an unrestrained youth resulted in serious injuries, and 4.1 percent of the crashes resulted in other types of injuries. It is important to note that these unrestrained youth statistics reflect both drivers and passengers. In 2011, the Texas Child Fatality Review Team data showed that the teen driver was unrestrained in 32 percent of the teen driver deaths reviewed.

In addition to the risks of being unrestrained in a vehicle, the risk associated with driving while under the influence of alcohol is also important to consider. Youth are at risk of being in a crash while driving intoxicated. For youths aged 15-17, driving under the influence (DUI) of alcohol accounted for 1.56 percent of all DUI crashes in rural counties and .75 percent of crashes in urban counties in 2013.

The risk of a DUI fatality is not just with the driver, but also lies with the passenger and others involved in the crash. Between 2007 and 2013, there was a DUI in approximately 20 percent of all fatalities for youth age 15-17 years old (see Figure 7.5). The percent of all motor vehicle fatalities that involved a driver under the influence is higher for 17-year olds than for any other age younger than 18 years old.

Figure 7.5

Percent of Fatalities at Each Age Where a Driver Was Under the Influence, Texas 3-Year Rolling Percent 2007-2013

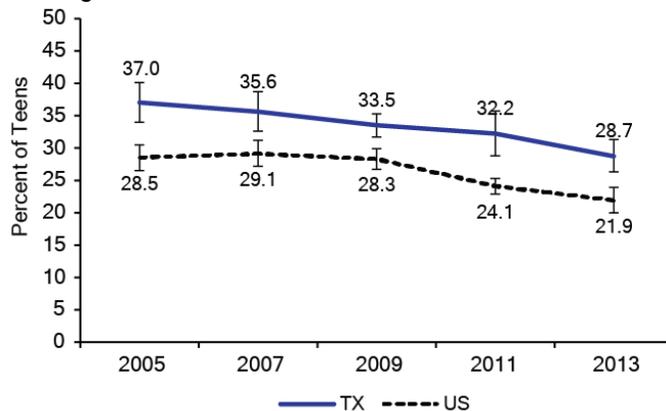


Source: TX Dept. of Transportation, Motor Vehicle Data Report
Prepared by: Office of Program Decision Support

According to the 2013 CDC Youth Risk Behavior Surveillance System (YRBSS), 28.7 percent (C.I.: 26.3-31.3) of Texas youth reported that they were a passenger in a vehicle with a driver who had been drinking alcohol (see Figure 7.6). There has been a significant decrease in this rate since 2005. However, this rate was still significantly higher than the national average of 21.9 percent (C.I.: 20.0-23.9) in 2013.

Figure 7.6

Percent of Teens Who Rode with a Driver Who Had Been Drinking Alcohol, 2005-2013

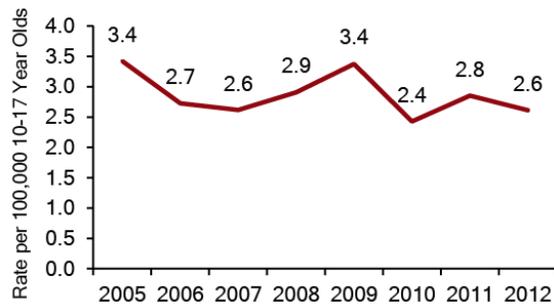


Source: 2005-2013 Youth Risk Behavior Surveillance System
Prepared by: Office of Program Decision Support

Suicides

Texas has seen relative stability in the suicide rate for youth 10-17 years old from 2005 to 2012 (see Figure 7.7). However, the suicide rate among 15-17 year olds has risen. This age group carries the highest risk for suicide among all children younger than 18 years old. It is important to note that about three quarters of child suicides in Texas in any given year involve youth older than 15 years old.

Figure 7.7
Suicide Rate for 10-17 Year Olds, Texas 2005-2012



Source: 2005-2012 Texas death file, 2012 Population projections, 2005-2011 Population estimates
Prepared by: Office of Program Decision Support

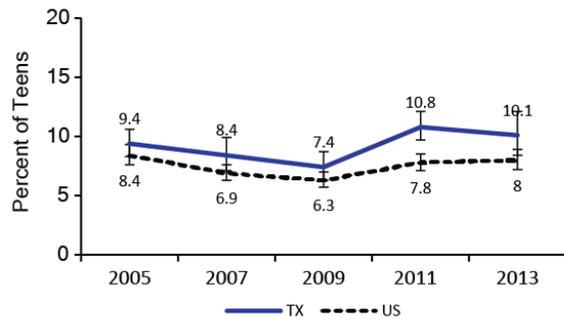
In 2011, Texas Child Fatality Review Teams examined 77 percent of all youth suicides in Texas. The teams determined that 65 percent of these suicides could have been prevented. In 2011, firearms (44 percent) and strangulation/hanging (36 percent) were the two most prevalent ways that children younger than 18 years old committed suicide.

As with other causes and manners of death, understanding the context that leads to the suicide is important. The teams identified several psycho-social factors that they determined had contributed to the death. In 32 percent of the cases reviewed, family relationships—arguing with parents, parents getting a divorce or family discourse—were contributing factors. Of the identified problems contributing to the suicide, peer relations (i.e., fighting with peers, fighting with a boyfriend or girlfriend, or breaking up with a boyfriend or girlfriend) was the third most prevalent factor.

The link between depression, anxiety, and suicidal behaviors has been well established. In Texas, 3.2 percent (C.I.: 2.2-4.6) of youth 15-17 years old reported having a clinically diagnosed depressive episode in the past year, and 1.8 percent (C.I.: 1.2-2.7) reported a diagnosed episode of anxiety. The rate of any depressive episode over the course of the lifetime is higher among these youth, with 4.6 percent (3.5-6.2) reporting a history of diagnosed depression and 2.2 percent (C.I.: 1.5-3.3) reporting diagnosed anxiety.

However, it is also important to point out that there is a discrepancy between the prevalence of depression and the percent of youth that reported attempting suicide in the past year (see Figure 7.8). Based on 2011 YRBSS data, 10.1 percent (C.I.: 8.4-12.1) of youth in grades 9-12 had attempted suicide in the past year, which is almost 5 times the rate of youth with diagnosed depression.

Figure 7.8
Percent of Teens Who Had Attempted Suicide in the Past Year, 2005-2013



Source: 2005-2013 Youth Risk Behavior Surveillance System
 Prepared by: Office of Program Decision Support

Additionally, significantly more female youths reported that they had attempted suicide than male youths, whereas there were no significant gender differences in depression history. From the data, it is clear that other psycho-social factors may contribute to suicide predisposition, or that there may be a significant portion of youth with undiagnosed or unrecognized depression.

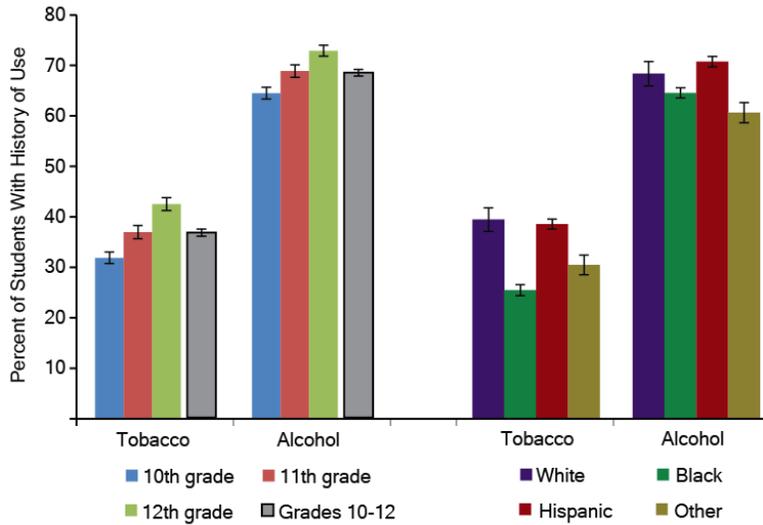
Substance Use

Among the 2014 Title V Focus Group participants, both fathers and mothers said that a top concern of theirs for an adolescent child was exposure to drugs, alcohol, and sexual activity. According to the 2012 TSSSU, the most prevalent substance tried at least once by 10-12th grade students in Texas is alcohol (see Figure 7.9). It is important to note that the YRBSS reports that the rate of trying tobacco is higher than alcohol use among students in these grades. Among 12th grade students, the YRBSS estimates that 52.4 percent had tried cigarettes, whereas the TSSSU reports that rate to be 42.3 percent. The TSSSU has a sample size of 38,951 students, so utilizing data from the TSSSU is preferred over the YRBSS.

As would be expected, the rate of ever trying alcohol significantly increased with grade level. Black 10-12th grade students report lifetime alcohol use at a significantly lower rate than Hispanic youth.

Figure 7.9

Percent of 10-12th Grade Students Reporting Ever Trying Tobacco or Alcohol by Grade and Race/Ethnicity, Texas 2012



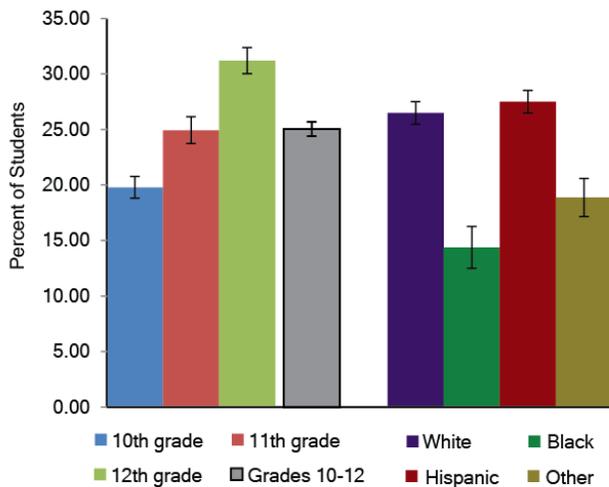
Source: Texas School Survey of Substance Use, 2012
Prepared by: Office of Program Decision Support

When assessing recent use (use in the past month), the same patterns emerge, with significantly greater prevalence in older grades and higher use among Hispanic and White youth than with Black youth.

Binge drinking is defined as drinking five or more drinks in one setting on the TSSSU. Overall, 25 percent (C.I.: 24.4-25.7) of youth reported binge drinking in 2012 (see Figure 7.10). As with alcohol use in general, these rates were significantly higher among White and Hispanic youth than among Black youth.

Figure 7.10

Percent of 10-12th Grade Students Reporting Binge Drinking in Past Month by Grade and Race/Ethnicity, Texas 2012

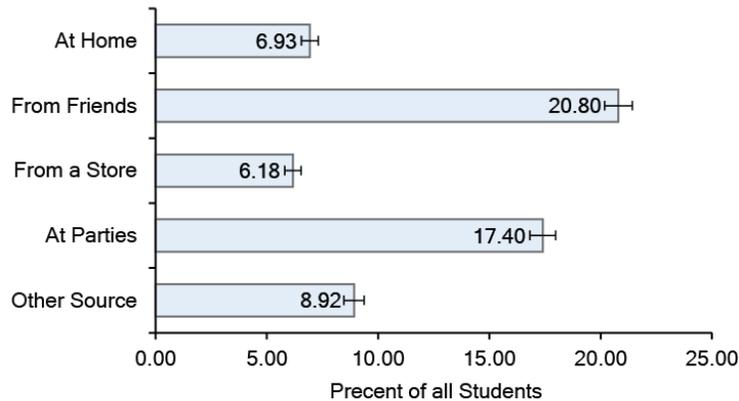


Source: Texas School Survey of Substance Use, 2012
Prepared by: Office of Program Decision Support

Parents in the Focus Groups also expressed concern about their adolescent “falling in with the wrong crowd.” The sentiment expressed in this statement suggests that peers have an influence on behavior

and peers may be a gateway to risky behaviors. TSSSU data concerning where 10-12th grade students are likely to get alcohol illustrates this peer effect (see Figure 7.11). The most prevalent place students reported access to alcohol “most of the time” was from friends or at parties.

Figure 7.11
Where 10-12th Grade Students Reported that They Get Their Alcohol from “Most of the Time”, Texas 2012

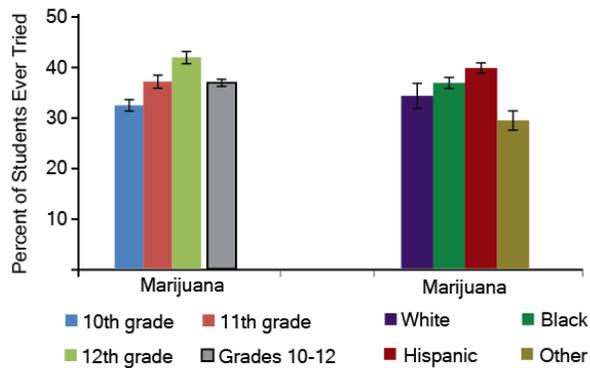


Source: Texas School Survey of Substance Use, 2012
Prepared by: Office of Program Decision Support

Marijuana is the most frequently used illicit substance in the U.S. among adults and youth. While popular perception is that marijuana is generally safe, the long-term effects of marijuana use among adolescents is currently being debated within the developmental neuroscience literature.

According to TSSSU data, there was little difference between race/ethnic groups based on any history of trying marijuana in 2012 (see Figure 7.12). Hispanic youth had a significantly higher prevalence rate than White youth, but not higher than Black youth. The prevalence rate for Black youth is not significantly different than White youth.

Figure 7.12
Percent of 10-12th Grade Students Reporting Ever Trying Marijuana by Grade and Race/Ethnicity, Texas 2012



Source: Texas School Survey of Substance Use, 2012
Prepared by: Office of Program Decision Support

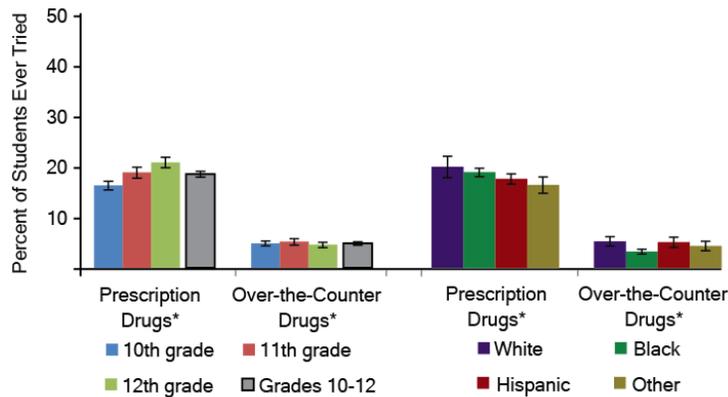
The patterns of marijuana use in the past month follow the history of use data. It is also important to point out that 37.8 percent of youth who had a history of marijuana use also indicated that they had not used it in the past year.

One of the debates surrounding the long-term consequences of marijuana use on brain development centers around differentiating the effect of marijuana-only use from poly-use effects. In particular, marijuana-alcohol co-use is prevalent among adolescents, and this co-use pattern is at the center of this debate. Studies have found adverse effects on adolescent brain structures and physiology that are rapidly developing during this developmental period. The likely behavioral consequences of these physiological effects focus on processing speed (i.e., quick reactions to unexpected events), memory, and executive functioning (i.e., the ability to hold several tasks in mind at the same time, the ability to switch between tasks, and the ability to control impulses). Co-using adolescents have less cognitive flexibility (i.e., ability to switch between tasks and rules), have impaired working memory, slower motor speed, and are less accurate on cognitive tasks than non-users.

In Texas, this co-use is prevalent, in that 12.1 percent (C.I.: 11.6-12.6) of all 10-12th grade students reported using both marijuana and alcohol in the past month. Of all past-month marijuana users, 77.4 percent who used marijuana had also used alcohol in the past month. Because of this high rate of co-use, the neurological and behavioral consequences, regardless of whether they are due to co-use or to marijuana use specifically, are relevant toward understanding the public health impact of adolescents using these substances.

Two issues that are gaining in importance across the country are over-the-counter medicine abuse and prescription drug abuse. According to the 2013 Title V Community Outreach Survey, 23.3 percent of respondents indicated that abuse of prescription drugs was a top concern for their community. The use of both of these categories of drugs is relatively low in Texas among adolescents when compared to alcohol, marijuana, or tobacco, but the use rates are too high to ignore. TSSSU data indicate that 18.5 percent (C.I.: 18.0-19.1) of 10-12th grade students reported using prescription drugs for nonmedical use at least once in their lifetime, and 4.9 percent (C.I.: 4.5-5.2) reported using over-the-counter medication (see Figure 7.13). There are no significant race/ethnic differences for either category.

Figure 7.13
 Percent of 10-12th Grade Students Reporting Ever Trying Prescription or Over-the-Counter Drugs for Recreational Use by Grade and Race/Ethnicity, Texas 2012



Source: Texas School Survey of Substance Use, 2012
 Prepared by: Office of Program Decision Support

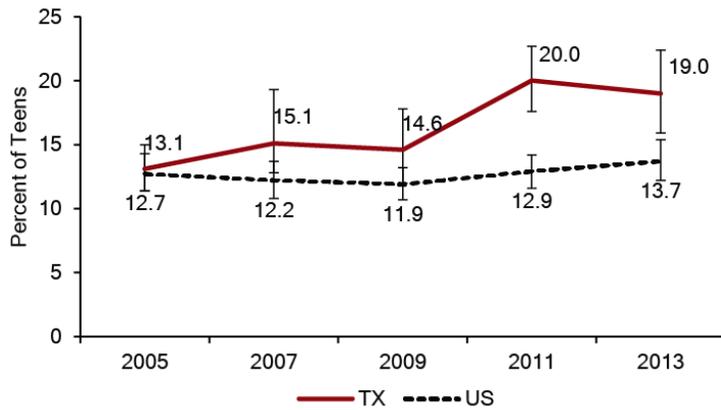
Use in the past month was significantly lower for both, with 7.5 percent of 10-12th grade students reporting recent prescription drug abuse and 1.6 percent reporting recent over-the-counter drug abuse. As with lifetime use, there are no significant race/ethnic differences in these prevalence rates.

Sexual Behaviors

The adolescent birth rate was discussed in Chapter 4, and so, the focus in this section will be on sexual behaviors. Data from the 2013 YRBSS estimates that 45.9 percent (C.I.: 42.1-49.8) of Texas students in grades 9 through 12 have ever had sexual intercourse. Of the 36 states that are reporting 2013 YRBSS data, Texas ranks as having the 12th highest prevalence.

Given that Texas has the third highest adolescent pregnancy rate of all states and the District of Columbia, it is clear that many of these students are having unprotected sex. Indeed, among students that were currently sexually active, 19.0 percent (C.I.: 15.9-22.4) reported not using any method to prevent pregnancy during their last sexual encounter (see Figure 7.14). This rate is the highest of the 31 states that collected YRBSS data on this issue in 2013.

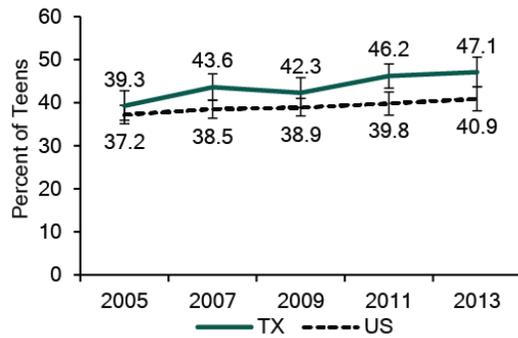
Figure 7.14
Percent of Teens Who Used No Method to Prevent Pregnancy, 2005-2013



Source: 2005-2013 Youth Risk Behavior Surveillance System
Prepared by: Office of Program Decision Support

Condoms are effective for preventing pregnancy and reduce the risk of spreading some sexually transmitted infections. In 2013, 47.1 percent (C.I.: 43.7-50.6) of sexually active students in Texas reported that they did not use a condom during their last sexual encounter. This 2013 rate is significantly worse than the rate of no condom use reported in 2005 (see Figure 7.15).

Figure 7.15
Percent of Teens Who Did Not Use a Condom During Last Sexual Intercourse, 2005-2013

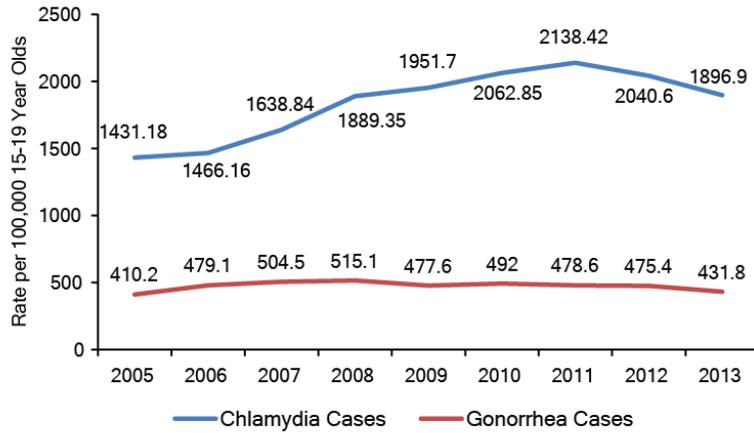


Source: 2005-2013 Youth Risk Behavior Surveillance System
Prepared by: Office of Program Decision Support

Sexually Transmitted Infections

Chlamydia and Gonorrhea are the two most prevalence sexually transmitted infections among youth aged 15-19. In 2013, the rate of Chlamydia cases was more than 3 times that of Gonorrhea (see Figure 7.16). The rates of both have increased since 2005. The infection rate for Chlamydia appears to have peaked in 2011, with the rate falling in 2012 and 2013. The infection rate for Gonorrhea peaked in 2008, but has yet to return to 2005 levels.

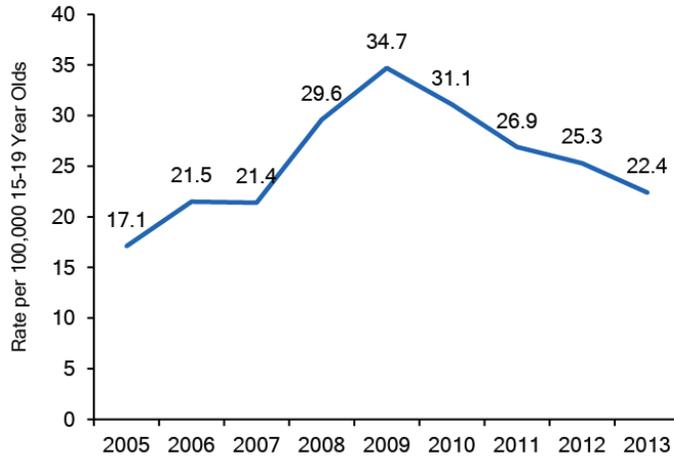
Figure 7.16
Chlamydia and Gonorrhea Rates for Youth 15-19 Years Old
Texas, 2005-2013



Source: Texas STD Surveillance Report
Prepared by: Office of Program Decision Support

The rate of Syphilis among youth has also increased since 2005 (see Figure 7.17). It appears that this rate peaked in 2009, but as with Gonorrhea and Chlamydia, this rate has not yet fallen to 2005 levels.

Figure 7.17
Total Syphilis Rates for Youth 15-19 Years Old Texas, 2005-2013

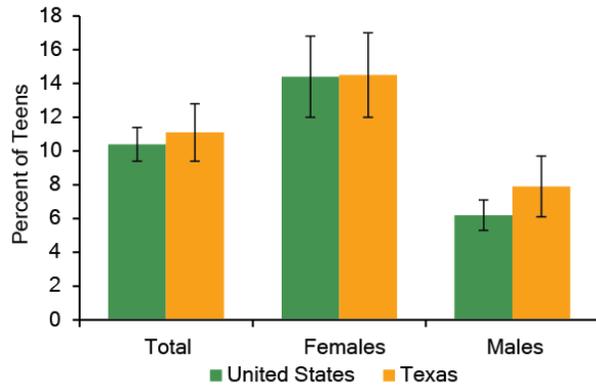


Source: Texas STD Surveillance Report
Prepared by: Office of Program Decision Support

Dating and Intimate Partner Violence

Another aspect of sexual behavior is the prevalence of violence surrounding that behavior. This violence can take the form of forcing another individual into an intimate situation. Dating violence in the YRBSS is defined as being forced to kiss, touch, or have intercourse with someone they were dating or going out with in the past 21 months. The reported prevalence of this type of violence differs between male and female students (see Figure 7.18).

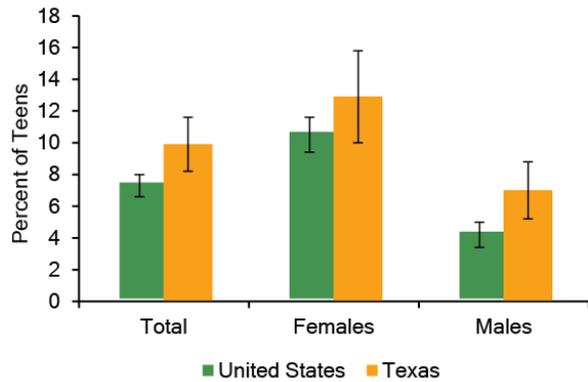
Figure 7.18
 Percent of Teens Reporting Experiencing Dating Violence, 2013



Source: 2013 Youth Risk Behavior Surveillance System
 Prepared by: Office of Program Decision Support

There are differences between males and females in the prevalence of forced sexual intercourse. Females reported a significantly higher prevalence of forced sexual intercourse in 2013 than did males (see Figure 7.19).

Figure 7.19
 Percent of Teens Reporting Being Forced to Have Sex, 2013



Source: 2013 Youth Risk Behavior Surveillance System
 Prepared by: Office of Program Decision Support

In 2013, Texas had a significantly higher overall prevalence of students reporting forced intercourse than estimates for the United States. This difference is because male students in Texas report a significantly higher prevalence of forced intercourse than is estimated for the country as a whole.

In the 2014 Title V Community Outreach Survey, parents were asked if they knew where to find information about dating violence. Only 38.9 percent of respondents with children younger than 18 years old knew where to find resources about dating violence. Of those that knew where to find resources on this topic, 42.5 percent said that they received this information from schools.

Obesity

Of the respondents to the 2014 Title V Community Outreach Survey, 54 percent of parents indicated that “overweight/obesity among children and adults” was one of their top five health concerns. Additionally, 40.5 percent of the respondents indicated that “the lack of exercise/physical activity” was one of their top five health concerns. Throughout each chapter, obesity and its correlates have been analyzed in terms of how parents can impact this rate. For adolescents, the analyses presented here will focus on the impact of the school environment and peer influence.

In Texas, obesity rates are lower for older students than younger students. The SPAN conducted during the 2009-2011 school years found that only 59.6 percent (C.I.: 56.5-62.7) of 8th grade students were healthy weight, which is significantly lower than the 64.7 percent (C.I.: 62.8-66.6) of 11th grade students that were found to be healthy weight. The difference between the two grade levels is not due to basic differences in physical activity, sedentary behavior, or dietary behavior across the state as a whole.

Within the child research literature, there are questions concerning the relation between the food environment around the school, a youth’s food choices, and ultimately, the obesity rates within the school. The 2009-2010 SPAN data was linked to the mRFEI (See Chapter 3) to assess this relationship in Texas. The results of this analysis showed the concentration of low income students in the school (as measured by the percent of students enrolled in free and reduced lunch) was a bigger predictor of obesity than the food environment in which the school was located [69]. While interactions between race and the food environment were found, as was seen with pre-pregnancy obesity and mRFEI (see Chapter 3), this environmental factor did not have a straightforward relationship with the level of obesity/overweight for individuals in the census tract. Our findings compliment a recent meta-analysis that concluded the location of the school had little relationship to obesity in the community [70]. The meta-analysis suggested that the child’s “outside of school” food purchases may be a more important factor to consider than the food environment, and this behavior should be directly measured across food environments to better understand obesity rates.

The public health and health psychology literature has also focused on body weight perception as a point of concern among high school students. For some students, there are gaps between their perceived weight and actual weight. Historically, the issues of perceived and actual weight have focused on students that are underweight because of the relation this has with body dysphoria and anorexic behavior. However, Texas SPAN data show that this perception gap is at both the low and the high end of the BMI scale for those who are underweight or obese. The disconnection between perceived body weight versus actual BMI can have detrimental health outcomes, such as obese or overweight youth not recognizing their weight problem.

It has also been found that the gap between perceived body weight and actual BMI can be related to the child’s history of being bullied [71]. Students that perceived themselves as weighing too little had three times the risk (O.R. 3.2, C.I.: 1.3-7.6) of being bullied than those who reported that they weighed the right amount. Those students who perceived themselves as weighing too much had a risk more than twice as high (O.R. 2.33, C.I.: 1.1-5.1) as those who perceived themselves as weighing the right amount. Both of these results controlled for the student’s actual BMI as well as gender, grade, race/ethnicity,

and the socio-economics of the school. It is important to point out that males were significantly more likely to show these effects than females. This result suggests that in the context of bullying, males maybe at particular risk for having this perception gap. Being a victim of bullying has been linked to a variety of negative health behaviors including substance use, mental health problems, and possibly suicide ideation. The relationship with perceived weight, obesity, and negative health behaviors cannot be ignored.

Throughout all of the chapters, one important piece that is missing is the role of obesity, physical activity, and diet in the health and well-being of CYSHCN. Part of the Focus Group discussion involved parents of CYSHCN and the impact on the parents and the child or youth.

Transition to Adulthood

Adolescence is viewed as a transitional period between childhood and adulthood, whose cultural purpose is the preparation of children for adult roles. It is a period of multiple transitions involving education, training, employment, and unemployment, as well as transitions from one living circumstance to another. The transition to adulthood including adult medical care for developing children/youth and CYSHCN was identified by Texas stakeholders as a major issue that Title V should focus on. Locating resources for teens is challenging for parents. Parents who completed the 2014 Title V Community Outreach Survey often did not know where to go for information about planning for life after high school (only 39.4 percent knowing of a resource), unless that planning involved going to college (53.0 percent knowing of a resource).

Part of successful transition to adulthood is a youth taking responsibility for his or her medical care. This responsibility involves knowing the legal limits and rights of youth in seeking and following medical care. Knowledge of where to find information and resources about the medical rights of adolescents was low among respondents to the 2014 Title V Community Outreach (Parent) Survey. Only 20.4 percent knew where to find this information.

Transition to adult medical care is particularly challenging and an important phase for CYSHCN. The need in this community and the transition experiences of these children has become a barometer for transition services for all children. Texas is one of the worst performing states in the country with provision of adequate transition services according to the NS-CSHCN. According to this survey, 35.4 percent of children were receiving adequate transition services. However, this percentage may actually be lower. A recent survey of 906 parents with CSHCN found that only 20 percent indicated that they felt prepared for their child to transition to adulthood. From this survey, it is also clear that parents are looking for expert guidance on transition planning, so it is important to look to at both provider behavior and systems data to understand this need.

A recent analysis of the survey of CSHCN examined the possible risk factors that were associated with children having inadequate transition services in Texas. The analyses further examined factors that separated Texas from the two highest performing states (Kansas and Utah) and two states of similar size (California and Florida). As is found across the nation as a whole, Texas identified the lack of a medical

home as a significant risk for children not receiving adequate transition services. Additionally, it was found that medical home utilization also differentiated Texas from high performing states.

In addition to this analysis, CYSHCN program directors and staff were surveyed about their state's policies and transition services. The results have led to a better understanding of how state-level factors could influence the provision of transition services. None of the states surveyed had a clear policy about when transition services should be provided or what those services should look like. Additionally, only the highest performing state had a centralized location that providers and parents could go to for tools and guidance on transition services.

Additional analyses also identified provider level factors that interacted with the child's particular health care need and could be influencing the provision of transition services. Parents of children with an emotional, behavioral, or mental health problem were significantly less likely (O.R. 3.85; C.I.: 1.75-8.49) to report that their child's provider encouraged the child to take responsibility for "taking medication, understanding his/her diagnosis, or follow medical advice" even after controlling for race/ethnicity, poverty, and medical home utilization compared to children with only a physical disability. Additionally, these children were at risk for not receiving care in a medical home (O.R. 1.62; C.I.: 1.02-2.57) compared to children with a physical disability only. The open question from these results is: where are these children receiving care for their behavioral health issues?

Parents in the 2014 Title V Community Outreach Survey were asked, "How difficult is it to find a behavioral health provider for a child?" Among parents with a child younger than 18 years old, the median level of difficulty for finding a behavioral health professional for a child was 5 out of 6, with 6 being extremely difficult. The mental and behavioral health workforce shortfall in Texas and the nation has been well documented (see Chapter 2), with major policy recommendations being made to address these shortfalls. The need for these services among adolescents is clear, and the need to mitigate these shortfalls for children and youth is also clear.

Positive Youth Development

Positive youth development helps youth acquire the assets they need to become healthy and productive adults [72]. These assets or building blocks are often acquired through family interaction and the social support that youth receive as a result. According to the 2013 YRBSS, 87.5 percent (C.I.: 86.1-88.9) of Texas youth in grades 9-12 reported that they had eaten dinner with their family on at least one day during the week before completing the survey. Moreover, 40.8 percent (C.I.: 38.1-43.5) reported that they had eaten dinner with their family every single day during the week. YRBSS data also showed that 83.6 percent (C.I.: 84.4-88.2) of students talked to their parents about school at least once a month in 2013, and 38.1 percent (C.I.: 35.1-41.0) of students even talked to their parents about school every day.

Positive youth development is also acquired through academic achievement and extracurricular activities at school [72]. The majority of students surveyed on the YRBSS in 2013 described their grades as mostly As (30.2 percent; C.I.: 25.8-34.7) or mostly Bs (46.4 percent; C.I.: 44.4-48.5). Nearly two thirds (64.9 percent; C.I.: 62.1-67.7) of students also indicated that they spent at least one hour during an

average week participating in school activities, such as sports, band, drama, or clubs, with 8.5 percent (C.I.: 7.0-9.9) reporting that they spent 20 hours or more during an average week.

Finally, feeling valued within their community is important for positive youth development [72]. According to YRBSS data, students surveyed in 2013 strongly agreed (15.0 percent; C.I.: 13.1-16.9) or agreed (31.1 percent; C.I.: 28.9-33.3) that they mattered to people in their community. However, 35.2 percent (C.I.: 33.3-37.1) were unsure about whether or not they mattered, and 11.2 percent (C.I.: 9.8-12.6) disagreed or 7.5 percent (C.I.: 6.2-8.8) strongly disagreed with this statement. Of particular concern is the finding that 14.3 percent (C.I.: 11.4-17.2) of females compared to 8.3 percent of males (C.I.: 7.2-9.3) disagreed that they mattered to people in their community. Equally concerning is that a significantly greater percentage of Hispanic students (42.2 percent; C.I.: 37.2-47.2) were unsure about whether or not they mattered within their community compared to Black (35.0 percent; C.I.: 29.3-40.7) or White (30.0 percent; C.I.: 27.5-32.5) students. Clearly, more services are needed in Texas to ensure that youth feel acknowledged in their communities using a positive youth development approach.

Chapter 8. Children with Special Health Care Needs: Stand Alone Needs Assessment

This chapter is a stand-alone needs assessment for the Children with Special Health Care Needs (CSHCN) Services Program. This chapter repeats important findings from the overall needs assessment, but also presents new data and analyses from the parent outreach survey, national surveys, and the focus groups conducted with parents of special needs children. This chapter was written in collaboration with the CSHCN Services Program. OPDS acknowledges and the lead that the CSHCN Services Program took with writing this document for their program and their stakeholders.

INTRODUCTION

The Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) defines CSHCN as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”ⁱ Over the years, the term children and youth with special health care needs (CYSHCN) has become the preferred reference to acknowledge the unique needs and strengths of adolescents and young adults. According to the *2009/10 National Survey of Children with Special Health Care Needs (2009/10 NS-CSHCN)*, approximately 900,000 children in Texas meet this definition. Title V of the Social Security Act, authorizes states to use funds to develop comprehensive, family-centered, community-based, culturally competent, coordinated systems of care for these children and their families.

The MCHB has identified the following six Core System Outcomes that provide a framework for examining the needs of CYSHCN and their families and the quality of the system that serves them:ⁱⁱ

- Families of CYSHCN partner in decision-making regarding the child’s health
- CYSHCN receive coordinated, ongoing, comprehensive care within a medical home
- Families of CYSHCN have adequate public and/or private insurance to pay for needed services
- Children are screened early and continuously for special health care needs
- Community-based services are organized so families can use them easily
- Youth with special health care needs receive the services necessary to make transitions to adult health care.

This document outlines the results of a Five-Year Needs Assessment for maternal and child health programs and programs that serve CYSHCN. The assessment process identifies areas of need and points of interventions for the programs to target to improve the health and well-being of those in the population. This needs assessment includes analysis of national and state surveys, as well as information gathered at stakeholder meetings and focus groups with parents of CYSHCN.

The clear result of this assessment process is that all system and individual level indicators for CYSHCN are inter-connected. No single indicator exists as its own topic and all indicators are predictive of and related to each other. The key and challenge of improving the health of families and CYSHCN is providing resources and intervening early to improve outcomes across the life course. It is clear from families and from stakeholders that to improve well-being, family professional partnerships need to be developed early and services need to be provided continuously and be based on the needs of the family.

From my perspective, the family recognizes that care coordination and medical home are two critical components of their child's health care that can simplify the family's life. The longer a family is forced to take on these components themselves, the harder it is to incorporate new services into the child's health care as family members assign these duties to themselves. Families rarely turn down services, but coordination may need to be more intentional – providers need to recognize the family's process and navigate/negotiate duties. It has been my experience that ongoing conversations should take place to clarify who is doing what for the child.

Texas' Association of Maternal and Child Health Programs Family Delegate

METHODOLOGY

The Title V Five Year Needs Assessment represents a collaborative process between the Office of Program Decision Support (OPDS), the Office of Title V and Family Health (OTVFH) and the CSHCN Services Program to assess the current state and needs of the Maternal and Child Health (MCH) population in Texas.

The analysis was designed to have three complimentary components: 1) analysis of existing data; 2) community outreach surveys designed to assess perceived needs and strengths within the community; and 3) qualitative data from focus groups and stakeholder meetings that build on the outreach surveys.

The OPDS was responsible for analyzing existing data and for developing and analyzing the results of the outreach surveys in partnership with the OTVFH and the CSHCN Services Program. SUMA Social Marketing, Inc. conducted the focus groups and stakeholder meetings.

After a review of the 2009/10 NS-CSHCN to assess specific aspects of each performance measure, the CYSHCN Outreach Survey evaluated areas of underperformance, including transition and care coordination. Additional questions were developed to assess the need for respite care, the level of emergency preparedness, and health insurance needs. Overlap existed with the general community survey on questions related to community engagement and community and health concerns. The survey was reviewed by the Texas DSHS Institutional Review Board and was granted exempt status prior to distribution. The survey was in English and Spanish, and made available in electronic and paper form to families receiving CSHCN Services Program Health Care Benefits. The CSHCN Services also worked with community based contractors and through various distribution lists to engage families of CYSHCN throughout the state in completing the survey. A total of 923 were received, with a total of 312 being completed in Spanish.

Stakeholder meetings were held in each of the state's eight Health Service Regions (HSR) and included professionals, providers and local health administrators. The stakeholder groups were predominantly held in English, with bilingual sessions in El Paso and Laredo. Of the 128 stakeholder participants, 41% were identified as stakeholders working with CYSHCN and their families.

A total of 11 focus groups for parents of CYSHCN were held in each HSR. Spanish focus groups took place in El Paso, Dallas and Laredo. There were 102 participants in the focus groups, with 44% being Spanish dominant participants.

TEXAS OVERVIEW

Given the size of Texas, the distance some individuals must travel to receive services is a significant barrier to accessing and receiving those services. Texas' land area is approximately 262,000 square miles and accounts for 7.4 percent of the total United States. Texas has a mixture of 254 urban, rural, and border counties. According to the Texas State Data Center, the majority of Texans live in urban areas (88.5%). Texas is one of four states to share a geographic border with Mexico and has the longest border of all four states. There are four counties along this border with populations greater than 100,000. Texas has six major cities that are located in counties where the Hispanic population makes up more than 50 percent of the population in the county: San Antonio, Corpus Christi, Brownsville, Laredo, El Paso, and Odessa.ⁱⁱⁱ

Texas has an estimated population of over 26 million^{iv} and, according to 2013 Census estimates, has been the second fastest growing state in the nation since 2010.^v The *2009/10 NS-CSHCN* shows that 13.4 percent of Texas children (versus 15.1% nationally) had special health care needs. Of those children identified as CYSHCN within Texas, 39.4 percent were Hispanic. About 1/3 of the Hispanic CYSHCN population spoke Spanish as the primary household language,^{vi} consistent with the state as a whole.

In addition to the increase in the state's population, the Texas Birth Defects Registry has seen an increased incidence of certain diagnoses, including Down Syndrome and congenital heart defects. Changes in the prevalence of these and other diagnoses impact health care delivery systems, including the CSHCN Services Program. Therefore, ensuring infrastructure to serve these children and families is essential in the state.

Poverty, lack of health care coverage, and limited access to providers underlies many health disparities. Texas has a greater proportion of children younger than 5 years of age living below 100 percent FPL (12.5 %) than any other state.^{vii} Children below the poverty level comprised 39.3 percent of the population younger than 18 years of age.^{viii} In Texas, 21.9 percent of CYSHCN lived below the poverty level, which is comparable to national rates (22.2% of CYSHCN nationwide).^{ix}

Approximately 23 percent of all Texans were uninsured in 2008-2012, according to the American Community Survey. Among children younger than 18 years, Texas ranked 49th for children with health care coverage only above California.^x At the time of the *2009/10 NS-CSHCN*, 15.6 percent of CYSHCN had been without health care coverage at some point within the last year compared to 9.3 percent nationally.

As of December 2014, 165 of the 254 Texas counties were designated as whole county Primary Care Health Professional Shortage Areas by HRSA by having a shortage of primary medical care, dental, or mental health providers. As of September 2014, data from the DSHS Center for Health Statistics reported 3,694 pediatricians in Texas, with 140 counties not having a pediatrician.

CORE SYSTEMS INDICATORS

Review of existing data, including the *2009/10 NS-CSHCN*, indicates that the core systems indicators for CYSHCN in Texas are often below that of other CYSHCN throughout the nation. Texas ranked in the bottom quartile of states and territories in the outcomes of children receiving their care within a medical home (40.1% in Texas compared to 43% nationally) and those receiving the services necessary to make the transition to adult health care (35.4% in Texas compared to 40% nationally).

In addition, Texas ranked below the national average on three of the four remaining core outcomes, including:

- (1) families of CYSHCN have adequate private and/or public insurance to pay for the needed services (57.9% in Texas compared to 60.6% nationally);
- (2) children are screened early and continuously for special health care needs (76.8% in Texas compared to 78.6% nationally); and
- (3) community-based services are organized so families can use them easily (56.6% in Texas compared to 65.1% nationally).

Texas was at the national average of 70.3 percent for CYSHCN whose families partner in decision making. Overall, 17.8 percent of CYSHCN in Texas were served by a system of care that met all age-relevant core outcomes.

Texas and national data clearly indicate the critical relationship between a medical home and adequate transition to adult care. The CSHCN Service Program worked with the Graduate Student Epidemiology Program to conduct an analysis comparing Texas' performance on the delivery of transition services for CYSHCN to services offered in the highest performing states (Kansas and Utah) and states demographically similar to Texas (California and Florida). Major findings of the studies revealed that across all states, CYSHCN who did not have a medical home were less likely to receive satisfactory transition services, and CYSHCN in Texas were significantly less likely to be in a medical home than those in high performing states.

TRANSITION

Due to advances in health care, CYSHCN are living longer, healthier lives. Most are surviving into adulthood, highlighting the need for services and help to transition into adult care.^{xi} Transition is a dynamic, lifelong process that seeks to meet youth's individual needs as they move from childhood to adulthood.^{xii} This definition supports the life course perspective and the ongoing developmental nature of transition services which were acknowledged by focus groups and stakeholder participants. The Waco stakeholder group, in particular, indicated that a focus on life course is a regional priority need. One focus group parent stated:

I can say for my six-year-old that I don't think we've used the word "transition," but we've started talking about putting down on the paper the things that are working so that each year we can build on it. I think that's a successful long-term plan: to truly start as young as possible, get all those successes that are working and just let it roll from year to year, and then talk about what that transition looks like for the next year.

Parent from San Antonio

Transition and long-term planning can trigger anxiety and concern among parents. In the CYSHCN Outreach Survey in 2014, only 20 percent of respondents felt prepared for their child to transition to adulthood. Over 40 percent of respondents indicated that they had not prepared for transition. This low response is especially notable when considering the average age of children of respondents was 12.4 years.

What's going to happen to our children when they turn eighteen? It makes me anxious not knowing if they will have the resources for a job, living independently, or have the doctors they need.

Parent from El Paso

A key finding from the focus groups of parents with CYSHCN was that participants had a wide range of ideas about when transition planning should start, when the transfer of care should happen, and of the various aspects of transitioning to adulthood, including health care, education, social supports and legal transition.

There's so many elements of transition. There's transition in education, transition in healthcare providers, and transition in how they physically grow. There's transition in me and how I am as a parent.

Parent from Houston

Parents in one Spanish speaking focus group were unaware of the term *transition* altogether. Others perceived no need to consider transition planning, noting that their child's pediatrician has agreed to continue to see them after they become adults.

Even families that are aware of transition resources face difficulties receiving services needed to prepare for the move to adult health care. Respondents in the stakeholder meetings noted that few doctors have the passion or willingness to take on the primary care role and coordinate the many specialists typically seen by young adults whose medical needs are complex. Many adult providers cited a lack of training, time, and adequate payment as barriers to providing care to young adults with special health care needs.^{xiii}

Medical homes can help ease these difficulties that families of transition-age youth face. Receiving care within a medical home is recommended by the AAP, AAFP, and ACP no later than age 12 as the first step in the transition planning process.^{xiv} Ongoing, coordinated care helps ensure that youth with special health care needs transition to adult care or an adult model of care. However, as Texas children get older, fewer receive care within a medical home (43 percent of children age 0-5, 40 percent of children age 6-11, and 38 percent of children age 12-17).^{xv} Of the 35.4% of CYSHCN in Texas who received adequate transition services, 60.6% received care within a medical home.^{xvi} In contrast, of CYSHCN who did not receive adequate transition services, 78.1% did not receive care within a medical home.

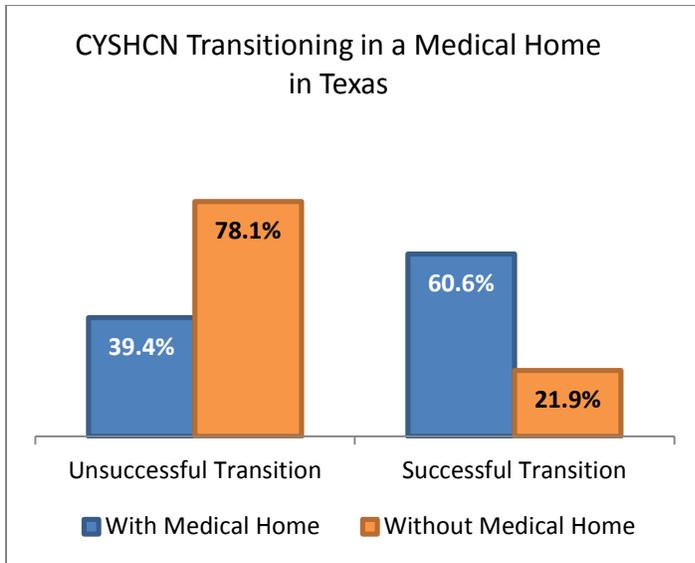


Figure 1 2009/10 NS-CSHCN

Most respondents of the CYSHCN Outreach Survey who indicated that they have prepared for transition have done so by themselves. The CSHCN Program recognizes the diversity, experience and skills of parent and caregivers, but with other Needs Assessment findings such as limited access to resources, this finding is concerning. Focus group participants conveyed that they were unsure where to go for assistance with transition planning. Stakeholders echoed the concerns that families do not have the information, services, or support needed to help their children transition from pediatric to adult care. Stakeholders cited a lack of written transition plans as a barrier to transitioning to adult providers. Participants in the Arlington stakeholder group, in particular, felt that transition across life stages left families with unmet needs due to lack of coordination and continuity among health care providers in general, and across specialists in particular.

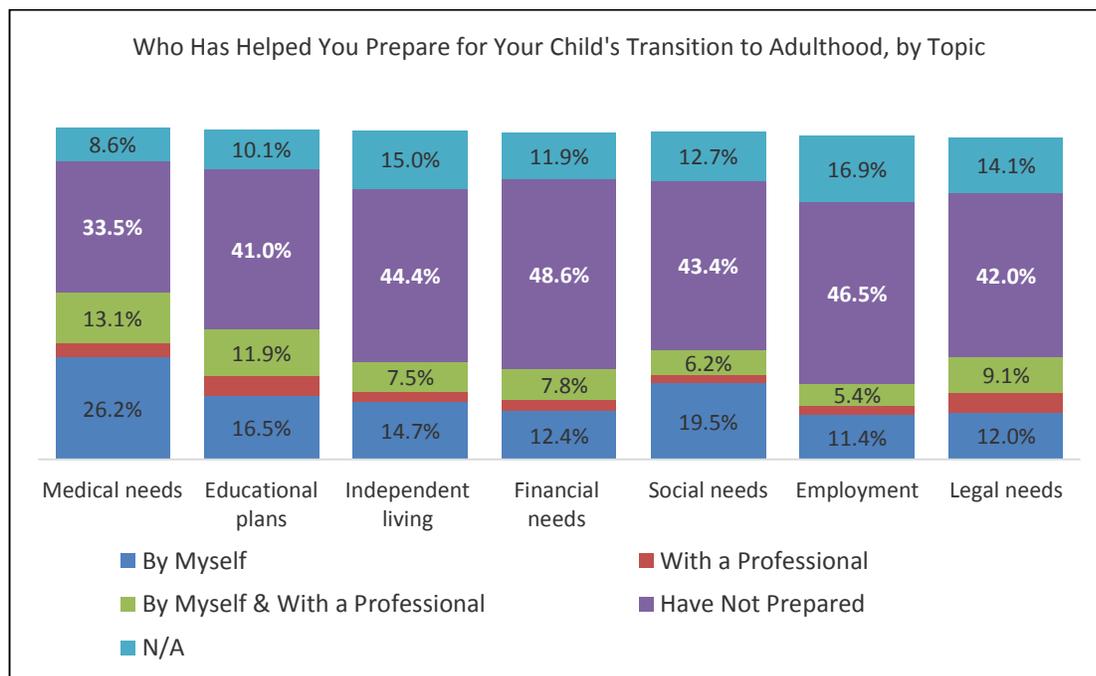


Figure 2 CYSHCN Outreach Survey

MEDICAL HOME

A medical home is an approach to providing comprehensive primary care that facilitates partnership between patients, physicians, and families. Care within a medical home should be comprehensive, coordinated, continuous, accessible, family-centered, culturally competent and compassionate.^{xvii} Positive results have been found between medical home activities and outcomes in family-centeredness, effectiveness, timeliness, health status and family functioning.^{xviii}

Review of the *2009/10 NS-CSHCN* shows that receiving care within a medical home makes it more likely to meet the other core systems outcomes for CYSHCN, not just the transition services previously discussed. In Texas, children who received their care within a medical home were more likely to have consistent and adequate public or private insurance (73.2% versus 47.7%), more likely to meet the outcome for family partnerships (93.9% versus 54%), more likely to be screened early and continuously for special health care needs (82.4% versus 74.7%), and more easily access community based services (78.2% versus 42.4%).

PROVIDERS:

A basic component of the medical home is having a place to go when the child is sick. In the CYSHCN Outreach Survey, 77% of respondents indicated that they have a usual source of sick care, with the majority of this care taking place in a doctor's office (55.8%) or with the child's specialist (25.6%). However, over 54% of families reported they did not have a medical provider where they live as a barrier to receiving care. Provider shortages, including primary and specialty care physicians, were noted by stakeholder groups. Stakeholders in San Antonio specifically indicated the need for more case managers to help with access to care for CYSHCN. In addition to a lack of providers, participants reported a lack of willingness by providers to work with CYSHCN.

Provider shortage is not limited to primary care or specialty physicians. Children and youth with special health care needs face additional access issues related to oral health regardless of their source of health care coverage.^{xix} Stakeholders commented on the limited number of dental providers, citing unwillingness of providers to accept patients with special health care needs, particularly those with developmental disabilities. Children who require intensive oral health treatment and/or anesthesia are in a particularly difficult situation.

Access to mental health providers and services was also cited as priority need by stakeholders. As with primary care physicians and pediatricians, the majority of the counties in the state have too few school psychologists and too few psychiatrists. Most border counties in Texas qualify as mental health professional shortage areas. Parents of focus groups of parents with CYSHCN in the southern border region of the state indicated the importance and the need for mental health support for both their children and themselves.

However, adequate access to care is not just about finding someone to provide services. Most families participating in focus groups report a positive relationship with their child's health care providers and indicate trust as the number one factor in the relationship. These parents trust doctors if they feel they are truly heard and if the provider relates directly to their children while treating the child as an individual. Parents want doctors to know and respect that they are the experts on their own child.

I am comfortable with a doctor if they come in to see [child] and they address [child] instead of talking over her like she's an object. I will always go back to a doctor who believes in her. Don't

tell me the negatives about my child – believe in my child. If you believe in my child, then you're part of my team.

Parent from Houston

CARE COORDINATION

Comprehensive, coordinated care within the medical home can help link CYSHCN and their families to necessary services and supports in the community. According to the 2009/10 NS-CSHCN, less than one quarter of CYSHCN in Texas received any help in arranging or coordinating care. The CYSHCN Outreach Survey also supports that coordination of care is a challenge, with 71.6% of respondents reporting that they coordinate their child's care themselves.

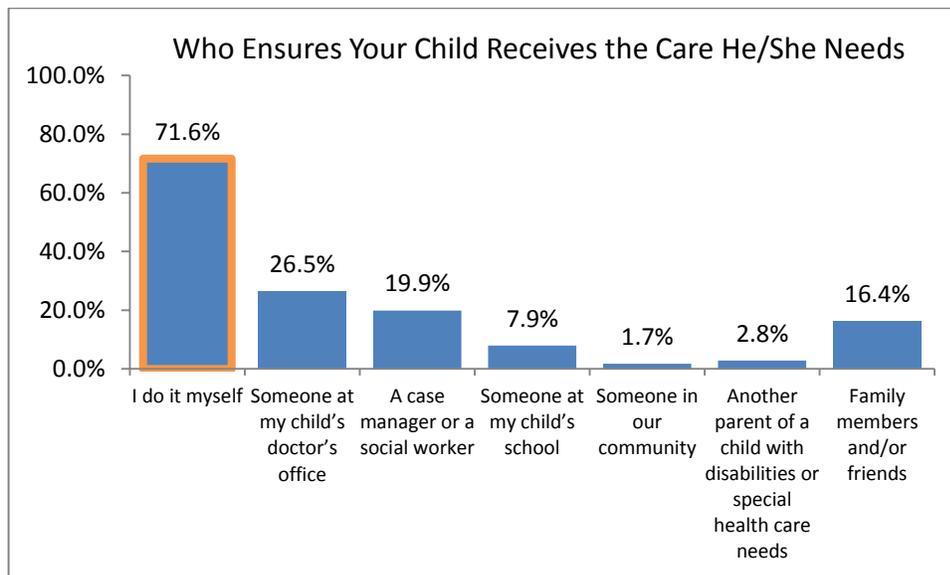


Figure 3 CYSHCN Outreach Survey

Stakeholder groups noted the gaps in care that exist when care is not coordinated among providers, including specialists. This can lead to a delay in referral and lack of continuity of care. In Tyler, stakeholders agreed that collaboration and coordination were a regional priority and that coordination was needed at several levels: among local health care providers and social service organizations, across state and federal partners, and between specialists and social service providers for CYSHCN.

Comments from parents participating in the focus groups supported the finding that care coordination is primarily performed by the parent and many were not familiar with the term *care coordinator*. Most parents who have sought care coordination for their children among social workers, case managers and nurses were not successful. Many parents indicated that they had looked for the type of services provided by a care coordinator through a variety of providers. Many had been disappointed by the services they received. Some parents said that they would not entrust this type of responsibility to anyone but themselves. However, parents thought that having a care coordinator would enable them to work outside of the home.

My daughter sees about fourteen different specialists and she's got a lot going on. I usually take two to three days of my week, and I know I need to get at my desk and just sit there and call and follow up and call. I have my call days. Two to three days per week, every week.

Parent from Houston

I'm the expert about my child. Nobody knows her like I do and nobody knows what her needs are more than I do, so it'd be difficult for me to sit there and explain something to somebody for 20 minutes about what it is that I need to do and how it needs to get done, compared to I just do it and it gets done easily.

Parent from Houston

ACCESS AND AVAILABILITY OF RESOURCES

The 2009/10 NS-CSHCN indicates that nearly one quarter of CYSHCN nationally did not receive at least one of the services that they needed. Stakeholder groups and focus group participants also cited lack of specific therapies and limited access to services as barriers. Both groups noted that while services may be available, they are not being accessed by families due to multiple factors. Stakeholder group participants indicated lack of awareness of resources by both families and providers and focus group parents cited lack of communication of available resources by providers. Although there were some regional differences with regard to available resources and community activities, a general lack of access was a significant finding for all focus groups. Parents noted that even though community resources may be available, they frequently cannot access them, due to difficulties in finding a trustworthy caregiver, lack of extended family support, bias toward their children in public, and expense. Families indicated that they most frequently learn about resources from other parents. Families also noted that services are often offered during the standard workday, making it difficult to utilize these services.

Survey respondents and family and stakeholder groups were asked questions related to accessing respite services, specifically. While the 2009/10 NS-CSHCN shows that parents of 6.7 percent of CYSHCN nationwide reported a need for respite care, the CYSHCN Outreach Survey revealed 52 percent of parents in Texas indicated a need for this resource. The 2009/10 NS-CSHCN survey asked parents, "During the past 12 months, was there any time when you or other family members needed respite care?" compared to the CYSHCN Outreach Survey, which asked, "Do you ever feel that you need a short term break (respite) to help care for your child?" The inclusion of the words "short term break" in the CYSHCN Outreach Survey may have attributed to differences in parents who reported the need for respite, as some parents may not be aware of the term on its own. Stakeholder groups endorsed the need for caregiver respite. Parents in focus groups said respite provides an opportunity to spend time with their other children, go grocery shopping, have dates with their spouses or simply rest:

It gives us our sanity. If we don't have respite, we don't have our sanity. Taking care of your kids 24/7, without sleep 24/7 a lot of times, and you don't have any kind of break, you go a little crazy.

Parent from Houston

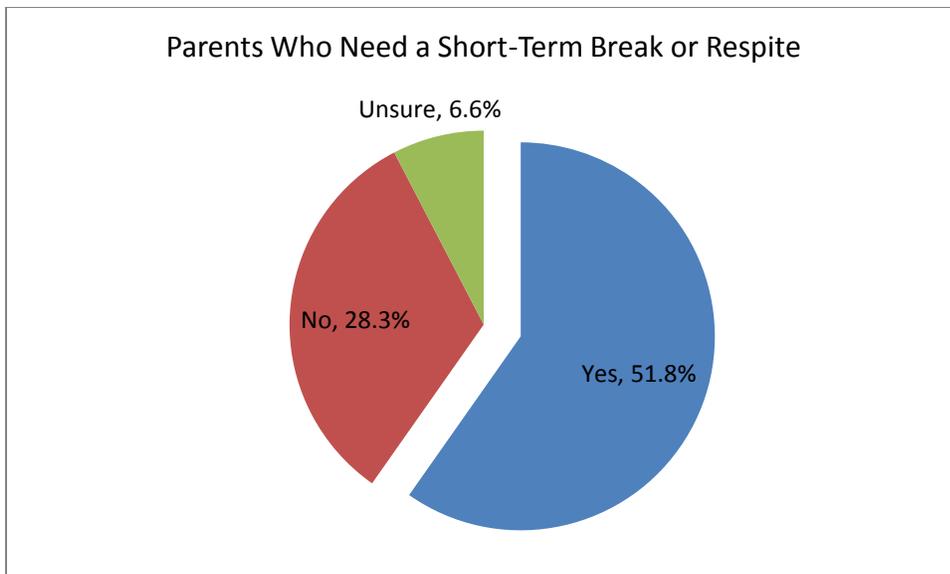


Figure 4 CYSHCN Outreach Survey

In the 2009/10 NS-CSHCN, Texas was higher than the national average in families reporting they received all of the respite care needed in the last 12 months (63% versus 50.5%). Despite the recognized need, many families are faced with barriers to receiving respite. Only 34 percent of families surveyed through the CYSHCN Outreach survey had received respite, with funding cited as the most common barrier, followed by lack of knowledge about respite and difficulty finding people who can provide respite. Parents participating in focus groups indicated barriers to respite included provider restrictions, issues with reimbursement and lack of qualified providers. Many families felt there is a lack of qualified respite providers they can trust.

Transportation poses a unique and significant challenge to parents of CYSHCN. Lack of transportation was noted by 57.3 percent of families in the CYSHCN Outreach survey as an obstacle to seeking care for their child. Stakeholder groups reported that people living in rural areas may not have access to public transportation and have to travel hundreds of miles for health care, while people living in urban areas may have limited public transportation and costly fares. Family concerns with transportation include exposure to germs while ride-sharing, expenses, and slow public transportation systems.

Another barrier to accessing care identified in the Outreach Survey was not having health insurance (53.5%). Children without health insurance are less likely to have a usual source of care.^{xx} While only 3.1% of respondents to the Outreach Survey indicated they had no form of health care coverage, 56.6% of parents indicated that they are unable to pay for all of their child's medical needs, with less than half (40.1%) of families reporting that insurance covers all of their child's medical needs.

SPECIFIC TOPICS

Preparing for an emergency or disaster can require additional planning for families of CYSHCN that can be supported within a medical home. Natural disaster preparedness is necessary in Texas which is subject to tornados, hurricanes, ice storms and major flooding. While regional risk for each type of disaster is different, parents in all areas of the state must be prepared. The CYSHCN Outreach Survey found that only 34.5 percent of respondents have prepared for an emergency or natural disaster and only 15 percent indicated that they obtained assistance in making a plan. Of those receiving help, the

majority of families indicated help was received through family members. Despite not speaking with providers on this subject, most parents participating in focus groups have taken measures to prepare for a natural disaster and said they felt prepared to successfully handle an emergency.

The top health concerns for CYSHCN Outreach Survey participants were overweight/obesity and lack of exercise/physical activity. Families in focus groups of parents with CYSHCN felt that doctors were more likely to discuss obesity, diet, and exercise only if the child has a specific issue in one of those areas; preventive care was not addressed in doctor visits. When obesity does become an issue and doctors discuss it with families, families reported that they are not provided with tools and resources to help their children maintain a healthy weight with diet and exercise. Not having the tools to help change eating habits is a particular problem for CYSHCN since the child may be fixated on a type of food or have sensory issues that make changing food difficult.

A lot of kids have problems with textures and eating. When they're little, anything they eat, they're happy about, which can then be a problem when they're older.

Parent from Houston

Sexuality is a topic that is often overlooked for CYSHCN, but could successfully be addressed within a medical home.^{xxi} All children and youth, including those with special health care needs, should have information about sexuality and reproductive health before they reach puberty. Stakeholders stressed the need for families to have specialized information on puberty and sexuality. The stakeholder group in San Antonio cited the need for health education for adolescents, particularly education about sexuality and substance abuse.

COMMUNITY INTEGRATION

CYSHCN and their families live within their communities and have many of the same needs as those of typically developing children. All families contribute to and are impacted by their communities. The extent to which communities are accessible and welcoming minimizes the sense of isolation experienced by many CYSHCN and their families. Most focus group participants said they feel alone in their journey regardless of the resources, accessibility, or activities available to them in their community. Accessibility at home can be the first major barrier to community engagement. For example, one parent in a focus group is rarely able to take her daughter anywhere because there is not a ramp outside her home for her daughter's wheelchair.

Many focus groups parents expressed a need for their community to be accessible so their children with disabilities could fully participate alongside typically developing peers.

Why don't you make it fun for the whole place, for everybody, free to the public to learn? Like, "This is what this is or this is how it is to have [a special needs child]."

Parent from Lubbock

While some focus group participants felt comfortable in their community and were satisfied with the activities available to their children, many still reported feeling isolated. Indeed, respondents of the CYSHCN Outreach Survey indicated lower levels of community participation than respondents of the Title V Parent Survey. Only 27.6 percent of parents with CYSHCN volunteered in the school or community compared to 35.4 percent of parents in the Title V Parent Survey. Parents noted a lack of programs and facilities that are able to accommodate their children and stressed the need for communities to create more accessible parks and recreation centers, adaptive playgrounds, and

inclusive sports programs and community-wide events. One of the top community concerns identified in the Outreach Survey was access to affordable and convenient places to exercise. The places that provide opportunities for socialization, such as restaurants, bowling alleys, parks, and other venues may not be physically accessible and even if they are, families may not feel comfortable or welcome.

Parents in focus groups perceived their community as excluding them with harsh judgment, thoughtless actions, cruel words, and impatience. As a result, parents look for support first and foremost from other parents of CYSHCN; only parents who have been through what they have been through can understand them. Social media, such as the internet and Facebook, and faith communities help provide opportunities for support among parents of CYSHCN.

Parents expressed the desire for more education about CYSHCN for the community at large to help promote integration.

A lot of people can't handle them [CYSHCN]. They're only used to certain people. I started taking my son to day care, he would get used to it, but it's just if they could handle him. Every autistic child is different – none are the same. Some of them are not trained to take care of special needs children.

Parent from Lubbock

The Outreach Survey indicated that parents' top community concern was bullying (38.2%). Promoting community integration by raising awareness to increase understanding can also help reduce parents' concerns in their community.

My daughter used to go to a school, and they used to have an assembly once a year. They would talk about each child [with special health care needs] and say, "This is what they'll do, and expect for them to do this." It would decrease bullying so kids expected, "Okay, [child] is jumping up and down – she does that because that's part of her processing."

Parent from Lubbock

CONCLUSION

The Fiscal Year 2015 Title V Five Year Needs Assessment highlights several key areas of ongoing needs within Texas. Central themes emerging during the Needs Assessment process include access, education and coordination of resources and services. Priority areas identified include transition from pediatric to adulthood, medical home and care coordination, and community integration.

Based on outcomes from the Title V Five Year Needs Assessment, DSHS has developed proposed priority statements for CYSHCN and their families for FY 2016 through FY 2020:

- Promotion of community integration
- Continued advancement of medical home services
- Increased access to and improved care coordination
- Increased medical home capacity
- Promotion of appropriate services to transition to adulthood
- Improved access to community-based services, including respite
- Supporting CYSHCN and their families across the life course

- Enhance family/professional partnerships within systems serving CYSHCN

CAPACITY

The Department of State Health Services (DSHS) administers all programs funded through the Title V Maternal and Child Health Services Block Grant to States, including the Children with Special Health Care Needs (CSHCN) Services Program. DSHS provides essential public health services within a structure defined by five divisions and eight Health Services Regions (HSRs) statewide for the provision of essential public health services to all Texans. DSHS is the state agency responsible for oversight and implementation of public health and behavioral health in the state, and this focus provides the agency with a broad range of responsibilities and opportunities associated with improving the health and well-being of Texans, including children and youth with special health care needs (CYSHCN). Its vision of a “healthy Texas” and its mission “to improve health and well-being in Texas” are accomplished in partnership with numerous academic and research institutions, various agencies, and family and provider partnerships across the state. Service system partners such as DSHS HSRs, DSHS hospitals, local health departments, Federally Qualified Health Centers (FQHCs) and contracted community service providers serve as an important role in working collaboratively to address the existing and future issues faced by the agency.

The CSHCN Services Program began in 1933 and is situated within the Purchased Health Services Unit (PHSU) of the Specialized Health Services Section (SHS) within the Division for Family & Community Health Services (FCHS). The Office of Title V and Family Health (OTVFH) is also located within the FCHS Division. The shared organization allows for enhanced partnership between the OTVFH and the CSHCN Services Program. The Specialized Health Services Section includes several other specialized health services programs, such as the Kidney Health Care Program, the Hemophilia Assistance Program, the Newborn Screening Unit, Texas Health Steps (THSteps) (Early and Periodic Screening, Diagnosis, and Treatment), and the Health Screening and Case Management Unit. Each of these areas actively collaborates with the CSHCN Services Program.

Guided by state and national performance measures, the CSHCN Services Program develops and administers a comprehensive health care benefits program which includes Family Support Services and provides medical expertise and consultation to providers of CYSHCN. Case management is provided to CYSHCN and their families through community-based contractors and regional DSHS staff across the state. Additionally, Family Support and Community Resource contractors provide services such as respite care, family to family networking, and educational workshops and conferences. Three case management contractors receive additional medical home support funding to build infrastructure around medical home within their practice. The program has many years of involvement and collaboration working closely with families, family organizations, other programs, agencies, organizations, advisory committees/councils, and stakeholder groups representing consumers, providers, and advocates improving the systems of care for CYSHCN and their families and promulgating the importance of statewide collaboration to address and make progress toward the Title V CSHCN performance measures. Some of these affiliations include Association of Maternal and Child Health Program (AMCHP), the Children’s Policy Council, the Promoting Independence Advisory Council, the Texas Pediatric Society, the Texas Council on Developmental Disabilities, Early Intervention Childhood (ECI) Advisory Council, and the Interagency Task Force for Children with Special Needs.

With decades of combined experience in Maternal and Child Health and additional training and expertise in working with CYSHCN, the CSHCN Services Program staff are qualified to implement and carry out this program. In addition to being a physician who is board certified in Pediatrics, Internal

Medicine and Allergy and Immunology, the Title V CSHCN Director is a graduate from the Maternal and Child Health Public Health Leadership Institute and serves as the Manager of Systems Development Group and Assistant Medical Director of PHSU. Systems Development Group includes 6 full time Program Specialists dedicated to the CSHCN Services Program. This includes the State Transition Specialist who received a Master's Degree in Public Affairs and completed the Public Management and Leadership Program at the University of Texas at Austin. Staff have presented on topics related to CYSHCN on both the state and national level. Program specialists with over 25 years of combined experience working with contracts, serve as CSHCN Services Program subject matter experts for community-based contractors by providing technical assistance, education, and resources. The CSHCN Services Program employs a full-time program specialist who is a parent of CYSHCN and who participates in the program development, decision-making process and provide ongoing program insight and feedback. In addition, the State Adolescent Health Coordinator in the OTVFH serves as Texas' Family Delegate to AMCHP, is a former AMCHP Family Scholar, and serves on the AMCHP Annual Conference Planning Committee. As a parent of a young adult with special health care needs and with over 20 years' experience in the interest of CYSHCN, she is a valued participant in the Texas Statewide Medical Home Workgroup (MHWG) and the Texas Title V Transition Workgroup (Transition Workgroup) and serves on the board of the Texas Medical Home Initiative (TMHI). The TMHI is multi-stakeholder group whose goal is to lay a foundation that ensures access to a medical home for all Texans through invigorating the practice of primary care.

Through its interagency coordination efforts, the CSHCN Services Program has been effective in making other agencies aware of the CSHCN Title V performance measures, and, in many cases, uniting support for working toward achieving those measures. Program staff partner with the Texas Education Agency to help ensure that the public education infrastructure supports CYSHCN. These initiatives include the development of a legislatively mandated transition and employment guide and partnering with the Education Services Centers (ESCs) throughout the state to provide technical assistance and resources to educators. Collaboration with federal and state Medicaid programs occurs extensively through the participation of the PHSU Medical Director in the Benefits Management Workgroup, a Medicaid and CSHCN Services Program policy development and coordination workgroup led by HHSC and the claims contractor for Medicaid and the CSHCN Services Program. Recent legislation mandated the establishment and implementation of the STAR Kids Medicaid managed care program to provide services for children with disabilities to improve coordination and customization of care, access to care, health outcomes, cost containment, and quality of care. The STAR Kids model requires utilization of a health home, care management, and provision of comprehensive coordination of acute care and long-term service benefits. The CSHCN Services Program has provided resources and input into the development of this model.

The CSHCN Services Program collaborates and partners closely with many state initiatives promoting medical home and transition including the Statewide Association of Regional Medical Home AdvanCement (STARMHAC), a previous awardee of a HRSA State Implementation Grant for Systems of Services for CYSHCN (D70 grant), and the planning committee for the annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care. Along with the Texas Family Delegate for AMCHP, the Title V CSHCN Director serves on the planning committee for the annual Texas Primary Care and Health Home Summit. Within the CSHCN Services Program, staff members lead the statewide MHWG and the Texas Title V Transition Workgroup. These are broad-based multi-stakeholder groups involving family members, representatives from family organizations, staff from various state agencies, providers, representatives from insurance companies, advocacy organizations, and other interested stakeholders. These groups meet quarterly to spearhead activities that promote state

progress toward goals and objectives related to each respective strategic plan. The MHWG goal is for all children in Texas, including CYSHCN, to receive health care in a medical home, and a key part of the strategic plan is to increase the number of health care practitioners who provide a medical home. The mission and vision of the Transition Workgroup are “To promote a collaborative approach to the provision of transition services for youth in Texas with disabilities and special health care needs and their families” and “successful transition outcomes for all youth in Texas with disabilities and special health care needs and their families.” The Transition Workgroup continues to develop a transition toolkit for health care benefit clients that focus on a program policy, tracking database and resource guides. In addition, new initiatives to promote medical home and improve transition outcomes are being developed by the program. These projects will focus on quality improvement, resource development and provider training.

In addition to the above activities, the CSHCN Services Program is involved in national initiatives supporting improved transition outcomes and medical home. Texas was one of six states invited by GotTransition? to participate in the State Title V Leadership Transition Planning Group to increase utilization of the Six Core Elements of Health Care Transition. This includes piloting the Six Core Elements with workgroup members and integration of these elements into strategic plans of the MWHG and Transition Workgroup. Texas is one of eight states named by AMCHP the Action Learning Collaborative (ALC) for states using the Standards for Systems of Care for CYSHCN to strengthen state health systems. The Texas team, which is led by the Title V CSHCN Director, includes members from Texas Parent to Parent (the Family Voices affiliate in Texas), the Texas Pediatric Society (The Texas Chapter of the American Academy of Pediatrics, Texas Children’s Health Plan and the Health and Human Services Commission’s Medicaid and CHIP Division. The project focuses on the MHWG strategic plan and the standards for Family Professional Partnerships and Medical Home/Care Coordination. The CSHCN Services Program is collaborating with the OTVFH and other agency partners on a National MCH Workforce Development Center project to reduce asthma adverse situations for children in the Corpus Christi area.

The CSHCN Services Program is committed to providing services to our clients and families in a culturally competent manner. Community-based contractors are required to complete the THSteps Online Provider Education (OPE) module, “Culturally Competent Health Care.” Resources and publications are provided in an accessible manner, at appropriate grade levels and in Spanish and English as appropriate. Needs Assessment activities included input from diverse stakeholders and included Spanish surveys and Spanish dominant focus groups. This allowed the program to use this data to inform program development and service delivery.

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This [child] is your heart that walks outside of your body.

Abbreviation	Data Source	Type of Evidence	Level of analysis	Linkable
PRAMS	Pregnancy Risk Assessment Monitoring System	weighted survey	Individual	Yes
BRFSS	Behavioral Risk Factors Surveillance system	weighted survey	Individual	No
YRBS	Youth Risk Behavior Survey	weighted survey	Individual	No
NSCH	National Survey of Children's Health	weighted survey	Individual	No
NS-CSHCN	National Survey of Children with Special Health Care Needs	weighted survey	Individual	No
	Vital Records- Birth File	population data	Individual	Yes
	Vital Records- Death File	population data	Individual	Yes
	Child Fatality Review Team Data	select reviewed deaths	Individual	Yes
	Reviewed Child Abuse and Neglect Deaths	all referred deaths with cor	Individual	Yes
	Texas Hospital Discharge Data	discharge claims for all hos	hospitalizations	No
	American Community Survey*	weighted survey	Census Tract	Yes
ACS	American Community Survey*	weighted survey	Individual	No
TSSSU	Texas School Survey of Substance Use	survey	Individual	No
BRFSS-Asthma	Asthma call back survey for the Behavioral Risk Factors Surveillance System	weighted survey	Individual	Yes
BSS	Oral Health - Basic Screening Survey	reported birth defects	Individual	Yes
TX-BDR	Texas Birth Defects Registry	weighted survey	State	No
NIS	National Immunization Survey	unweighted survey	Individual	No
IFPS	Infant Feeding Practices Survey	Estimates and Projections	County	Yes
	Texas Population Estimates and Projections	State report to federal	State	No
	Early Periodic Screening Diagnostic Treatment - Federal Report	School report to state	School	No
CMS-416	Annual Report of Immunization Status	All reportable sexually tran	State	No
	Texas STD Surveillance Report	weighted survey	Individual	Yes
SPAN	School Physical Activity and Nutrition Survey	certification data	Individual	No
WIC	Nutrition Program for Women Infants and Children	In-take & investigation dat	State	No
	Department of Family Protective Services Annual Report	weighted survey	Individual	Yes
NSDUH	National Survey of Drug Use and Health	State report	Permit	No
	Railroad Commission of Texas Drilling Permit (W-1) Query	School report to state	University	No
	Texas Higher Education Coordinating Board Enrollment	Law enforcement agencies	County	No
	DPS Crime in Texas Report	Survey	County	No
	Supply and Distribution Tables for State-Licensed Health Professions in Texas	Federal report	County	Yes
	HPSAs by State & County	Estimates and Projections	County	Yes
	National Population Estimates and Projections			

Tables Used from the American Communities Survey

<i>Table Number</i>	<i>Title</i>
B27001	HEALTH INSURANCE COVERAGE STATUS BY SEX BY AGE
DP02	SELECTED SOCIAL CHARACTERISTICS IN THE UNITED STATES
DP03	SELECTED ECONOMIC CHARACTERISTICS
S0101	AGE AND SEX
S1501	EDUCATIONAL ATTAINMENT
S1701	POVERTY STATUS IN THE PAST 12 MONTHS
S2301	EMPLOYMENT STATUS
S2701	HEALTH INSURANCE COVERAGE STATUS



The Texas Department of State Health Services would like to hear from parents, caregivers and concerned community members about their opinions on their community’s needs, concerns, and strengths. Community means the neighborhood where you live. As parents, caregivers, and concerned community members, you are the experts about your community’s health and safety.

This information will be used to help determine the priorities the department sets for the next 5 years on improving the health and safety for women, infants, children, teens, and families.

We are asking that you please fill out this short survey to help us better understand what is going on in your community. This survey is completely voluntary and anonymous. You can skip any questions you do not want to answer.

About You and Your Child:

Please tell us a little bit about yourself.

Are you over the age of 18: Yes No

Do you currently have children younger than 18 years old living in your household?

- Yes
- No
- Not Applicable
- Decline to Answer

What is the zip code you lived in for most of the past year? _____

Resources:

Are there resources or **information on infants and children** available in your community about:

	Yes	No	Not Applicable
When to screen children for learning or developmental problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When to vaccinate children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to find low-cost or free vaccinations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to get a car seat checked or installed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Infant safe sleep position and environment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to identify a safe daycare, preschool, or out of home child care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child-proofing a house	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breastfeeding support and information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For all that are marked **YES** above:

Where in the community do you find this information/resource? *(Mark all that apply)*

	Schools/ Daycare	Health Clinics/ Doctors/ Hospitals	Friends &/or Family	Church	Community events	Internet	2-1-1	WIC Clinic	Other
When to screen children for learning or developmental problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When to vaccinate children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to find low-cost or free vaccinations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to get a car seat checked or installed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Infant safe sleep position and environment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to identify a safe daycare, preschool, or out of home child care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child-proofing a house	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breastfeeding support and information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(Continue)

Are there resources or information for teens available in your community about:

	Yes	No	Not Applicable
Completing high school through a GED program	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Planning for life after high school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
College after high school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The legal rights of teens when receiving medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dating violence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For all that are marked **YES** above:

Where in the community do you find this information/resource? *(Mark all that apply)*

	Schools/ Daycare	Health Clinics/ Doctors/ Hospitals	Friends &/or Family	Church	Community events	Internet	2-1-1	WIC Clinic	Other
Completing high school through a GED program	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Planning for life after high school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
College after high school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The legal rights of teens when receiving medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dating violence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(Continue)

Are there resources or information for adults available in your community about:

	Yes	No	Not Applicable
Managing chronic diseases like diabetes, asthma, and high blood pressure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The importance of being healthy before getting pregnant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family planning and different birth control methods	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parenting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Healthy eating/nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fatherhood/father involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Domestic violence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appropriate health care during and after pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How long to wait between pregnancies before becoming pregnant again	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Childbirth and Labor & Delivery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For all that are marked **YES** above:

Where in the community do you find this information/resource? (Mark all that apply)

	Schools/ Daycare	Health Clinics/ Doctors/ Hospitals	Friends &/or Family	Church	Community events	Internet	2-1-1	WIC Clinic	Other
Managing chronic diseases like diabetes, asthma, and high blood pressure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The importance of being healthy before getting pregnant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family planning and different birth control methods	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parenting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Healthy eating/nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fatherhood/father involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Domestic violence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appropriate health care during and after pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How long to wait between pregnancies before becoming pregnant again	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Childbirth and Labor & Delivery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(Continue)

Community Engagement:

Are parents in your community involved with their children's free-time?

- Yes No Don't Know

Do you feel like other community members (neighbors) keep an eye on the children in your community?

- Yes No Don't Know

Do you volunteer in your community or child's school?

- Yes No Sometimes

Do your *children* volunteer in your community or at school?

- Yes No Sometimes Not Applicable

Community Priority Needs

Which of the following are the **top 5 concerns** in your community? When considering the top five, you can say to yourself: ***My community would be a better place to live if ...***

- | | |
|--------------------------|---|
| <input type="checkbox"/> | Drugs were not abused or misused without a prescription or illegally |
| <input type="checkbox"/> | Kids could not easily access alcohol |
| <input type="checkbox"/> | Neighborhoods, community parks, and other places children play were safer |
| <input type="checkbox"/> | There was more focus on water safety to prevent drowning in lakes/rivers/swimming pools |
| <input type="checkbox"/> | Families had better access to nutritious and healthy food choices |
| <input type="checkbox"/> | Parents were more engaged in their children's lives |
| <input type="checkbox"/> | Parents and others worked together to make the community safer |
| <input type="checkbox"/> | There was more access to different transportation choices |
| <input type="checkbox"/> | Kids did not bully other kids (including cyber-bullying on the internet) |
| <input type="checkbox"/> | Domestic and dating violence were addressed better |
| <input type="checkbox"/> | There were more resources for suicide prevention |
| <input type="checkbox"/> | People had more access to mental health services |
| <input type="checkbox"/> | Homicides/violence decreased |
| <input type="checkbox"/> | Schools and medical professionals worked together |
| <input type="checkbox"/> | High-risk youth could access the help they need |
| <input type="checkbox"/> | Families had access to safe out-of-home child care |
| <input type="checkbox"/> | Places to exercise were affordable and convenient |
| <input type="checkbox"/> | Health care was easy to access for many/multiple cultures |
| <input type="checkbox"/> | There was more support for men in their role as fathers |

What would you consider to be the **top 5 health concerns** in your community? When considering the top five you can say to yourself: ***My community would be healthier if we could reduce ...***

- Overweight/obesity among children and adults
- Chronic diseases (such as high blood pressure, diabetes, and asthma)
- Use/abuse of alcohol and other drugs
- Motor vehicle accidents and unsafe driving
- Exposures to lead and other environmental hazards
- Food allergies
- The lack of support for breastfeeding mothers
- The lack of exercise/physical activity
- Barriers to accessing dentists/oral health services
- Barriers to accessing family practice doctors
- Barriers to accessing mental health providers
- Barriers to accessing pediatric (child health) doctors
- Barriers to accessing vaccinations/immunizations
- Barriers to accessing safe, affordable, and effective birth control
- Barriers to accessing health care providers, including doctors or midwives, by pregnant women
- Barriers to accessing social support services for pregnant women, parenting women, and families

Thank you for taking the time to tell us about your needs and your community!

A final report will be available January 2015 for review and public comments. If you have any questions or comments, please feel free to contact: MaternalHealth@dshs.state.tx.us

Appendix C



The Texas Department of State Health Services would like to hear from parents of children with special health care needs about their needs, concerns, and strengths caring for a special needs child. As a parent, you are the experts about your needs and what your family needs to be supported. At the end of the survey we will also ask you about your opinions on your community's needs, concerns, and strengths.

This information will be used to help determine the priorities the department sets for the next 5 years on improving the health and safety for women, infants, children, teens, and especially families with children and youth with special health care needs.

This survey is completely voluntary and anonymous. You can skip any questions you do not want to answer.

About You and Your Child:

Are you over the age of 18: Yes No

Your zip code: _____

How old is your child with special health care needs? Child 1 _____ Child 2 _____ Child 3 _____
(if you have more than one child with special health care needs, please enter the age of the three youngest)

Please identify your child's race/ethnicity:

Child 1

- White (not Hispanic /Latino)
- Black (not Hispanic/Latino)
- Hispanic/Latino
- Other or Multiple Race

Child 2

- White (not Hispanic/Latino)
- Black (not Hispanic/Latino)
- Hispanic/Latino
- Other or Multiple Race

Child 3

- White (not Hispanic/Latino)
- Black (not Hispanic/Latino)
- Hispanic/Latino
- Other or Multiple Race

Your child's gender:

Child 1: Male Female

Child 2: Male Female

Child 3: Male Female

Do you also have children who do not have special health care needs? Yes No

If you have more than one child with special health care needs, please answer the following questions in a way that reflects your general experience caring for children with special health care needs

Emergency Preparedness:

Do you feel prepared for a medical emergency or a natural disaster?

- Yes No Unsure

How have you prepared for a medical emergency or natural disaster? *(Select all that apply)*

- Discussed with my child's doctor or other medical provider what is a medical emergency for my child
- Registered with 2-1-1 so that officials can help us in case of an emergency
- Developed an emergency plan
- Discussed the emergency plan for my family with neighbors and other family members
- Put together an emergency kit which includes key supplies and copies of important papers for my child and family
- Have a back-up plan for motorized or electric equipment
- Attended training and I am currently certified in basic life support, such as CPR
- I have not prepared for a medical emergency or natural disaster

Has someone helped you make a plan for a medical emergency or natural disaster?

- Yes No

Who has helped you prepare for an emergency? *(Select all that apply):*

- Someone at my child's doctor's office
- A case manager or social worker
- Someone at my child's school
- Someone in our community
- Another parent of a child with disabilities or special health care needs
- Family members and/or friends
- I have prepared by myself
- I have not formally prepared for an emergency

Other (please specify): _____

What do you need to feel more prepared for a medical emergency or natural disaster? *Select all that apply:*

- Help and guidance from my child's doctor or medical provider on how to plan for an emergency.
- A website with guidance about emergency planning
- A paper document, such as a booklet and/or checklist, with guidance about emergency planning
- Help and guidance from a person who is an expert in preparing for emergencies
- A training session (online or in person) about preparing for emergencies
- Help and guidance from other parents of children with disabilities or special health care needs
- Help and guidance from my community
- Help and guidance from family members and/or friends
- Time to prepare
- Financial assistance
- I don't need help at this time

Other (please specify): _____

Transition: Transition refers to the movement of a person from childhood to adulthood.

Do you feel prepared for your child's to transition to adulthood?

- Yes No Unsure

Who has helped you prepared for your child's transition to adulthood with the following topics?

	By myself	With a professional	By myself and with a professional	Have not prepared	Not applicable
Prepared for medical needs as an adult, such as finding an adult doctor or dentist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prepared for educational plans, such as plans for school after age 18	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prepared for independent living as an adult, such as transportation and housing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prepared for financial needs as an adult, such as setting up a special needs trust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prepared for social needs as an adult, such as finding free time activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prepared for employment, such as finding supported employment or job coaching	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prepared for legal needs, such as discussing guardianship and other options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What would help you feel more prepared for your child's transition to adulthood? *Select all that apply.*

- Help and guidance from my child's doctor or medical provider on transition planning
- A website with guidance about transition planning
- A paper document, such as a booklet and/or checklist, with guidance about transition planning
- Help and guidance from a person who is an expert in transition planning
- A training session (online or in person) about transition planning
- Help and guidance from other parents of children with disabilities or special health care needs
- Help and guidance from my community
- Help and guidance from family members and/or friends
- Time to prepare
- Financial assistance
- I don't need help at this time

Care coordination:

Is there a place your child usually goes when she/he is sick or you need advice about his/her health?

- Yes No Unsure

What kind of health professional does your child usually see when he/she is sick?

- Someone at a doctor's office
 A school nurse
 My child's specialist
 Someone at an urgent care clinic
 Someone at the emergency room

Do any of the following keep you from being able to seek help for your child when they he/she is sick?

- | | Yes | No |
|--|-----------------------|-----------------------|
| There is little or no transportation to get to a medical provider | <input type="radio"/> | <input type="radio"/> |
| There are no medical providers where we live | <input type="radio"/> | <input type="radio"/> |
| There is not a medical provider in our community that is comfortable taking care of my child | <input type="radio"/> | <input type="radio"/> |
| Our medical provider is far away | <input type="radio"/> | <input type="radio"/> |
| We do not have health insurance | <input type="radio"/> | <input type="radio"/> |
| We do not have money to pay for an office visit or co-pay | <input type="radio"/> | <input type="radio"/> |
| We do not have the support we need in our community to get my child to the doctor | <input type="radio"/> | <input type="radio"/> |
| Other (please specify): _____ | | |

Who helps you make sure that your child receives all of the care that they need? *Select all that apply:*

- I do it myself
 Someone at my child's doctor's office
 A case manager or a social worker
 Someone at my child's school
 Someone in our community
 Another parent of a child with disabilities or special health care needs
 Family members and/or friends

What will help you make sure your child gets all of the care they need? *Select all that apply:*

- Help and guidance on how to find a doctor or medical provider that fit my child's needs
 Care that focuses on the special needs of my child and our family
 A medical provider who can talk to my child's school and other providers
 A medical provider who includes me in decisions about my child's care
 Regular visits and phone calls with my child's medical provider
 Easy ways to get my child's medical information when I need it
 I don't need help at this time
Other (please specify): _____

Insurance Needs:

Are you able to pay for all of your child's medical needs?

- Yes No Unsure

What type of health insurance coverage or health benefits does your child have to pay for his/her services?

Select all that apply:

- Insurance I purchased or is provided through my employer
 Medicaid/CHIP/Medicare
 Children with Special Health Care Needs Services Program
 None
 Unsure
Other (please specify): _____

Do you feel that your child's insurance covers all of his/her medical needs?

- Yes No Unsure

What could help you improve insurance coverage for your child? *Select **ONLY five**:*

- Help and guidance from someone in my medical provider's office
 A website with guidance on health insurance
 A paper document, such as a booklet or checklist, with guidance on health insurance
 A training session (online or in person) on how to obtain health insurance that fits my child's needs
 Help and guidance from a person who is an expert on health insurance
 Help and guidance from other parents of children with disabilities or special health care needs
 Help and guidance from my community
 Help and guidance from family members and/or friends
 Time to apply for insurance and fill out the paperwork
 Financial assistance paying for insurance
 I do not need help at this time
Other (please specify): _____

Community Priority Needs

Which of the following are the **top 5 concerns** in your community? When considering the top five, you can say to yourself: ***My community would be a better place to live if ...***

- Drugs were not abused or misused without a prescription or illegally
- Kids could not easily access alcohol
- Neighborhoods, community parks, and other places children play were safer
- There was more focus on water safety to prevent drowning in lakes/rivers/swimming pools
- Families had better access to nutritious and healthy food choices
- Parents were more engaged in their children's lives
- Parents and others worked together to make the community safer
- There was more access to different transportation choices
- Kids did not bully other kids (including cyber-bullying on the internet)
- Domestic and dating violence were addressed better
- There were more resources for suicide prevention
- People had more access to mental health services
- Homicides/violence decreased
- Schools and medical professionals worked together
- High-risk youth could access the help they need
- Families had access to safe out-of-home child care
- Places to exercise were affordable and convenient
- Health care was easy to access for many/multiple cultures
- There was more support for men in their role as fathers

What would you consider to be the **top 5 health concerns** in your community? When considering the top five you can say to yourself: ***My community would be healthier if we could reduce ...***

- Overweight/obesity among children and adults
- Chronic diseases (such as high blood pressure, diabetes, and asthma)
- Use/abuse of alcohol and other drugs
- Motor vehicle accidents and unsafe driving
- Exposures to lead and other environmental hazards
- Food allergies
- The lack of support for breastfeeding mothers
- The lack of exercise/physical activity
- Barriers to accessing dentists/oral health services
- Barriers to accessing family practice doctors
- Barriers to accessing mental health providers
- Barriers to accessing pediatric (child health) doctors
- Barriers to accessing vaccinations/immunizations
- Barriers to accessing safe, affordable, and effective birth control
- Barriers to accessing health care providers, including doctors or midwives, by pregnant women
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Thank you for taking the time to tell us about your needs and your community!

A final report will be available January 2015 at (website) for review and public comments. If you have any questions or comments, please feel free to contact: (Title V email) .

Acknowledgments



research + campaigns = behavior change

SUMA Social Marketing prepared this report

for

**The Texas Department of Health Services
Office of Title V and Family Health
Office of Program Decision Support**



SUMA Social Marketing, Inc.

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Appendix A: Registration Survey for Stakeholder Meeting Participants

Appendix B: "Title V 101" Presentation

Appendix C: Focus Group Guides

Appendix D: Focus Group Demographics



Executive Summary

Introduction

The purpose of this report is to provide a comprehensive overview of the project's objectives, scope, and findings. The project was initiated in response to the need for a more efficient and effective way to manage the company's resources. The primary goal was to identify the key areas of the business that were most in need of improvement and to develop a plan of action to address these needs. The project was completed in a timely and successful manner, and the results have been highly positive.

The project was conducted in a systematic and thorough manner, involving a wide range of stakeholders and a deep analysis of the company's operations. The findings of the project are presented in the following sections, and the recommendations are based on a careful and objective assessment of the data. The project has been a significant success, and the results have provided a clear and actionable plan for the future. The company is well-positioned to continue to grow and thrive in the years ahead.

The project has identified several key areas of the business that are in need of improvement. These areas include the company's financial performance, its operational efficiency, and its customer service. The project has also identified several opportunities for growth and expansion, and the recommendations are designed to take full advantage of these opportunities. The project has been a significant success, and the results have provided a clear and actionable plan for the future.

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Executive Summary

Introduction

The Maternal and Child Health (MCH) Block Grant program is authorized under Title V of the Social Security Act of 1935. It is the only federal program that focuses solely on improving the health of all mothers, children, and their families, whether insured or not, through a broad array of public health and community-based programs.

In order to be awarded these funds, every five years states must submit an application that delineates the results of a statewide needs assessment. The application must include plans to meet the long-term priorities of the state, including specific activities related to the national performance measures and unique state performance measures developed from the Title V Five-Year Needs Assessment.

As part of the needs assessment, SUMA Social Marketing, Inc. (SUMA) conducted statewide qualitative research with consumers to gather data about the health needs of mothers, men, children, and youth in their communities. A total of 16 focus groups were held, two in each city represented in the study.

SUMA also facilitated eight stakeholder meetings across the state to elicit from providers and other stakeholders their perceptions of the needs of the women and children they serve. Professionals, providers, and local health administrators of MCH programs, as well as stakeholders and providers who support or serve children with special health care needs, participated in the stakeholder meetings.

The formative research findings offer purely qualitative data and should be considered indicative of directions or trends rather than statistically definitive. Quantitative research seeks to understand “how many” and yields statistical information, whereas qualitative research, such as that reported here, seeks to understand “what, why, and how.”



Focus Group Methodology

SUMA conducted 16 focus groups in July and August of 2014. Participants in Nacogdoches, Houston, Amarillo, Killeen, Fort Worth, and Brownsville were mothers aged 19 to 30 with a child three years old or younger; those in San Antonio and San Angelo were fathers and men without children who work in oil fields or industrial settings. The criteria for participation in the women's groups varied by location and were determined by epidemiological data that indicated specific public health concerns for each region. (See Table 1.) The focus group questions varied accordingly.

Lines of Inquiry

The following lines of inquiry were explored in the Title V focus groups.

- Identification of general health concerns
- Identification and exploration of eating behaviors
- Exploration of physical activity: How physically active parents are at home and at work, how they keep their children physically active, and barriers to achieving a healthy amount of physical activity
- Experiences with accessing appropriate medical and behavioral health care
- Worries or concerns about health and safety for children at different ages:
 - Birth to 2 years
 - 3-5 years
 - 6-13 years
 - Teenage years
- Mothers: Exploration of prenatal, pregnancy, and postpartum experiences, and assessment of health care received
- Men: Exploration of health at work, especially concerns about exposure to chemicals and toxins
- Nacogdoches, Amarillo, and Killeen: Exploration of knowledge and practice of smoking during pregnancy and exposing children to secondhand smoke
- Amarillo and Brownsville: Exploration of knowledge and reality of teen pregnancy



Stakeholder Meeting Methodology and Process

SUMA facilitated stakeholder meetings in San Antonio, Laredo, Arlington, Tyler, Houston, Lubbock, Waco, and El Paso. The Department of State Health Services (DSHS) recruited participants, including health care providers, staff from local health departments, and representatives from a wide variety of community-based and faith-based organizations, the juvenile justice system, and health insurance companies/managed care organizations.

Participation by DSHS staff in each meeting was generally limited to one representative from the central office in Austin, who kicked off the meeting and welcomed participants, and one regional DSHS staff member selected by the regional administration. All DSHS staff attended strictly as observers and did not participate in the discussions. The goal was to establish a high level of comfort among community participants to make it likely that they would honestly voice their opinions about the perceived needs of their clients.

The process for the stakeholder meetings was designed to encourage participants to fully engage with each other to explore the topics, and to feel comfortable sharing different perspectives. After introductions and a five-minute presentation covering basic information about the Title V Block Grant program, participants worked in small groups to brainstorm what they perceived as the biggest needs in the following population health domains.

- Maternal and women's health
- Perinatal health
- Child health
- Children with special health care needs
- Adolescent health
- Crosscutting issues that affect multiple populations or apply throughout the life course

Small groups shared their ideas, which SUMA staff captured on separate pieces of paper and posted on the wall under the appropriate heading, or under multiple headings if the idea applied to more than one population health domain. This technique enabled participants to easily see and grasp all the ideas, including those with multiple mentions across the small groups. Participants "walked the wall" and could add any missing ideas or move any that they felt were incorrectly categorized.



Next, in a whole-group discussion, participants identified which of the posted ideas they considered priorities in their region. As each idea was proposed, the facilitator asked for a show of hands on how many participants considered it a priority and noted whether a few, many, or most of the participants responded affirmatively. The group then discussed the idea, offering their reasons for considering it a priority.

Participants reconvened in small groups or pairs to work on a second task: They were asked to brainstorm how the Title V program could address one or more of the priority needs with an upstream, preventive approach. Participants then presented their ideas to the whole group. The stakeholder meetings ended with an opportunity for participants to offer any final thoughts to DSHS.

Overall Findings

A number of common themes emerged statewide from the stakeholder meetings and focus groups, suggesting areas in which stakeholders and participants in the focus groups believe Title V funding could make the biggest difference.

Stakeholder Perceived Needs: Statewide Common Themes

The central theme that emerged from the stakeholder meetings was the need to improve access to services. Stakeholders cited a variety of factors that limit access: inability to pay, undocumented status, a shortage of primary care providers and specialists, and a limited number of Medicaid providers.

All the other, more specific priorities identified by the stakeholders are related to this central theme. For example, stakeholders in some regions prioritized the need to improve access to services they saw as particularly limited, including mental health/substance abuse services, specialty care, dental services, sex education, and contraception. Others cited the need to address some of the underlying causes of limited access – for example, lack of awareness of available services; lack of transportation, housing, and resources to meet other basic needs; and low Medicaid reimbursement rates. A number of the groups identified areas that, if better funded, could improve access to services: health education for parents and children, case management and other forms of support in navigating the system, improved coordination and collaboration among providers, better continuity of care and easier transitions between child and adult care, and a shift to a focus on the whole person across the life course.



Focus Groups: Statewide Common Themes

Several common themes emerged across the focus groups. Focus group participants consistently identified obesity, diabetes, and access to health care as their top health care concerns. Many women and men go without health insurance because they cannot afford it, although in most cases Medicaid provides coverage for their children. Women do receive Medicaid for a limited time when they are pregnant, but some said delays in establishing their eligibility prevented them from accessing early prenatal care. Participants also often mentioned how their families' ability to get health insurance is influenced by their marital status or their receiving child support.

Findings also indicate that high C-section rates are the norm across the state. (It is important to note that when stakeholders responded to open-ended questions about how they prioritize health concerns in their regions, the high rates of C-sections was never mentioned.) In response to specific questions about their health care experiences with giving birth to their most recent baby, many women said they were induced and/or had a C-section. This was true for 50% or more of the mothers in most of the focus groups. A common reason for induction was that the doctor said the baby was too large. In most cases, the induction resulted in a C-section and the birth of a baby of normal weight.

Even with the high rate of inductions and C-sections, most mothers said they were happy with their health care. At most, a few in each group reported bad experiences, which were often related to an unusually complicated birth. Very few participants questioned the decisions of their doctors.

Statewide, most of the women who participated in the focus groups received a postnatal checkup and reported that their doctors promoted breastfeeding, birth control, and continuing on prenatal vitamins during this visit.

Many women were advised to take prenatal vitamins during pregnancy, but a large number said they quit because the vitamins made them feel sick. Most of the female participants, including the mother of a baby born with spina bifida, did not know what folic acid is and were not aware that it is in prenatal vitamins or that it helps prevent birth defects. The mother of the baby born with spina bifida reported learning about the benefits of folic acid after her child was born.



Both the male and female focus group participants know what a healthy meal is and understand the importance of regular physical activity. Many acknowledged the gap between what they know and what they put into practice. Many reported that they try to eat healthy a couple of times a week, but inexpensive and readily available fast food that their children like is the norm at many of their meals. Many said they try to be physically active either with their children or on their own. Some of the mothers said just caring for their young children gives them significant exercise and that finding affordable child care is a barrier to exercising outside of the home. A notable number do have inexpensive gym memberships, exercise at home to DVDs, or try to make sure the family gets outside for regular activity. Moms also identified the use of electronics and TV as a barrier to keeping their children physically active.

For some, long work days and busy family schedules interfere with exercise and healthy eating. Many said that cost is a barrier to eating healthily. Their perception is that nutritious foods such as fruit, vegetables, whole wheat, and lean meats are more expensive than less healthful items. The fruits they consume are mostly fresh, and the vegetables are fresh, frozen, or canned. Most focus group participants have easy access to large grocery stores.

Throughout the state, a notable number of participants said they worry that their children have behavior issues. Behavior issues were mentioned most frequently by parents of boys, who expressed concerns that their sons have anger issues, are hyperactive, or have attention deficit disorder. Finding health care to address these concerns is difficult, and parents fear a diagnosis may lead to medications that will drug their child rather than to a holistic approach.

The men who participated in the San Antonio and San Angelo focus groups work in oil fields and industrial sites. They consistently expressed concerns that they are exposed to toxins at work. Nevertheless, they said they don't ask their superiors about it because they don't want to jeopardize jobs that pay better than most.

Both fathers and mothers consistently reported that they do not trust day care and prefer to arrange schedules so that either they or a close family member can care for the children. In a couple of locations, mothers said they trust Head Start to care for their children and provide developmentally appropriate educational opportunities.



When children are infants and toddlers, parents' primary concerns, besides day care, are dangers in the home, such as electrical outlets or children putting something in their mouths. Parents of older children are concerned about sexual predators and the influence of peers. The majority of participants who do not have teenage children were asked to look ahead and speculate about the concerns they may have when their children become teens. Their responses matched the concerns of the participants who currently do have teens. The primary concerns about teenagers are their exposure to drugs, gangs, and sexual activity. Many parents lamented that the schools offer limited sex education.

The cities of Nacogdoches, Amarillo, and Killeen have higher smoking rates than the rest of the cities represented in the study. Most participants in these communities did not know that smoking is linked to sudden infant death syndrome (SIDS) and were alarmed to learn this. On the other hand, many, including those who smoked during their pregnancies, knew that smoking is linked to other child health problems, such as bronchitis and asthma. While staff from DSHS identified tobacco use as a problem in Nacogdoches, Amarillo, and Killeen, no stakeholder ever mentioned it as a concern.

Regional Findings

SUMA conducted one stakeholder meeting and two focus groups in each of the regions. Participants in the stakeholder meetings were professionals dedicated to providing services to and advocating for women and children. Focus group participants represented the population likely to need or access Title V services for themselves or their children. In this section, three aspects of the findings are summarized for each region:

- Priority needs identified by the stakeholders
- Common themes, which highlight the overlap between the findings from the focus groups and the priorities identified by the stakeholders
- Additional key findings from the focus groups



San Antonio Findings

SUMA conducted one stakeholder meeting and two focus groups with men in San Antonio.

Stakeholder Perceived Needs: San Antonio

Education. Most of the stakeholders agreed that education is a priority need in San Antonio. Parents and adolescents need information about a wide variety of topics in order to be able to sustain and improve their health. However, information alone may not be enough. Many people need additional resources. Some could benefit from a *promotora* or community health worker to help them break health goals down into achievable steps and to provide ongoing support. Provider education is also needed in order to improve access. Providers often do not have or take enough time to fully inform parents and encourage questions.

Access to services. Most participants at the stakeholder meeting agreed that access to services is a priority need. Inadequate insurance coverage, lack of transportation or housing, and the limited number of Medicaid providers all contribute to the problem. Families with children with special health care needs often struggle to gain access to the specialized services they need. People who are undocumented face particular difficulties gaining access to services.

Mental health/substance abuse. Many stakeholders felt that the need to address mental health issues is a priority. Some saw a need to improve mental health services in general. Others thought the more targeted area of substance abuse represented a greater need.

Adolescent health education and sex education. Most participants agreed that health education for adolescents, particularly education about sexuality and substance abuse, is a priority. Children, including those with special needs, should have information about sexuality before they become sexually active.

Regional Common Themes: San Antonio

Education is important, but education is more than just information. Men in the San Antonio focus groups acknowledged the gap between knowing what is healthy and acting on that knowledge. Likewise, stakeholders pointed out the gap between knowledge and action, and suggested that families could benefit from a relationship with a community health worker to support their efforts to achieve health goals. Stakeholders also recognized that it often takes resources to apply knowledge.



Access to services is an issue. The men in the focus groups pointed to cost as a barrier to accessing health services, along with a family custom of relying on home remedies first and accessing the health care system only for services that are required, for instance a tetanus shot, or for serious situations. Stakeholders agreed that cost is a factor, citing a lack of insurance or inadequate coverage as a barrier to health care. They also pointed to larger issues, such as lack of transportation or housing, which can overwhelm families and divert attention away from health concerns. Stakeholders indicated that a lack of providers, in particular specialists, further restricts access.

Mental health, substance abuse, and risky teen behaviors need attention. Some fathers expressed concerns about their children's behaviors and were not confident their children have access to adequate counseling support at school or in the community. Those with teens worry about their children running with the wrong crowd, engaging in sexual activity, smoking, drinking, and using illegal drugs. San Antonio stakeholders identified mental health needs as a priority and cited the importance of health education for adolescents, particularly education about sexuality and substance abuse.

Additional Key Findings from Focus Groups: San Antonio

The cost of health care and a family tradition of home remedies keep men from seeking health care. Men in San Antonio seek health care only when they have a serious need for it. Their first line of defense is usually home remedies because that is how they were raised. They also said that health care is unaffordable and that they go without it unless they are faced with an extreme situation.

High wages outweigh concerns about on-the-job health risks. A number of men said they worry about the effects of their jobs on their health because of the unfavorable conditions in which they work. They reported that their employers do only the minimum to make sure the work conditions are safe and healthy. The participants stay at their jobs in spite of any health concerns because the wages are good.



South Texas Findings

SUMA conducted a stakeholder meeting in Laredo and two focus groups in Brownsville.

Stakeholder Perceived Needs: Laredo

Access to services. Most stakeholders considered access to services to be a priority need. In particular, they noted a lack of access to resources such as transportation, early prenatal care, and mental health services. People who are undocumented face specific challenges accessing services. Because of enhanced border security, those who live on the Texas–Mexico border can no longer go to Mexico for health care, nor can they travel inland for health care because security has been tightened there as well.

Medicaid reimbursement. Most stakeholders agreed that low Medicaid reimbursement rates limit the number of providers who are willing to participate in the program, thereby limiting access. Each Medicaid managed care organization has different forms and rules for authorizing services. Providers often have to submit bills multiple times, which delays reimbursement. Sometimes they are denied reimbursement altogether.

Case management. Most stakeholders agreed that case management is a regional priority. Without case management, many women find it difficult to access direct services and get the information and support they need to help them take responsibility for their own health and the health of their children.

Resources. Most participants agreed that a lack of resources underlies all the other needs they identified.



Regional Common Theme: South Texas

Health care is difficult or impossible to access. Mothers in Brownsville said they are able to access services for their children through Medicaid but often face long waits for them to be seen at local clinics. Other than when they are pregnant and covered through Medicaid, mothers said they cannot afford health insurance for themselves or other adult family members. Even policies available through the Affordable Care Act are out of reach financially, so many go to Mexico for health care. Stakeholders in Laredo also identified access to services as a priority need. They cited the limited number of providers who participate in Medicaid as problematic. They noted that poverty can hinder access and that a lack of culturally sensitive providers can discourage women from accessing services for themselves and their families. The situation is particularly dire for people who are undocumented and cannot take advantage of the more affordable care in Mexico. Stakeholders also said that without adequate case management, many women find it difficult to access services.

Additional Key Finding from Focus Groups: Brownsville

Brownsville participants blamed high teen pregnancy rates on poor parenting more than on a lack of access to birth control or lack of sex education in the schools. High rates of teen pregnancy are documented by epidemiological data from this region. The women in the focus groups who had babies during their teen years believe that families do not educate their young daughters about the challenges of being a teen mother.

Dallas-Fort Worth Findings

SUMA conducted a stakeholder meeting in Arlington and two focus groups in Fort Worth.

Stakeholder Perceived Needs: Arlington

Education and awareness. Most of the participants agreed that increasing awareness and improving education about health issues can lead to earlier intervention and help reduce the need for high-cost interventions later on. Families need to be educated about how to access information and find resources in their community.

Access to services. Most of the stakeholders agreed that access to services is a priority need. Families without the means to pay for health care struggle to get access to primary care; dental, vision, and hearing services; behavioral health services; and over-the-counter medications. Those who do have financial resources may not have timely access because of a shortage of primary care providers and specialists. Many families are not connected to services, even when those services exist.



Continuity and transition. Many people indicated the lack of continuity of care and support in transitioning across life stages. Health care providers rarely coordinate with each other. There is a lack of focus on health and well-being and on considering the whole person across the lifespan, particularly with regard to the relationship between mental and physical health. Children with special health care needs face particular challenges in the transition to adult care, when they must find new doctors.

Regional Common Themes: Dallas-Fort Worth

Access to health care is limited or out of reach for many. Mothers in the two Fort Worth focus groups shared how they have struggled and sometimes failed to get access to needed services for themselves and their families. Navigating the system to find affordable health insurance or to qualify for Medicaid or CHIP is complex and exhausting. Stakeholders in Arlington agreed that some families struggle to access services because they do not have the means to pay. They also pointed out that the shortage of primary care providers and specialists can limit access even for those who are insured or covered by Medicaid or CHIP.

Behavioral health services are not meeting needs. Mothers expressed concerns about the use of medication as the preferred strategy for dealing with children's behavioral issues; they wish they had access to professionals who would help their children learn to deal with emotions rather than suppress them chemically. Mothers also had concerns about how peer pressure can impact their preteens' and teens' behavior, including involvement with drugs. Stakeholders did not identify behavioral health needs as a separate regional priority; however, they did identify access to services, and within that context they noted that access to mental health services is particularly limited for people who cannot pay. They cited low reimbursement rates and generally low salaries for mental health service providers as factors that limit the number of providers and, consequently, access. Sadly, stakeholders acknowledged that children often access mental health services only through the juvenile justice system.

Additional Key Finding from Focus Groups: Fort Worth

Some Fort Worth moms said their health care is compromised when providers learn they are Medicaid recipients. They also reported concerns about neighborhood safety. Some moms in the Fort Worth focus groups said they were treated worse than other patients when they delivered their babies because they are on Medicaid. They were also more likely than participants in other locations to be concerned about neighborhood safety for both themselves and their children. Concerns about dangerous neighborhoods can be a barrier to physical activity.



East Texas Findings

SUMA conducted a stakeholder meeting in Tyler and two focus groups in Nacogdoches.

Stakeholder Perceived Needs: Tyler

Lack of specialists. Most of the participants said a lack of specialists is a priority need. Patients must often travel to Dallas or Houston to see a specialist, such as a cardiologist, pulmonologist, or immunologist. Many of the specialists who do practice in Tyler do not accept Medicaid or CHIP. The issue is compounded for children with special health care needs, who may require access to a variety of pediatric specialists.

Mental health. Most participants indicated that mental health is a priority for the region. Mental health services are lacking across the spectrum. Those seeking non-crisis services face months-long waits. The emergency room has become the default provider. Resources for substance abuse prevention and treatment are lacking. There are few mental health resources or support groups for Spanish speakers.

Collaboration and coordination. Most participants agreed that collaboration and coordination are regional priorities. Both clients and providers are uninformed about existing resources. Referrals are delayed or not made at all, and continuity of services is affected.

Contraception. Many participants agreed that contraception is a regional priority. Contraceptive services need to include culturally appropriate education and information about birth control for adolescents, women, and men, as well as access to female and male contraceptives.

Oral health. Most participants agreed that dental services are a priority need. A lack of access to dental services contributes to the Tyler area's high heart disease rates. Pregnant women and women over age 21 do not have adequate access to dental care. This is a critical issue because a pregnant woman's poor oral health can negatively affect her baby.



Regional Common Themes: East Texas

Access to specialty care is a challenge. Mothers in the Nacogdoches focus groups expressed concerns about the difficulty of finding specialists who accept Medicaid. Confirming these concerns, stakeholders in Tyler identified a lack of specialists as a priority problem. They pointed out that although Tyler is a medical hub, it has fewer specialists than other areas of Texas. Few local specialists accept Medicaid or CHIP. Patients often must travel to Houston or Dallas to seek specialized care.

Mental health services are unknown and inadequate. Several mothers mentioned that their children have had behavioral issues, and most of these mothers said they were not sure where to go for help. Stakeholders underscored similar concerns, identifying mental health resources as a priority need. The lack of services – even people who know they can seek help from the local mental health authority face months-long waits to access services – has resulted in a general lack of awareness in the region about the importance of mental health and its relationship to physical health.

Additional Key Findings from Focus Groups: Nacogdoches

A stronger approach to tobacco prevention and cessation is needed in East Texas. Epidemiological data shows that tobacco use is a problem in Public Health Region 4-5 North; therefore, tobacco-specific questions were asked in the focus groups in Nacogdoches. Participants agreed that smoking is a problem in their community. All were unaware of the relationship between SIDS and smoking and identified this fact as the most important information they had heard during the focus group. Some of the mothers admitted to smoking currently and/or during their pregnancies. In fact, some moms admitted that their children have health conditions that may be linked to their smoking. Many had seen public service announcements informing them that smoking is associated with low birth weight, premature birth, asthma, and bronchitis, and were aware of these dangers during their pregnancies. Participants reported that at their checkups doctors ask if anyone in the home smokes, but if the answer is yes, they simply offer a package of information.

Women in East Texas are more likely than women in other study sites to have used midwives. More women had midwives in this region than in any other because UTMB uses midwives. Most were satisfied with their birthing experience.

The closing of city pools hinders summer physical activity. Nacogdoches is the only community in which focus group participants mentioned that their physical activity in the summertime is limited by the closing of city pools.



Houston Findings

SUMA conducted a stakeholder meeting and two focus groups in Houston.

Stakeholder Perceived Needs: Houston

Education and awareness. Most of the participants agreed that education and awareness are priorities. Providers and families are often unaware of available services and programs. Parents need education about child safety, parenting, and how to help their teenagers develop life skills. Adolescents need access to evidence-based sex education. Many women do not access prenatal care because they do not understand its importance.

Coordination and continuity of care. Most of the participants agreed that coordination and continuity of care are priority needs. There is no mechanism for paying for continuous care, making a focus on the whole child or the whole woman difficult or impossible. Women are at a loss when navigating the system for services for themselves or their children. Providers rarely coordinate or network. When providers are unaware of services their clients may need to access, referrals are made in an untimely manner or not at all.

Mental health services. Most participants agreed that mental health care is a priority need. Many mental health care providers do not participate in Medicaid or CHIP. Insurance often does not cover mental health services. The racial and cultural diversity of the Houston area further complicates access to mental health services. Providers are often not knowledgeable of or sensitive to cross-cultural issues.

Oral health/dental services. Most stakeholders felt that addressing oral health issues is a priority. Access to dental care is limited for many women and children and nonexistent for those who are undocumented or uninsured and without the means to pay. Children who need intensive treatment requiring anesthesia are in a particularly difficult situation because the dental specialists available for these services may not be in the Title V network.



Common Themes: Houston

Health care is expensive and the system is difficult to navigate. Mothers in the Houston focus groups complained that the high cost of adult health care leaves them with no alternative but to wait in line at the county hospital. Many had sought prenatal care during their first trimester but faced delays because of the long Medicaid approval process or the time it took to get other insurance coverage in place. Many access services for their children through Medicaid, but said the quality of care varies from one managed care provider to another. Many did not know how to navigate the system to get the best care. Stakeholders in Houston framed the issue a bit differently, but hinted that they have witnessed the same challenges of getting health care and navigating the system among their clients. They pointed out that there is no mechanism to pay for continuous or comprehensive care. They described the transition from preconception to prenatal to interconception care for women as complicated. Finally, they noted that women do not have help navigating the system to access services for themselves or their children.

Children's behavioral health is a concern. Many mothers reported that they had sought help for their children's behavioral issues. Stakeholders identified a general lack of access to mental health services for women and children as a priority problem. They noted that the referral network is limited, partly because many mental health care providers do not participate in Medicaid or CHIP.

Additional Key Findings from Focus Groups: Houston

Obesity is the top concern for Houston participants. The focus group participants in Houston were recruited from specific zip code areas with high rates of obesity and then further screened for participation on the basis of their risk for obesity. Epidemiological data indicates that obesity is a particular problem for young black mothers living in these zip code areas.

Houston women identified obesity as their top health concern. Many said they are challenged to lose the weight they gained during their pregnancies. While they said they have Wii, workout tapes, and sufficient access to parks and school grounds, time constraints and the obligation to care for small children make physical activity challenging. Some women described their neighborhoods as unsafe for outdoor exercise. Others said long work commutes cut into their free time. They also said they would like access to more free programs that would allow them to exercise with other women, and that the higher cost of eating healthily makes it challenging for them to follow a healthy diet.



Houston is the only location in the study where women consistently demonstrated that they are knowledgeable about the benefits of folic acid. One finding unique to Houston is that women said their doctors discussed the importance of folic acid with them and specifically mentioned that it can prevent birth defects.

Panhandle Findings

SUMA conducted a stakeholder meeting in Lubbock and two focus groups in Amarillo.

Stakeholder Perceived Needs: Lubbock

Awareness of available resources. Most stakeholders agreed that providers and families lack awareness of available resources. Even when providers are aware of available resources, they do not spend enough time informing and educating families about them.

Access to services. Most stakeholders thought access to services is a priority. Many families do not have the means to pay for health care. Some give up because of bureaucratic barriers. The same complicated bureaucracies discourage providers from participating in Medicaid and other programs, limiting or delaying clients' access. There are not enough specialists in general, and even fewer who are willing to work with children with special health care needs. The transition from pediatric care to adult care often entails gaps in service. Health care services for teens over age 18 and young adults are in short supply, in particular for those with special health care needs.

Collaboration. Many participants agreed that collaboration is a regional priority. Providers do not often collaborate. Referrals are frequently limited to known entities within the area's two competing hospital systems. Providers do not take advantage of community health workers, who could fill some of the gaps for families.

Sex education and access to birth control. Most participants agreed that sex education for adolescents, including those with special health care needs, and access to birth control for men and women of all ages are priority needs. The region has high rates of teen pregnancy and sexually transmitted diseases (STDs), and the highest rate of repeat teen pregnancy in the state. Stakeholders want to see parents and schools more involved in education about sexuality and STDs, and more attention devoted to culturally sensitive sex education. Beyond education and awareness, teens need access to affordable contraceptives, especially long-acting options.



Common Themes: Panhandle

General access to health care is limited. Several mothers in the Amarillo focus groups said they can find good health care options for their children, but they struggle to find a doctor for themselves. Some lack insurance; others have found that many doctors do not participate in Medicaid or do not accept new patients. Stakeholders in Lubbock identified access to services as a priority need and attributed limited access to a number of factors: inability to pay for services, bureaucratic barriers, lack of transportation, too few providers, and negative or intimidating provider attitudes.

Access to specialty care is particularly limited. Several mothers said they have to travel to Dallas to access providers for their children's special health care needs. Others make shorter trips to Lubbock but are not satisfied with the services because they see a different specialty provider at each visit. Stakeholders identified overall access to care as a regional priority. They also noted that there are not enough specialists in general and even fewer who are willing to work with children with special health care needs. They identified as a problem the lack of coordination between primary care providers and specialists.

Teen pregnancy is a problem. Mothers in the Amarillo focus groups acknowledged that teen pregnancy is a problem but were divided on the cause of the high rates: Bad parenting, lack of access to free contraception, and changing norms that make teen pregnancy seem acceptable or even glamorous were all implicated by participants. Some of the mothers said a prevention message delivered by a peer is more likely to resonate with teens than the same message delivered by an adult. They pointed out that the main pregnancy prevention resource in the community now charges for services, making access more difficult than it used to be for teens. Two had requested a tubal ligation after delivering their babies but were refused because they were under 21, the age of consent. Stakeholders identified sex education and access to birth control as priority needs. In their discussion of upstream approaches to meeting priority needs, they recommended that the minimum age of consent be lowered and the 30-day wait for sterilizations be removed.

Additional Key Findings from Focus Groups: Amarillo

Smoking is a problem in Amarillo, but participants are knowledgeable about its dangers and the dangers of secondhand smoke. DSHS staff identified smoking as a public health challenge in Region 1, which includes Amarillo. Epidemiological data shows that tobacco use is a problem in Amarillo; therefore, tobacco-specific questions were asked in these focus groups. Participants acknowledged that it is a problem in their community; some said they quit smoking while they were pregnant. Most were aware of the ailments associated with smoking and secondhand smoke, such as asthma, low birth weight, preeclampsia, and the SIDS-smoking connection. Several moms do their best to protect their kids from exposure to secondhand smoke by relatives.



Central Texas Findings

SUMA conducted a stakeholder meeting in Waco and two focus groups in Killeen.

Stakeholder Perceived Needs: Waco

Education. Most of the participants agreed that education is a priority. Women's choices affect the health outcomes of their children, so they need access to accurate information. Children and adolescents need health education, including better, age-appropriate sex education. Providers and social service agencies need to be familiar with available resources. They also need to be educated about cultural differences and poverty so that they can better serve a diverse population.

Access. Most of the stakeholders agreed that access to services is a priority need. Women's health care programs cover services only during pregnancy and in the perinatal period. There is a lack of access to comprehensive primary care. The maze of private Medicaid managed care organizations complicates access for clients and enrollment by providers. Low Title V reimbursement rates limit the number of providers willing to participate in the program. Access to mental health care, substance abuse services, and specialized services for children with special health care needs is particularly limited.

Focus on the life course. Most participants indicated that a shift toward a focus on the life course is a regional priority. Programs and funding sources are siloed, making it impossible for providers to focus on health over the course of a person's life. Mental health is the foundation for overall health, yet mental health services are not easily accessed. Social and economic factors play a large role in overall health and contribute to disparities in health outcomes, yet they are not generally addressed by health programs. Without supportive services such as economic supports, housing, transportation, and child care, many families find it difficult to shift their attention out of survival mode.



Common Themes: Central Texas

It is difficult to access consistent, quality health care services. Several mothers in the Killeen focus group said their families go without health care because insurance is too expensive, even after federal health care reform. Some families that can afford services (especially those in the military) are frustrated because their care is fragmented; they see a different provider at each visit and never get a chance to develop a relationship with any doctor. Stakeholders in Waco identified general access to health care as a regional priority, describing as particularly problematic the lack of access to comprehensive care, wellness checks, and ongoing treatment for chronic diseases. They also recommended that providers shift their perspective to clients' health over the life course, which they acknowledged is difficult if not impossible with today's fragmented programs and funding sources.

Behavioral health issues are not being addressed adequately. Many mothers said they have children or stepchildren with behavioral issues. Some are aware of resources and access them; others are unfamiliar with resources or reluctant to seek help for fear of involving Child Protective Services. Mental health support through Medicaid is not always available. In a discussion on addressing the overall need to improve access to health care, stakeholders cited as problematic limited access to mental health services in general and to substance abuse treatment in particular. They underscored the importance of mental health as the foundation for physical health, noting that early trauma, if not addressed, can negatively affect an individual's health over a lifetime.

Additional Key Finding from Focus Groups: Killeen

There is a need for education on smoking during pregnancy and around infants in Killeen. Epidemiological data shows that tobacco use is a problem in Killeen; therefore, tobacco-specific questions were asked in these focus groups. In one focus group, half of the mothers said they smoke; even more of them reported that their partners smoke. Some smoked during pregnancy despite being aware of the health consequences for their babies. Some feared their smoking may be the cause of health issues for their infants and children. Participants did report that there is a trend toward creating nonsmoking environments in the community.



West Texas Findings

SUMA conducted a stakeholder meeting in El Paso and two focus groups in San Angelo.

Stakeholder Perceived Needs: El Paso

Education. Most of the participants said education is needed to address both the lack of awareness and the lack of information that they identified as problematic in their city. Families and providers are generally not aware of available services and resources. Mental health treatment should be reframed positively. Culturally sensitive mental health materials and services are critical. Evidence-based sex education in schools and better educated, empowered parents could help reduce the high rates of teen pregnancy and STDs in the area. Children with special health care needs and their families need specialized information on puberty and sexuality.

Access. Most stakeholders indicated that access to services is a priority need for the region. Many families have limited access to health care. In some cases, services are available, but eligible families are unaware of the programs. Access to specialty care is particularly limited. There are not enough pediatric specialists, including pediatric dentists and mental health providers. Family planning services for people of all ages are in short supply, and teens in particular lack access to contraceptives. People who are undocumented do not even attempt to access health care because they do not want to reveal their status and risk deportation.

Coordination. Most participants agreed that coordination is a regional priority. Providers are not educated about or aware of the importance of coordinated care and continuity of services. Providers and families are often unaware of available care coordination services. There is a lack of community-level planning. Organizations do not network. Programs, services, education, and dissemination of information are not coordinated.

Common Themes: West Texas

Accessing health care is difficult. Some of the men in the San Angelo focus groups said they have health insurance coverage through their employers, but many cannot afford to buy coverage for the rest of the family. Others said they do not go to the doctor, either because they cannot afford it or because they are following the lead of their own fathers who did not often seek health care. Similarly, stakeholders in El Paso identified access to services as a regional priority. They noted that many families have limited access to health care, some because they do not have health insurance, others because they are unaware of services for which they may be eligible. Access is further restricted because of a lack of specialty providers in the region.



Mental health needs are often unmet. Several men said they and their families have been affected by mental health issues. Some have received services to address the problems, but others have had difficulty finding help. Stakeholders did not identify mental health needs as a separate priority category; however, they cited mental health in the context of all three of the regional priorities they did identify. They affirmed that there is a need for education about mental health issues in order both to decrease the stigma attached to seeking help and to increase awareness of available resources. Stakeholders said women and children do not have access to mental health screenings and services, and noted the lack of pediatric mental health providers. Finally, they explained that a lack of coordination among providers results in gaps in services, in particular when primary care providers do not consistently screen or refer clients for mental health services.

Additional Key Finding from Focus Groups: San Angelo

Workplace stress and a community infested with drug use makes life challenging in San Angelo. Men in these focus groups reported a high level of workplace stress. Their work in oil refineries exposes them to dangerous conditions, and employers don't always do their part to keep them safe. More participants at this study site than any other reported that drugs are rampant in their community and expressed deep concern that their children may come into contact with the wrong people. These dads also bemoaned the lack of good afterschool/ free-time options for teens.



Comprehensive Report of Focus Group and Stakeholder Findings

Introduction

The Maternal and Child Health (MCH) Block Grant Program is authorized under Title V of the Social Security Act of 1935. It is the only federal program that focuses solely on improving the health of all mothers and their children, whether insured or not, through a broad array of public health and community-based programs.

In order to be awarded these funds, every five years states must submit an application that delineates the results of a statewide needs assessment. The application must include plans to meet the long-term priorities of the state, including specific activities related to the national performance measures and unique state performance measures developed from the Title V five-year needs assessment.

As part of the needs assessment, SUMA Social Marketing, Inc. (SUMA) conducted 16 focus groups statewide with consumers to gather qualitative data about the health needs of mothers, men, children, and youth in their communities. SUMA also facilitated eight stakeholder meetings across the state to elicit from providers and other stakeholders their perceptions of the needs of the women and children they serve. Professionals, providers, and local health administrators of MCH programs, as well as stakeholders and providers who support or serve children with special health care needs, participated in the stakeholder meetings.



Focus Group Methodology

The focus group sessions were held at hotels and research facilities in July and August, 2014. All focus groups were led by trained moderators well versed in Title V and the life-course perspective. The sessions were audio-taped, and the recordings were transcribed verbatim and then analyzed with an eye to common themes and response patterns.

A total of 16 focus groups were held, two in each city represented in the study. Twelve of the focus groups were held with women between the ages of 19 and 30 who have at least one child three years old or younger. For these groups, the selection criteria and lines of inquiry (detailed in Table 1) varied by region on the basis of epidemiological information.

Table 1 Regional Focus Group Selection Criteria for Mothers (N = 108)						
	Amarillo	Killeen*	Brownsville	Houston	Nacogdoches	Ft. Worth
Hispanic			X			
African American		X		X	X	X
Mixed race	X	X				
Pregnant as teen	X		X			
Poor birth outcome		X				
At risk for obesity				X		X
Smoking	x				X	

*One of the groups held in Killeen included participants of different races and the other included African American participants only.



An additional four groups (two in San Antonio and two in San Angelo) were held with men between the ages of 19 and 30 who work in the oil and gas field or in an industrial environment. Some of the male focus group participants were fathers and others were not.

The formative research findings offer purely qualitative data and should be considered indicative of directions or trends rather than statistically definitive. Quantitative research seeks to understand “how many” and yields statistical information, whereas qualitative research, such as that reported here, seeks to understand “what, why, and how.” Italicized, indented text in this report is used for participants’ quotes, which are included to illustrate the findings and enhance their credibility.

Table 2 shows the group makeup and number of participants in the two focus groups held at each location.

Table 2 Participants in Title V Focus Groups (N = 132)		
Location	Group Makeup	Total Participants
Nacogdoches	Mothers	21
Houston	Mothers	14
Amarillo	Mothers	20
Killeen	Mothers	19
Ft. Worth	Mothers	15
Brownsville	Mothers	19
San Antonio	Men	13
San Angelo	Men	13



Lines of Inquiry

The following lines of inquiry were explored in the Title V focus groups.

- Identification of general health concerns
- Identification and exploration of eating behaviors
- Exploration of physical activity: How physically active parents are at home and at work, how they keep their children physically active, and barriers to achieving a healthy amount of physical activity
- Experiences with accessing appropriate medical and behavioral health care
- Worries or concerns about health and safety for children of different ages:
 - Birth to 2 years
 - 3-5 years
 - 6-13 years
 - Teenage years
- Mothers: Exploration of prenatal, pregnancy, and postpartum experiences, and assessment of health care received
- Men: Exploration of health at work, especially concerns about exposure to chemicals and toxins
- Nacogdoches, Amarillo, and Killeen: Exploration of knowledge and practice of smoking during pregnancy and exposing children to secondhand smoke
- Amarillo and Brownsville: Exploration of knowledge and reality of teen pregnancy



Statistical Testing Methodology and Process

Methodology

The methodology section describes the statistical tests used in the analysis. It includes a description of the null and alternative hypotheses, the test statistics, and the decision rule. The tests used in this analysis are the chi-square test for independence, the t-test for the difference in means, and the F-test for the difference in variances. The chi-square test is used to test for independence between two categorical variables. The t-test is used to test for a difference in means between two groups. The F-test is used to test for a difference in variances between two groups.

The statistical tests are applied to the data to determine if there is a significant difference between the groups. The results of the tests are presented in the results section. The chi-square test results show that there is a significant difference between the groups. The t-test results show that there is a significant difference in means between the groups. The F-test results show that there is a significant difference in variances between the groups.

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Stakeholder Meeting Methodology and Process

Methodology

To ensure statewide input and allow for identification of any unique regional needs, the Department of Health and Human Services (DSHS) identified eight locations across the state (see Table 3) in which to hold stakeholder meetings. SUMA staff handled scheduling and logistics. With two exceptions, the stakeholder meetings were held in hotels. Houston stakeholders met at the United Way Community Resource Center, and stakeholders in Lubbock met at the Lubbock Memorial Civic Center.

DSHS recruited participants through existing, extensive e-mail contact information. Interested stakeholders completed an online survey to provide details about their areas of expertise and interests, including whether they focus primarily on the general population of women and/or children or work primarily with children with special health care needs and their families. (The complete text of the online survey is included in Appendix A.) SUMA monitored survey responses and provided preliminary lists of participants, enabling DSHS to do additional outreach in locations with low registration and among any populations that were underrepresented, particularly professionals working with children with special health care needs.

DSHS participation at each meeting was generally limited to one staff member from the central office in Austin, who kicked off each meeting and welcomed participants, and one regional DSHS staff member selected by the regional administration. The one exception was Tyler, where two DSHS representatives from the region attended: the Regional Medical Director and one regional staff member. All DSHS staff attended strictly as observers and did not participate in the discussions. The goal was to establish a high level of comfort among community participants to make it likely that they would honestly voice their opinions about the perceived needs of their clients.

The stakeholder meetings took place between July 30 and August 26, 2014. Table 3 shows the total number of participating community stakeholders, as well as the sizes of the subpopulations of stakeholders who work with children with special health care needs and their families for each location. DSHS observers are not included in the participant counts.



Table 3		
Participants in Stakeholder Meetings (N = 128)		
Location	Total Stakeholders	Stakeholders Working with Children with Special Health Care Needs and Their Families
San Antonio	26	8
Laredo	15	3
Arlington	8	1
Tyler	11	2
Houston	24	0
Lubbock	15	5
Waco	15	2
El Paso	14	4

Overall, nearly half of the participants represented organizations dedicated to providing education, mental health/substance abuse services, social services, case management, and/or advocacy for women and children. Among them were representatives of a number of community-based and faith-based organizations, as well as organizations focusing on children with special health care needs. Approximately 25% of the participants represented health care providers (for example, Federally Qualified Health Centers [FQHCs] and other community-based clinics), university health care systems, hospital districts, dentists, or private providers. Representatives from a wide variety of local health department programs made up approximately 10% of the participants. The remaining participants included representatives from the juvenile justice system, managed care organizations/health insurance companies, and durable medical equipment providers.

As with the focus groups, the information obtained through the stakeholder meetings should be considered purely qualitative data indicative of directions or trends rather than statistically definitive.



Process

The process for the Title V stakeholder meetings was designed to encourage participants to fully engage with each other in exploring the topics and to feel comfortable sharing different perspectives. After a brief welcome by DSHS staff and a round of participant introductions, the SUMA facilitator laid out the objectives for the meeting:

- Gain a basic understanding of Title V
- Brainstorm needs and problems for the six Title V population health domains
- Identify needs that should be considered regional priorities
- Brainstorm how Title V could address some of the identified priorities with specific upstream/prevention approaches

The facilitator gave a five-minute presentation covering basic information about the Title V Block Grant program to ensure that all participants had the same baseline understanding. (Appendix B includes the slides used for the presentation.)

After the presentation, the facilitator asked participants who work with children with special health care needs and their families to identify themselves. The facilitator also asked those knowledgeable about mental health issues to identify themselves. Participants were then organized into small groups, with those with expertise in special health care needs and mental health issues distributed across the groups as evenly as possible. Small groups brainstormed responses to the following question:

Based on your own knowledge and experience, what do you see as the biggest needs in the following population health domains?

- Maternal and women's health
- Perinatal health
- Child health
- Children with special health care needs
- Adolescent health
- Crosscutting issues that affect multiple populations or apply throughout the life course



The small groups reported their ideas to the entire group. During these reports, SUMA staff captured each idea on a separate piece of paper and posted each one on the wall under the appropriate heading, or under multiple headings if it applied to more than one population health domain. This technique enabled participants to easily see and grasp all the ideas, including those with multiple mentions across the small groups. Participants “walked the wall” and could add any missing ideas or move any that they felt were incorrectly categorized.

Next, in a whole-group discussion, participants identified which of the posted ideas they considered priorities in their region. It was made clear that there was no need for consensus. As each idea was proposed, the facilitator asked for a show of hands on how many participants considered it a priority and noted whether a few, many, or most of the participants responded affirmatively. The group then discussed the idea, offering their reasons for considering it a priority.

The small groups then reconvened to work on a second task, the instructions for which are presented below.

Pick a few needs that you consider priorities AND that are familiar to the people in your group. For each need that you choose, answer the following question:

What are some ways Title V could address this need upstream? In other words, how could Texas use Title V funds to prevent the need from developing in the first place, or at least reduce it? Be as specific as possible. Consider the life course perspective.

Most small groups selected one priority need and developed ideas about how Title V could address that need. The small groups later presented their ideas to the whole group. This part of the process was modified slightly in Houston, where a large number of stakeholders had registered. Instead of having the small groups reconvene for this second task, participants were asked to talk briefly in pairs to formulate ideas for addressing priority needs using upstream approaches, and then the whole group discussed the ideas. This approach resulted in more ideas, so it was used for the remainder of the stakeholder meetings.

Each meeting ended with an opportunity for participants to offer any final thoughts to DSHS.



San Antonio Findings

SUMA conducted two focus groups with men and one stakeholder meeting in San Antonio. Focus group findings and stakeholder perceptions are reported below, followed by common themes that arose in both the focus groups and the stakeholder group.

Focus Groups: San Antonio Men

Finding: San Antonio men generated a long list of top health concerns. Chief among them are diabetes, cancer, and obesity.

- Diabetes
- Cancer
- Obesity
- Asthma
- Hypertension
- Heart problems
- High cholesterol
- Alzheimer's disease
- Heat exhaustion/dehydration

Finding: San Antonio men can easily describe a healthy meal. However, many admitted that they might "eat healthy" only once or twice a week at the most. Many mentioned chicken or fish, potatoes or corn, and a steamed vegetable as components of a healthy meal. They typically shop at Walmart or H-E-B, and most have convenient access to stores. Fill-in trips for staples might take place at H-E-B or Walmart, or they might go to a convenience store or smaller local market. These men buy fresh fruits and fresh, frozen, or canned vegetables.

Really nutritionally balanced, when you get down to it: protein, a healthy protein. I stay away from red meat, go with fish or chicken. It has a vegetable, and it has some sort of fruit.



Factors that help them eat healthfully are a desire to economize, a desire not to eat out, and their knowledge of the benefits that healthy foods deliver (better health, especially heart health, for instance). Their challenges include time constraints, feeling tired after a long day, inaccessibility of healthy options, and/or the fact that kids often rebel against eating healthy or unfamiliar foods.

When I eat healthier, I definitely feel better.

You get to look forward to more longevity of life because you won't have heart problems.

The biggest challenge is just really availability, because the bad stuff, it's everywhere.

You can look at pretty much any corner, and there's probably a McDonald's or a Burger King or something.

I drive a long drive. On the way, I'm stopping at Jack in the Box, order a burger, the same thing. I feel bad, too, because I sometimes pick up my boy a Happy Meal because I'm too tired to go home and cook.

"Dad, I want pizza." Nowadays kids want pizza or McDonald's. When you do make a real good meal at the house, they're like, "I don't want that. I want pizza."

Some people don't know how to cook, or some people don't have the time. Maybe the wife and husband work.

Finding: Perhaps not surprisingly given the physical nature of their work, many of the San Antonio dads consider the exercise they get on the job enough and do not seek other forms of exercise. Although several said they play sports or try to work out, most reported that they get their physical exercise from their jobs. However, many still feel that that is not enough. These respondents said about three days a week of exercise is adequate, but they don't always get that amount outside of their jobs. While some feel comfortable letting their kids play in the neighborhood or on their own land, others said their neighborhoods are not well lit or not very safe, making it difficult for their kids to play outside. Some coach their children's sports teams, and others take advantage of local parks and recreation centers when they want to keep their kids active outside of the home.

Maybe if you didn't work, working out every day would be fine. We're all working every day.

I'm working 80 to 90 hours a week. It doesn't leave much time or energy to want to work out, or play soccer, or go to the gym.

Where I live, my street is dark, so it's hard for my son to be outside playing if he wants to, because it gets pretty dark. Not well lit.



Positives that help these men get the proper amount of physical exercise for themselves and their children include wanting to “look good,” improve heart and overall health, relieve stress, and get higher-quality sleep. Their challenges to exercise are many, including not knowing how to work out (especially at the gym, with the intimidating number of machines), lack of time, lack of child care at gyms, and fatigue at the end of a 12- to 14-hour workday.

I feel bad because my wife, she wants to go to the gym, but I get home, and I'm like, "I don't really feel like going." I worked all day in the sun. I just don't feel like going. I feel bad, because she wants to go.

You can't take a five-month-old to the gym – most of them have an age limit.

Finding: These men identified cost as a big barrier to health care. At least one father in the San Antonio groups said that although his kids have coverage under Medicaid, he has no health care coverage for himself. However, many gave the impression that they do not go to the doctor, regardless of insurance coverage. Quite a few of these men said they only go if they are compelled to (e.g., for a tetanus shot or work physical exam) or if the problem is serious enough to warrant a visit (e.g., hand surgery, allergic reaction to a bee sting).

I don't have anything. My kids have Medicaid, but I don't have any insurance. If something happens to me, I have to pay out of my pocket.

The last time I went, I needed to repair tendons and ligaments in my hand. I'm still paying on it. It's been five years.

Interestingly, some of the men's reluctance to visit a doctor seems to have been handed down from their own parents. Many mentioned being given “home remedies” when they were kids instead of visiting the doctor, or having parents who didn't visit the doctor themselves.

Apples and cough syrup.

[My parents] don't go to the doctor. My mom will schedule it. She won't go. I don't think my dad's ever been.



Finding: These men do receive communications from their employers about health concerns, but they are generally not interested. Many said their employers do talk to them about health concerns – especially regarding work-related conditions – but they seem fairly uninterested in what their employers have to say. Messages about drinking water, staying in the shade, and generally staying safe on the job seem like “old news” to these men. They also said their workplaces periodically hold presentations and meetings on health care coverage.

They just say to make sure I use a harness up in a tree or something. That's just about it. Wear the safety goggles, the face shield, the hat, and the ear plugs. That's it.

Sometimes in our company they have a person, like “Tomorrow ‘so-and-so company’ will be out there to talk about insurance. If you need insurance, stop by and listen to what they have to tell you.” Stuff like that.

A number of San Antonio men said they worry about the effects their jobs can have on their health, given the unfavorable conditions in which they work.

I'm in the mechanic room. It's a lot of fumes all day long.

There's a monitor ... some of the chemicals that they have are hazardous. You kind of have to make sure they're not present. ... I'm sure we breathe some of that, unfortunately. ... When I get home I try to take off all my clothes before I go in the house or take it off and throw it outside. ... It smells. When I'm out there working for a long amount of time, my breath smells like it, too.

It's bad. Sometimes I step outside. You get used to it after a while.

Despite their concerns, these men seem resigned to the working conditions.

It's good money, so I do it.

It's part of work.

I know it's bad. I've kind of grown into it, pretty much.

However, at least a few feel their employers could do more to help protect their health.

Don't just identify the hazards; do something to correct it.



Finding: Some San Antonio dads are concerned about their children's behavioral issues. Some men indicated that they feel the schools and school counselors are a good resource for them if their kids have behavioral problems, but others said the schools haven't helped.

We're still trying to figure out if he has ADD or not. You can tell by his behavior; sometimes he's very hyper. That's a concern to us.

My second oldest, she's got ADD. She's got dyslexia, too. She was real mean, real aggressive. They helped her with medication. She's okay now. She's not getting in trouble, not getting sent to the principal's office every day.

Finding: These men appear to turn to alternatives to day care. One mentioned relying on a father-in-law to take care of his kids, while another said he and his wife have their child with them all the time.

My baby is only nine months. ... We try to always take care of her ourselves, and we don't leave them with anybody, really.

Findings Related to Concerns About Health and Safety of Children of Different Ages

- **Birth to 2 years.** Interestingly, concerns about this stage of life were minimal in these focus groups.
- **3-5 years.** The fathers' wariness of day care begins in this phase of their children's life.

I didn't really leave my kid with anybody I didn't trust. Basically, just Mom or Grandma. That was about it.

There are so many things that can go wrong. You see it all over the Internet ... somebody losing your kid, "Oh, I didn't know; we lost him for two hours." I think I'd go crazy if I got a call, "We can't find your son or your daughters."

I'm real cautious who I leave my kid with, especially my little girl. There are a lot of sexual predators out there. You don't even know who they are. The majority of people, they don't even register at all.



Those who have put their children in day care (or who would consider doing so) talked about the types of things they investigated (or would investigate) to reassure themselves.

Serious background check.

Someone who's experienced.

I would stay there for a day; see how they did.

The one that I had my kids go to, they had bars in the front. When it was time for school, everybody had to drop their kids off and the doors would lock. It was pretty safe. There was a high fence all the way around.

The San Antonio dads also expressed concerns about toddler safety in the home.

Keeping the cupboard doors closed, not letting them stay on their own.

Being sure they don't roll down the stairs.

- **6-13 years.** Dads expressed concern about leaving their children in this age range home alone. Those with younger children, projecting forward a few years, said they will try to get their kids involved in afterschool activities, especially sports. Even if it takes time or effort, these dads seem willing to invest in getting their kids in the right place to avoid problems.

[You need to get] them to where it is. Even if it's not down the street, you get them there. I suppose you can. I would.

It's more of being a parent, number one. The options are there. It's just us being a parent to them. When there's a will, there's a way.

- **Teens.** A couple of the dads in the San Antonio focus groups had teenage children. Concerns about this age group often center on other people's children: what kind of parents they have, whether they are the "wrong crowd," and whether they're in a gang. Drugs, alcohol, and smoking are also concerns for these dads.

Bad habits, bad parenting for other kids.

It's not the neighborhood. It's the people in the neighborhood.

I hope ... parents that they're with or the kids that they're with aren't using any type of drugs or things like that.



Stakeholder Perceived Needs and Problems: San Antonio

Thirty-seven stakeholders registered for the San Antonio stakeholder meeting. Twenty-six participated, including a number of health care providers (university-based, private, and one with an FQHC), various social service providers, mental health/substance abuse service providers, two representatives from the juvenile justice system, a community health worker, a durable medical equipment provider, and three representatives of programs of the local health department (WIC, dental, and teen pregnancy prevention). The great majority of the participants work in San Antonio; a few traveled in from Austin for the meeting. Of the 26 who participated, eight indicated that they had knowledge of and experience with children with special health care needs and their families. Two staff members from DSHS observed the meeting.

Identified Priorities

San Antonio stakeholders identified four priority needs and problems for their region. Three fall within the category of crosscutting issues: education, access to services, and mental health/substance abuse prevention and treatment. The fourth priority, adolescent health education and sex education, is specific to teens.

Education. Most of the participants agreed that education is a priority need. Parents and adolescents need to know how to improve their health and need to be made aware of available resources. They need information about a wide variety of topics in order to be able to sustain and improve their health. However, the need for education goes beyond information, as some people have information but fail to apply it. Supporting parents in improving their mental health and self-esteem is a critical step toward helping them put the information they already have into practice. Many need someone like a *promotora* or community health worker to break the process down into small, achievable steps – using language they can understand – and to support them as they make progress. If parents know someone is there to help, they will be more confident, empowered, and likely to follow through.

Resources may be needed before people can apply the education they receive. For example, a mother may know that it is not safe for her baby to sleep in bed with her, but if she does not have the money to buy a crib, she cannot apply that information. Other times, parents are simply not ready to change. It may take a lot of follow-up and repeated education. The use of evidence-based practices can help increase the likelihood of successful education.



Access to services. Most participants agreed that access to services is a priority need. Lack of access can result from different factors: People may not have transportation or housing; they may be uninsured or underinsured; access to health care and mental health care providers may be restricted because of a shortage of providers in general or the limited number who participate in Medicaid in particular. People who are undocumented face particular difficulties gaining access to services.

Families with children with special health care needs are also seriously affected by a lack of access to the specialized services they need. The number of children coming into state custody due to medical neglect is on the rise. These children often have multiple disabilities, and their parents are overwhelmed. Providers often do not have enough time to fully inform them and encourage them to ask questions. Alternately, providers may believe they have informed the parents when, in reality, the parents have not understood but do not feel empowered enough to ask questions. Provider education is an important need that must be addressed to improve access to services.

Mental health/substance abuse prevention and treatment. Many stakeholders felt that addressing mental health issues is a priority. Some saw a need to improve mental health services in general; others thought the more targeted area of substance abuse represented a particularly great need.

Adolescent health education and sex education. Most participants agreed that health education for adolescents, particularly education about sex and substance abuse, is a priority. They expressed their conviction that children, including those with special needs, should have information about sexuality before they become sexually active.

The San Antonio stakeholders shared different perspectives on sex education. Some felt the schools need to do more and provide comprehensive, evidence-based sex education to younger students, including information about pregnancy and sexually transmitted disease (STD) prevention. Others felt the responsibility for education about sexuality lies with the parents. They acknowledged that parents often lack the skills to educate their children in this area or are uncomfortable raising the topic, and that they could benefit from education on how to talk with their children about sexuality.

The issue of providing sex education to children is a complex one. Stakeholders pointed out the common perception among parents that teaching children about sexuality encourages them to become sexually active. This perception may discourage parents from bringing up the topic themselves or allowing their children to participate in a sex education class at school. Participants suggested that education about sexuality be reframed or renamed so that it is not taboo. They suggested the focus be placed on physiology, health, and well-being rather than on sex acts.



How to Address the Priorities with an Upstream Approach

Each small group brainstormed ways to address the priority of its choice. Two groups addressed education, one addressed access, and one addressed adolescent health education and sex education.

Education. One of the two groups that addressed education noted that it is the path to help people make positive changes in their lives and their health. This group identified a few critical points that could make a difference.

- Parents have to start the process early, in the home, through books and book sharing, because literacy opens the door to a love of learning and upward mobility.
- Teen parents often drop out of school because they do not believe they can graduate. School districts need to have programs that allow them to return later to finish. Currently, some districts offer that option, but not all.
- In many respects, middle school is a crossroads for youth. All students need to have the option of taking either an apprenticeship or an academic path so that they will be employable when they finish school no matter what their interests and aptitudes may be.
- Money management education in high school is also critical.

The second group that addressed education stressed that efforts to educate must be culturally sensitive and delivered through different modalities and technologies. Mentors such as *promotoras* and community health workers are important because they go directly to the people through community-based work, rather than expecting people to find support and information on their own.

Access to services. The group that addressed access to services identified the following specific interventions that they believe would improve access to services.

- Expand Medicaid in Texas.
- Develop a way to better identify who provides which service, so that providers can link individuals to the services they need.
- Develop better strategies for getting information about insurance and services to people in ways that do not rely on reading. Many people have limited literacy skills. Home visits are one option.
- Streamline and improve Medicaid transportation. The current system delivers clients to medical appointments, but it is not unusual for those clients to wait hours to be taken home.
- Create options for one-stop centralized service to help people access the full range of services.



Adolescent health education and sex education. The group that addressed adolescent health and sex education shared the following ideas.

- Make available a life skills curriculum to address parenting, abstinence, and other health issues. Use proven best-practices models that include a peer support network component. Since attending this type of classes is voluntary, provide incentives – for example, car seats and other basic resources needed by teen parents.
- Provide consistent funding to fully implement and sustain education programs. Allow providers to bill for evidence-based education services such as classes and support groups, rather than have to depend on grant funding.

Additional Needs and Problems

During the small group brainstorming activity, participants in San Antonio identified a wide variety of perceived maternal and child health needs and problems. Table 4 presents the ideas that participants did not choose to include in the top regional priorities described above. Some of the additional needs and problems reported in Table 4 below, and in the corresponding tables covering each of the other regions, may overlap with those priorities; however, they are listed to accurately document and acknowledge the opinions expressed by participants during the meetings. The additional needs and problems listed in each table are taken from the pages SUMA staff created as the members of the small groups reported their lists of perceived needs and problems to the whole group (one idea per page).



Table 4
Additional Perceived Needs and Problems: San Antonio

Population Health Domain	Needs/Problems
Maternal and women's health	<ul style="list-style-type: none"> • Access to annual visits • Education about drug use (over-the-counter, prescription, and illegal drugs) • Address domestic violence • Child care • Lack of knowledge about types of support that are available • Education for pregnant women about body changes • Access to prenatal care and training in parenting skills • Medication evaluation • Information about birth options • Postpartum assistance and support • Access to family planning • Prenatal care, including education about nutrition and vitamins • Immunization education • Prevention of unplanned pregnancies • Education about preconception health • General nutrition education
Perinatal health	<ul style="list-style-type: none"> • Education about sudden infant death syndrome and shaken baby syndrome • Nutrition education • Realistic child development expectations • Information about brain development • Education about how breastfeeding benefits mother and baby
Child health	<ul style="list-style-type: none"> • Annual checkups, including screening for hearing • Well-child checkups • Helping parents understand that children experience stress • Access to good nutrition • High cost of child health care • Education on oral health and the need for dental care • Low awareness of infant and child mental health and a lack of providers proficient in trauma-informed care



Population Health Domain	Needs/Problems
Children with special health care needs	<ul style="list-style-type: none"> • Limited access to care for children with special health care needs – more case managers are needed • Access to medical equipment (cost is often high) and education about the equipment • Lack of specialists • Respite for caregivers • Parents of children with birth defects do not know what resources are available or which providers take Medicaid, and providers do not realize there are teams in place to help them address birth defects • Opportunities for socialization for children and families • Therapies – for example, occupational, speech, physical, and applied behavior analysis • Medications • Services to help children with special health care needs transition to adult services • Training for parents/caregivers of children with special health care needs • Education on the indicators of abuse • Services for children with dual diagnoses (e.g., developmental disability and mental health needs)

Final Comments for DSHS

- Incentives are important to mark milestones and small successes, even if it is nothing more than a piece of paper.
- Health can only exist within the context of a safe, stable relationship.
- Health literacy must be addressed. A June 2014 television news story¹ reported that one in four San Antonio residents is functionally illiterate. This means they cannot read well enough to decipher a prescription or fill out a job application. Providers need training to work with clients with low literacy skills. Institutions need information about how to pair icons with words.
- Providers need a place to easily find resources so they can more effectively refer clients. The Community Health Bridge website, though not ideal, is an example.
- Persistence is key. Change does happen. It used to be okay to smoke in public, even in hospitals. We need to keep telling women not to drink alcohol when they are pregnant.

¹ KGNS, "One in four San Antonio adults 'functionally illiterate,'" <http://goo.gl/WGg7H7> (June 30, 2014)



San Antonio: Regional Common Themes

The lines of inquiry for the focus groups necessarily differed from the questions posed to the stakeholders. Focus group participants represented the population likely to need or access Title V services for themselves or their children; participants in the stakeholder meetings were drawn from the group of people dedicated to providing services to and advocating for women and children. The regional common themes, discussed below, highlight the overlap between the findings from the focus group and the priorities identified by the stakeholders.

Education is important, but education is more than information. Fathers in the San Antonio focus groups acknowledged the gap between knowing what is healthy and acting on that knowledge. For example, they were able to describe a healthy meal and understood the importance of physical activity for themselves and their children, but they admitted they faced numerous challenges in consistently making healthy choices. They are aware that their working conditions could have a negative impact on their own health but are resigned to these dangers because of economic realities. Likewise, stakeholders pointed out the gap between knowledge and action, and suggested that families could benefit from the support of a community health worker or *promotora* to help them identify health goals and break the tasks down into small, achievable steps. Stakeholders also acknowledged that it often takes resources to apply knowledge, and families may lack the necessary resources.

Access to services is an issue. Fathers pointed to cost as a barrier to accessing health services, along with a family custom of relying on home remedies first and accessing the health care system only for required services like a tetanus shot or serious situations. Stakeholders agreed that cost is a factor, citing a lack of insurance or inadequate coverage as a barrier to health care. They also pointed to larger issues, such as lack of transportation or housing, which can overwhelm families and take their attention off health concerns. Stakeholders indicated that a lack of providers, in particular specialists, further restricts access.

Mental health, substance abuse, and risky teen behaviors need attention. Some fathers expressed concerns about their children's behaviors and are not confident their children have access to adequate counseling support at school or in the community. Those with teens worry about their children running with the wrong crowd, engaging in sexual activity, smoking, drinking, and/or using illegal drugs. San Antonio stakeholders identified addressing mental health issues for children of all ages as a priority. They also cited the need for health education for adolescents, particularly education about sexuality and substance abuse.



South Texas Findings

SUMA conducted two focus groups with mothers in Brownsville and a stakeholder meeting in Laredo. Focus group findings and stakeholder perceptions are reported below, followed by common themes that arose in both the focus groups and the stakeholder group in South Texas.

Focus Group Findings: Brownsville Mothers

Finding: Mothers in Brownsville agree that their top concerns are weight/obesity and related health conditions:

- Weight/obesity
- High blood pressure
- Diabetes
- Stroke
- Cholesterol
- Breast cancer
- Heart problems
- Thyroid problems
- Anorexia/bulimia
- Kidney disease
- Asthma
- Allergies
- Stress/anxiety
- Paralysis

Finding: Moms in Brownsville buy fresh fruits and vegetables but find that they do not always have to time prepare healthy meals. Most moms described a healthy meal as one consisting of a protein source such as chicken or eggs, cereal, soup, rice, and vegetables such as cauliflower, carrots, potatoes, or broccoli. Many moms make soups containing chicken, vegetables, and pasta or rice several times a week. They typically shop at H-E-B because the vegetables there are fresher and it's cheaper than other stores, including Walmart.

[I shop at H-E-B] because it's cheaper than Walmart and they have the combo locos where you get coupons for free things.

At HEB the fruit is really good, very fresh. The vegetables.



The moms in the Brownsville focus groups try to shop several times a month. Some shop weekly so they can get fresh food throughout the month; they reasoned that if they were to buy a bunch of vegetables at the beginning of the month, they would go bad before they could eat it all. Moms said they buy mostly fresh fruits and vegetables, and that they buy only certain foods in cans, including tomatoes, corn, tuna, and beans. Staples in their households are milk, chilies, garlic, juice, tortillas, onion, eggs, chicken, cereal, and bread. Their families eat cereal at breakfast and sometimes for dinner as well. Fruit is popular with their kids; the moms said it is a healthy food they have no problem getting their children to eat.

Moms said they do not have the time to cook all the healthy meals they would like to for their families. Work, school, child care, and housework take up the time they could otherwise be devoting to food preparation. Some moms have found it helpful to have a meal plan for the week or to be organized when it comes to cooking and leftovers, but what they wanted most of all was help from their partners during mealtimes. They wished their husbands would watch the kids so they could take the time to prepare a healthy meal without having the children running around the kitchen. Some moms cave and buy fast food for their picky eaters, reasoning that eating a Happy Meal is better than not eating at all.

My son asks for pizza the most, more than burgers, but I try to not give him too much pizza because if I give him pizza of course he eats it. But my oldest son, I really struggle getting him to eat. I don't know if it's his age or maybe because ... I don't know if it's a parasite or digestive problems. But the doctor told me that at his age, between 2 and 3, they don't want to eat. The good thing is, he asks me for a lot of cereal, he drinks milk. So the doctor said not to worry, that's okay because milk has calcium.

Well, I buy ... the thing is, my daughter weighs 20 pounds and she's three months. My three-year-old weighs 23 pounds. So sometimes just to get her to eat, I buy her the Happy Meal because she will eat that, and if I make her something else she won't. Because she's going to want eggs and wings all day long.



Finding: Most Brownsville moms have access to classes and places to do physical activity with their families, but cost and time are barriers for them. Many moms go for walks and go to the park with their children for physical activity. Some of their children play sports and ride bikes. The moms had differing opinions on how much physical activity is enough.

I think it's twenty minutes that you need to walk, run, do whatever you like doing.

I do 45 minutes of Insanity. It's an exercise video.

Well, it's not exercise, but going out to walk, you don't necessarily have to exercise. Just walking, I think.

I do two hours. One hour of Zumba, twenty minutes jogging on the machine. The rest I do in thirty-minute sessions.

An hour and a half per day.

For me, half an hour playing with my daughter. She really likes to play with the ball, so I run around.

It depends on the person.

Regardless of their ideas of what constitutes "enough" physical activity, the moms are split on whether they feel they are getting the correct amount. Moms who do think they get enough exercise said that sore muscles and feeling tired after activity is their evidence that they have gotten the correct amount. Moms who do not believe they are active enough cited lack of motivation, the high cost of exercise classes, and neighborhood issues, such as cars driving too fast on their street or loose dogs, as barriers to their getting the right amount of physical activity. For these moms, the principal motivations to get active are their children, a desire to look nice in their clothes, and a desire to improve their health.

In fact, I just started because I honestly never walked. So I started because it's not for any reason, but I go downtown here in Brownsville and my feet start hurting. I can't tolerate it, so I said, "No, I need to start walking."

Because you have to want it for yourself. If you don't love yourself you won't take care of yourself and you can't love other people.

Doing your exercise also changes you. You are not as stressed out, you sleep better, your anxiety gets better.



Several of the moms have access to gyms, exercise classes, bike trails, tracks, and basketball courts in their apartment complexes or at nearby parks or schools, but safety is still a concern for some in this community.

Safety in the neighborhood, because they came after me with a knife once.

Our [school playgrounds] are closed. I tried to go running once and got there, and it was closed off. They lock it up with a chain. I think they do it for safety reasons. Gangs could go in and use it.

There's always a light that goes out [at the basketball court], they don't fix it. It's too dark.

Cost is a bigger barrier to getting enough physical activity than it is to eating healthier for the Brownsville moms. Several reported that gym memberships are cost-prohibitive at \$20 to \$40 per month. Moms want more free classes or parks they could use to get in better shape. They also want their families to spend less time in front of screens (cell phones, video game consoles, television, etc.) and more time being active. When it comes to exercising, some moms are encouraged and helped by family, but others are embarrassed and have received negative comments from their families about their weight and about their attempts to start exercising more regularly.

Everyone, whether it's family or people who see you and say, "Oh, you used to be so skinny and now you're fat!" That happens to me, and I'm not even that fat.

Embarrassment. People might make fun of you. Then you feel bad and don't want to anymore, or even if they don't, they're not watching you or making fun of you, but you think they are, they're saying, "Oh, look at her."

When you start walking they say, "Oh, let's see how far she can go."



Finding: Brownsville moms need access to affordable health care coverage for themselves once they lose Medicaid coverage after giving birth. Many moms in the focus groups go across the border to Matamoros, Mexico to receive health care because care is too expensive in the United States. The moms said that they are covered only when they are pregnant; once their Medicaid runs out after they give birth, they can no longer get affordable care for themselves in this country.

I get sick and I go to Mexico because I don't have medical coverage here.

My dad also had a lump, and he said he was going to go to the doctor because your bank will automatically take it out of your check. They just gave him a shot, checked him with a Q-tip, and gave him some medication. The co-pay cost him about \$70. He said, "For \$15 I would have gone to Matamoros and they would have done the exact same thing."

Ten or twenty dollars is the most you'll spend [in Matamoros].

Moms whose children are covered by Medicaid take them to the family clinics in Brownsville, but reported long waits at the clinics. Some moms brought up "Obamacare" insurance, saying it is too costly and does not seem to help people the way the President said it would.

Because the insurance Obama just came out, which is too expensive. If he wanted everyone to have insurance, we can't afford it And now they're saying you're going to be fined if you don't get insurance.

For me, if I get sick, I don't have enough to pay forty to fifty dollars a month for Obamacare. I go to Matamoros and that's it.

Finding: The Brownsville moms experienced a lack of consistency and quality in their prenatal/pregnancy/postpartum care. These moms had first sought prenatal care between six weeks and five months of pregnancy. The doctors discussed breastfeeding, prenatal vitamins, the dangers of smoking, and conditions such as Down syndrome and SIDS during these prenatal visits. Most reported that they received great care from their doctors. These moms prepared to give birth by watching videos, discussing with their mothers and friends, and going to classes. Many took classes at WIC that covered how to eat healthy while pregnant and feed their babies after birth.



None of the Brownsville moms used a midwife or doula. A couple of them mentioned that they had “labor coaches,” although it was unclear to what extent those coaches aided or replaced their doctors. Many moms had C-sections and many were induced because the baby was too big, the mother was past her due date, the mother had previously had a C-section, or for similar reasons. Some moms felt that they did not have a say in these birthing decisions, but that the doctors made the choice for them.

I was not dilated enough ... I went on a Monday and the doctor asked if I'd had my last checkup, and I said no. So he said, "Unless you start walking or something, but I don't see that you're going to have a normal delivery," because my daughter was very big Six pounds 14 ounces, 19 inches.

I think doctors sometimes just don't have the patience, or it's easier for them.

It's true, they don't ask you. They don't. Like she says, they don't want to go through the trouble. Since they already know you've had a C-section, they want to do it again.

At the six-week visit, doctors asked the moms what kind of birth control they were using. Many focus group participants mentioned getting birth control via injection in the doctor's office, others said they would be on birth control only for the couple of months while they were still covered by Medicaid after giving birth. At this visit, the doctors also continued to encourage the moms to breastfeed and keep taking their prenatal vitamins. The moms know many of the benefits of breastfeeding for the woman, such as disease prevention and weight loss. Many had tried breastfeeding, and several continued to breastfeed their children for several months.

Finding: Brownsville moms said too many teenagers in their community are getting pregnant, and put the blame on poor parenting rather than on lack of access to birth control or lack of sex education. These moms said they see a lot of young women getting pregnant. While a couple of them said that access to condoms would help prevent teen pregnancy, many said that parents bear the greatest responsibility for teaching their children how to be prepared. The moms said that what they would tell young girls about becoming teenage mothers is that they would not be able to enjoy their youth if they had the responsibility of a child in addition to school and everything else.

Parents give them a lot of freedom now. I think in the past parents would talk to them, and now with technology they don't really talk anymore.

I think even though it looks bad or they might see me as a liberal mom, I'm going to give her condoms when she gets older.

I say the problem is with the parents already. They don't talk to their children.



Finding: Moms go to their family doctors when seeking help with children's behavioral issues, although they are concerned that the only treatment offered may be medication. Moms see more children medicated for ADHD in the United States than in Mexico, and they are concerned that too much medication could be harmful to young kids. They turn to their family doctors for advice on dealing with their children's behavioral issues, although some do not ask their doctors for help for fear that the child will be diagnosed with ADHD and prescribed medicine that the parents do not want the child taking. Some moms wanted more affordable sports activities in their community so the "hyper" kids could go burn off their extra energy in a constructive way.

I would not feel comfortable telling the doctor, because my husband already told me, if we go to the doctor they're going to want to give him medication. We know a boy who was like that. Like all kids, they run around. But they give them medication and they kept raising the dose. Now you look at the boy and they say he doesn't even answer well, he talks back.

Well, my daughters are both hyperactive, the six- and two-year-old, but once I asked her, "Why are you so hyperactive?" and I asked the nurse who helps my pediatrician, and she said to me, "What would you prefer: to see her like that or see her taking medication?" And I said "No, see her this way." The medication just drugs them.



Findings Related to Concerns About Health and Safety of Children of Different Ages

- **Birth to 2 years.** Moms who have children in Head Start trust the program to look after their children well and engage them in enriching activities. Some moms had heard from friends or family members about children being mistreated or even abused at day care, and said they would prefer to leave their children with a family member they trust. Some said day care is unaffordable at \$100 per week.
- **3-5 years.** The main concern moms had regarding children in this age range is safety as they grow and start leaving the house more often. Moms worry about them playing with other children and potentially getting hurt. Living in unsafe neighborhoods with poor lighting causes moms to worry about strangers potentially harming their children.
- **6-13 years.** While they have heard positive things about Head Start and would like to enroll their children in the program, moms have also heard from friends that a child could be on the waiting list for a year or more. Moms are particularly enthused about Head Start's focus on learning and development and that they can trust the program to serve the kids healthy food. Moms feel that when it comes to playing, their kids are safest in the house or being watched over by a parent the entire time they are outside.
- **Teens.** Concerns about pregnancy and STDs are common for moms with children in this age range. Moms do not think there are enough community spaces such as recreation centers, parks, or Boys & Girls Clubs for teenagers to use. Instead, they said teens hang out at the mall or at clubs where they are unsupervised. When asked what would help them raise their teenagers, some moms said they would like to take a class but have not heard of any being offered in their area.

Finding: As the focus groups were wrapping up, moms said the most important thing they discussed was teen pregnancy. They saw themselves as agents of change that could actively give information and advice to the teens around them to help prevent teen pregnancy.



Stakeholder Perceived Needs: Laredo

Twenty-three stakeholders registered for the meeting, and 15 participated. The participants included a physician in private practice; a representative from a community-based clinic; a health care provider from a hospital; representatives of a managed care organization, a durable medical equipment provider, and the Area Health Education Center; a representative of the Texas A&M University Colonias program who trains community health workers; three representatives from the City of Laredo Health Department, one from the Cameron County DSHS, and two from the local juvenile justice system. Three participants indicated that they had experience with children with special health care needs. Two staff members from DSHS observed the meeting.

Identified Priorities

Laredo stakeholders identified four priority needs and problems for their region, all of which fall within the category of crosscutting issues: access to services, reimbursement issues, case management, and resources. They discussed these needs and problems in detail and acknowledged that they are all interconnected.

Access to services. Most stakeholders thought access to services is a priority need. In particular, they noted a lack of access to resources such as transportation, early prenatal care, and mental health services. There is a general lack of access to health care providers because of Medicaid reimbursement issues.

People who are undocumented face specific challenges accessing services. Because of enhanced border security, those who live on the Texas-Mexico border can no longer go to Mexico for health care, nor can they travel inland for health care because border security has been tightened there as well.

Economic and cultural issues also hinder women's access to services. There is a lack of culturally sensitive education and services. Women living in poverty are likely to be more focused on feeding their families and taking care of their children than on their own health needs. Ironically, accessing SNAP often contributes to poor health, because this benefit allows the purchase of junk food.

Medicaid reimbursement. Most participants indicated that resolving Medicaid reimbursement issues is a regional priority because it impacts the number of providers willing to participate in the program, resulting in limited access to services. Each managed-care organization has different forms and rules for authorizing services.



Providers often have to submit bills multiple times, delaying reimbursement; sometimes they are not reimbursed at all. The Texas Medicaid and Healthcare Partnership (TMHP) website is not user-friendly and not kept up-to-date.

Case management. Most participants agreed that case management is a regional priority. The majority of first-time mothers in Laredo are young – under age 25. Many are overwhelmed as new parents. Case managers are needed to help them understand the importance of prenatal care, good nutrition, breastfeeding, immunizations, well-child and dental care, and keeping their appointments. They need information about child development. They may have mental health needs or an STD that requires diagnosis and treatment. In a word, case managers are needed to help this population get the support and services they need to access resources, get information, and follow through.

Funding for case management was cut in 2004. Direct services have been prioritized over case management, but the two are closely linked. Without case management, many women find it difficult to access services and get the information and support they need to help them take responsibility for their health and the health of their children. The qualifications and requirements for case managers limit the number of professionals who can provide the necessary services.

Resources. Most participants agreed that a lack of resources underlies all the other needs they identified: case management, streamlining Medicaid processes and systems, and access to services.



How to Address the Priorities with an Upstream Approach

One small group brainstormed ways to address the need for resources. The other generated ideas regarding case management and access.

Resources. The first small group offered the following ideas related to resources.

- Resources may not be allocated in ways that meet the greatest needs. A community needs assessment should be conducted to find out what resources are available, what is needed, and how the existing resources could be reallocated to address the greatest needs. This would require shared decision-making and collaboration across the community.
- Consistency in funding is needed to make programs sustainable. Many organizations that work with women and children have seen cuts in their resources. For example, one organization had to cut back from 16 *promotoras* to three. Additional resources are needed for transportation.
- The bulk of the resources should be devoted to prevention, awareness, education, and training, rather than to intervention.
- Telehealth could help close the gaps in places where providers are not available.

Access to services. The second group suggested that the state could improve access by increasing the number of providers who participate in Medicaid. Places to start would be:

- Standardizing forms and rules for authorizations across managed-care organizations
- Creating a streamlined provider Medicaid enrollment process so providers can see patients sooner
- Improving the reimbursement process

The State could also make it easier for women to access services by increasing coordination and collaboration among federal programs in order to create a single enrollment process. A mother/child who is eligible for more than one program – for example, CHIP Perinatal, Title V, and WIC – should not have to give the same information to each program in three separate enrollment processes. As an added benefit, streamlining the enrollment process and getting children into CHIP Perinatal sooner would free up Title V money for more prevention-oriented purposes or more case management.



Case management. Two actions could help meet the need for more case management:

- Provide additional funding for the program.
- Broaden the qualifications for the type of professionals who can provide case management and bill for it.

Additional Needs and Problems

During the small group brainstorming activity, participants in Laredo identified a wide variety of perceived maternal and child health needs and problems. Table 5 presents the ideas that participants did not choose to include in the top regional priorities described above.



Table 5
Additional Perceived Needs and Problems: South Texas

Population Health Domain	Needs/Problems
Maternal and women’s health	<ul style="list-style-type: none"> • Lack of affordable access to care • Lack of timely prenatal care • Lack of access to family planning and postpartum services • Substance abuse • Women are uninsured or underinsured • Lack of case management • Lack of access to dental services • Domestic violence, machismo, and reproductive coercion are common • Need for early diabetes detection and control • Women who are diagnosed with diabetes often depend on free food, which is high in carbohydrates • Access to dental services
Perinatal health	<ul style="list-style-type: none"> • Address problems with provider reimbursement • Lack of case management
Child health	<ul style="list-style-type: none"> • Access to mental health services • Insufficient case management • Improve parenting skills, including fathering skills • Lack of support systems for emotional issues such as school failure and other traumas • Lack of access to dental services • Systems issues: some parents rely on a child’s disability to get Social Security disability benefits. The child may not actually have a disability and gets mislabeled.
Children with special health care needs	<ul style="list-style-type: none"> • Lack of or untimely provider reimbursement • Lack of specialists (primarily due to reimbursement issues) • Managed care providers have problems with forms; the TMHP website “is a mess” • Lack of case management



Population Health Domain	Needs/Problems
Adolescent health	<ul style="list-style-type: none"> • Substance abuse, especially abuse of emerging synthetic drugs • Access to mental health services • Children do not come to wellness checkups • Adolescents who are diagnosed with diabetes often depend on free food, which is high in carbohydrates • Adolescents and young adults ages 14–23 are getting pregnant and need information about pregnancy and child development • Access to family planning • Address domestic violence
Crosscutting issues	<ul style="list-style-type: none"> • Parents' lack of follow-up • Limited family involvement • Social pressures and cultural issues limit parental involvement in children's education • Parents are not holding children accountable • Problems with managed care providers • People are not enrolled; they lack knowledge of available services • Lack of coordination across providers • Survival needs trump health needs • Lack of or untimely provider reimbursement, or providers have to resubmit paperwork • Bureaucratic burdens • Education and outreach, <i>promotoras</i> • The Supplemental Nutrition Assistance Program (SNAP) allows junk food



South Texas: Regional Common Themes

One common theme, discussed below, emerged from the findings from the focus groups with mothers in Brownsville and the priorities identified by stakeholders in Laredo. It is important to note that while both of these locations are in South Texas and on the Texas-Mexico border, these two communities may have less in common with each other than those in the other regions included in the study, where the stakeholder meeting and focus groups took place either in the same community or within a tighter geographic range.

Accessing health care is difficult or unattainable. Mothers in Brownsville said they are able to access services for their children through Medicaid but often face long waits for them to be seen at local clinics. Other than when they are pregnant and covered through Medicaid, mothers said they cannot afford health insurance for themselves or other adult family members. Even the policies available through the Affordable Care Act are out of reach financially, so many go to Mexico for health care. Stakeholders in Laredo also identified access to services as a priority need. They cited the limited number of providers who participate in Medicaid as problematic. They noted that poverty can hinder access and that a lack of culturally sensitive providers can discourage women from accessing services for themselves and their families. The situation is particularly dire for people who are undocumented and cannot take advantage of the more affordable care in Mexico. Stakeholders also said that without adequate case management, many women find it difficult to access services and get the support they need to take responsibility for their health and the health of their children.



Journal of North Carolina

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Editorial Board

- Editor: [Name]
- Editorial Board: [List of names]



Dallas-Fort Worth Findings

SUMA conducted two focus groups with mothers in Fort Worth and a stakeholder meeting in Arlington. Focus group findings and stakeholder perceptions are reported below, followed by common themes that emerged for the Dallas-Fort Worth area.

Focus Groups: Fort Worth Mothers

Finding: Fort Worth mothers generated a varied list of top health concerns on the basis of illnesses they see in their communities and their family histories. Their top concern was access to, coverage, and cost of health insurance, followed by diabetes, weight and obesity, and ADHD.

- Challenges of health insurance (access, cost, coverage)
- Diabetes
- Weight/obesity
- ADHD
- Cancer
- Heart disease
- High blood pressure
- Mental health
- Stroke
- Stress
- Bone disease
- Vision
- Lupus
- Sickle cell anemia



Finding: Most of the Fort Worth moms serve “comfort foods” or fast foods to their families, but try to buy fresh vegetables. Most of the home-cooked meals described by the moms in the Fort Worth focus groups were typical of Southern cuisine: fried chicken, meatloaf, ham, pork chops, catfish, greens, cornbread, green beans, potatoes, and macaroni and cheese. Many moms cited baked chicken as a healthy food that they cook for their families. Fast food and frozen pizzas are typical meals for their families, although they know they are unhealthy and are trying to avoid such foods.

I'm not really big on cooking. I'm just now starting to cook more. In my house, normally we don't really eat out a lot because I don't feel good after I eat McDonald's or go to Whataburger, something like that anymore. I used to eat it every day, but now we wake up, she eats cereal for both. They eat cereal. They like milk and cereal, or they eat Toaster Strudel a lot. Lunch is normally – yeah, they eat, like, pizza. I'm bad, pizza, freezer food. When I do cook, I don't really fry a lot because I'm not really good at it. We eat a lot of baked chicken, a lot of baked chicken.

Several of the moms in the Fort Worth focus groups go to multiple stores in order to get the freshest or best-priced items. For example, most participants shop at Walmart, but many reported that the produce there is often of poor quality, so they make a separate trip to Albertson's or Super 1 Foods to get fresh fruits and vegetables.

They get picked over, and then someone – right now – I got irate yesterday because I went to Walmart and I was trying to get some strawberries. The strawberries had mold on them, and I was so pissed off. I put them back. I said, “I don't even want it no more.”

I won't buy fruit from Walmart. Preferably Albertsons or ALDI or something.

Typically, I buy meat from another store. Then I go to Walmart. Yeah, I'm with her, the fruit at Albertsons is way better than at Walmart. It just depends on what kind of day you have and you just go from there.

Those who said they do not have the time to go to multiple stores shop at Walmart because it has everything they need in one place.

A lot of times you don't care about the prices. You just want to get it, get everything, get out, go home, get situated. I would love to coupon and go to different stores if I had the time, if I could. Walmart is just convenient.



Even with the rotten, moldy produce, Walmart's Savings Catcher app persuades moms to keep shopping at Walmart by offering gift cards for using the app. By offering extra money to help them feed their families, Walmart keeps the moms' business even when the quality of food in its stores is disappointing.

You just scan in the barcode. It's called TC, or you just type in the numbers on the Walmart website and it will give you, like, up to three days to show you the savings. It will accumulate the balance on a card for you.

Walmart – they have a Savings Catcher. If you do it right and use your receipt, you're going to get a lot of money back, because I do it all the time.

Some moms said they go to the corner store when they run out of an item such as milk or hair gel during the month. Those moms said they might also pick up candy, cakes, or summer sausages, and a few mentioned buying cigarettes while they are at the convenience store. Some also mentioned shopping at the Dollar Tree.

I'm a corner store girl. When my food runs out, I'm a corner store girl.

The Fort Worth moms buy mostly fresh fruits and both fresh and canned vegetables, saying they buy frozen vegetables when they want to stock up. They said it is challenging for them to stop eating high-fat foods that they like, such as bacon, soda, fried foods, and candy. Several moms said that they do not drink enough water. Lack of time to cook and the perception that healthy foods are expensive and not tasty were cited as challenges to eating better. One mom shared a success story in that she was down to one soda a day and had completely eliminated fried food from her household. Another said she tried to cook healthier than her mother did by eliminating bacon grease.

I don't cook like my mom raised us, with bacon grease.

The feeling of doing something good for themselves and the desire to set a good example for their children motivate these moms to try to eat healthy.

I would say for me it was my kids. They're wanting to get in the kitchen a whole lot more and help out. I just don't want to teach them all the bad stuff, to fry chicken, add a whole bunch of salt, add a whole bunch of this. I want to keep it simple and light and fun for them.

I would say the feeling of just knowing that you're eating something healthy, the feeling after. Just knowing that nothing's going to happen.



Finding: Fort Worth moms get their physical activity during the course of their day, and do not typically find additional time to exercise. Many of the moms said they stay active by following their kids around, running errands, participating in their kids' sports practices, and doing housework. Overall, the moms recognized the need to be physically active but found their lack of motivation and lack of time in their busy days to be barriers to getting the exercise they think they need. A few moms said they do not think they get enough physical activity during the day. Some of those who work outside the home as janitors or home health care providers said they do a lot of lifting and walking. A couple of the moms have tried classes such as Zumba or gym memberships in the past, but said there was not enough time in the day and cost is a factor. Some also said they have exercise DVDs that they also use on and off.

Being motivated is number one. You have to be motivated. Oh, my God, if you're not motivated, it's not going to happen. That's my problem – motivation. That's why I need a partner [to exercise with].

Mine is dancing. Me and my husband and my family, we will dance. We love to dance.

I stay active because my baby likes to stay active. She likes to go outside and do this and that and wants to run around the house.

Of course, I run around with the kids and stuff. I'm in and out constantly all day. They go to three different schools, so I'm literally in and out of doctor appointments, so I don't have time to just sit.



When asked how their children get physical activity, some mothers responded that they limit their children's time outdoors either because of safety concerns or because they want them focused on their schoolwork. These moms want their children to play outside only when they can be there watching over them. Active Wii games, going to the park, playing sports, and recess at school are some of the ways their children are physically active. Some bemoaned the fact that they have a difficult time getting their children to go outside because they prefer the television, computer, or phone. In the summer, some moms have access to pools for their children to go swimming.

To be perfectly honest, in this town – and I'm not even trying to detour things – but it's not a social norm to see African American women or black people just in your neighborhood walking with your sports things on. You're liable to get stopped. What are you doing? Why are you out here? It just don't really go.

When it becomes a certain time, when I go to work and I get home, it's already 5:30. Of course, I have to feed the kids, and then when it starts getting dark I pretty much, I really don't go outside. I really don't want them outside. Just because things happen. The world is changing, so I really try to be in the house before it's completely dark outside. I'm scared.

Participant #1: *A challenge is trying to get them out of the house so they can do something.*

Participant #2: *Between the TV, tablets, games and phone.*



Finding: Health care coverage is difficult for Fort Worth families to navigate and afford. The mothers in the focus groups find it challenging to afford health care for their families. Several moms reported that it is difficult to navigate the Medicaid system and feel that they have to jump through hoops to secure coverage for themselves and their children. Even those who researched coverage through “Obamacare” found that the payments were unaffordable for them or that they did not qualify. Child support and Medicaid policies have complicated the process to the point of exhaustion for these busy moms. They expressed disappointment in the reality of “Obamacare,” when they had previously been excited about the possibility that this new policy would help them to protect their children’s health.

Obamacare basically hurt us more than it helped us.

I’m in a situation now to where I have to take my children off of Medicaid because they’re trying to force me to put their father on child support.

I had a situation that recently happened to me when I was working. They tried to take me off Medicaid for my baby and for me as well, because I was making too much money. I had to go on a medical leave in order to receive my Medicaid for my baby. That’s the only reason. That was a big problem to me as well.

My boyfriend broke his neck in a car wreck a month ago in two spots. They took him to Harris. They released him the next day with a neck brace because he did not have insurance – a neck brace and muscle relaxers and pain medication and that was it. He had a concussion, a broken neck, bruises all over his shoulders and his back ... He is the breadwinner, and I’m a stay-at-home mom.

One mother told the group that she has been offered insurance through her job at a doctor’s office, but she cannot afford it. She is uninsured, but her children are covered by CHIP. Another explained her point of view that the current system makes it difficult for people to choose to get ahead.

It is designed to hold you down to fail. If you make too much, you can’t receive things like food stamps or Medicaid, but if you don’t receive food stamps and Medicaid then you don’t have money to pay for things like electricity or a car ... so you either work, or you don’t work to receive government assistance.



Finding: Like the moms in other cities, the Fort Worth moms experienced a lack of consistency and quality in their prenatal/pregnancy/postpartum care. Most moms went for their first appointment when they were two weeks to three months pregnant. Many took prenatal vitamins during their pregnancies, and a few were still taking them at the time of the focus group. They said that their doctors told them the prenatal vitamins are good for their skin, hair, and nails, and that they will help them recover from childbirth. For these reasons, they have tried to keep taking them.

Many participants did not know what folic acid is. One woman joked that it is in tooth paste. Some knew it is a vitamin but were confused about the benefits. No one mentioned that it prevents birth defects.

It helps with your pH balance. It keeps you balanced on the inside, because anything can throw off our pH – having sex with your boyfriend. Their pH is higher than ours, and both have to be at a certain level. It just helps maintain that. I don't sweat as much when I take folic acid. It's a vitamin.

It will help your hair, skin, and bring the nutrition that your baby took out of you and your hormones ... it's still good for you.

Several turned to the Internet to get more information about their pregnancy milestones, asking "Doctor Google" to get second opinions.

Some moms reported having great health care during their pregnancies, although others felt that health care staff treated them worse than other patients because they were on Medicaid.

With my last son, my husband and I tried for a whole year to get pregnant. ... To me, the quality of health care is disrespectful. My nurse actually told me, "You're on your fourth child? Don't you think it's time for you to slow down or stop trying?" Excuse me? I didn't know you were the Medicaid authority. They treat you like you are a single black mother. They ask questions like "Where does the father live?" Even though the father is my husband and lives in the same house as I do!



Several moms were induced, and many had C-sections. None used a midwife, although one mom said she was initially interested in using one but then decided that having a doctor and going for frequent checkups would be safer. Many moms had heard of doulas, but they had not sought one out. One mom said the hospital where she delivered her baby had a doula who came in and helped coach her through her delivery.

All three of mine was scheduled, all three C-sections. I didn't want it that way, but I was told that after the first one, you couldn't even talk about VBAC [vaginal birth after Cesarean] with a Medicaid doctor. It just was like a big no. "Don't ever bring that up again." It was just a risk for them. They weren't willing to take the risk of it. I just had to do it, and each one was scheduled and cut and that was it.

I cried to my doctor so much that she's like, "You know what, we're going to come in for a last visit. If everything's okay, I'll induce you." I went in, everything's okay. She induced me. With my son, the same thing. The last two weeks I was miserable. He kept checking me. My cervix was still too thick. He kept saying, "Just come back." I went on a Tuesday, he checked me, he was like, nothing had changed. He was like, "Come back Friday and if nothing has changed we'll induce you on Monday."

The moms said that their doctors spoke to them about birth control, breastfeeding, and postpartum depression at their postpartum visit. They also reported that the doctors asked how their spouses were treating them, probing for any instances of abuse in the home. Four moms had their tubes tied. One requested to have her tubes tied after having her second child, but her doctor refused to perform the procedure on the grounds that she was still young at 26.

When I went to my first appointment at the – when I found out that I was pregnant, when they asked me how many kids did I already have and I said one. When she found out that I was on my second child, she asked me if I wanted to get my tubes tied. I actually told her yes, but she was like, "With you still being young, I wouldn't recommend it because then you might want to have another one."



Finding: When dealing with behavioral concerns, Fort Worth moms want options other than medication. Doctors and counselors are the resources moms turn to for help if their children have behavioral problems. One mom recounted that her son was jumping around the doctor's office when they went in for an appointment and the doctor recommended that the child be checked for ADD. The mom then took the child to a specialist for a screening. Some moms expressed concerns about what they consider to be the overmedication of children for behavioral issues and wish they had access to psychologists or other professionals who would help their children learn to deal with their emotions rather than suppress them chemically. They want parenting classes to help them communicate better with their children and better protect them as they grow up.

I see it already in my daughter's – the way she reacts, the way she – she will, out of nowhere, just probably hit her brother with a truck or something, out of nowhere. Yeah, and she is so sweet, but then I know where it's just like – rather than them medicate her, I would rather somebody give her coping skills instead of [medication.]

When I bring up topics and subjects, she don't want to talk about it with me. I want to talk to somebody who can help me talk to my daughter, my kids, period. The last thing I want is them to come outside and get some ill-advised information from somebody.... I just want the line of communication to be open with them.

A few participants admitted suffering from mental health conditions. One shared that her son is bipolar and has ADHD but received care and help from MHMR.



Findings Related to Concerns About Health and Safety of Children of Different Ages

Fort Worth moms are greatly concerned about their children's safety around strangers when they are away from home.

- **Birth to 2 years.** Moms of babies who are crawling and beginning to walk have concerns about them being exposed to things that could harm them, such as household chemicals or choking hazards. Most said they prefer not to leave their babies in day care or even with family members because they do not trust them to look after them properly. They also mentioned the importance of immunizations.

I'd say, as far with relatives as well, because relatives are not going to watch your baby – even though it could be your mom, your sister, that's your baby. Nobody is going to watch your baby like you can.

You can watch on the news the way they do these kids, and I've walked in on a day care provider snatching my one-year-old baby up.

I'm big on talking to them, like, no more baby talk. We're going to talk because my mom was an abused child. Her biggest thing with us was, you have to know how to talk, tell, you can tell. You learn to talk so you can tell me. I picked up on that. I taught my daughters early to talk. When I drive them to day care, tell me what happened, is everything okay? My whole thing is the learning and the learning quick.

[My priority with] my child's health is to make sure they have their shots and taking care of their teeth and making sure they're getting the proper sleep and making sure I'm doing my part as a parent.

- **3-5 years.** The main concern for mothers of children this age is “stranger danger.” Many moms seek to keep these kids at home, at school, or at family functions only. They worry about what strangers may say or do to their children, who are not old enough to spot danger themselves. They also try to instill healthier eating habits in kids this age by buying more vegetables and being a role model.
- **6-13 years.** Parents are concerned about peer pressure and the kids their children are hanging out with. Some moms only allow their children to play outside or be away from home on a school trip only if they are under adult supervision.
- **Teens.** With their teenagers' know-it-all attitudes, some moms are concerned that they may get in over their heads in potentially dangerous situations. One mom told the group that her daughter's classmates sell drugs, and she has tried to warn her daughter against getting mixed up in drugs or reporting anything to her teachers for fear of reprisals from the dealers. To a lesser degree, moms worry about sex among teens in general.



Stakeholder Perceived Needs: Arlington

Sixteen stakeholders registered for the meeting; eight participated. Four participants represented programs of the JPS Health Network (dental, school-based clinics, and adolescent health). Two represented community-based organizations (one dealing with children's mental health and one with teen healthy choices), and two represented health care providers, including the local FQHC. One participant indicated she worked with children with special health care needs. Two DSHS staff members observed the meeting.

Identified Priorities

Arlington stakeholders identified three priority needs for their region. All three fall within the category of crosscutting issues: education and awareness, access to services, and needs related to continuity and transition.

Education and awareness. Most of the participants agreed that education and awareness are priority needs, and that increasing awareness and improving education about health issues can lead to earlier intervention and help reduce the need for high-cost interventions later on. In particular, the group cited the need for nutrition education to help prevent obesity, and prenatal education so mothers can learn how to keep their children healthy. Families need to be educated about how to access information and find resources in their community so they do not think of state and federal resources as the first stop. Educating employers is also important: If businesses understand that employee health affects their bottom line, they will be more likely to fund educational efforts for their own employees and engage with community-based organizations to improve health in the broader community. Some companies work with international organizations to fund health education and services in other countries, but they do not recognize that the same needs exist here.

Access to services. Most of the participants agreed that access to services is a priority need. Access may be restricted for a variety of reasons. Families without the means to pay struggle to get access to primary care; dental, vision, and hearing services; behavioral health services; and over-the-counter medications. Those who do have financial resources may not have timely access because of a shortage of primary care providers and specialists, especially providers for children with special health care needs. Many families are not connected to services, even when they exist.



Behavioral health services in particular, including substance abuse treatment services, are very limited for people who cannot pay. Low reimbursement rates, generally low salaries for behavioral health providers, a limited workforce, and lack of funding for mental health services all contribute to restricted access. Families do not have access to support services that could prevent a mental health crisis. Children often have to get into trouble before they can receive counseling or therapy. Once law enforcement is involved and the children are processed through the juvenile justice system, they have access to mental health services. However, accessing services this way has the undesirable long-term consequence that a child with a record is more likely to become an adult offender.

Cultural factors also come into play. Tarrant County is among the nation's top ten counties in terms of refugee resettlement, with refugees from all over the world. There are numerous Arabic, Tongan, and Vietnamese speakers in the county. Refugee children have often experienced traumas in their home countries and need support in their own languages. Facilities may have interpreters, but they are not always available and do not work in all language pairs. The state's translation line also does not provide services in all languages. In short, translation and interpretation services are desperately needed.

Beyond the language issue, clients naturally adhere to the rules of their own culture. Health care providers are rarely informed enough to deal appropriately with clients from widely diverse backgrounds, which can discourage access. For example, it is a strong taboo for a male nurse to enter the room of a female Arabic hospital patient. A woman whose culture prizes large families may not understand the need for contraception or may be offended by a health care worker who is promoting it.

Continuity and transition. Many participants feel that continuity of care and transition across life stages is rife with unmet needs. There is a lack of coordination and continuity among health care providers in general, and across specialists in particular. Providers use different electronic health care records that do not communicate across systems. Even in the best-case scenarios, there are gaps between referrals.

Children with special health care needs face challenges in the transition to adult care, when they must find a new doctor. Few doctors have the passion or willingness to take on the primary care role and coordinate the many specialists typically seen by young adults whose medical needs are complex.

There is a lack of focus on health and wellbeing, and on considering the whole person across the lifespan, particularly in terms of the relationship between mental and physical health.



How to Address the Priorities with an Upstream Approach

Each small group brainstormed ways to address the priority of its choice. One group recommended actions that could address both access and continuity of care. The other recommended strategies to promote education and awareness.

Access to services and continuity of care. The first group identified the following interventions they believe will improve both access and continuity.

- Provide wraparound services to teach family members skills and connect them to resources they will need for a lifetime.
- Provide patient navigators to help coordinate care and link clients to information and services.
- Provide funding for classes to help people learn how to be healthy and prevent health issues. It takes resources and time to offer such classes, and the cost is not reimbursed because classes are not considered a form of health care.

Education and awareness. The second group shared the following ideas.

- Fund ongoing social media campaigns to deliver the education message. This includes funding staff that monitors and manages the outgoing information in order to ensure accuracy and to direct people to reliable information sources and resources for early intervention.
- Develop a health app or direct people to existing reputable websites and apps.
- Fund live-chat staff to provide age-appropriate information for people who have health questions or need to secure referrals or access resources. Students or interns could play this role.
- Educate corporations about the health needs of their employees and the community.

Additional Needs and Problems

During the small group brainstorming activity, participants in Arlington identified a wide variety of perceived maternal and child health needs and problems. Table 6 presents the ideas that participants did not choose to include in the top regional priorities described above.



Table 6 Additional Perceived Needs and Problems; Dallas-Fort Worth	
Population Health Domain	Needs/Problems
Maternal and women's health	<ul style="list-style-type: none"> • Lack of nutrition education to keep children healthy • Young parents lack knowledge and parenting skills
Perinatal health	<ul style="list-style-type: none"> • Access to birth control
Child health	<ul style="list-style-type: none"> • Shortage of specialists, including behavioral health care providers • Homeless children • For cultural reasons, parents do not take children to preventive and primary care providers unless their "own" methods have not worked • Lack of coverage for dental, vision, and hearing services • Refugee children from around the world have experienced trauma
Children with special health care needs	<ul style="list-style-type: none"> • Complexity: families of children with special health care needs are used to dealing with multiple specialists. It is hard to find primary care providers who will consider the whole person. • Services are unintegrated and choppy; lack of continuity for children with special health care needs • Shortage of specialists • Not enough help for children's transition to adult providers; lack of transition plans
Adolescent health	<ul style="list-style-type: none"> • Limited affordable mental health services • Lack of education, especially nutrition education, leading to health issues when teens later become adults and seniors • Kids are having kids and do not have the skills to parent • Health education is not mandatory • Lack of help transitioning to adulthood • The denial of the need for sexual health education is a barrier to treatment. Parents say their children are not having sex, but somehow they got STDs. • Access to birth control • Lack of early access to behavioral health counseling. Adolescents have to "get in trouble" before they can access counselling. There is no funding stream for behavioral health services. • Shortage of specialists • Homelessness



Final comments for DSHS

- To better understand the needs of Title V clients, read *A Framework for Understanding Poverty* by Ruby Payne (<http://www.amazon.com/Framework-Understanding-Poverty-4th-Edition/dp/1929229488>).

Dallas-Fort Worth: Regional Common Themes

Two common themes, discussed below, emerged from the findings from the focus groups with mothers in Fort Worth and the priorities identified by stakeholders in Arlington.

Access to health care is limited or out of reach for many. Mothers in the Fort Worth focus groups shared their struggles, and sometimes their failures, to get access to needed services for themselves and their families. Navigating the system to find affordable health insurance or to qualify for Medicaid or CHIP is complex and exhausting. Stakeholders in Arlington agreed that some families struggle to access services because they do not have the means to pay. They also pointed to a shortage of primary care providers and specialists that can limit access even for those who are insured or covered by Medicaid or CHIP.

Behavioral health services are not meeting needs. Mothers expressed concerns about the use of medication as the preferred strategy for dealing with children's behavioral issues. They wish they had access to professionals who would help their children learn to deal with emotions rather than suppress them chemically. Mothers also had concerns about how peer pressure could impact their pre-teens' and teens' behavior, including involvement with drugs. Stakeholders did not identify behavioral health needs as a separate regional priority; however, they did identify access to services, and within that context they noted that access to mental health services is particularly limited for people who cannot pay. They cited low reimbursement rates and generally low salaries for mental health services providers as factors that limit the number of providers and, consequently, access to services. Sadly, stakeholders acknowledged that children often access mental health services only through the juvenile justice system.



Best Texas Locations

It's a great idea to visit Texas before you move here. You can see the state's diverse landscapes, from the rolling hills of the Hill Country region to the rugged mountains of Big Bend National Park. You can also experience the state's rich culture and history, from the cowboy culture of the West to the vibrant music scene of Austin.

How to Choose the Best Texas Location

When choosing the best Texas location for you, there are several factors to consider. First, think about your lifestyle and what you want in a home. Do you want a quiet, rural setting or a bustling city? Do you want a large, open space or a more compact, urban environment?

• Climate

• Cost of living

• Job opportunities

• Quality of life

• Proximity to family and friends

• Access to amenities

• Safety and security

Second, think about your budget. Texas is a large state with a wide range of housing options, from affordable rental properties to expensive luxury homes. Consider your budget and what you can afford to pay for a home in the location you're considering.

Third, think about the local economy and job opportunities. If you're moving to Texas for work, it's important to research the local job market and see if there are any opportunities in your field. You can also look into the local economy and see if there are any industries that are growing in the area.

Fourth, think about the quality of life in the location you're considering. This includes factors like the cost of living, the availability of amenities, and the overall atmosphere of the area. You can research the quality of life in different parts of Texas and see if it matches what you're looking for.

Fifth, think about your proximity to family and friends. If you have family or friends in Texas, it might be a good idea to choose a location that is close to them. This can make it easier to visit and stay with them, and it can also provide a support system as you settle into your new home.

Sixth, think about the safety and security of the location you're considering. You can look into the crime rates in different parts of Texas and see if they are low. You can also look into the safety of the area and see if there are any potential risks.

Finally, think about the overall appeal of the location you're considering. This includes factors like the scenery, the culture, and the history of the area. You can research the overall appeal of different parts of Texas and see if it matches what you're looking for.



East Texas Findings

SUMA conducted two focus groups with mothers in Nacogdoches and a stakeholder meeting in Tyler. Focus group findings and stakeholder perceptions are reported below, followed by the common themes that emerged for East Texas.

Focus Groups: Nacogdoches Mothers

Finding: Mothers in Nacogdoches generated a long list of health concerns but agreed that their top concerns are weight/obesity and related illnesses.

- Weight/obesity
- Diabetes
- Blood pressure
- Heart problems
- Getting access to a yearly physical
- Affordable insurance for adults
- Knowledge/education about parenting and raising children

Finding: Mothers in Nacogdoches know how to describe a healthy meal. Choosing to make and serve that meal, rather than fried or fast food, is the biggest challenge for most. The majority of the moms described a healthy meal as consisting of a baked protein such as chicken or fish, potatoes or corn, a green vegetable, and bread. They typically shop at Walmart or Kroger, and most have convenient access to stores. They claimed to buy primarily fresh fruits and fresh or canned vegetables. Some moms said it is easier to buy healthful foods at the beginning of the month when they have sufficient food stamps; however, others pointed out that healthy foods cost more and exhaust the food stamps too quickly. Later in the month, when the stamps are gone and money is low, participants described their experiences of subsisting on easily accessible options: canned foods they have in stock, fast foods, or pizza delivery (when gas money is low).



What most helps moms to eat healthily is the motivation to provide a healthy diet for their children. A few said they are trying to prevent their children from growing obese by cooking healthy, low-fat meals. They are challenged by being too tired from work, which leads to microwaving dinner or picking up fast food. Others mentioned that cooking healthily takes more time, and they are short on time after working late. The third challenge moms mentioned most often is money. Their perception is that healthy food costs more than less healthy choices.

Just took my three-year-old to her WIC appointment. They say she is big for her age and told me to cut down on her milk. She loves her milk. Every morning she wants chocolate milk made with chocolate syrup. She won't drink it if I don't do it. I can't deny my baby her milk. I won't deny her.

My kids make me want to feed them food that is good. My kids always want to know what is next. So, I make a list and put it on the refrigerator so they can see what is next.

... Eat well when food stamps come. We eat out when they don't come.

Time is the challenge. It's easier to pop something in the microwave or get fast food.

Finding: Moms agree that Nacogdoches offers plenty of opportunities to get physical exercise. Nonworking moms think they get enough exercise by keeping the house clean and following their children around. They said the city has numerous nice parks, and both the school grounds and the university are open to the public. However, they lamented the city's closing of all the public pools, which means that many of their children don't have a place to swim anymore. There is a good recreation center, but many of the classes and sports it offers require fees, which prevents some from taking advantage of them. Some participants mentioned that better programs are available for older, school-aged children than for children under the age of five. Several said they work to keep their children outdoors as much as possible, and they feel that Nacogdoches offers safe places to do that. Working moms, especially those with desk jobs, claimed that a bigger problem is getting enough exercise for themselves.



The positive factors that help these moms get the proper amount of physical exercise for themselves and their children include having an established exercise/activity routine, neighborhood parks and school playgrounds within walking distance, and participation in sports. They are challenged by fatigue and stressed out at the end of the day, which leaves little time for personal activity. They said the greatest challenge for their children is tearing themselves away from the television, Xbox, and electronics in general.

I trick the kids. We wash our cars, line up, and have relay races, anything so they don't know they are exercising.

I take my kids to the park. We like to go to the SFA Park. I try to keep them out of the house as much as possible.

My challenge is stress. I'm so busy – I work, cook for the kids, pay the bills – it stresses me out. Sometimes I'm just too tired.

Video games, cell phones, tablets, electronics in general: It makes it so hard to get them out of their rooms.

Finding: There is a need for education on smoking during pregnancy and around infants in Nacogdoches. The focus group moms agreed that smoking is a problem in Nacogdoches. They said a lot of people in the area smoke, and once they start, it is hard to get away from it. Several said they smoked during their pregnancies and are currently smoking. They mentioned seeing television commercials about the dangers of smoking during pregnancy. In response to those advertisements, one smoker said, “When one is a smoker, just knowing that smoking is harmful to you and your baby doesn't do anything to help you quit smoking; it just makes you feel bad.” However, thanks to the commercials, they are aware that smoking is associated with low birth weight and premature birth, and that secondhand smoke around children already born contributes to asthma and bronchitis.

Moms said the information they receive from health care providers has not been helpful. According to the participants, the health care provider asks if anyone in the home smokes. If the patient says no, the provider moves on. If the patient says yes, she is given a packet of information to read.



The correlation between smoking and SIDS was news to most of the moms. One mom related a story about a family member who smoked and whose baby died from SIDS. No one had told the parents that smoking might have been involved, but the focus group participant made the correlation.

... She was in the bed with them and she was dead, but they had a cat in the house and they smoked, so I don't know what happened.

I believe my babies have bronchitis because I was smoking. It's not a severe case of it, but they all have bronchitis.

In the commercial she has a baby premature from smoking cigarettes. It says when you smoke, it can affect them, whether you're pregnant or not.

Finding: Families need better access to specialty health care that accepts Medicaid in Nacogdoches. Moms spoke at length about the difficulty of paying for adult medical care. It is a bit easier for them to afford care for their children on Medicaid. Most feel okay about the care their families get, except for the unavailability of specialists when children or adults have problems requiring specialized care. They commented that it is a challenge to find specialized caregivers who take Medicaid. The moms discussed the upgrade in the care a patient receives once he or she is assigned "Superior" status, and several exchanged ideas on how to get classified with that status.

It's hard getting medical care for yourself if you're on Medicaid anyway. It's hard getting anywhere if you're not on Medicaid.

You have to pay cash unless it's for a Pap smear.

If the dad is paying child support, they cut you off the Medicaid.

My kids are on Medicaid, but they also have insurance. Medicaid pays me my insurance premiums. They send me my insurance premiums back because it's more cost-effective for my kids to be on my insurance than on Medicaid.



Finding: Like the moms in other cities, the Nacogdoches moms sense that their prenatal/pregnancy/postpartum care lacks consistency and quality. The moms in these focus groups revealed that they first sought prenatal care between six weeks and six months of pregnancy. Those who sought care later in their pregnancies admitted that they were in denial and hoping that the pregnancy was not a reality. Others delayed seeking prenatal care because they were waiting for Medicaid approval. They agreed that it takes a long time to get approval, and they would like it to go faster.

Almost all participants had started taking prenatal vitamins, but about three fourths stopped taking them because they were difficult to swallow or made them feel nauseous. Almost half did not talk to their doctors about stopping. Of those who did, only one said her doctor discussed the importance of taking folic acid. Several admitted that they don't know what folic acid is; their doctors did not bring it up. Some were advised to take Flintstones Gummies vitamins and iron.

A few moms in each focus group took prenatal classes at Heartbeat Pregnancy Center and thought they were moderately helpful. They typically rely on friends or family members to pass along their own experiences.

A total of 16 participants in both groups were induced for a variety of reasons; nine of these inductions resulted in C-sections. Some said they were induced because they were told their babies were going to be too big, but the babies were born at normal birth weights. A couple of participants who were induced were past their due dates, and others showed signs that the baby was possibly in distress. Most said they did not dilate enough to proceed with the birth, and the baby was delivered by C-section. Few had problems with the birth itself.

UTMB, the primary medical center in Nacogdoches, uses midwives for births, so most of the participants had a midwife. Most were satisfied with the process.

Most of the moms went for their six-week checkup. Birth control was discussed prior to the birth, and some had their tubes tied after the birth. Several were advised to breastfeed, and some of them took that advice. Those who breastfed understood the importance of taking prenatal vitamins while breastfeeding.

Finding: Several children of the focus group moms have behavioral issues, but most of the moms are not sure where to go for help. They ask friends and family, and some turn to doctors. Several mentioned that their children have "anger issues," but only one participant took her child to The Burke Center to have him diagnosed with ADHD. Her older child has autism, and she is accustomed to talking with her doctor. Several said they talk to their peers and family members about their children's behavioral issues, since they do not always have access to the specialist.. Almost everyone agrees that they would like to have more resources and information about how to deal with children's behavioral issues.



Finding: Moms fear leaving their children in day care. The Nacogdoches moms agreed that their children are precious cargo, and for that reason they will not leave them in unknown day care situations. They feel the safest place for a child is with them, their mothers, or other close relatives.

Findings Related to Concerns About Health and Safety of Children of Different Ages

- **Birth to 2 years.** Most moms said they will not leave their children in day care until they can talk – and as a result, they leave them in compromised family situations. For example, a couple of the mothers mentioned leaving their children with grandparents who smoke. Others said infant care is unaffordable at \$120 per week and up.
- **3-5 years.** Children this age are into everything, but at least they can talk and tell you if something is not going right. Moms of children this age agreed that Head Start is a good place to put them, but it takes a lot of work to get children into the program. They also need more flexible hours. Most day care is available from 8 a.m. to 6 p.m., but most shift work runs from 7 a.m. to 7 p.m., so it is difficult to make arrangements. A few mentioned the Boys & Girls Clubs, but were not sure if they cost money.
- **6-13 years.** Moms are concerned about leaving their children home alone, but feel that there isn't much they can do about it. They rely heavily on school counselors to identify when things aren't right. Mothers with children of this age are already concerned about leaving them home without supervision and vulnerable to doing drugs or having sex.
- **Teens.** No one in the Nacogdoches groups had teens, but they were concerned about this age, particularly the single moms. They have hopes that their children will be “good” teenagers but do not know of resources to help them. Boys & Girls Clubs got a few mentions in the discussion of resources for this age group.

Finding: As each of the focus groups was wrapping up, participants said the most important and comforting thing they learned was that other people are experiencing the same issues as they are. Almost everyone said the relationship between smoking and SIDS was news to them.



Stakeholder Perceived Needs: Tyler

Nineteen stakeholders registered for the Tyler meeting, and 11 participated.

Three participants represented community health centers – two from a local FQHC and one from another local clinic. Two participants from the university health system attended. The local school district, local health department, and community-based organizations focusing on youth education, substance abuse, domestic violence, and services for the blind and visually impaired were also represented. Two participants indicated that they work with children with special health care needs. Three staff members from DSHS, including the regional medical director, observed the meeting.

Identified Priorities

Tyler stakeholders identified five priority needs and problems for their region, all crosscutting issues: a lack of specialists, mental health, collaboration and coordination, contraception, and oral health.

Lack of specialists. Most of the participants said a lack of specialists is a priority need. Tyler is a health care hub for the region. Health care is the largest employment sector, and the number of hospital beds is above the state average. However, the region lacks specialists. Patients must often travel to Dallas or Houston to see a cardiologist, pulmonologist, immunologist, or other specialists. Many of the specialists who practice in Tyler have never accepted Medicaid or CHIP, and some who did participate in these programs in the past have stopped because of reimbursement issues with Medicaid-managed care organizations. The issue is compounded for children with special health care needs, who may require access to a variety of pediatric specialists. When a patient sees more than one specialist, the providers rarely communicate or coordinate with each other, leading to gaps in care.

Mental health. Most participants indicated that mental health is a priority for the region. Mental health services are lacking across the spectrum. Those seeking non-crisis services face a three- to six-month wait at the local mental health authority. Mental health treatment beds are in such short supply that the emergency room has become the main provider. People who speak Spanish do not have access to mental health resources or support groups. Abuse of methamphetamines is common, but resources for substance abuse prevention and treatment are lacking. The general lack of mental health resources in the region has resulted in a lack of awareness about the importance of mental health and its relationship to physical health. Mental health issues are often unidentified or unacknowledged because of stigma.



Collaboration and coordination. Most participants agreed that collaboration and coordination are regional priorities. Clients and providers lack awareness of existing resources. Referrals are delayed or not made at all, and continuity of services is affected. Coordination is needed at several levels:

- Among local health care providers and social service organizations
- Across state and federal partners
- Between specialists and social services providers for children with special health care needs

Contraception. Many participants agreed that contraception is a regional priority. Family planning is an important life course issue. The needs include education and information about birth control for adolescents, women, and men, as well as access to female and male contraceptives. Education must be culturally appropriate. For example, presenting condoms as protection against STDs instead of as contraception may help overcome certain cultural barriers.

Oral health. Most participants agreed that dental services are a priority need. There is a lack of awareness about the relationship between oral hygiene and overall health, such as the fact that poor oral health is correlated with heart disease. A lack of access to dental services contributes to the Tyler area's heart disease rates, which are the highest in the state. Pregnant women and women over age 21 do not have adequate access to dental care. This is a critical issue because a pregnant woman's poor oral health can negatively affect her baby.

How to Address the Priorities with an Upstream Approach

One small group brainstormed ways to address mental health needs. The other generated ideas to address collaboration and coordination.



Mental health. The first small group offered a few ideas on ways to address the region's mental health needs, sparking a whole-group discussion about the difficulties of upstream prevention. With the stigma attached to mental health issues, people often wait until their world is falling apart before they seek help. Participants struggled to bring a prevention perspective to what is typically a reactive situation. The following ideas emerged.

- Fund mental health crisis intervention facilities to change the pattern of law enforcement involvement and services in emergency rooms.
- Fund a new kind of mental health facility to help people who are in danger of experiencing a crisis but are not quite there yet. These would be acute care facilities for mental health, a parallel to urgent care facilities for physical health.
- Strengthen existing collaborations. Mental health resources may be available, but providers and families do not know about all of them.
- Tie benefits to requirements to attend classes in substance abuse prevention, life skills, and/or parenting.
- Educate the general population about mental health issues. Engage with faith-based and other community-based organizations to provide training on how to recognize mental health and substance issues, and how to help someone before an issue reaches the crisis stage. Erase the stigma. Offer Mental Health First Aid training.²

² Mental Health First Aid USA, <http://www.mentalhealthfirstaid.org/cs/> (2013).



Collaboration and coordination. The second small group offered the following ideas to address various aspects of collaboration and coordination.

- Conduct focus groups to identify the needs of families.
- Once the needs are known, work with public schools and universities to disseminate information about available resources so that families receive the same message from the kindergarten teacher and the college professor.
- Form strategic collaborations between agencies and organizations. Include nontraditional partners, such as firefighters, who are not usually included in conversations about health but have direct access to people in their homes. Encourage ongoing collaboration and information-sharing through regular gatherings (such as dinners with guest speakers), with rotated responsibility for hosting. The more informed the providers and community-based organizations are, the better they can inform clients.
- Collaborate across the community to identify priorities and formulate a common message. For example, if dental health is the priority for the month, people will hear the same message everywhere they go. Engage with faith-based communities to help develop and share the message.
- Set up a central information bank/clearinghouse of resources with a searchable, user-friendly database that is easy to update and is kept up-to-date. The 2-1-1 line is not updated.
- Establish community-specific websites with user-friendly search engines to help families and providers locate resources.
- Fund community helpers to disseminate accurate, culturally appropriate information in multiple languages.
- Educate the general population through public service announcements, health fairs, and other events.

Additional Needs and Problems

During the small group brainstorming activity, participants in Tyler identified a wide variety of perceived maternal and child health needs and problems. Table 7 presents the ideas that participants did not choose to include in the top regional priorities described above.



Table 6
Additional Perceived Needs and Problems: East Texas

Population Health Domain	Needs/Problems
Maternal and women's health	<ul style="list-style-type: none"> • Education for young and first-time parents • Access to mental health services
Perinatal health	<ul style="list-style-type: none"> • Postpartum care and education • Lack of education on environmental hazards
Child health	<ul style="list-style-type: none"> • Lack of pediatric specialists and resources, even if clients are able to travel to major urban areas
Children with special health care needs	<ul style="list-style-type: none"> • Lack of specialists • Lack of access to case management • Lack of a reliable clearinghouse for resources for children with special health care needs; 2-1-1 is not always accurate for clients or providers
Adolescent health	<ul style="list-style-type: none"> • Stigma and societal norms discourage parenting education for teens, especially for dads • Need for education on parental involvement • Lack of pediatric specialists • Need for better continuity of referrals • Lack of "dad friendly" facilities and information/materials that are for adolescent dads
Crosscutting issues	<ul style="list-style-type: none"> • Clients with felony convictions have disenfranchisement issues • Need for technology competence • Need for life skills and esteem building • Lack of nutrition education and obesity prevention • Lack of Medicaid transportation for the family unit • Lack of Medicaid transportation for children who need to see a specialist • Lack of "dad friendly" facilities and information/materials • Lack of parent support services • Unreliable and inaccurate information; home remedies are used instead of real medicine • Access to and funding for annual exams • Misunderstanding of health recommendations because of social norms • Lack of access or gaps in access to services • Lack of training for frontline staff: misdirection/bias/misinformation from staff results in lack of access • Lack of access for clients who are undocumented • Need for education and awareness



East Texas: Regional Common Themes

Two common themes, discussed below, emerged from the findings from the focus groups with mothers in Nacogdoches and the priorities identified by stakeholders in Tyler.

Access to specialty care is a challenge. Mothers in the Nacogdoches focus groups expressed concerns about their difficulty finding specialists who accept Medicaid. Confirming these concerns, stakeholders in Tyler identified a lack of specialists as a priority need. They pointed out that even though Tyler is a medical hub, it has fewer specialists than other areas of Texas. Compounding the lack of access, very few local specialists accept Medicaid or CHIP. Some have never participated in these programs; others once participated but have withdrawn because of low reimbursement rates. Consequently, patients often must travel to Houston or Dallas to seek specialty care.

Mental health services are unknown and inadequate. Several mothers mentioned that their children have had behavioral issues, and most of these mothers said they were not sure where to go for help. They wanted to know more about available mental health resources and to learn how to deal with difficult behaviors. Stakeholders underscored these concerns as well, identifying a lack of mental health resources as a priority need. They pointed out that even people who know they can seek help from the local mental health authority face months-long waits to access services. This lack of services has resulted in a general low level of awareness of the importance of mental health and its relationship to physical health in the region.



Houston Findings

SUMA conducted two focus groups with mothers and a stakeholder meeting in Houston. Focus group findings and stakeholder perceptions are reported below, followed by overall findings for the Houston area.

The focus group participants in Houston were recruited from specific zip code areas with high rates of obesity and further screened for participation based on their risk for obesity.

Focus Group Findings: Houston Mothers

Finding: The mothers in the Houston focus groups agreed that their top health concerns are weight/obesity, cancer, and affordable access to quality health care. This group also mentioned asthma and parenting education as top health concerns.

- Weight/obesity
- Cancer
- Access to affordable insurance/good health care for adults
- Asthma
- Knowledge/education about parenting and raising children

Finding: Mothers in the two focus groups in Houston described a healthy meal as consisting of a protein, a starch, a green vegetable, and bread. Some said their children like vegetables more than they do. They said that cooking healthy is easier on the weekends than during the week, when many are working. They don't want their children to become "McDonald's kids." They typically shop at H-E-B or Walmart, and while most have convenient access to stores, several said they drive out of their neighborhoods for better fruits and vegetables. They claimed to buy primarily fresh fruits to eat and frozen fruits mainly for smoothies. Some buy canned pineapple and apple sauce. As for vegetables, they buy all three forms: fresh, frozen, and canned. Several said they buy canned vegetables primarily because they are much cheaper than fresh. They buy staples at CVS and Walgreen's because these stores are close to home. In the first focus group, the moms discussed the free-meal programs provided in the schools. They complained that these meals have declined in both quality and quantity since they were in school. They said that children are served sugary pastries and that the quantity of food served for lunch is very small. Their children come home "starving."



What most helps them eat healthily is a motivation to provide a healthy diet for their children and having good examples from other mothers. One participant said that buying a crock pot has helped her have healthier meals ready when she gets home from work, which prevents her from stopping for fast food. These moms are challenged by feeling tired or not having enough time. Their children beg for fast food and don't like the vegetables and healthy foods they cook.

I always make a dessert and tell my children they have to eat their vegetables before they can have dessert. It works.

My kids like veggies more than I do. They eat pretty healthy; healthier than me.

Since my son is here, I definitely try to cook at home more and give him his starch, his vegetables; because I don't really want him being a McDonald's kid or a Burger King kid.

I get off at 5 p.m., then fight traffic and pick up the kids from day care. When do you have time to cook?

Finding: Many Houston moms think they get enough exercise by keeping up with their children and living their lives (e.g., walking up and down stairs, cleaning house, walking the dog). Several mentioned having a Wii or workout tapes, and others do calisthenics at home. However, they find these activities repetitive and boring, so they are not always inclined to follow through. Most said the city has sufficient parks, and school grounds and track fields are open to the public. One mom said she attends a free boot camp at the high school. The moms mentioned that there are good recreation centers, but the YMCA in the southwest area has closed. They gave mixed reviews of their neighborhoods. Several said they try to get their children to the park early, before it gets dark. Some live in apartment complexes where they do not feel safe letting their children play outdoors.

Some moms said they gained a lot of weight with their pregnancies and are motivated to lose weight and return to their former size. They are challenged by a lack of time and money. They wish the recreation centers had more free programs or that they had greater access to centers with babysitting.

My kids don't ever get tired. I don't worry about them getting enough exercise.

Even with just one child, you're on a budget and it's kind of difficult to pay \$39 for a month when you know she needs her diapers.

I get tired, and when I'm tired I have a lack of motivation. I don't feel like working out.

I think they should have more YMCAs that offer a sliding scale like the zoo does. At the zoo, everyone that has a WIC card is free.



Finding: Moms said health care is too expensive in the Houston area, and those on Medicaid said Harris County Hospital sometimes has long waits. Houston moms complained a great deal about expensive medical care and their difficulty in paying for adult medical care. As a result, they are compelled to go to County Hospital and wait in line. They concurred that it is an all-day trip, which is impossible for those who work outside the home. Getting health care for their children is easier because they are on Medicaid, but quality varies with the type of Medicaid policy one has. Most feel that Amerigroup is the best type of policy with the fewest restrictions. Some participants tried to instruct others in the group on how to negotiate a better policy for themselves.

If you're stuck on a certain program you can't go to just any hospital. They don't take the insurance. You have to go back and switch off it.

They're going to send you to County Hospital. That takes forever. You have to wait all day at County Hospital.

I don't have insurance. They kicked me off my dad's policy when I was 21, so I got Medicaid. But they kicked me off Medicaid when I got a job. I never really go to the doctor so I just don't have insurance.

Finding: Most Houston moms thought their prenatal/pregnancy/postpartum care was very good. They first sought prenatal care between one month and 8½ months of pregnancy. Most moms sought care during the first trimester, but a few admitted they were in denial about the reality of the pregnancy. Like mothers in other cities, several were waiting for Medicaid approval. They wanted to go earlier in the pregnancy, but many said that the approval process for Medicaid took two months or longer after they realized they were pregnant and applied. Others said they had problems getting other insurance in place when they did not qualify for Medicaid.

Taking prenatal vitamins was not as much of a problem in Houston as it was in other cities. Many moms were given the alternative of other vitamins if they could not take the first ones they tried. Most also said their doctors had discussed the importance of taking folic acid with them. A few in each focus group took prenatal classes, but some did not because there was a charge for taking them. Some got literature, while others relied on anecdotal information from family and friends.



Numerous participants were induced, for a variety of reasons: Several were past their due dates, and others showed signs that they or the baby were possibly in distress (e.g., high blood pressure, breech birth). At least half of the participants had C-sections. Some of these moms said the labor went on too long, others that they did not dilate enough to proceed naturally. Some wished they had had a vaginal birth, although almost none of them questioned the health care provider at the time. They assumed their provider's first choice would have been a vaginal birth. No one used a midwife. A few participants had premature births.

Most said they went in for their checkup at six weeks or close to six-weeks. Birth control was discussed both prior to and after the birth, but some wished they had received more advice about what the best choices were. They found the checkup only marginally helpful.

The majority of the Houston moms received recommendations to breastfeed, and most of them tried. They did not recall getting much instruction during a lactation consult, and most that kept up with breastfeeding did so because the baby latched on easily and the process went smoothly. Those who abandoned it mentioned feeling a lot of pain or finding the process awkward. Several said they were advised to continue prenatal vitamins while breastfeeding.

I know for me it was a problem with getting on the Medicaid. It was taking so long just to get it approved. I would turn in everything that they needed, proof of pregnancy, and it was like they were losing it. "We didn't get this." "We didn't get that."

I feel like I wish people would've told me all the stuff they don't tell, the Chapter 13 in their book called The Stuff That They Don't Tell You. I just wish that people would've come and told me so that I could be more prepared.

I didn't want to have my baby early. I wish I didn't get induced. I don't even really know why I did. I just remember he said, "Yeah, you should get induced," because my blood pressure was on and off – both high and low. I remember I really didn't want to go in, but I did because I was nervous. It just was horrible.

I wanted to straight breastfeed, because my other two didn't want it. I said, "Let me try this." She latched right on. Breastfeeding is actually a lot healthier.



Finding: Initially, moms in Houston claimed their children don't have behavioral problems, but in discussion later on, many acknowledged that they have sought help. Several mentioned that their children have learning differences and/or "anger issues." A few said their children have been diagnosed with ADHD or autism, and others have experienced problems resulting from traumatic life experiences. They mentioned "The Premier" and school counselors as most useful in helping them identify resources.

My eight-year-old goes to Premier for ADHD, ADD, and autism. She repeated second grade, so we think she has a learning disability. I was in an abusive relationship for a year with my son's dad, and she saw some stuff. I think that kind of affected her.

We saw different people and said the same story. Nothing was getting done. They gave us to The Premier, and she's been able to talk with somebody.

Finding: Moms in general do not feel they have the resources to leave their children in quality day care centers, so they choose to stay home or resign themselves to suboptimal care. Their mantra is, "Nobody's going to take better care of your baby than you can."

Findings Related to Concerns About Health and Safety of Children of Different Ages

- **Birth to 2 years.** Moms worry about their kids' putting objects in their mouths or pulling things off of surfaces and on top of themselves. Good child care is unaffordable for most. One mom said she chooses to drive across town to leave her child in a center that provided onsite, real-time access to day care, at a cost of \$230 per week.

Health-wise as for me, their immune system is not as strong. I'm very particular of taking my kids out, people coughing and germs flying around.

They are putting everything in their mouths. Why is everything not clean?

First she went to the Junior Harvard Academy and now she goes to Kids R Kids. I like that day care because I can watch it anytime from my phone, the video. It's so much more expensive, but I can afford it – I just don't like paying for it.



- **3-5 years.** When children reach this age, moms are relieved that they can talk and tell them if anything goes wrong, but they worry about their interactions with day care workers and other kids. Some are concerned that their children will not be intellectually stimulated and will be set in front of a television for the day.

When they get up to that 3-4-5 age, they want to play with other kids. I don't want anybody hitting one of my kids; that would be a big issue.

After my child is 3, I feel like they should be teaching them stuff, not playing all the time or sitting in front of the TV and watching shows.

Some Head Start schools take them at three years old. It's effective and so good when they go, "Mommy, guess what I did today!"

- **6-13 years.** Parents of children in this age range are most concerned about safety in the school itself. Other students can be mean, and they want to know their children are not only being intellectually challenged but also safe from bullying and other stressors. A few have concerns about children being home alone.

Nowadays there's so much stuff happening at the school. It's like you're always going to be worried. Your child is not with you. They have to go to school; that's the law. It's always going to be on your mind.

Kids are so mean and bullies these days. My daughter was teased because she's got eczema, and someone thought she was dirty. She cried the whole day.

- **Teens.** Most of the moms in Houston have young children, so teen behavior is currently less of a challenge for this group. They assume the answer is to keep teens active and challenged and not give them too much time to get in trouble. They mentioned the YMCA and Boys & Girls Clubs as resources. Thinking back to their own experiences as teens, they recommended a structured environment.

My mom kept [my brother and me] active. They didn't want me just to be at the house not doing anything.

For some, it's hard to go to work, and then you don't have anyone to watch your kids because maybe you don't have family in the area.



Stakeholder Perceived Needs: Houston

Thirty-three stakeholders registered for the Houston meeting, and 24 participated. Area local health departments were well represented. Six staff members of the Houston Department of Health and Human Services attended, representing a variety of programs directed at women and children; two representatives of the Harris County Public Health and Environmental Services participated. The remaining participants included health care providers from the local hospital district, an FCHQ, and other health care systems, as well as individuals involved in the WIC program, juvenile justice, health insurance, mental health, and children's advocacy. None of the participants indicated that they work with children with special health care needs. Two staff members from DSHS attended the meetings as observers.

Identified Priorities

Houston stakeholders identified four priorities for their region. All four of them fall within the category of crosscutting issues: education and awareness, coordination and continuity of care, mental health services, and oral health/dental services.

Education and awareness. Most of the participants agreed that education and awareness for families and providers is a priority. Providers and families alike are generally not aware of available services and programs.

Parents are not being educated about child safety, parenting, or how to help their teenagers develop life skills. The issue is complicated by the fact that many families are in survival mode. They are dealing with immediate concerns related to safety, security, and food. Health is not on their radar.

Adolescents do not have access to evidence-based sex education at school. Homelessness among teens is also a growing problem. Once out of their parents' home, they are unaware that they may have access to health services.

There is a general lack of health education for women of childbearing age. Many women do not access prenatal care because they do not understand its necessity. Although breastfeeding has become more common, many women still do not understand how important it is. Women and providers, particularly those in rural areas, are often unaware of Title V services.

The Gulf Coast region is culturally very diverse, making health literacy a challenge. There is a huge need for culturally sensitive providers and programs. Targeted outreach and education are needed.



Coordination and continuity of care. Most of the participants agreed that coordination and continuity of care are priority needs. No mechanism exists for paying for continuous care, making it difficult or impossible for providers to focus on the whole child or the whole woman. Title V covers only prenatal medical and dental services.

Pregnant women frequently experience gaps in care as they transition from Title V to CHIP Perinatal. Title V pays for only two visits while a woman is establishing eligibility for CHIP Perinatal, a process that may take a long time and result in a break in services. Also, women have only 60 days of Title V services for themselves after delivering their babies.

The journey from preconception to prenatal and finally to interconception care is not easy. Women are at a loss when navigating the system for services for themselves or their children. It is difficult to sort out which programs may be available through schools and which of the variety of other programs are worthwhile and/or available to them. Parents do not always understand the need to ensure continuing care for children with chronic diseases.

Providers rarely coordinate or network. Clinics and hospitals do not have the ability to share records. Even within a single organization, coordination across programs may be faulty. When providers are unaware of services their clients may need to access, referrals are made in an untimely manner or not at all. In the worst-case scenario, a lack of coordination can be deadly. For example, prescription drug abuse has become more common in pregnant women because they take different medications prescribed independently by each of a number of providers.

Mental health services. Most participants agreed that mental health care is a priority need. Services for women and children are generally lacking, and the referral network is limited. Many mental health care providers do not participate in Medicaid or CHIP because of reimbursement issues. Insurance often does not cover mental health services, so families have no way to pay. The racial and cultural diversity of the Houston area also complicates access to mental health services. Providers are often not knowledgeable of or sensitive to cross-cultural issues.

The Houston stakeholders observed that women do not get counseling during pregnancy. Other than at FQHCs, providers do not routinely screen for postpartum depression during the perinatal period. Medicaid limits women to two postpartum visits, and Medicaid providers cannot follow up beyond those visits. They cannot continue to address postpartum depression or work with women on family planning, which is a factor in mental health.



Oral health/dental services. Most stakeholders felt that addressing oral health issues is a priority. Children lack access to dental care, and women lack access at multiple stages in life: before they conceive, while they are pregnant, and postpartum. Children who need intensive oral health treatment requiring anesthesia are in a particularly difficult situation because the dental specialists needed for these services may not be in the Title V network. People who are undocumented or uninsured do not have access to dental services. Even when services are available, many families do not understand the critical relationship between oral health and overall health, so they do not seek timely dental care.

How to Address the Priorities with an Upstream Approach

In pairs or in groups of three, participants brainstormed ways to address the priority of their choice. They then shared the following ideas for addressing each priority with an upstream approach.

Education and Awareness

- Increase awareness among providers about available resources and services.
- Increase outreach to clients and focus on health literacy.
- Value education enough to reimburse providers for providing it. Because they are not reimbursed, providers often do not spend adequate time educating patients. The results are painful and expensive. For example, newly diagnosed diabetics who do not learn how to use insulin or oral medications and manage food sources often end up in the emergency room.

Coordination and Continuity of Care

- Recruit more providers and expand the referral network.
- Eliminate geographical boundaries in referrals.

Mental Health Services

- Expand Medicaid services after delivery from 60 days to six months or a year.
- Provide more funding for mental health counseling.
- Expand mental health coverage so it can continue across the life course.
- Improve reimbursement rates and timeliness of payments to encourage more providers of mental health care to participate in Medicaid.
- Encourage providers to care for low-income women and children and those who are undocumented.
- Incentivize providers to screen for mental health.
- Cover more outpatient services.
- Allocate more money for education and training tools.
- Increase the number of counselors at schools.
- Use funds to raise community awareness about mental health issues and mental health care.



Oral Health/Dental Services

- Educate parents about the importance of dental care.
- Educate women about the importance of dental care for their children while they are pregnant (before the child is born).
- Draw the connection between dental health and overall health, especially for young parents who may not be aware of it. Poor dental health can lead to other serious health problems, and good nutrition is important for healthy teeth.
- Clear up misconceptions about baby teeth and emphasize the need to take good care of them. Head Start paid for hospitalization of a four-year-old to have all his teeth pulled and get dentures, because his parents had not taken care of his teeth.

Additional Needs and Problems

During the small group brainstorming activity, participants in Houston identified a wide variety of perceived maternal and child health needs and problems. Table 8 presents the ideas that participants did not choose to include in the top regional priorities described above.



Table 8
Additional Perceived Needs and Problems: Houston

Population Health Domain	Needs/Problems
Maternal and women's health	<ul style="list-style-type: none"> • Medical tests are often not reimbursed • Lack of specialists in rural areas • Limited access to services for women who are undocumented • Need for free contraceptives for women over age 23 • Lack of early prenatal care • Lack of screening referrals • Lack of insurance coverage
Perinatal health	<ul style="list-style-type: none"> • Only two visits are allowed under Title V • Service gap before the baby is enrolled in CHIP perinatal coverage • Medical tests are often not reimbursed • Chronic disease is not addressed beyond the pregnancy • Need to address maternal deaths related to prescription drugs • Hospital staff and nurses still do not understand the importance of breastfeeding
Child health	<ul style="list-style-type: none"> • Children are not showing up for oral health appointments • Lack of access to care for children • Parents lack motivation to get medical care for their children
Children with special health care needs	<ul style="list-style-type: none"> • Lack of access to specialty care providers • Lack of access for children who are not eligible for Early Childhood Intervention services
Adolescent health	<ul style="list-style-type: none"> • High school dropout rates have a negative impact on health • Lack of access to confidential birth control services • Lack of focus on adolescent health • Lack of adolescent immunizations • Lack of reproductive life planning • Lack of support systems for pregnant teens to help them finish school and develop employment skills • Need to address high teen pregnancy rates and unplanned pregnancies • Lack of early prenatal care • Adolescents are not getting HPV, hepatitis, and flu follow-up immunizations



Population Health Domain	Needs/Problems
Crosscutting issues	<ul style="list-style-type: none"> • Lack of transportation is a huge barrier to access in rural areas and in the city • Bureaucratic red tape is a barrier to access to health care • The high cost of health care restricts access • People who are undocumented face barriers to access, especially referrals

Final comments for DSHS

- The Gulf Coast region has a very diverse population. Many of its residents, including children from Central America, are undocumented. This diversity presents unique problems for Title V.
- Cross-cultural fears and attitudes regarding mental health issues must be taken into consideration.
- Title V representatives have no presence in the rural areas. They do not attend health fairs or other events where they could share information, so providers and nonprofits often are not aware of Title V services.
- Eligibility is too complicated, even for eligibility workers. Make eligibility requirements for state and federal programs similar to make it easier for clients and the people trying to help them.
- Connect data systems so that personal information only has to be provided once.
- Four agencies in Houston have been using the same eligibility software, Medicaider™, which has allowed them to coordinate and streamline eligibility for clients. They have heard that Title V is changing its billing and eligibility process and will require all Title V providers to use IBIS software. This change will double the work involved in their eligibility and billing processes, because providers will have to enter information into both IBIS and Medicaider.
- Transportation was mentioned once during the discussions. However, the person who brought it up stressed that in rural areas the lack of transportation is a huge barrier to access.



Houston: Regional Common Themes

Two common themes, discussed below, emerged from the findings from the focus groups with mothers and the priorities identified by stakeholders in Houston.

Health care is expensive and the system is difficult to navigate. Mothers in the Houston focus groups complained that the high cost of adult health care leaves them with no alternative but to wait in line, often all day, at the county hospital. Many had sought prenatal care during their first trimester but faced delays because of the time it took to get approved for Medicaid or other insurance coverage. They agreed that paying for care is less of an issue for children on Medicaid but acknowledged that quality of care varies from one Medicaid managed care provider to another. Many did not know how to sort through their children's options and navigate the system to get the best care. Stakeholders in Houston framed the issue a bit differently, but hinted at the same difficulty with getting health care and navigating the system. They pointed out that there is no mechanism to pay for continuous or comprehensive care. For example, Title V only pays for specific types of services, even if the woman or child needs additional services. They described the transition from preconception to prenatal to interconception care for women as complicated and noted that women do not have help navigating the system to access services for themselves or their children.

Children's behavioral health is a concern. Many mothers commented that they had sought help for their children's behavioral issues. They understand that students can be mean, and they want to know that their children are safe from bullying and other stressors at school. Stakeholders identified the need to address the general lack of access to mental health services for women and children as a priority, citing a referral network limited partly by the low rate of participation of mental health care providers in Medicaid and CHIP. They noted that in Houston, where the population is racially and culturally very diverse, providers who are unaware of or insensitive to cross-cultural issues present barriers to mental health services.



Ergebnisse

Die Ergebnisse der Untersuchung sind in Tabelle 1 dargestellt. Die Ergebnisse zeigen, dass die Teilnehmerinnen in der Gruppe, die die Intervention erhalten hat, eine signifikant höhere Zufriedenheit mit dem Training und den Trainerinnen sowie eine signifikant höhere Selbstwirksamkeit und eine signifikant höhere Motivation zur Teilnahme an weiteren Trainingsmaßnahmen aufwies als die Teilnehmerinnen in der Kontrollgruppe.

3.2.2. Zufriedenheit mit dem Training und den Trainerinnen

Die Teilnehmerinnen in der Gruppe, die die Intervention erhalten hat, zeigten eine signifikant höhere Zufriedenheit mit dem Training und den Trainerinnen als die Teilnehmerinnen in der Kontrollgruppe. Die Teilnehmerinnen in der Kontrollgruppe zeigten eine signifikant höhere Zufriedenheit mit dem Training und den Trainerinnen als die Teilnehmerinnen in der Kontrollgruppe.

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Panhandle Findings

SUMA conducted two focus groups with mothers in Amarillo and a stakeholder meeting in Lubbock. Focus group findings and stakeholder perceptions are reported below, followed by overall findings for the Panhandle.

Focus Group Findings: Amarillo Mothers

Finding: The top health concerns identified by mothers in Amarillo revolve mainly around the nutritional health of their families. For participants in one of the two Amarillo groups, fast food is the number-one concern, in part because of its effect on health. Moms in the other group are most concerned with proper diet and exercise. Participants in both groups are also concerned about various diseases, such as high blood pressure and diabetes.

- Nutritional concerns (e.g., diet, prevalence of fast food)
- Eating healthy and getting enough exercise
- Family history of disease (diabetes)
- Diabetes
- High blood pressure
- Heart issues
- Asthma
- Obesity
- Cancer
- Cavities

Finding: Mothers in Amarillo said they know what constitutes healthy cooking/eating, but some described meals (or accompaniments) that are less than healthy. While many started their meal descriptions with a healthy protein such as baked chicken, they also mentioned starchy side dishes such as macaroni, bread, or mashed potatoes. They tended to name at least one vegetable as part of a healthy meal.

Many said they typically cook three to four times a week because of time constraints (e.g., working late, other obligations), but others cook every night because of budgetary concerns.



Many indicated that they struggle with kids who have grown used to fast food, and they expressed considerable concern about it when asked. These moms talked about their efforts to wean their kids from fast and processed foods and get them used to — and liking — healthier alternatives. However, they also spoke of the challenges in the fight for healthier eating.

Normally I cook at home. We try not to eat out because it's expensive and because I don't like to eat out that much. I cook, but when I'm tired, my husband cooks. Tonight he made sloppy joes, but with green beans. We always have vegetables or fruits.

He doesn't like anything homemade. Only corndogs or chicken nuggets.

For some reason I can get mine to eat hot dogs, but nothing else.

Mainly she eats cereal. When she's not being picky, she'll eat off of our plate, but other than that she'll just get mad at us for trying. Cereal, crackers, things like that are what she'll eat. She refuses to eat anything else.

It's easier and quicker, and less cleanup. That's why I guess we just tend to get pizza or chicken nuggets, because it's easy, and they all like it. That's why. It's fast and easy.

These moms also talked about their own struggles to eat well. They want to be good role models for their kids and benefit from the energy that good food affords, but they feel challenged by cravings and lack of time to prepare healthy meals. Even grandparents can prove to be a challenge. Sometimes they do not back up healthy eating habits when children are with them.

My kids. I try to eat healthy for them.

[I want] not to have health problems.

I make sure my son eats healthy just so he doesn't have certain health problems like diabetes and things like that. I try to do it to teach him, too.

A challenge would be not having time to cook a meal.

My mom wants her grandkids to have the memory of her always having fresh-baked cookies at the house, so I would come to school, and my kids would stay there, and Grandma and Grandpa would just let them eat whatever they wanted.



Moms shop regularly, mainly at grocery stores such as United and Walmart, but occasionally pick up a few items at a convenience store when they are in a hurry. Most said they serve their families fresh fruits and vegetables, although they sometimes serve frozen as well. Canned vegetables do not appear to be used much by these moms.

Finding: The Amarillo moms were able to identify plenty of ways they and their children can stay active. Moms talked about doing things with their children, including going to the park or swimming at a friend's or relative's house. Many moms also have gym memberships they use, and some of these gyms offer child care, which helps them fit exercise into their schedules. A few exercise on their own, running or doing Pilates at home with the help of DVDs. Some also make a point of walking to destinations (e.g. the store, their mom's house) when they can.

Some moms also have active jobs that keep them on their feet, lifting and bending, but others have sedentary desk jobs that necessitate getting exercise elsewhere.

The energy and overall healthy feeling they get from exercise motivate these moms. However, their challenges include difficulty prying their children away from electronics (e.g., television, video games, computers); feeling too tired to exercise after a long day; being "lazy"; not having enough time to fit exercise into their schedule; and inclement weather, especially during the hot summers.

When I lived in Miami I used to always go to the gym. ... Now that I'm too busy with work ... I feel like I don't have the time to go out, take a walk, or go do some running or even go to the gym any more.

Being in a good mood and happy. All of the endorphins.

I think a positive thing is if you're healthy, your kids will be healthy.

Time. Just being too busy.

Finding: While these women seem savvy about the effects of smoking and secondhand smoke, they said others in Amarillo appear less concerned or less well-informed. Some of the focus group moms currently smoke, while others quit when they were pregnant. Those still smoking cited stress and smelling others' smoke as temptations that can draw them back into smoking, despite their best intentions to quit.



All moms in the Amarillo focus groups were able to list ailments that can be associated with smoking/secondhand smoke – for example, asthma, low birth weight, preeclampsia, whooping cough, and chronic ear infections. Several said they are aware of the SIDS-smoking connection.

My mom has a really bad addiction. She had a heart attack from it, and she still won't stop. She has to go in and get the artery that collapsed before re-fixed, because she just won't stop.

Women in one of the Amarillo focus groups said they have taken steps to mitigate the effects of secondhand smoke on their kids (for instance, one woman required a grandmother who smokes to change her shirt and wash her hands before she holds the baby). However, they are not always able to completely protect their children. A smoker at the park or a father who smokes (along with his family) can expose their children despite their best efforts.

I won't let my mom hold her or anything, until after she changes her shirt and coming inside. I make her wash her hands.

My neighbor, she'll smoke outside, her baby right here, and he's like three months old. She'll smoke right in front of him.

My kids have been around smoking since day one. Their dad, his whole family smokes. They chain smoke. I would try to keep them away, but he didn't ever listen to me.

Finding: Amarillo families need better access to specialty health care that doesn't require traveling to Dallas. Several Amarillo moms said their children have special health care needs that necessitate traveling to another city – often Dallas – for specialized care.

My youngest son was born with spina bifida. ... He goes to Texas Tech, but if something ... goes wrong, they'll fly us to Dallas. That's one thing I don't like about here in Amarillo. They don't have what he needs here.

I have to take my daughter to Lubbock for her club foot, so it's kind of an inconvenience.

My son wears braces ... and he has to walk with a walker. ... He's getting physical therapy here, but for his braces and everything, I have to go to Dallas to get all that.



A number of moms said they go to Texas Tech for their health care but criticized the inconsistency of not always seeing the same physician. Some also noted communication problems with doctors whose first language is not English.

Finding: Some Amarillo moms said that while they can easily find good health care options for their kids, they struggle to find the “right” doctor for themselves. This has caused some to forego going to the doctor altogether, opting to treat illnesses on their own instead.

Before my pregnancy and stuff, I never even looked their way, even when I was sick. When I got pregnant, I'd go to the doctors just for the baby, and Luna goes to the doctors, but as for us, we really just don't deal with them.

We've got the home medicines. We do everything at home that Grandma can try, and then we go to the doctor. If it's just worse and we can't cure it at home, then we go to the doctor.

Those who do go to the doctor — for example, a few with chronic illnesses — said it can be difficult to find a doctor who will accept new patients and take Medicaid.

Finding: Amarillo moms experience a lack of consistency in their prenatal/pregnancy/postpartum care. Moms revealed that they first sought prenatal care between three weeks and six months of pregnancy. A couple of participants who accessed prenatal care late in their pregnancies (at four months and six months) cited insurance issues as the reason they did not go in sooner. A few others who didn't go until later said they found out about the pregnancy late, when they had another health issue that needed medical attention.

Almost all participants started taking prenatal vitamins, but most stopped taking them either because they forgot or because the pills made them feel nauseous. Most said they just discontinued use without telling their doctors. One woman said that to make up for the lack of prenatal vitamins, she drastically altered her diet to take in the necessary vitamins and minerals, but others did not appear to have made any dietary changes.

A small number of participants said their doctors had talked to them about the importance of folic acid in preventing neural tube defects. However, one woman whose third child was born with spina bifida said she only found out about the importance of folic acid after his birth. She was told about folic acid at Scottish Rite Hospital in Dallas.



A number of respondents said they took childbirth classes prior to the birth of their child or children. One took a class because it was required by her military insurance. Some said they took parenting classes while still in high school.

A total of nine participants were induced – a few because they were past their due dates, others because of concerns for their own health or the baby's health. Birth experiences varied. Some said they had a difficult labor and birth, while others said things progressed very quickly and easily and they delivered with little trouble. Four Amarillo women had C-sections. Poor birth outcomes included a couple of babies who were born prematurely, one child born with spina bifida, and one with a club foot.

I was in labor for 35 hours, and then she got stuck in my hips. I had to beg for a C-section.

My first one, I was in labor for six hours. My second one was five. I didn't feel anything. ... I didn't even feel my daughter come out. I was just talking to the nurse, and I didn't even have to push. She just came out.

I had a lot of complications. My pregnancy was great, but my labor – they almost lost my son like three different times, because his heart rate kept dropping.

Only a few Amarillo moms said they had a midwife.

A number of women said they went in for their six-week checkup. A few who didn't get the checkup said they were off Medicaid and therefore the visit was not covered when the six-week point rolled around.

Birth control was discussed prior to delivery, and two of the women said they had their tubes tied (tubal ligation) after giving birth. Two moms in Amarillo had requested that their tubes be tied but were refused because they were not yet 21, the age of consent for a tubal ligation. Understandably, some of the women expressed frustration with this requirement.

I asked for one [tubal ligation]. I begged for my tubes to be tied, because I had my son, and [a] month later got pregnant with my daughter. Four months later I got pregnant with my other daughter. I'm done, I don't want any more kids. ... [But] they wouldn't tie my tubes. They said I wasn't old enough.

What I don't understand is, Medicaid won't pay for your tubes to be tied, but they would pay for another child's doctors and stuff like that for 18 years of life, instead of one time of surgery.



More than half of the moms in the Amarillo focus groups said they breastfed their babies, although not without some difficulty. Some said their breast milk didn't come in, so they were not able to breastfeed, and others had trouble with babies latching on. In one group, of those who did breastfeed, one discontinued because of a kidney infection, and others said their milk simply dried up. They discontinued anywhere from two to six months after childbirth. One mom said she intends to keep breastfeeding until her child has teeth or reaches 12 months, whichever comes first. Many said their doctors told them about the importance of continuing to take their prenatal vitamins while they breastfed.

Finding: Moms agreed that there is a teen pregnancy problem in Amarillo. They mentioned several factors that they believe contribute to high teen pregnancy rates in their city. Some said it has become the norm in their community for teens to be pregnant. They also said that bad parenting of teens, coupled with a lack of sex education at home or in school and no access to free birth control, leads to what they see as a pervasive teen pregnancy rate. Some even said they feel teen pregnancy has been glamorized by shows like *Teen Mom*.

Parents are too ashamed to talk about the kids' cycles. ... "Oh, I'm not going to talk to them about that." That's how my mom was with us.

My cousin, she's 15 and has two kids. Her sister, she's 24 and has eight kids. She just had another one, so nine. Her other sister's 18 and she has four kids. It just goes down the line.

It's just normal now, I think. If you see a girl that's 16 and not pregnant, you're like wow, she's not pregnant. It's surprising that they're not pregnant.

I don't think it's the culture, I think it's just how you were raised, and your parents.

I've only lived here two years and it seems like young women having kids young are the norm here.

I guess it's who you're raised by, also. My sisters and I were all raised by my grandma, and we all waited until we were out of school, high school. We did not have any boyfriends in high school.



Moms noted that there are some resources available for teens, including Haven Health Clinic (which has replaced Planned Parenthood). However, participants in one group noted that a drawback of Haven Health is that it charges for services, whereas Planned Parenthood had offered services for free. Moms in one group pointed out that teen moms can also find assistance through programs such as WIC and CareNet, which offers clothing and other support.

Moms in one group discussed the availability of day care at two of the Amarillo high schools, which they see as both a mixed blessing. Although it helps young moms finish their education, some fear it could also be sending the wrong message about teen pregnancy.

It is good, but then it's bad, too, because it's showing the other kids, "Hey, we got you if you have a baby at school."

"It's okay. We'll take care of them. You go to school. We got it."

Amarillo moms in one group said they feel that having someone talk to teens on their level is imperative in cutting down the teen pregnancy rate. Many acknowledged that a message coming from an adult is likely to be ignored, while the same message delivered by a peer has much greater influence.

Finding: A couple of the Amarillo moms said their children have behavioral issues and. While some know where to go for help, others do not. Two Amarillo moms mentioned Early Childhood Intervention (ECI) as a resource for children with both behavioral and medical problems. Others brought up the Family Support Center. One participant took her son to the Department of Health after the school expressed concern that he might have ADHD. A couple of the moms did not know where to go and learned of ECI during the discussion.

My son goes to ECI for his spina bifida to help him walk. It's like physical therapy. They do speech impediments. If your child's delayed, they'll help you with that.

He started acting out at school a lot, and so the principal there actually recommended — it's called the STAR program. We went to the Department of Mental Health, and we talked to the psychiatrist there, and he kind of did a little interview with him. He looked at me and he said, "Honestly, I don't think he's acting out because he has ADHD. I think he's just bored with the classroom setting that he's in and so that's the reason why he's acting out so much." ... He said, "If you want me to, I can diagnose him with ADHD." He asked me if I want him to diagnose him. I was like, "No, I'd rather you not."



Finding: While some moms utilize day care, finding the right one has taken work. Others said they prefer not to use day care because of quality and safety concerns.

Findings Related to Concerns About Health and Safety of Children of Different Ages

- **Birth to 2 years.** Moms with kids this age said they worry about things like product recalls and baby-proofing their homes. Some said they have been lucky to get their children into a school program (such as Early Head Start), but at least one said she is “too attached” to her child to put him in day care. Some of these moms are aware of a state-sponsored website that rates child care facilities and lists violations. A couple of moms said they have looked at the reports on the website to help them choose a day care.

I think all child-care places should have that online video thing where they can go in and check on them. Only the really expensive ones have it.

I don't want my child in a day care until she can fully talk and say sentences.

I went on the Web, that State of Texas website, and I background-checked the day care, background-checked the teachers and everybody.

Stakeholder Perceived Needs: Lubbock

Seventeen stakeholders registered for the meeting, and 15 participated. Participants included three representatives from the Texas Agrilife Extension Service, three from a local community health center, three from the local MHMR center, and two from a community-based organization that provides case management. Also represented were the Abilene-Taylor County Public Health District, a university health system, a health insurance provider, and a child development center. Five participants indicated that they work with children with special health care needs and their families. Two staff members from DSHS attended to observe the meeting.

Identified Priorities

Lubbock stakeholders identified four priority needs for their region. Three fall within the category of crosscutting issues: awareness of available resources, access to services, and collaboration. The fourth priority is specific to adolescents: sex education and access to birth control.



Awareness of available resources. Most participants agreed that both providers and families are unaware of available resources. For example, many families do not know about WIC, extended clinic hours, the 2-1-1 information line, contractors who serve children with special health care needs, or DSHS programs and public health services for which they may be eligible. The lack of utilization of DSHS programs is evidence of this perceived lack of awareness. Parents often do not know where to go for help and do not understand their options. Providers are often unaware of the full array of available resources, making it difficult for them to direct families to needed resources. The “red book” used by 2-1-1 operators is designed to direct families to available resources; however, it is only updated yearly, so it is not a reliable tool. The 2-1-1 line should not be the only source of information about resources.

Even when providers are aware of available resources, they do not spend enough time informing and educating families about them. There are multiple opportunities for education – for example, case management meetings, well checks, and sick checks – but providers do not spend enough time on comprehensive education.

Access to services. Most stakeholders consider access to services a priority. A lack of awareness of available resources contributes to limited access, but a number of other factors also come into play. Many families do not have the means to pay for health care. There is not enough funding for affordable programs and services. Some women and families give up trying to access services because of bureaucratic barriers. The same complicated bureaucracies discourage providers from participating in Medicaid and other programs, limiting clients’ access or resulting in untimely access.

Transportation issues result in restricted access to health care. Even in cities where public transportation exists, bus routes are limited and do not run after hours. Fares are costly. People who live in rural areas may have to travel hundreds of miles for health care without the benefit of public transportation.

There are not enough providers for women seeking prenatal care. It is also hard for women and children to access dental, hearing, neurological, and other specialty services. There are not enough specialists in general, and even fewer who are willing to work with children with special health care needs.

The transition from pediatric care to adult care often entails gaps in service. Health care services for older teens and young adults are in short supply. This problem is compounded for those with special health care needs.



Provider attitudes can discourage access, especially follow-up visits. When a woman has a history of substance abuse or has failed to seek early prenatal care, a provider who is perceived as judgmental can be intimidating, and the woman may decide not to go back.

Collaboration. Many participants agreed that collaboration is a regional priority. In children's health, there is a lack of coordination across health care providers (doctors, nurses, and others), teachers, and parents. For all populations, there is a lack of coordination and collaboration between primary care providers and specialists.

Providers do not collaborate widely among themselves. Referrals are often limited to known entities within the area's two competing hospital systems. Providers also compete to "make the reporting numbers" for their respective funders. Providers do not take advantage of community health workers, who could fill some of the gaps for families.

Sex education and access to birth control. Most participants agreed that sex education and access to birth control for adolescents is a priority need. The region has high rates of teen pregnancy and STDs and the highest rate of repeat teen pregnancy in the state. Schools do not offer sex education classes, and too many parents are uninvolved in educating their children about sex and STDs. Adolescents with special health care needs require this education as much as those in the general population. There is a need for culturally sensitive sex education that takes family belief systems into account. Beyond education and awareness, teens need access to affordable contraceptives, especially long-acting contraceptives.



How to Address the Priorities with an Upstream Approach

In pairs or in groups of three, participants brainstormed ways to address the priority of their choice. They then shared the following ideas for addressing each priority with an upstream approach.

Awareness of Available Resources

- Collect information about resources and share it with:
 - Doctors and hospitals
 - Child-care providers and workers
 - Community health workers
- Use social media.
- Build trust and a good reputation.

Access to Services

- Increase reimbursement to Medicaid, CHIP, and providers for children with special health care needs so they are more willing to participate in those programs.
- Increase outreach at the state level. Provide more funding for state-level awareness initiatives so contractors do not have to use their money for outreach and the message will be consistent across the state.
- When state agencies have projects with similar purposes and target audiences, pool money to avoid duplication.
- Improve the quality of service by reducing the number of clients served by social workers, case managers, and others who work in social services. No professional can provide quality service with a caseload of 120 clients.
- Shorten and streamline the provider enrollment and certification processes so providers do not have to jump through so many hoops to participate in state and federal programs.
- Reduce the amount of time it takes clients to get benefits. Share applications across agencies and programs so people can qualify for services sooner.

Collaboration

- Give providers incentives to collaborate, in particular so that specialists will work more closely with primary care providers. Collaboration is not a billable service, but outcome measures that encourage or require collaboration could be built into contracts.
- Organizations that get funding from the same stream are territorial. A clearing of the waters is needed. Organizations are not going to run out of clients, and everyone will make their numbers. Providers need to sit down with “competing” entities and work out which organization will serve which locations/groups.



Sex Education and Access to Birth Control

- Require medically based reproductive health education in schools.
- Change DSHS and Health and Human Services Commission (HHSC) policies to lower the age limits for the Texas Women's Health and Expanded Primary Health Care programs. This would allow funding for contraceptives for adolescents.
- Lower the minimum age requirement (currently age 21) and eliminate the 30-day waiting period for sterilizations.
- Educate elected officials. Providers need to step up and bring attention to teen pregnancy statistics. The schools will not offer real sex education unless local officials are behind it. Officials will not take action unless the communities most affected by teen pregnancy believe and communicate that it is a problem.
- Educate and empower parents. Parents may not be aware that teen pregnancy is a problem, may not believe it is a problem, may not feel empowered enough to speak up, or may be so busy working that they do not have time to speak up.
- Increase funding to educate adolescents about STDs.
- Make legislative changes so funding can be used for comprehensive sex education, not just abstinence programs.
- Frame teen pregnancy prevention as part of an immunization package. Pregnancy immunization provides four years of birth control.
- Frame reproductive education as a health issue, not a morality issue.

Additional Needs and Problems

During the small group brainstorming activity, participants in Lubbock identified a wide variety of perceived maternal and child health needs and problems. Table 9 presents the ideas that participants did not choose to include in the top regional priorities described above.



Table 9
Additional Perceived Needs and Problems: Panhandle

Population Health Domain	Needs/Problems
Maternal and women's health	<ul style="list-style-type: none"> • Need to raise awareness and increase education about obesity prevention • Need to educate providers and raise their awareness of the importance of general nutrition and nutrition for children with special health care needs • Need to educate providers on how to work better with "health" and the big picture
Perinatal health	<ul style="list-style-type: none"> • Need to educate providers and raise their awareness of the importance of general nutrition and nutrition for children with special health care needs • Need to address late entry into prenatal care • Need to educate providers about not acting judgmental: scolding a woman for starting prenatal care late may discourage her from coming back • Need to educate providers on how to better work with "health" and the big picture
Child health	<ul style="list-style-type: none"> • Educate providers on how to communicate better with parents – for example, how to explain the Apgar score to evaluate a newborn's physical condition • Lack of timely preventive care • Young parents do not know what "healthy" means • Need to improve parents' health literacy and comprehension • Need to get children to come in for well checks, not just immunizations • Need to improve parents' awareness of the importance of well checks
Children with special health care needs	<ul style="list-style-type: none"> • Need for services to help in the transition from pediatric to adult health care, and in accessing general health care providers and specialists for adults • Need for dental care • Need to get children to come in for well checks, not just immunizations • Lack of dental providers for children with special health care needs • Lack of specialists • Lack of funding for programs for children with special health care needs



Population Health Domain	Needs/Problems
Adolescent health	<ul style="list-style-type: none"> • Need to get adolescents to come in for well checks, not just immunizations • Lack of school-based clinics and well checks for teens
Crosscutting issues	<ul style="list-style-type: none"> • Problems retaining clients • Address the high rate of noncompliance: Is it due to lack of transportation? Language barriers? Young parents who do not want to ask questions? • General health education • Address intimate partner violence • Address the overall impact of obesity • Need for ongoing education and “refresher” courses in nutrition, hygiene, etc. • Need to address language and cultural barriers and the challenges of serving a refugee population speaking 56 different languages • Lack of parent education • Need to address abuse of children, adolescents, and women

Final comments for DSHS

- Involve a wider range of stakeholders in meetings like this one – for example, representatives of city government and education – not just the health sector.
- Thank you to DSHS for organizing the meetings across the state to give us a chance to provide input.

Panhandle: Regional Common Themes

Three common themes, discussed below, emerged from the findings from the focus groups with mothers in Amarillo and the priorities identified by stakeholders in Lubbock.

General access to health care is limited. Several mothers in the Amarillo focus groups said they can find good health care options for their children but struggle to find a doctor for themselves. Some lack insurance; others have found that many doctors do not participate in Medicaid or do not accept new patients. Stakeholders in Lubbock identified access to services as a priority need and attributed limitations to access to a number of factors: inability to pay for services, bureaucratic barriers, lack of transportation, too few providers, and negative or intimidating provider attitudes.



Access to specialty care is particularly limited. Several mothers said they have to travel to Dallas to access providers for their children's special health care needs. Others make shorter trips to Lubbock but are not satisfied with the services because they see a different specialty provider at each visit. Stakeholders identified overall access to care as a regional priority. They noted that there are not enough specialists in general and even fewer who are willing to work with children with special health care needs. They also identified as a problem the lack of coordination between primary care providers and specialists.

Teen pregnancy is a problem. Mothers in the Amarillo focus groups acknowledged the problem of teen pregnancy but were divided on the cause of the high rates: some attributed it to bad parenting, others to a lack of access to free contraception, and yet others to changing social norms making teen pregnancy seem acceptable or even glamorous. Some of the mothers said a prevention message delivered by a peer is more likely to resonate with teens than the same message would if it came from an adult. They pointed out that the primary pregnancy prevention resource in the community now charges for services, making access for teens more difficult than it used to be. Two of the participants had requested tubal ligations but were refused because they were under age 21. Stakeholders identified sex education and access to birth control as priority needs, noting that the region has high rates of teen pregnancy and STDs and the highest rate of repeat teen pregnancy in the state. They want to see parents and schools more involved in education about sex and STDs, and more attention devoted to culturally sensitive sex education. Stakeholders also said teens need access to affordable contraceptives. During their discussion about upstream approaches to meeting needs, they recommended that the minimum legal age of consent for sterilization (currently age 21) be lowered and the 30-day wait for sterilizations be lifted.



Central Texas Findings

SUMA conducted two focus groups with mothers in Killeen and a stakeholder meeting in Waco. Focus group findings and stakeholder perceptions are reported below, followed by the common themes that emerged for Central Texas.

Focus Group Findings: Killeen Mothers

Finding: The mothers in Killeen generated a long list of top health concerns, both physical and mental. Cancer, diabetes, and mental health issues headed the list.

- Cancer
- Diabetes
- Mental health issues (ADD/ADHD, PTSD, depression)
- Children's lack of exercise and social development resulting from too much screen time
- Obesity
- Hypertension
- Sleep apnea

Finding: Mothers in Killeen can readily describe a healthy meal. However, most actually cook healthy meals less than half of the time during the week. Most of the moms described a healthy meal as consisting of a baked or grilled protein such as chicken; a starch such as potatoes, corn, or bread; and a green vegetable, usually steamed. While they all know they should be healthier and want to eat this way, the majority said this type of cooking only happens two to three nights a week at the most.

My family is really bad. Me and my husband's schedules are completely two different schedules. I work mornings. He works afternoons, so it's really hard to actually have a meal, so we do a lot of fast food. We've actually been cutting back a lot – maybe once or twice a week now – but it was almost every day all week long, so we've cut back.

These moms typically shop at Walmart or H-E-B. Most have convenient access to stores, although many said they need to drive to get there. They claimed to buy primarily fresh fruits and fresh or canned vegetables.

I try to buy fresh vegetables. That's my main thing, not the canned stuff. I try to get fresh corn on the cob, fresh greens, or stuff like that so I can incorporate into each meal. At least they're getting something that's been growing, and not something that's been processed so much. Everything is just processed.



Factors that encourage moms to eat a healthy diet include a desire for better overall health (e.g., lower cholesterol) and the good feeling they get from eating healthy foods. A substantial challenge that prevents many from eating healthily is cost: They point out that healthy foods cost more than junk food, which often makes it hard to fit them into their budgets. Another challenge is convenience: Fast food is much more convenient for these women, who are often short on time and too tired to cook. Interestingly, kids' preferences did not come up as much among these women as it did in other cities. A few said their kids prefer "bad" foods, but most did not mention this as a significant challenge.

Eating healthy is more expensive, and that makes it hard.

Eating healthy is always more expensive than just getting something quick and fast to make.

When you have kids, a lot of the times they don't want the healthy food. They only want the chicken nuggets from McDonald's.

Finding: Killeen moms engage in several different activities to stay active, both with and without their kids. Many described the types of activities they like to fit into their schedules, including running, going to the gym, exercising at home with DVDs, and taking exercise classes with their kids. While some go to parks and recreation centers, others (such as those in the Cove neighborhood) said there are not many parks in their area. They need to either drive to Killeen to find parks or look to another resource for outside activities (such as their own backyards or a relative's backyard).

Our kids ... want to be outside all of the time, nonstop. They want to be out climbing the trees. They want to run. Anything they can do outside, they're doing it.

We take our kids to the park. Even though they're very young, they both love to be outside already. We take them to the park, and we play with them in the park. We try to be active with them.



Factors that positively help these moms get the proper amount of physical exercise for themselves and their children include having jobs that keep them active and keeping up with their children. Some are challenged by transportation. Some women share a car with their spouses and thus need to use public transportation, but bus stops are not always conveniently located. Others said time is limited, as are child-care options, and both these factors contribute to a lack of opportunity for exercise.

I refuse to let them stay in the house all day, especially my husband. My husband does not let them stay in the house all day. "You need to go outside."

We'll go to the park and just throw the ball, play catch and stuff, and then do cartwheels, run around.

My child's age makes it easy for me to work out. It takes a lot of energy.

Finding: There is a need for education on the hazards of smoking during pregnancy and around infants in Killeen. Smoking is an issue that concerns these moms.

Respondents in one of the Killeen focus groups noted that the trend in Killeen is toward creating nonsmoking environments at workplaces, colleges, and restaurants, although those in the other group indicated that there are still many places to smoke, and many smokers.

They're trying to do away with it. I know Temple College used to have smoking areas. Now there is a nonsmoking campus. Scott & White, you can't smoke if you work at Scott & White. You can't smoke anymore in restaurants.

At least half of the women in one group smoke; even more participants said their partners smoke. One woman said that, late in her pregnancy, she told her doctor she was going to quit smoking. The doctor responded that she was too far along and it would be traumatic for the baby. Some of the women said they tried to quit smoking during pregnancy. While a few managed to cut down on smoking, none managed to stop completely. Others mentioned partners who smoke, including one who did so around an infant born with breathing problems.



The information that moms got from health care providers seems to vary from person to person. Some said they were told about various ailments and concerns related to smoking and secondhand smoke, but others had not heard anything. A few respondents said their doctors told them about the connection between SIDS, low birth weight, and exposure to cigarette smoke, but others only knew about asthma and other chronic breathing problems that could result from exposure. Awareness of programs and products in this population is at a low level.

My doctor never told me anything about SIDS.

Finding: Moms in Killeen have some difficulty accessing good, consistent health care. For a number of Killeen women who are not in military families, paying for health care coverage is problematic, even with the new health care marketplace. Put simply, the monthly premiums are too expensive for them to pay while meeting their other financial obligations and, as a result, they go without health care.

My problem is they expect you to have insurance now with the whole new Obamacare. I can't find insurance that will cover me.

At least one military mom who does have health care coverage expressed frustration that she and her kids see a different doctor at every visit, making it impossible to forge a relationship with any one health care provider.

I know it's not necessarily Darnell's fault, but I saw a different person every single time. I was unable to develop a relationship with anybody. They were always changing in and out. My kids have not seen one same doctor at the same time, so they can't develop a relationship, and that just drives me absolutely crazy. You have to be able to have a relationship with your doctor to be able to talk to them about things and to be comfortable. You can't do that with the Army the way it is.

Finding: Like moms in other cities, the Killeen moms perceived a lack of consistency and quality in their prenatal/pregnancy/postpartum care. Moms generally started to get prenatal care anywhere from six weeks to three months into the pregnancy, although one mom discovered she was pregnant only two weeks before her due date. Their reasons for waiting to see a doctor ranged from not having insurance coverage to simply "not paying attention" and not actually finding out that they were pregnant until two or three months in.



Most women said they were pleased with the quality of their prenatal care. Several have doctors they “love,” and none seemed to have had traumatic or dissatisfying experiences. However, several women in one group who had the same doctor at one point in their pregnancies complained that she was not particularly communicative, causing at least some women to switch doctors midway.

I had to switch doctors, because she didn't really talk to me. ... She was trying to push for me to have another C-section. She didn't really ask me what I wanted. She was taking control over everything. I didn't want to do a repeat C-section. ... I just switched to a doctor that would involve me in the pregnancy.

While it appears that all women in the focus groups had started taking prenatal vitamins, quite a few said they stopped at some point during the pregnancy, usually because the vitamins nauseated them. Others commented that the vitamins are hard to swallow because they are large. A few said they were instructed to take Flintstones vitamins when they couldn't tolerate the traditional prenatal vitamins. Many women in the groups were aware of the importance of folic acid for the developing baby, having heard it either from their doctor or from a family member. However, some said they were not told and did not know about this.

A couple of women in each group took prenatal classes, but others said they learned from family members what they felt they needed to know. At least one consulted the Internet for information.

I do a lot of research. I'll be on Google all of the time just googling stuff.

Between having ... my husband and my mom and my dad, I didn't need it.

A total of eight moms in both groups were induced for a variety of reasons. In a couple of cases, the women were induced because they were past their due dates; others showed signs that the baby was in distress or the labor was not progressing. Six had C-sections.

I was overdue. My baby was like – I was supposed to have the baby on the seventh of December, but I didn't have the baby until the 19th of December. When I went in that day, the problem was that there was not enough water, amniotic fluid, so they had to induce me.

Only a couple of the Killeen women appear to have used a midwife.



Most of the focus group participants went for their six-week checkup. Some said that in addition to checking their sutures or incision, their doctors also discussed birth control with them. A number of respondents' doctors screened them for postpartum depression at that appointment. Of the few who did not go to their six-week checkup, one said she was told she could skip it as long as there were no problems, and another was so traumatized by her birth experience that she didn't want anything to do with the doctor or hospital after that.

They asked us to come with the baby after six weeks. If you have a problem, you can come get help with a problem. If you're feeling fine and if you're good, don't come and no checkup.

Some said their doctors talked to them about birth control at the six-week appointment, although others said this discussion took place when they were at the hospital for the delivery. One woman said her doctor implied that as long as she was breastfeeding, she didn't need to use birth control, something the other women in the group pointed out as erroneous.

She said, "Well, you're breastfeeding. ... You have more time to choose what kind of birth control you want."

When asked about breastfeeding, quite a few women said they had breastfed. Several stopped after a few months, but several more said they continued until the child was 15 or 16 months old. At least one mother is currently breastfeeding her child.

Finding: Many of the Killeen moms have children or stepchildren with behavioral issues. Some (for example, mothers from military families) are aware of resources that can help, but at least one non-military mom was concerned that summoning help could mean involving CPS, which she doesn't want to do. Many moms said that their kids on Medicaid have resources, including Care Options for Kids in Waco. However, one mom with kids on Medicaid was having trouble accessing care for her child precisely because he is on Medicaid.

As a civilian, just taking the kid to therapy involves CPS. It makes something bigger than it has to be.

Care Options for Kids. They're based out of Waco, but their therapists drive to your home. You don't go to the office. They come to you so that the kids are comfortable in their home, so that way you can see the therapist working with them. You can tell the therapist what's going on.



Findings Related to Concerns About Health and Safety of Children of Different Ages

Some Killeen moms have concerns about leaving their kids in day care. However, it is not clear how many focus group participants are using day care and how many are using another resource for child care (such as care from a family member).

I have safety concerns for my son because he can't talk. He can't communicate with me and tell me, "This person is doing this to me." Lately it's been a lot in the news, like children are being abused in day care centers. They were being drugged in day care centers to make them take naps. My son can't tell me what's going on. He doesn't know how to tell me. I don't want to find out later on when it's too late that he's been abused, or something like that. That's my concern.

- **Birth to 2 years.** In addition to concerns about the quality of child care, moms are concerned about threats to their child's overall safety (falls, choking, electrocution, etc.) and SIDS.

My son is eleven months old and he's a daredevil.

Now that she's walking around, I'm worried about her falling, or messing with the sockets, or falling off the couch because she's a heavy sleeper.

- **3-5 years.** With children able to communicate problems at this age, day care quality is less of a concern. However, the effects of being around other children weigh on moms with children in this age range.

Being around the other children and then getting sick, and him picking up really bad habits from other children, because I want my son to be brought up in a certain way. I don't want him to do stuff. If other kids are just able to run rampant, I don't want him to fall into their habits.

Mothers are also concerned with their kids' eating habits and school safety.

My concern is about school safety ... I'm always telling my mom I'm so scared about safety at school. A lot of things are happening. People are doing crazy things at school.

- **6-13 years.** While none of the mothers in the focus groups have kids in this age group, bullying, depression, drug use, and the emergence of other behavioral or mental issues came up as concerns relevant to this age range.



- **Teen years.** Again, none of the moms in these focus groups have teenage kids, but it is evident from their responses to the topic of teen challenges that none are looking forward to seeing their children enter those years.

I don't even want to think about it.

I was a horrible teenager.

It's going to be bad.

Teen pregnancy, STDs, and HIV are some of the concerns mentioned by Killeen moms.

Stakeholder Perceived Needs: Waco

Twenty-two stakeholders registered for the meeting; 15 attended. Four representatives from the local public health department attended. A number of community-based organizations were represented, including organizations focused on domestic violence, prenatal care, lactation support, pregnancy support, parenting education, child development, and services for children diagnosed with physical or psychological special needs. Representatives from a local health care system, the area FQHC, and two organizations focused on mental health/substance abuse also attended. Two participants identified themselves as knowledgeable of and experienced in the area of children's special health care needs. Two DSHS staff members observed the meeting.

Identified Priorities

Waco stakeholders identified three priority needs for their region. All three fall within the category of crosscutting issues: education, access, and a focus on the life course. Participants acknowledged that these priorities are interconnected.

Education. Most of the participants agreed that education is a priority. Starting before conception, women's choices affect the health outcomes of their children, so they need access to accurate information. Resources are needed for education about preconception health, contraception during the perinatal period, parenting, healthy communication within relationships, and mental health in general. Educational efforts should focus on the household, including extended family members who may live in the household and care for the children. Children and adolescents need health education, including better, age-appropriate sex education.



Provider education is also needed. Providers and social service agencies need to be familiar with the available resources so that they can direct families to appropriate services. Beyond knowledge about local resources, providers should better understand how critical timely referrals are for families. They need to use referrals appropriately and not feel pressured to take upon themselves responsibilities that others could handle better. For example, primary care providers may not be fully aware of the relationship between a pregnant woman's substance abuse and the health of her unborn child. The conventional wisdom would be to counsel the woman to stop using; however, a substance abuse counselor would understand that sudden withdrawal from certain substances can actually kill an unborn child. The counselor would be able to work with the woman to help her safely end the substance abuse. Providers also need education about cultural differences and poverty so that they can better serve a diverse population.

Access. Most of the participants agreed that access to services is a priority need. Several factors contribute to a general lack of access. Women's health care programs cover services only during pregnancy and the perinatal period. Access to comprehensive primary care, preconception care, ongoing well-woman checks, and care for chronic diseases is limited. When faced with a health issue, women often do not receive early care because they do not have the means to pay for it. Even access to covered women's health care services has been limited by budget cuts.

The complexities of bureaucracy limit access. The maze of private Medicaid managed care organizations complicates access for clients and enrollment by providers. Low Title V reimbursement rates limit the number of providers willing to participate in the program.

Children with special health care needs lack access to rehabilitation services (e.g., occupational therapy, speech therapy, applied behavior analysis, and nontraditional therapies such as equine therapy, also known as hippotherapy).

Access to mental health and substance abuse services is particularly limited. More resources are needed for substance abuse treatment. The reimbursement rates for treatment services are generally too low, and the rates for detoxification services vary widely depending on location. Hospitals are paid more than nonprofits for the same services. More resources for child care and transportation are needed to allow women to access substance abuse recovery supports, such as twelve-step programs, after their treatment.

Focus on the life course. Most participants indicated that a shift toward a focus on the life course is a regional priority. There is a general lack of understanding of the life course approach and numerous barriers to change.



Comprehensive health care is not available. Instead, programs and funding sources are siloed and fragmented, making it impossible for providers to focus on health over the course of a person's life. Title V focuses on women and children without emphasizing the role of fathers. Health education should target the whole household, not just women and children. Case management services may be available within a specific program, but there are no comprehensive case management services to provide support for families over the life course. The community as a whole does not affirm health through infrastructure such as sidewalks.

Mental health is the foundation for overall health. It is necessary in order for people to be receptive to health messages, yet mental health services are not easily accessed. Early trauma, if not addressed, can have negative effects on health over a lifetime. The Adverse Childhood Experiences (ACE) study conducted by Kaiser Permanente and the Centers for Disease Control and Prevention³ showed that adverse childhood experiences lead to poorer health outcomes and earlier death. Providers often lack the information and skills needed to offer trauma-informed care to families that have experienced intimate partner violence or substance abuse. There is a need to address the cycle of negative behaviors that begins with parents and older siblings and impacts the younger children. Parents need to be educated and supported to change the trajectory.

Social and economic factors play a large role in overall health and contribute to disparities in health outcomes, but they are generally not addressed by health programs. For example, the absence of supportive services such as economic supports, housing, transportation, and child care makes it difficult for many families to shift their attention out of survival mode.

³ <http://www.cdc.gov/violenceprevention/acestudy/>



How to Address the Priorities with an Upstream Approach

In pairs or in groups of three, participants brainstormed ways to address the priority of their choice. They then shared the following ideas for addressing each priority with an upstream approach.

Education

- Collaborate with other agencies and organizations that are already doing a good job of educating. DSHS should invest in collaborative work to draw in other stakeholders.
- Acknowledge that people learn differently – for example, some learn best through visual channels and others through auditory channels. Provide education in different modes.
- Provide accurate, centralized information about resources.

Access

- Ensure consistent funding for programs so clients can access services.
- Improve provider and family awareness of available resources and programs.
- Shorten the amount of time it takes for a Medicaid client to switch to a different managed care provider. Allow nonprofits and providers to call 2-1-1 on behalf of the client. Eliminate the typical hour- to 90-minute-long wait to speak with someone about Medicaid over the telephone.
- Simplify the Medicaid application.
- Reduce bureaucracy for providers and clients.
- Allow for a focus on regional/community priorities as opposed to statewide, one-size-fits-all programs and funding.

Focus on the Life Course

- Make funding flexible enough to allow for innovation, but balance innovation with evidence-based practices.
- Ensure continuity over time with comprehensive care.
- Identify root causes of issues and address them instead of dealing only with the presenting issue.
- Use the life course approach to understand the full constellation of issues. Deal with the whole family instead of cutting off the men.
- Use a holistic approach. Connect to a network of providers that can address the various facets of an issue.



Additional Needs and Problems

During the small group brainstorming activity, participants in Waco identified a wide variety of perceived maternal and child health needs and problems. Table 10 presents the ideas that participants did not choose to include in the top regional priorities described above.

Table 10 Additional Perceived Needs and Problems: Central Texas	
Population Health Domain	Needs/Problems
Perinatal health	<ul style="list-style-type: none"> • More interconception care for teens and young mothers to help them plan/prevent subsequent pregnancies; pregnancy spacing
Child health	<ul style="list-style-type: none"> • Behavioral health services for children to address trauma and other mental health issues
Children with special health care needs	<ul style="list-style-type: none"> • Lack of available foster families for children with special health care needs
Adolescent health	<ul style="list-style-type: none"> • Lack of substance abuse treatment for teen girls • Lack of behavioral health services • Need to acknowledge teen's voices – their definition of the problem • Lack of protection/prevention factors: problems are addressed after they occur – for example, teen pregnancy instead of pregnancy prevention • Need for more youth development to increase protective factors
Crosscutting issues	<ul style="list-style-type: none"> • Substance abuse prevention and treatment • Need for a program to address intimate partner violence • Need for behavioral health services • Need to collect the right data • Need to assess whether the right programs and policies are in place: Do they match the needs of the community? • Need for funding for interventions that are known to work and to address the real needs of the community



Central Texas: Regional Common Themes

Two common themes, discussed below, emerged from the findings from the focus groups with mothers in Killeen and the priorities identified by stakeholders in Waco.

It is difficult to access consistent, quality health care services. Several mothers in the Killeen focus group said their families go without health care because insurance is too expensive, even after federal health care reform. Some families that can afford services (especially those in the military) are frustrated because their care is fragmented; they see a different provider at each visit and never get a chance to develop a relationship with any doctor. Stakeholders in Waco identified general access to health care as a regional priority, describing as particularly problematic the lack of access to comprehensive care, wellness checks, and ongoing treatment for chronic diseases. They also recommended that providers shift their perspective to clients' health over the life course, which they acknowledged is difficult if not impossible with today's siloed and fragmented programs and funding sources.

Behavioral health issues are not being addressed adequately. Many mothers said they have children or stepchildren with behavioral issues. Some are aware of resources and access them; others are unfamiliar with resources or are reluctant to seek help for fear of involving Child Protective Services. Mental health support through Medicaid is not always available. As part of an overall need to improve access to health care, stakeholders cited as problematic limited access to mental health services in general and to substance abuse treatment in particular. They underscored the importance of mental health as the foundation for physical health and emphasized that early trauma, if not addressed, can negatively affect health over a lifetime.



What Topics Remain?

With regard to the topics that remain, the authors note that the topics that remain are those that are not covered by the current standards. The authors note that the topics that remain are those that are not covered by the current standards.

Language Arts Standards

The language arts standards are those that are not covered by the current standards. The authors note that the language arts standards are those that are not covered by the current standards.

- Reading
- Writing
- Speaking and Listening
- Language

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West Texas Findings

SUMA conducted two focus groups with men in San Angelo and a stakeholder meeting in El Paso. Focus group findings and stakeholder perceptions are reported below, followed by the common themes that emerged for West Texas.

Findings: San Angelo Men

Finding: Men in San Angelo generated a long list of health concerns, both physical and mental, but many said poverty and other stress-related issues are their top health concerns.

- Expensive health care system
- Stressful work/life situations
- Drugs
- Cancer
- Heart problems
- Poverty/paying bills

Finding: Men in San Angelo described a healthy meal as one that is cooked at home, as opposed to fast food. However, some admitted that the foods they cook at home often include microwaved chicken nuggets, ramen noodles, and macaroni and cheese. They began by describing a healthy meal as consisting of baked chicken or just chicken in general, but soon moved on to the foods they eat most often: grilled cheese, macaroni and cheese, peanut butter, and rice. Many expressed a desire to eat healthier but pointed out that tight budgets often prevent them from doing so.

My kids ask for chicken nuggets, macaroni and cheese, ramen noodles, cereal, fast food, and Mexican food. That's about all they will eat.

Any type of chicken, of course, is a healthy food, but I don't buy a lot of healthy food because I can't afford it. Healthy food comes in small packages, and we eat a lot. We can't afford to eat healthy most of the time.



Many of the men said they do the family grocery shopping. They typically shop at Walmart, H-E-B, or Lowe's Market. They said they normally have to drive to get good quality because there are no good stores in their immediate area. They buy fresh fruit from local stands or H-E-B, but mostly eat canned vegetables because they are cheap and last a long time.

We shop at Walmart, sometimes H-E-B, or Lowe's Market. If I have money I go to H-E-B, and if I don't have money I go to cheap stores like Walmart.

I don't go in my neighborhood. I drive to the base or go to a Walmart five miles away. I go to H-E-B for bananas, apples, and coffee. There is nothing in walking distance but a Stripes.

Factors that encourage them to eat a healthy diet include a desire for better health and fewer problems such as high cholesterol and diabetes. It also helps when one's peers and family are interested in eating healthy. Several noted that they don't always have enough money to consider healthy choices. However, they agreed that it is not always a matter of funds. They are constantly faced with temptations: Television commercials seductively push creamy, cheesy, high-fat, high-calorie treats, and the fast food venues close to their homes don't prominently display healthy choices. They doubt many people go to McDonald's and order the salad.

I don't always know what to choose and how to cook it well. I could eat healthier if I did.

I have taken over the grocery shopping because I can do it cheaper. She spends too much on non-grocery items.

It seems we are always eating on the run. Sometimes there ain't nothing like a Lunchable.



Finding: San Angelo men get about as much activity as they can stand at work, but they still come home and try to keep their children active as well. The activities they do in their line of work, coupled with the speed they are required to maintain, makes it very hard *not* to get enough activity. However, several wondered if that type of activity is really healthy because it involves an extremely high level of stress as well. Many enumerated the types of activities they arrange for their children: soccer, basketball, fishing, and going to the park. One has bought some land and has the whole family involved in clearing it and maintaining a nice garden. However, several mentioned that drugs are rampant in San Angelo, and they would never let their children play without supervision for fear that they would come into contact with the wrong people. They said that certain parts of town are better equipped for outdoor activity, with nice sidewalks. The neighborhoods they themselves live in do not, so they don't let their children go out alone. Some said their kids don't want to go out because it is so hot all summer.

Work, it's very physical. Pull a 25-pound casing – up to 1,200 casings a day. And the driller says, "You better get it done quickly. You better not get caught talking. Move it."

Certain areas are better for sidewalks. In the rich part of town there are sidewalks that can hold big strollers. I would not consider riding a bike – the city here is just not set up for bike riding.

Nowhere is lighted. The city has decent soccer leagues. The fields were lit real good at first, but not anymore. The streets don't all have street lights. You can't see down the river.... A kid drowned down there not long ago.



Finding: San Angelo men said the pay for oil and gas work is very high in comparison with other jobs in the area, but the physical and mental toll it takes to get the job done is even higher. Men described a work environment rife with dangerous conditions and employers who don't always seem to be doing their part to keep the workers safe. However, because the pay is good, workers are expected to accept the conditions without complaint. These men see the tradeoff as worth it because it allows them to provide for their families.

Any jobs that pay good are dangerous jobs. Health and safety goes out the window.

There's lots of talk at work about safety. The safety man from the HR office comes out – he's OSHA-appointed. They tell you to sit down if you get hot, but if you actually do that, the supervisor will give you heck. They see you act hot and hit you with a water hose, and then you're wet all day. It ain't right, but it pays good.

We have chemicals – lime, caustics – that we have to breathe it in every day. "That's why we pay you \$22 an hour. Sign this and don't let it touch you."

That's why you don't see any old roughnecks.

Want to eat healthy? Got to live dangerously.

Finding: Health care coverage varies, as do the focus group participants' feelings about it. While some said they get full health coverage for any incidents that happen at work, getting coverage for their off-the-clock life (and for their families) is more problematic. High deductibles mean they can't always afford to see their doctors, even if their premiums have been paid. Because accessing health care is an expensive proposition, some simply don't do it. Some also said their own parents – often their fathers – did not go to the doctor, so they don't either. Some make sure their kids are covered (many by Medicaid), but they themselves do not have health insurance.

You only have full coverage for the things that happen to you at work.

If it was just yourself, it would be okay, but throw a wife and kids in there, and you have to work overtime to pay for it. Four hundred dollars for each check for a bad policy.

There are doctors on every corner. But I have Medicare, and lots of doctors don't take Medicare.

The last time I went, I was a freshman in high school when I blew out my knee. I don't need them. You spend too much for too little.

I had an abscessed tooth. I was denied coverage, and the dentist said, "Two hundred dollars, or you can't see me."



Finding: Some of these men said mental health issues have affected them and their families, but help is not always forthcoming. Some men have been able to access care for themselves and/or family members, but others reported problems getting diagnosed and receiving help for their mental health issues. Interestingly, given their reluctance to access care for physical problems, a number of these men do seem open to getting help for behavioral/emotional issues, although a couple of them said there are no behavioral or emotional health resources readily available for their kids. Like parents in other cities, some dads expressed frustration with CPS involvement that they consider unwarranted.

I have PTSD, but moved to a new town, and there's not a VA here or close by.

My kids are having emotional troubles. A lot of things are going on in my personal situation that is not good. My family situation is not good. I'm not proud of it, but I would go if I needed it.

My kid won't eat, but if I try to make him eat, CPS will come and get me. If you say you can't handle your kid, CPS will show up in a minute and take your kids away.

They don't have a program to send kids.

They don't have counseling for kids.

Finding: Many dads are reluctant to put their kids in day care. These respondents rely on their wives to stay home with the kids. One said he and his wife carefully screen and interview day care providers to ensure that they are making the right choice. This is especially important given the fact that young kids can't speak and let their parents know if something bad is going on.

I have my wife stay home, because it's too hard to find someone.

Between the car, gas, child care, et cetera, it's better for my wife to stay home and take care of the kids.

I don't leave them anywhere but with family.



Findings Related to Concerns About Health and Safety of Children of Different Ages

- **Birth to 2 years.** In addition to concerns about the quality of child care, dads expressed concerns about health ailments such as seizures, SIDS, and jaundice, and nutritional concerns such as whether their kids are getting the “right” foods.

I have to make sure they are eating right. ... The right stuff, good formula.

My daughter went to day care and came home with bite marks and lice. Day cares may be safe, but if they are, you can't afford them.

- **3-5 years.** With children able to communicate problems at this age, day care concerns are somewhat fewer but still on the minds of these dads. Fathers with kids this age also worry about molestation and making sure that their kids don't pick up bad habits by seeing what Mom or Dad does.

Kids pick up bad habits. He sees Dad smoke and picks up cigarette butts and tries to smoke them.

I talk to them every day about what happened [that day]: “Did anyone touch you?” Et cetera. The population here is 140,000. There are lots of sex offenders here.

- **6-13 years.** Fathers with kids this age start worrying about what kinds of other kids their own kids are spending time with. Molestation continues to be a worry for some. Places such as the Boys & Girls Clubs and the YMCA can offer afterschool programs that help, but not all the dads in the San Angelo focus groups were aware of them or taking advantage of them.
- **Teen years.** Sexual issues – having “the talk” with their teens – are on the minds of many dads with kids in this age range. They continue to be concerned that their kids may spend time with the “wrong crowd,” and several lamented the lack of good afterschool/free-time options for their kids.

I'm trying to have “the talk.” I don't want to be a grandpa.

Older kids are a bad influence. They need more places that are age appropriate and safe for kids to hang out.

I'm not sure where teenagers hang out in San Angelo. They hang out at the mall and stare at everyone and steal. They need something to do in the summer and after school. Nobody is watching.



Stakeholder Perceived Needs: El Paso

Twenty-nine stakeholders registered for the El Paso meeting, and 14 participated. Three representatives of the local health department attended, including the director and two staff members from the dental clinic. Three different insurance companies/managed care organizations were represented, as were community-based organizations focusing on child development, mental health/substance abuse, and breastfeeding.

Representatives from the local MHMR center and the Education Service Center also attended. Four participants indicated that they work with children with special health care needs and their families. Two staff members from DSHS and one from the Texas HHSC observed the meeting.

Identified Priorities

El Paso stakeholders identified three crosscutting priorities for their region: education, access, and coordination.

Education. Most of the participants said education is needed to address both the lack of awareness and the lack of information in the El Paso area. Families and providers are generally not aware of available services and resources. Some families are unaware of the need for a service even if they have the means to pay for it. For example, many children who are covered by insurance are not getting well-child checks. Families and providers are not aware of available services for children with special health care needs.

Education could prevent or reduce the incidence and severity of numerous health issues and help create a culture of wellness. For example, nutrition education could help prevent gestational diabetes and child obesity; interconception education and family planning could reduce the cycle of unplanned pregnancies; education about the relationship between oral health and overall health could reduce heart disease; and education about the HPV vaccine could prevent cancer. High rates of teen pregnancy and STDs could be reduced by evidence-based sex education in schools and by educating and empowering parents to become more informed and better able to teach their adolescent children about anatomy, sexual health, healthy relationships, pregnancy, STDs, and substance abuse. Children with special health care needs and their families need specialized information on puberty and sexuality.



There is a particular need for education about mental health in the region. Families and providers are not aware of available mental health services. The issue needs to be reframed positively. In the Mexican culture, mental health issues are stigmatized and likely to be left undiagnosed or untreated. Bullying is common and is compounded by machismo and gangs, some related to the drug cartels across the border. Culturally sensitive mental health materials and services are critical.

Access. Most participants indicated that access to services is a priority for the region. Many families have limited access to health care. An estimated one third of the children in El Paso do not have health insurance, so they are not able to access services. For example, they do not get screened or treated for lead exposure – a critical gap, in light of the fact that El Paso had a copper smelter that contaminated the environment with lead. Women who do not get prenatal care are at greater risk of having low-birth-weight babies. El Paso’s rate of low-birth-weight babies is twice the national average, and the area has a high rate of babies in the neonatal intensive care unit. Children with special health care needs are on waiting lists for services. In some cases, Title V services are available for these children, but families do not access them because they are unaware of the program. Likewise, care coordination and case management services may be available, but families do not access them because they are unaware they exist.

People who are undocumented do not have access to services. In the past, providers did not ask about a person’s legal status, but that practice has changed. Now, only citizens are entitled to receive services. The undocumented do not even attempt to access health care because they do not want to reveal their status and risk deportation.

Low reimbursement rates contribute to the lack of access to certain services. For example, pediatricians are not reimbursed for all the recommended pediatric screenings in the Texas Health Steps Periodicity Schedule, so they may skip some of the screenings.

Access to specialty care is particularly limited. There are not enough pediatric specialists: El Paso has only one pediatric cardiologist, one pediatric pulmonologist, and two pediatric neurologists. The number of dental facilities is also limited. Children in the general population may have difficulties accessing dental care because of the long distance or lack of transportation to dental facilities. People of all ages with disabilities, especially developmental disabilities, face even greater challenges because not enough specialty dentists are willing to work with that population.

Women, children, and adolescents lack access to mental health screenings and services. There are very few pediatric mental health providers. Adolescents have limited access to suicide prevention programs and substance abuse treatment. The region has high rates of posttraumatic stress syndrome. Many people have experienced trauma during military service; others, including children, have experienced or witnessed violence in Juarez, Mexico.



There is a lack of family planning services for all ages, and a lack of birth control for teens. Not enough programs addressing sex education are available. Parents do not know how to help their teens, and the schools are not doing it either.

Coordination. Most participants agreed that coordination is a regional priority. Providers are not educated about or aware of the importance of coordinated care and continuity of services. For example, primary care providers do not consistently screen or refer clients for mental health services. Many do not use up-to-date technology, such as electronic health records, which would facilitate better care coordination. Families with children with special health care needs do not have the information, services, or support they need to help their older children transition from pediatric to adult care, which is based on a very different model. Providers and families are often unaware of available care coordination services.

There is a lack of community-level planning. Organizations do not network. Programs, services, education, and dissemination of information are not coordinated. Many organizations are not aware of 2-1-1, do not list their services with 2-1-1, and therefore are not in the referral network. The health department and schools do not coordinate health education, including sex education.

How to Address the Priorities with an Upstream Approach

In pairs or in groups of three, participants brainstormed ways to address the priority of their choice. They then shared the following ideas for addressing each priority with an upstream approach.

Education

- Use different methods of communication to target multiple generations: “old school” methods such as flyers, posters, and newspapers, as well as newer communication channels such as Facebook, Snapchat, Instagram, and Twitter. Grandparents often care for children, so young parents are not the only target audience.



Access

- Increase funding.
- Address provider reimbursement issues. Providers are not participating in Title V or other programs that serve women and children because of low reimbursement rates.
- Streamline and simplify the Title V provider enrollment process.
- Improve the Title V application/enrollment process for potential clients.
- Increase collaboration with other programs that serve families, women, and children – for example, WIC – so staff can provide information about Title V to the families those programs serve.
- Use multiple communication channels to let families know about Title V – for example, online outreach, handouts, and state-level outreach.
- Provide medical transportation services through Title V.
- Provide support to help families navigate the system and access services.
- Identify and eliminate the barriers that families face. For example, ensure that callers reach a real person or get a prompt call back, and ensure that online application systems work as designed.

Coordination

- Make an online list of Title V providers available to all providers and to the public.
- Create a system for Title V health care providers to refer clients to Title V dentists, and vice versa.
- Build into Title V contracts requirements for collaboration and coordination with other Title V providers and with other providers in the community as well.
- Foster a culture of collaboration. Build local collaboratives that report to a state-level collaborative, so that local communities can share information and experiences and learn from each other.

Additional Needs and Problems

During the small group brainstorming activity, participants in El Paso identified a wide variety of perceived maternal and child health needs and problems. Table 11 presents the ideas that participants did not choose to include in the top regional priorities described above.



Table 11
Additional Perceived Needs and Problems: West Texas

Population Health Domain	Needs/Problems
Maternal and women's health	<ul style="list-style-type: none"> • Medicaid for the mothers should not be limited to two months after birth • Women who are undocumented • Lack of well-woman screenings • Replace the funding for family planning services that was cut
Perinatal health	<ul style="list-style-type: none"> • Lack of screening for postpartum depression (only one postpartum visit is allowed)
Child health	<ul style="list-style-type: none"> • Children from Mexico who have experienced violence and have mental health needs • Services for children who have experienced sexual abuse • Lack of early developmental screening – pediatricians are inconsistently following the policy/periodicity schedule under Texas Health Steps
Children with special health care needs	<ul style="list-style-type: none"> • Lack of early developmental screenings – special needs are often identified at school, but they could have been identified earlier
Adolescent health	<ul style="list-style-type: none"> • Teen pregnancy prevention • Address negative perceptions about seeking mental health services • Address high rates of obesity
Crosscutting issues	<ul style="list-style-type: none"> • Policy changes – increase reimbursement for providing information, education, and services in general • Dissemination of prevention information • Family planning services



Final Comments for DSHS

- Mothers have to work, so grandparents often care for the children. Information should target the older generation too.
- Recruit retired people to help educate families.
- Make policy changes. Take on the junk food industry and the media for promoting alcohol and tobacco.
- Keep up with the times. Prohibiting state employees from using Facebook is cutting them off from a primary means of communication with the public.
- Increase funding for breastfeeding promotion and the number of mother-friendly worksites and hospitals.
- Review the services that are covered by Title V and expand the list when that makes sense. For example, Title V covers a dental treatment called full-mouth debridement, but not scaling and root planing, which are often necessary as part of the treatment. Few parents can afford to pay for scaling and root planing out of pocket, so Title V dentists provide only half of the needed treatment.
- Review the Title V formula for geographic distribution of funds and consider communities of need versus of communities of wealth.
- Increase cultural competency.
- The counties surrounding El Paso and on the Texas-Mexico border are really struggling. We need more funding for the region.
- Thank you to DSHS for coming to El Paso and listening to us.

West Texas: Regional Common Themes

Two common themes, discussed below, emerged from the findings from the focus groups with fathers in San Angelo and the priorities identified by stakeholders in El Paso.

Accessing health care is difficult. Some of the fathers in the San Angelo focus groups said they have health insurance coverage through their employers, but many cannot afford to buy coverage for the rest of the family. Others said they do not go to the doctor, either because they cannot afford it or because they are following the lead of their own fathers, who rarely sought health care. Similarly, stakeholders in El Paso identified access to services as a regional priority. They noted that many families have limited access to health care, some because they do not have health insurance, others because they are unaware of services for which they may be eligible. Access is further restricted by the lack of specialty providers in the region.



Mental health needs are often unmet. Several fathers said they and their families have been affected by mental health issues. Some have received services to address the problems, but others have had difficulty finding help. Stakeholders did not identify mental health needs as a separate priority category; however, they cited mental health within the contexts of all three of the regional priorities that they did identify. They pointed to a need for education about mental health issues in order both to decrease the stigma attached to seeking help and to increase awareness of available resources. Stakeholders said women and children do not have access to mental health screenings and services, and noted the dearth of pediatric mental health providers. Finally, they noted that a lack of coordination among providers results in gaps in services, in particular when primary care providers do not consistently screen or refer clients for mental health services.



Conclusion

In the introductory section, the author discusses the importance of the research and the need for a comprehensive review of the literature. The author then presents the research objectives and the research questions. The author also discusses the research methodology and the data sources. The author then presents the research findings and the conclusions. The author also discusses the implications of the research and the future research directions.

The research findings indicate that there is a significant relationship between the variables. The research also shows that the research objectives have been achieved. The author concludes that the research has provided valuable insights into the research topic.

The research also shows that there are several limitations to the research. The author discusses these limitations and suggests ways to overcome them. The author also discusses the implications of the research and the future research directions. The author concludes that the research has provided valuable insights into the research topic.

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Conclusion

In summary, the research conducted with stakeholders and consumers as part of the Title V five-year needs assessment indicates that Texas families face numerous health challenges. Statewide, the top concern is access to affordable health care for adults. Most parents reported that their children have Medicaid coverage but said it is often jeopardized by the parents' marital status or child support. Access to pediatric specialists is difficult outside of large metropolitan areas, and access to mental health care is difficult statewide.

Providers and families alike are generally not aware of available services and programs. An increased focus on health care services that are available across the life span is important.

Prenatal/perinatal/postpartum care lacks consistency across the state. Prenatal care is often delayed as women wait for Medicaid approval. Induction and C-section rates are high, with over 50% of female focus group participants reporting that their labor was induced and/or they had a C-section. A large majority did attend a postnatal follow-up, at which they were counseled about birth control, breastfeeding, and, in some cases, postpartum depression.

Efforts to educate about the dangers of smoking during pregnancy and around infants and children need to be continued. This is especially true for education about the link between smoking and SIDS. Smoking cessation programs and policies to limit smoking are also key.

Consumers consistently identified diabetes, cancer, and obesity as their top health concerns. While they understand the link between these diseases and diet and exercise, they find it challenging to adopt healthy lifestyles because of time constraints and their perception that healthy foods are more expensive than less nutritious foods. Most parents and stakeholders agreed that health education for adolescents, particularly evidence-based sex education, is a priority.

Addressing the complicated reimbursement process and the low reimbursement rates for Medicaid providers is key to improving health care for many Texans. Implementing a system that encourages health care providers to participate in Medicaid will expand access and improve care across the state.



Children with Special Health Care Needs Title V Needs Assessment Comprehensive Focus Group Report

Texas Department of Health Services

February 2015

suma
SOCIAL MARKETING

research + campaigns = behavior change

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for

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Appendices

Appendix A: Parents' Resource Needs Assessment

Appendix B: Focus Group Guide



Executive Summary

Introduction

The Maternal and Child Health (MCH) Block Grant Program is authorized under Title V of the Social Security Act of 1935. It is the only federal program that focuses solely on improving the health of all mothers, children, and their families, whether insured or not, through a broad array of public health and community-based programs.

In order to be entitled to these funds, every five years states must submit an application that contains the results of a statewide needs assessment. The application must include plans to meet the long-term priorities of the state, with specific activities related to the national performance measures and unique state performance measures developed from the Title V five-year needs assessment.

As part of the needs assessment, SUMA Social Marketing Inc. (SUMA) conducted statewide qualitative research with parents of children with special healthcare needs to gather data about resources, access to care, and health needs in their communities. Eleven focus groups were held across the state with parents of children with special healthcare needs; eight groups were conducted in English and three in Spanish.

The formative research findings offer purely qualitative data and should be considered indicative of directions or trends rather than statistically definitive. Quantitative research seeks to understand “how many” and yields statistical information, whereas qualitative research, such as that reported here, seeks to understand “what, why, and how.”

Focus Group Methodology

A total of eleven focus groups were held in the cities of Lubbock, San Antonio, Temple, Jasper, Houston, El Paso, Dallas, and Laredo. (See Table 1 for a breakdown of focus groups by language, city, and number of participants.) Participants were parents who have a child with special healthcare needs who require more support than a typically developing child, and/or who has a physical disability that has lasted or will last for more than 12 months.

The recruitment methodology for these focus groups entailed a multi-referral system consisting of the Children with Special Health Care Needs (CSHCN) Services Program, community-based organizations, social workers and case managers, and a professional recruiting firm.

Lines of Inquiry

The following lines of inquiry were explored in the Title V focus groups.

- Identification of local resources for children with special healthcare needs
- Identification of barriers to accessing medical and behavioral healthcare
- Exploration of unique challenges faced by families of children with special healthcare needs
- Exploration of the term *care coordinator* and the concept to which it refers
- Experiences with healthcare providers, particularly physicians
- Exploration of local community support for parents and their children
- Identification of transportation resources, difficulties, and issues
- Parent planning for medical emergencies and natural disasters
- Exploration of transition planning, the impact of obesity, and respite care resources

Key Findings: Resources and Access to Care

Key Finding: Parents said that even though community resources may be available for their children, they frequently cannot access them. They cited a variety of reasons for this, including not knowing about the resources, difficulty in finding trustworthy caregivers, lack of extended family support, bias toward their children in public, and unaffordability. This finding led to a more nuanced definition of what access to care really means for parents of children with special needs. Just because a resource is available in their community does not mean a parent can truly access or utilize it, for a number of compounded and complex reasons. Parents identified the following priority needs in their communities:

- More day care.
- After-school and sports programs for children with special healthcare needs.
- Therapies in all modalities.
- expanded medical office hours to improve access to appointments.
- More sensitivity training about special healthcare needs for the community at large.
- A care coordinator for their children (while the idea of care coordination wasn't well known to parents, once it was explained to them they readily identified it as a paramount need in their lives).
- Better education about/more assistance with transition planning;
- Access to qualified, trustworthy respite care providers.
- More accessible parks and adaptive playgrounds.

Key Finding: Parents living in larger urban areas reported having more resources and opportunities for their children than parents living in smaller communities.

However, accessibility is still an issue. Although there were some regional differences with regard to available resources and community activities for children with special needs, a general lack of access was a significant finding in all focus groups. In very rare situations, parents chose to move their families to a different city with more resources for their child's particular disability.

Houston

A majority of the parents in Houston feel there are many activities, events, and resources for their children in the community. By and large, Houstonians feel quite comfortable taking their children out into the community. Like the San Antonio parents, however, the Houston parents said they have to take an active role in advocating for all these programs and events for their children.

Dallas

Like the Houston parents, most of the parents in English-dominant Dallas focus group think their community has plenty of events and opportunities for their children, but that they need to be better publicized so parents will know about them. Conversely, quite a few parents in the Dallas Spanish-dominant group said they do not feel there are many activities for their children with special healthcare needs in their community. Participants in the Dallas Spanish-dominant group, not all of whom were bilingual, were the only participants to mention language as a barrier to care or resources.

San Antonio

San Antonio parents said they feel the local special healthcare needs community is quite active and the nearby city of Boerne has a Special Olympics that is very popular and active. Parents in this community said there are actually a lot of resources for children with special healthcare needs, but also that parents need to seek out the information – it just isn't readily publicized. San Antonio boasts one of the resources most often mentioned in any group: Morgan's Wonderland, an ultra-accessible theme park.

Jasper

Judging by the comments of parents in the focus groups, of all the regions included in the research, Jasper seems to have the fewest resources for children with special healthcare needs and their parents. Parents in this group said they work tirelessly to find the limited resources available in their town, be they medical providers, therapists, or after-school programs. Parents in this group want and need the support of other parents like themselves but said they have difficulty finding them. Some drive to nearby Lamar or Beaumont to participate in support groups.

Laredo

Parents in Laredo also said their community lacks sufficient resources for children with special healthcare needs, including doctors. Several mothers said they frequently have to travel to other cities, particularly San Antonio, for care. Laredo parents also described a limited number of support groups for parents; some would like to see more support groups specifically for parents with children with cerebral palsy.

El Paso

Parents in El Paso said they needed more specialists, particularly neurologists. Some parents in this group also experienced what can be described as the situation of the working poor: They earn too much money to qualify for many needed services, but not enough to cover the costs themselves. There was a consensus among the El Paso parents that the greatest need of schools and teachers is additional funding for training and support services.

Lubbock

Parents in Lubbock listed a number of special healthcare needs programs in their community that provide activities and weekend events, including the Burkhart Center at Texas Tech University, High Pointe Village, and Mosaic. However, they also described a lack of adequate community resources for their children, including insufficient day care, after-school care, and camps. Six of the nine participants in Lubbock said they have difficulty finding childcare for their children during the day. The closest day care for children with special healthcare needs is in Amarillo.

Temple

Temple parents were in general agreement that they feel quite isolated in their community and that there isn't much in the way of resources for them or their children. They echoed the sentiment of Lubbock parents when it came to the unmet need for day care and daytime activities for their children. Parents said their community needs more recreation centers, camps and sports programs that cater to their children. The two resources that Temple parents mentioned most often and described as most helpful were the Children with Special Needs Network (CSNN) and the Heart of Texas Central Independent Living (HOCTIL) in nearby Belton. Temple parents also said they appreciate the wide range of medical services available at the Scott & White Healthcare center.

Key Finding: Parents said there isn't enough communication and publicity about resources and issues in their city pertinent to children with special healthcare needs. Parents in every focus group said they aren't being informed or educated enough about the resources, events, research, and legal transition issues that impact their children's wellbeing. Many also said they think there should be more print and online directories with comprehensive resource listings for children with special healthcare needs.

Key Finding: Networking with other parents of children with special healthcare needs is the most valuable way parents learn about resources in their community. Parents in all regions reported that they learn about local resources for their children from a variety of sources, including providers, schools and friends. Nevertheless, they most frequently learn from other parents of children with special healthcare needs.

Key Finding: Therapies for their children emerged as one of the resources most valued by parents. Desired modalities include speech, occupational, physical, music, applied behavioral, and food therapy, to name a few. Equine therapy was also mentioned in several of the groups. Parents in all groups extolled the benefits of therapies for their children because they can see how much they improve all facets of their children's functionality – physical, emotional, and relational. They described advancements in their children, such as increased motor function and mobility, improved communication skills, better behavior, greater socialization, and improved diets, as a result of therapy. Jasper parents described a significant lack of therapists in their area. Some of them reported having to drive an hour or more to therapy appointments. Some parents said therapies provide the secondary benefit of offering a social outlet for both their children and themselves.

Key Finding: Parents said their communities lack after-school, day care, and sports programs for children with special healthcare needs. Parents in the focus groups often face a lack of school programs and facilities that can accommodate children with special healthcare needs. Consequently, many of them can feel bereft of options for after-school or day care activities for their children, as well as of opportunities for their children to get enough physical exercise. Day programs would also serve a socializing function for their children, many of whom find it difficult to leave their home due to disability.

Key Finding: Medical and therapy appointments are frequently offered only during the standard 9 a.m.-5 p.m. workday. Parents said it is difficult to get to these appointments due to work obligations, the need to take their children out of school, and transportation challenges. Parents talked about the difficulty of taking their children out of school or day care to get to a medical or therapeutic appointment. Most said physicians cannot or will not talk to them over the phone about medical issues, and their offices are open only from 9 a.m. to 5 p.m., and almost never on weekends.

Discussion of the difficulty of getting to healthcare appointments during the day brought up another common barrier for parents: They need someone to stay at home with their other children when they are out, whether the child left at home is typically developing or has special healthcare needs.

Key Finding: Parents said they would like to see more education about children with special healthcare needs for the community at large. They think mixing children with special healthcare needs and typically developing children would help foster this type of education. Parents said they would like to see more community-wide events, venues, or parks that were inclusive of both children with special healthcare needs and children who are typically developing. They believe this would improve understanding and acceptance of children with special healthcare needs among those who may currently feel judgmental towards them.

Key Finding: Both parents who have an only child with special healthcare needs and parents who also have typically developing children reported significant challenges. Parents whose only child has special healthcare needs are concerned not only about the social isolation their children experience due to a lack of peers and playmates, but also about the isolation they themselves experience as parents and as a family. Parents with both a typically developing child or children and a child or children with special healthcare needs said the typically developing children frequently feel left out or ignored, and may experience sadness and stress about their sibling's condition. Parents also talked about the financial cost associated with caring for their children with special healthcare needs and how it can adversely affect the opportunities for their typically developing children, such as higher education and family vacations.

Key Findings: Care Coordination

Key Finding: Most parents have not heard of a care coordinator. Upon learning the definition of “care coordinator,” most parents said they are the care coordinator for their child. Parents quickly saw the benefits of having a care coordinator and embraced the idea of another advocate, besides themselves, for their children when it comes to communicating with healthcare providers and agencies. Parents in all groups talked about how much time they spend on the phone each week talking to insurance carriers and providers and how much having a care coordinator to do these tasks would free them up to do other things, such as spend time with their children and families and even be able to work outside the home.

Key Finding: Most parents have sought out this type of care coordination for their children among social workers, case managers and nurses, without much success. Many parents said they have looked for the type of services a care coordinator would provide through a variety of providers, including social workers, case managers, and nurses; some even approached health insurance companies about this type of service. Many had been disappointed with the services they received and, with one exception, nobody described a person they had worked with who was sharing pertinent information, such as test results, with the team of the child’s providers. Some parents thought individual case managers they work with provide a certain amount of helpful care coordination, but they feel these case managers may not be willing or able to provide much information beyond their own specific agency.

Key Finding: Some parents expressed concern about trusting their children’s healthcare to a care coordinator and said they are the experts on their children’s needs. Some parents said they wouldn’t entrust this type of responsibility to anyone but themselves. Some expressed doubt that a care coordinator would work on behalf of their children’s best interests rather than for their agency of employment. In addition to trust, some parents felt a care coordinator couldn’t provide the level of care they themselves can because they know their children so well. Others had experiences with case managers whose caseload was too heavy to really provide the level of care for their children they needed and wanted.

Key Finding: Parents thought that having a care coordinator to help them coordinate their child’s medical care would enable them to work outside the home. The inordinate amount of time parents must spend on the phone making medical appointments or trying to get benefits for their children makes it difficult for many to be employed outside the home. This is particularly true of mothers. Many of those who do have a job said they constantly worry about losing their jobs because they must take so much time off to coordinate their children’s health and medical needs.

Key Findings: Community Support

Most focus group participants said they feel alone and isolated in their journey as parents of children with special healthcare needs, regardless of the resources, accessibility, or activities available to them in their community. Even in large cities such as Houston, where there are so many opportunities to participate in the community, participants still reported a sense of isolation. Parents said that many family activities other parents take for granted are often difficult for parents of children with special healthcare needs; this contributes to a sense of isolation from the community at large. Parents *in all the cities* lingered after the focus groups to exchange resources and telephone numbers, and some even went to lunch together.

Key Finding: Parents in every group said they build their community with other parents who have children with special healthcare needs, because they understand each other's world. Parents living in a "world" that is largely devoted to meeting the health and medical needs of their children said they find support and camaraderie in talking with other parents in similar situations. They said only parents who have been what they have been through can truly understand them and provide the kind of emotional support they need.

Key Finding: Social media and the Internet provide opportunities for parents to build a support community that is not just local but global, as they connect with other parents around the world. Many parents said they use the Internet to find in-person and online support groups as well as resources for their children. Social media emerged as an important source of information for parents. They look for support first and foremost from other parents of children with special healthcare needs, and they are looking online more and more to connect with other parents. Facebook was mentioned in every group as a valuable online resource to connect with other parents and join support groups.

Key Finding: Parents said they feel supported within the special healthcare needs community but experience more judgment outside those enclaves in the public community. They often feel misunderstood by other parents and people because of their children's behavior or appearance. Even in cities where plenty of activities may be available for children with special healthcare needs, some parents do not get out of the house much because they don't want to face the harsh judgment, thoughtless actions, or cruel words of others towards their children. Parents in all focus groups reported they sometimes experience judgment in their communities when they go out in public with their children, and some described instances in which people told them they should spank their children because they perceived them as misbehaving.

Key Finding: Faith communities can be a significant source of support for many parents of children with special healthcare needs. By and large, faith communities are a source of support for many families, particularly in the smaller communities such as Jasper and Temple. El Paso parents also mentioned the support they derive from their faith communities. In Jasper, four of the five participants mentioned their church *first* when asked about community support in their area. However, some parents feel they do not find support in their faith community, including the one mother in Lubbock who went to half a dozen churches before she found one that welcomed her and her autistic son.

Key Findings: Working with Healthcare Providers

Key Finding: A majority of the parents in all groups have a positive relationship with their children's healthcare providers and said that trust is the number one factor in that relationship. A parent's ability to trust a provider emerged as the single greatest factor in their relationship with them. First and foremost, they need to trust the doctor and his/her expertise in treating their child. Parents work hard to find the right physician and/or specialist for their children, and parents in multiple groups told stories of walking out of a doctor's office if he/she didn't have enough expertise in their child's particular condition and did not care to learn. They left and didn't go back. Parents trust doctors more if they feel they truly *listen* to them and also relate directly to their children while talking *to them* as individuals. Parents clearly prioritize trust in their providers, but they also spoke of a number of factors that make them feel *comfortable* with a provider, including the feeling that they genuinely care about them and their child, are willing to be honest with them about difficult topics, and sincerely believe in their child.

Key Finding: Parents want doctors to know and respect that they are the experts on their own children. Parents in all groups resoundingly stated they were the experts on their children, even though they may not have the medical expertise doctors have. It was critical to them that their providers acknowledge this and in fact *trust them* to know what is best for their children. They want doctors to work collaboratively with them to treat their children.

Key Finding: Parents frequently complained about medical office staff. They would rather have more direct access to their doctors than spend so much time on the phone with nurses and administrative staff. Although most parents are happy with their children's providers, some complained about the service they receive from their nursing and administrative staff. They encounter some difficulties when support staff cannot answer their questions quickly and accurately, lose paperwork, or schedule appointments in an untimely manner.

Key Findings: Transportation

Key Finding: Transportation poses a unique challenge to parents of children with special healthcare needs. The myriad factors parents must consider when taking their children to a medical appointment complicate the issue of transportation for them. Many of their children are in wheelchairs, on ventilators, or in need of a special car seat. Others have children with heightened sensory issues or compromised immune systems that make ride sharing options more problematic. A few parents in the groups do not own cars, but a majority do. Transportation-related concerns parents shared included concerns about their children being exposed to germs while ride-sharing, parking garage expenses incurred during medical appointments, and slow public transportation systems that make them late for healthcare visits.

Key Finding: Many parents said the Medicaid Medical Transportation Program service delivery is too slow and time-consuming. Almost all the parents in the focus groups use their own cars to drive their children to healthcare appointments; very few use the Medicaid Medical Transportation Program vans. Those who do talked about the difficulty with having to schedule their provider appointments around van pickup times and spoke at length about how much time pickups and drop-offs take. Some parents in Lubbock and Laredo said that the Medicaid program provides transportation for the special healthcare needs child only, not siblings. This makes it difficult for parents to utilize the system because they then have to find childcare.

Key Finding: Parents find the Medicaid Medical Transportation Program reimbursement process time-consuming, but most agree it is worth it. Most parents complained about the lengthy paperwork associated with getting mileage, tolls, and food and lodging reimbursement from Medicaid. Some parents also had issues with Medicaid denying or delaying payment because they weren't able to reach the provider in a timely manner. However, in spite of these difficulties, most parents did appreciate the reimbursement that Medicaid provides.

Key Findings: Medical Emergency and Disaster Preparedness

Key Finding: Most parents, while not having a cohesive disaster plan, have taken some measures to prepare for a natural disaster. Many of them have reached out to 2-1-1, first responders and utility companies to let them know they have a child with special healthcare needs in the home. Although most parents said they don't have a formal disaster plan in place, they have taken a number of steps to ensure their children and homes would be safe in the event of a natural disaster. Many have registered their home addresses with their city utility office to ensure power during a crisis. Some had emergency bags packed; they listen and learn about natural disasters on television and the radio. Some parents across the groups had even learned how to stockpile medications for their children, in spite of insurance limitations on prescription refills.

Key Finding: Many parents said that although they have not necessarily had conversations with their providers about medical emergency planning, they feel prepared to successfully handle an emergency with their children. Parents said they trust in their ability to galvanize a response to any medical crisis involving their children. Most parents said they feel more confident in their ability to handle a medical emergency with their children than a natural disaster. Some parents said they have a one-page document written with and by their doctor to take with them to the emergency room that details the child's condition, medications, and other pertinent information. Parents with children with seizure disorders seemed more likely to report they'd had a conversation with their provider about planning for a medical emergency.

Key Finding: Spanish-dominant parents are particularly unprepared for a natural disaster or medical emergency. Most of the parents in the Spanish-dominant focus groups said they have not had a conversation with their providers about what to do in the case of a medical emergency with their children beyond telling them to call 9-1-1 or take their child to the emergency room. Parents in Laredo, like those in the Dallas Spanish-dominant group, reported that they have done virtually no planning for a disaster. None of the parents in any of the Spanish-dominant groups had registered their homes with the city utilities department or with first responders such as the local fire department. Even though almost half the parents in El Paso have attended a class on natural disaster, one parent said she felt they were informed but *not prepared*. Several other parents agreed. None of the parents in this group have a bag packed for their children in case of a disaster.

Key Finding: A variety of factors influence whether parents evacuate or shelter in place during a disaster, including their child’s age, disability level, and prior disaster experience. The Houston focus groups afforded researchers a unique opportunity to analyze two completely different approaches to disaster response. Most parents in Group 1 said they would shelter in place in the case of another hurricane or natural disaster. In contrast, most parents in Group 2 said they would evacuate in the event of a disaster. The children of the Group 1 participants were older than those of the participants in Group 2: Six of the nine participants in Group 1 had teens with special healthcare needs. They had actually lived through a hurricane evacuation with their children, in stop-and-go traffic in hot cars, whereas the parents in Group 2 had younger children and hadn’t had the same experience.

Key Findings: Transition

Key Finding: Transition means a variety of things to most parents: it implies not only the transition from childhood to adulthood, but educational, medical, and developmental transitions as well. Parents in all focus groups except the Dallas Spanish-dominant group were familiar with and understood the term *transition*. The Dallas Spanish-dominant parents thought transition planning meant preparing emotionally for the inevitable death of the child. Although many parents agreed that planning for a child’s transition into adulthood needs to start as early as possible, there was broad consensus that the timetable for transition planning is actually conditioned on each individual child’s unique development, abilities, medical condition, and circumstances. Medical provider transitions are another source of concern for some parents; they aren’t sure what to do in terms of medical care once their children transition out of pediatrics. And even though parents think legal guardianship is an important issue, many avoid doing anything about it – or even thinking about it – because they believe the legal fees will be prohibitive.

Key Finding: Transition planning for adulthood and long term care for their children triggers anxiety and concern in many parents. The discussion of planning for their children’s transition to adulthood, and particularly for their children’s care should they die, elicited some of the strongest emotional responses in the focus groups. Parents can feel overwhelmed and sad at the thought of what might happen to their children after they leave their home as adults, or if the parent dies.

Key Finding: Parents aren’t sure where to turn for adulthood transition planning assistance. Middle schools are mandated to provide transition planning at ARD meetings. This is often the first support or direction many parents have in transition planning for adulthood.

In spite of this, many parents feel they are on their own for adulthood transition planning. Many parents mentioned the topic of legal guardianship for their children and said both healthcare providers and the schools have prompted them to consider this option. However, many parents think getting legal guardianship of their children is expensive due to legal fees, and the perceived cost was, in fact, a barrier to this type of transition planning.

Key Findings: Obesity and Exercise

Key Finding: Parents said their doctors are more likely to discuss obesity, diet, and exercise with them if their child has a specific issue in one of these areas. Although some parents said their doctors talk with them about their children's diet and fitness in general terms, most said these conversations take place because of the child's condition and diagnosis. Most parents said they are careful to monitor their children's weight because extra pounds negatively impact their functional mobility as well as their health. Parents often have to lift their children in and out of wheelchairs, beds, etc. They said this can become more difficult as the child gets older, and also if the child is overweight.

Key Finding: When obesity does become an issue, many parents said doctors talk to them about weight loss but don't give them the tools that would really help them help their children lose weight. Many parents said some doctors don't understand how difficult it is to get their children to eat, or not eat, certain foods. They said they want more specific directions from their providers on how to help their children lose weight, rather than just be told that their child needs to lose weight. For example, rather than just telling a parent to quit giving her child a cookie, why not suggest she break it up into smaller portions or give her a healthier, low-calorie recipe?

Key Finding: Parents want more adaptive physical exercise programs in their communities so their children can get more exercise. Parents in most of the groups said their community does not have enough in-school or after-school exercise and sports programs for children with special healthcare needs. Parents think their children would benefit not only from the physical exercise, but also from social opportunities to play with other children. Parents in most of the focus groups also said they would like to see more sensory gyms available for children with special healthcare needs, as well as wheelchair-accessible pools.

Key Finding: Parents in all regions said their communities need more accessible parks and adaptive playgrounds. Parents said they go to various places so their children can exercise to the best of their ability, whether it involves bowling, visiting a park, or playing at the local playground. Most parents take their children to parks, and participants in almost every group said their city needs more parks, particularly accessible parks with adaptive playgrounds.

Key Findings: Respite Care

Key Finding: Many parents have heard of respite care but aren't always sure where to find it. Parents in the groups unanimously agreed that respite care is very valuable and important to them and their families. However, many of them said they weren't sure where or how to find a qualified respite worker for their children. In fact, some parents had never heard of respite care; awareness of respite care was particularly low in Dallas in both the English- and Spanish-dominant focus groups. Most parents in the larger urban areas had heard of respite care and about three quarters of the Houston parents have actually used it. San Antonio parents had all heard of respite care, but almost half of the participants in that group rely on family members for respite care rather than agencies. Most of the parents in Laredo also do not receive respite care services, because they don't know where to look for services, don't qualify for services, or have a family member helping them with caregiving.

Key Finding: Parents in every group expressed a strong need to be able to trust the respite care provider who cares for their children in their absence. Many feel there is a lack of qualified respite care providers they can trust. The need for a trustworthy, qualified respite care provider was one of the most unanimous findings across all topics discussed in the focus groups. Parents feel very protective of their children with special healthcare needs, many of whom are quite vulnerable due to their disabilities. Parents don't want just anybody watching their children, and they will go to great lengths to secure a qualified provider. Many parents said the ideal respite care provider would be another parent of a child with special healthcare needs or someone highly trained in caring for children with special healthcare needs.

Key Finding: Parents said some restrictions on respite care providers are a barrier to care. These barriers included time limits on respite care by certain providers; their perception that respite workers cannot legally administer medications to their children; respite agency and MDCP policy restrictions on family members, household members, and people under the age of 18 providing respite care; and policies prohibiting payment for respite care for siblings.

Key Finding: Parents think the Medicaid respite reimbursement wage is too low to attract qualified respite care providers. The Medicaid reimbursement for respite care is approximately \$9 or \$10 per hour. Many parents feel they cannot find qualified caregivers at this rate. Some parents are willing to pay more for a highly qualified respite care provider, bypassing the reimbursement system entirely.

Parent Focus Group Findings

Introduction

The Maternal and Child Health (MCH) Block Grant Program is authorized under Title V of the Social Security Act of 1935. It is the only federal program that focuses solely on improving the health of all mothers, children, and their families, whether insured or not, through a broad array of public health and community-based programs.

In order to be entitled to these funds, every five years states must submit an application that contains the results of a statewide needs assessment. The application must include plans to meet the long-term priorities of the state, with specific activities related to the national performance measures and unique state performance measures developed from the Title V five-year needs assessment.

As part of the needs assessment, SUMA Social Marketing Inc. (SUMA) conducted statewide qualitative research with parents of children with special healthcare needs to gather data about resources, access to care, and health needs in their communities. Eleven focus groups were held across the state with parents of children with special healthcare needs; eight groups were conducted in English and three in Spanish.

Lines of Inquiry

The following lines of inquiry were explored in the Title V focus groups.

- Identification of local resources for children with special healthcare needs
- Identification of barriers to accessing medical and behavioral health care
- Exploration of unique challenges faced by families of children with special healthcare needs
- Exploration of the term *care coordinator* and the concept to which it refers
- Experiences with healthcare providers, particularly physicians
- Exploration of local community support for parents and their children
- Identification of transportation resources, difficulties, and issues
- Parent planning for medical emergencies and natural disasters
- Exploration of transition planning, the impact of obesity, and respite care resources

Methodology

The focus group sessions were held at hotels, libraries, and research facilities in January 2015. All focus groups were led by trained moderators well versed in Title V and children with special healthcare needs. The sessions were audio-taped, and the recordings were transcribed verbatim and then analyzed for common themes and response patterns.

A total of eleven focus groups were held in the cities of Lubbock, San Antonio, Temple, Jasper, Houston, El Paso, Dallas, and Laredo. (See Table 1 for a breakdown of focus groups by language, city, and number of participants.) Participants were parents who have a child with special healthcare needs who requires more support than a typically developing child, and/or who has a physical disability that has lasted or will last for more than 12 months.

The recruitment methodology for these focus groups entailed a multi-referral system consisting of the Children with Special Health Care Needs (CSHCN) Services Program, community-based organizations, social workers and case managers, and a professional recruiting firm.

Table 1 Participants in Title V CSHCN Focus Groups (N = 102)			
Location	English-Dominant	Spanish-Dominant	Total
Lubbock	9	0	9
San Antonio			20
Group 1	11	0	
Group 2	9	0	
Temple	10	0	10
Jasper	5	0	5
Houston			18
Group 1	9	0	
Group 2	9	0	
El Paso	0	9	9
Dallas			18
Group 1	9		
Group 2		9	
Laredo	0	13	13
Total	71	31	102

Italicized, indented text in this report is used for participants' quotes, which are included to illustrate the findings and enhance their credibility. Names have been changed to protect the confidentiality of the participants.

Definitions of Qualitative Data Statements

It is important to note that the findings presented in this report are qualitative in nature rather than quantitative. Qualitative research—conducted through observation, in-depth interviews, and focus groups—seeks to understand the story behind the numbers. Open-ended questions probe issues more deeply in an attempt to understand “how” and “why,” as opposed to quantitative research, which seeks statistically definitive answers of “how many.” Because this is a qualitative study, it was not designed to be statistically valid, and therefore should be viewed strictly as directional, not definitive. The value of these data is in how they can inform the design and implementation of programs, messages, and future campaigns. SUMA has developed *approximate* quantitative estimates that are referenced in many of the qualitative statements and findings presented throughout the report. Quantity-related terms are interpreted as follows.

Few: under 25%

Some: 25% - 50%

Half: 50%

Many: over 50%

Most: 80% or 90%

All: 100%

Key Findings

Resources and Access to Care

Key Finding: Parents said that even though community resources may be available for their children, they frequently cannot access them. They cited a variety of reasons for this, including not knowing about the resources, difficulty in finding trustworthy caregivers, lack of extended family support, bias toward their children in public, and unaffordability. This finding led to a more nuanced definition of what access to care really means for parents of children with special needs. Just because a resource is available in their community does not mean a parent can truly access or utilize it, for a number of compounded and complex reasons. Perhaps a primary reason is that they don't know the resource exists, or if they do, they aren't sure how to access it.

I'd like to know everything that there is to get all of the services that are available. It seems like sometimes the social service organizations within themselves have bad communication, and then the information doesn't get to me until a year later.

— San Antonio

Trust emerged as a significant issue for parents, especially with regard to its impact on their access to respite care providers. Parents may know that respite care is available in their community, but finding a respite worker they can *trust* with their child's care is another issue altogether and, in fact, a barrier to access.

You hand your child over [to the respite care provider], and if you don't know them, they're strangers. Again, this is your heart that walks outside your body.

— San Antonio

Many parents in all the focus groups said they felt isolated on their journey with their children. For a variety of reasons, they often don't have established networks of support they can call on. Some parents reported feeling judged by their extended families about how they parent their children with disabilities, limiting the respite care or childcare options they might otherwise have had access to. This, in turn, can make it much harder to attend medical appointments during the day, because they have no one to watch their other children while they are gone.

Participant 1: *My other family don't want to come to my house because they think my son is spoiled. It just keeps my other family away, and I'm just by myself on the support system. I don't have anyone to back me up and say, "It'll be okay, just stick through it."*

Participant 2: *My family doesn't really have a lot of involvement. They don't understand the situation. When he has meltdowns, they don't understand. They think he is throwing a fit. His dad's side.*

— Lubbock

Parents in most of the groups reported instances of bias or judgment toward their children when they were out in public. People often stare, make rude comments, or admonish them to spank their children due to misbehavior. For this reason, while restaurants and bowling alleys may technically be accessible in their community, some parents do not feel comfortable accessing them with their children with special needs.

He acts like a five-year-old and you can't imagine how many times I've had restaurant and store owners say, "You know, if you would take care of him properly, this wouldn't be a problem. You don't spank him enough, why don't you teach him better?" They don't ever say, "Oh, is there a problem?"

– Temple

Parents reported financial barriers to accessing available resources, such as costly gym memberships for children with special healthcare needs and the costs associated with procuring legal guardianship over their children. Parents may know a lawyer they could consult about legal guardianship for their children, but many perceive the costs as prohibitive – so much so that they simply don't pursue it.

None of us wants to think about what is going to happen if something happens to you and your husband, but you know? It could. That is another thing I need to do, but we haven't done because I barely have enough money to make it through all her medical, much less creating something to carry on.

– Houston

Resource Needs Assessment

Parents said that much of their life is organized around meeting the needs of their children, which can be all encompassing given the severity of their disabilities. They spend a tremendous amount of time researching healthcare services for their children, talking on the phone with providers, taking their children to appointments, and filling out paperwork.

Parents talked about the extensive variety of resources their children need on a daily basis and the many agencies, departments, and organizations that help them. They identified the following priority needs in their communities: more day care; after-school and sports programs for children with special healthcare needs; therapies in all modalities; expanded medical office hours to improve access to appointments; more education about special healthcare needs for the community at large; a care coordinator for their children¹; better education about/more assistance with transition planning; access to qualified, trustworthy respite care providers; and more accessible parks and adaptive playgrounds.

Parents said their most valued resources include the Medicaid waiver and insurance buy-in programs, parent networks, after-school and sports programs, therapies in all modalities, respite care, doctors and specialists, and health insurance. These services empower them to improve their children's quality of life, and consequently their own.

You get everything with the waiver programs. Nursing fall under that umbrella. Therapies fall under that umbrella. Because you qualify for the waiver, you are qualified for all the medical equipment and supplies.

— San Antonio

Therapies emerged as one of the *most helpful* resources for parents because they said they see so much advancement in their children's abilities as a result of therapy. Applied behavioral therapy (ABA) was mentioned in almost every group as a tremendous asset to their children's functioning in daily life.

Participant 1: *I think they need to have ABA if they are over three or preschool.*

Participant 2: *ABA should not be just for autism, but for all disabilities. You could have a child with any disability have behavioral issues that ABA would help – you would benefit from it.*

— Houston

¹ While the idea of care coordination wasn't well known to parents, once it was explained to them they readily identified it as a paramount need in their lives.

Parents in many of the groups described their local schools as *least helpful* to them, citing lack of support and programming for children with special healthcare needs and, in some instances, a special education teacher shortage. They also noted the dearth of after-school programs that could accommodate their children with special healthcare needs.

Typically what I see in the schools is that they're underpaid just like any teacher, but special needs, like the life skills, they don't have the staff or the training that they need. Not for lack of trying, but they don't have the support from the administration or the State.

– Temple

Parents also complained about the enormous amount of paperwork required to receive Medicaid waiver benefits and other programs and to complete renewals for different programs. Some wondered why there couldn't be a centralized database system that would simplify the process.

Participant 1: It's very overwhelming to have a special needs child. I've thought for years, there's got to be a simpler way. Why can't there be some centralized thing – why are there ten different programs, ten different applications?

Participant 2: It's a lifelong diagnosis, and I'm filling out the same paperwork, the same form, over and over. I don't have the time.

– San Antonio

Parents in each city were asked to list the resources they access most frequently, sometimes even on a daily basis, for their children. They were asked to identify those resources that were most helpful as well as those they felt they needed more of in their community. A compilation of these resources can be found in Appendix A.

Table 2 below lists the resource needs identified by parents in all eight cities.

Table 2: Parents' Resource Needs Assessment ²							
Lubbock	San Antonio	Temple	Jasper	Houston	El Paso	Dallas	Laredo
Day care	Connection to colleges	Day care	Therapy providers (all types)	Day care for teens/adults	More funding for schools; teacher training and more support services	<u>Spanish Group</u> Day care	More family therapy options
Teacher education about special needs	Vocational help	Recreational resources	Connection to other parents of children with special needs	Adaptive play centers	Equine therapy	Music therapy	More funding for schools
Student education to decrease bullying	Transportation (wheelchair accessible)	Summer programs	More specialists	ABA for all ages and diagnoses	Money for medication	Aquatic therapy	Longer therapy appointments (physical, occupational)
Greater knowledge of sign language in general population	Long-term planning	Care coordinator	Centralized database that lists pediatric special needs conditions and treatment	School compliance	More specialists, especially neurologists	Physical exercise programs	Financial assistance with college, scholarships
Adjustment therapy	Legislation for new kinds of medications	Day program for tweens and teens	Centralized medical records database	Access to schools closer to home	More communication between schools and doctors	Technical devices to communicate	Financial assistance with transition-related costs (e.g., adult insurance premiums)
After-school care, summer programs	More communication to parents about federal and state laws impacting their children	Better respite options		Social opportunities	More therapy sessions covered by insurance	Advanced treatment options (e.g., stem cell research)	
Social activities and sport programs with typically developing children		Continuity of care in hospital system		Care coordinator		<u>English Group</u> Resource directory	
		In-home services		Outreach programs		PE programs	
		Faster access to services & DME		Sensitivity training for the public			
		Resource network for parents					

² Parent-generated list of resource needs assessment recorded by focus group moderators on flip charts during the discussions

Key Finding: Parents living in larger urban areas reported having more resources and opportunities for their children than parents living in smaller communities.

However, accessibility is still an issue. Although there were some regional differences with regard to available resources and community activities for children with special needs, a general lack of access was a significant finding in all focus groups. This theme resonated throughout the groups in discussions on many different topics. The relative abundance of resources for children with special healthcare needs in large cities such as Houston and San Antonio do not offset the difficulty parents sometimes have in accessing them. In very rare situations, parents chose to move their families to a different city with more resources for the child's particular disability.

Houston

A majority of the parents in Houston feel there are many activities, events, and resources for their children in the community. By and large, Houstonians feel quite comfortable taking their children out into the community.

There's so much to do in the disability community in the Houston area. We're busy every weekend. We are always busy. We have to turn things down because there's so much to do with our kids.

– Houston

That's the great thing about Houston. It's big enough to where most everybody is compliant and a lot of people are very friendly when they see a child or parent struggling with a child with a disability. They're like, "Let me open the door for you. Is there anything I can help you out with?"

– Houston

Like the San Antonio parents, however, the Houston parents said they have to take an active role in advocating for all these programs and events for their children. Parents in both urban and rural areas spoke of the need to advocate for special healthcare needs programs and events in their community.

I don't think any of that [activities, programs] would have been possible if it wasn't for the fact that we advocate. You don't ask, you don't get. If you actually put yourself out there and you ask for this or ask for that, there's a lot of changes that could happen.

– Houston

Dallas

The English-dominant focus group held in Dallas included parents from surrounding communities, such as McKinney and Irving. Like the Houston parents, most think their community has plenty of events and opportunities for their children, but that they need to be better publicized so parents will know about them. Some parents said they had to go to neighboring Plano, Frisco, or Lewisville to find activities for their children. Participants said Texas Parent to Parent (TxP2P) was active in the Dallas-Ft. Worth area and a good resource for connecting with other parents to learn what is going on in their community.

Conversely, quite a few parents in the Dallas Spanish-dominant group said they do not feel there are many activities for their children with special healthcare needs in their community. However, one Spanish-dominant parent said there actually are many such activities, but few people know about them. She then shared a number of low-cost or free activities with the group, who welcomed the information.

Participants in the Dallas Spanish-dominant group, not all of whom were bilingual, were the only participants to mention language as a barrier to care or resources. One Dallas Spanish-dominant parent said she experienced racism at the Medicaid office.

We don't know how to speak English. I understand it, but I don't know how to answer back.

– Dallas (Spanish-dominant)

I qualified for Medicaid, so I filled out the applications and everything. When I went to the office, they just looked at me and saw I was Hispanic. They told me, "You don't qualify. Go to your country." I felt so bad. I got depressed and would cry and all that. My sister told me, "Keep moving forward, don't give up." Yes, because my daughter has convulsions

– Dallas (Spanish-dominant)

San Antonio

San Antonio parents said they feel the local special healthcare needs community is quite active and the nearby city of Boerne has a Special Olympics that is very popular and active. Parents in this community said there are actually a lot of resources for children with special healthcare needs, but also that parents need to seek out the information – it just isn't readily publicized. Parents listed resources such as church ministries and programs, support groups such as Kinetic Kids, Morgan's Wonderland theme park, and online Meet-up groups for parents of children with autism and Asperger's syndrome. Local grocery chain H-E-B also offers employment opportunities for children with special healthcare needs in the San Antonio area.

I think Boerne is really great for a small community, and I recognize a lot of the kids from our Special Olympics group. If I go to H-E-B, I see a lot of them employed there. In our community, there are a lot of employers that are working with schools to try and work to help with employee management and transitioning.

– San Antonio

What I've seen with this community and with the philanthropists within this area, there seems to be more a surge and more of an awareness. It's being brought to the forefront now – you have the Morgan's Wonderland.

– San Antonio

Even though San Antonio has many resources for families of children with special healthcare needs, some parents said they are still on waiting lists or don't feel that all the resources are consolidated in one place and easy for parents to find.

We need more programs out there because there are waiting lists. If there's only one program out there, of course there's going to be a waiting list. Why can't we have two, how come we can't have three?

– San Antonio

The Kansas county I used to live in had a booklet. It wasn't all-inclusive, but it did list support groups. They automatically mailed me a new one every year. I haven't seen anything like that here.

– San Antonio

Jasper

Researchers observed that Jasper seemed to have the fewest resources for parents and children of all the regions. This east Texas town is the smallest of the research areas, and a two-hour drive from the nearest large urban center, which is Houston. It was also the location of the smallest focus group, with five parents in attendance. Parents in this group said they work tirelessly to find the limited resources available in their town, be they medical providers, therapists, or after-school programs. Parents in this group want and need the support of other parents like themselves but said they have difficulty finding them. Some drive to nearby Lamar or Beaumont to participate in support groups.

Parents said that in addition to turning to case managers and agency personnel, they try to find resources on their own. Many described a sense of futility despite their efforts.

We never get answers. "We can help you." Okay – how can you help me? "Tell us what you want." Don't ask me that. I don't know what I want. What do you offer? They don't know what they offer and they can't tell you in ten words or less.

– Jasper

Parents said they need the few support groups that are actually in their area to provide more childcare services, so they can get the support they need.

There was a support group I would have liked to go to at my church, but they posted right on their page, "Sorry, we don't provide childcare." I don't want to leave my child with a regular babysitter and I don't know who in our area is experienced enough that I would trust leaving my child with them.

– Jasper

Laredo

Parents in Laredo also said their community lacks sufficient resources for children with special healthcare needs, including doctors. Several mothers said they frequently have to travel to other cities, particularly San Antonio, for care. Laredo parents also described a limited number of support groups for parents; some would like to see more support groups specifically for parents with children with cerebral palsy.

There are no programs, there aren't enough doctors. I'm from El Paso, where there's a lot of help. There's a tremendous difference here in Laredo.

– Laredo (Spanish-dominant)

Parents in the Laredo Spanish-dominant group also spoke to inadequate programming within the school curriculum for their children with special healthcare needs.

My son is a slow learner and they are not helping me. He flunked first grade, but they sent him to second grade because of the State. A teacher recently noticed him, and I am now very grateful to her.

– Laredo (Spanish-dominant)

El Paso

Parents in El Paso said they needed more specialists, particularly neurologists. Some parents in this group also experienced what can be described as the situation of the working poor: They earn too much money to qualify for many needed services, but not enough to cover the costs themselves.

Many times they see your income and tell you that you don't qualify. I paid the first four years of my daughter's therapy; I think I would have been able to buy another house with that money. Barely two years ago, I finished paying the credit cards, because she had five therapies per week.

– El Paso (Spanish-dominant)

There was a consensus among the El Paso parents that the greatest need of schools and teachers is additional funding for training and support services. Parents in this group described a strong local parent network, and many of the women in the group already knew one another through their involvement with a variety of local programs.

You notice we all know each other. It's been through CDIC [Children's Disabilities Information Coalition].

– El Paso (Spanish-dominant)

Parents in El Paso perceive a lack of communication between the schools and their children's providers, which results in unnecessary confusion and difficulty.

If you have a diagnosis, the school won't necessarily accept it. For example, I took my autism diagnosis to the school and they say he is mentally retarded. I told them that wasn't true because the doctor said he is deaf-mute. The education law says the school doesn't have to take the doctor's diagnosis into account.

– El Paso (Spanish-dominant)

Lubbock

Parents in Lubbock listed a number of special healthcare needs programs in their community that provide activities and weekend events, including the Burkhart Center at Texas Tech University, High Pointe Village and Mosaic. However, they also described a lack of adequate community resources for their children, including insufficient day care, after-school care, and camps. Six of the nine participants in Lubbock said they have difficulty finding childcare for their children during the day. The closest day care for children with special healthcare needs is in Amarillo.

Participant 1: *I need just regular, pay-for-it day care. They won't take my son at all because of the liability risk, so I've had to literally just juggle my childcare and working and going to school.*

Participant 2: *When my daughter was younger, I would have given anything for special needs day care.*

Participant 3: *They have one in Amarillo that only accepts special needs kiddos, and they bring the therapists in.*

– Lubbock

Parents indicated that they do not think the Lubbock schools provide enough programming resources and support for their children. They also said there are not enough special education teachers. Parents in this group agreed they would like to see mandatory teacher education about children with special healthcare needs.

The schools are set up like a maze. By that, I mean their interest is not to help, although they say they will. They are reluctant to open up about the things they are willing to do. It drains from LISD. I think too that every time there is a budget shortfall, the first thing they cut in Texas is education.

– Lubbock

Some parents said they lack a centralized source for finding healthcare providers, and that not all providers are particularly welcoming of their children.

Dentists. Believe it or not, we took our son to a dentist, and he didn't believe in autism. He didn't tell me. He told my wife that it was a parenting issue.

– Lubbock

Temple

Temple parents were in general agreement that they feel quite isolated in their community and that there isn't much in the way of resources for them or their children.

There's not anything. Unless a parent starts a program, like a rec program. We have a lot of really awesome parents that start soccer leagues and baseball, but it's the parents saying, "We need to do something for our kids."

– Temple

The two resources that Temple parents mentioned most often and described as most helpful were the Children with Special Needs Network (CSNN) and the Heart of Texas Central Independent Living (HOCTIL) in nearby Belton. Temple parents also said they appreciate the wide range of medical services available at the Scott & White Healthcare center.

I will say the Special Needs Network does try to find activities, but enough ... as we go to a CSNN outing as parents we can relax. We're around other parents just like us, our kids can go to a movie theater together and make as much noise as they want and we're not worried about it.

– Temple

Parents in Temple echoed the sentiment of Lubbock parents when it came to the unmet need for day care and daytime activities for their children. They said their community needs more recreation centers, camps, and sports programs that cater to their children.

Parents in Temple also said they lack a centralized and “transparent” resource for finding all of the available activities and programs for their children. One parent likened her search for resources for her children to trying to get into a “secret society.”

Participant 1: *You can call ten different times and get nine different answers and then finally get the right answer.*

Participant 2: *When you’re going to do it, there’s a lack of responsiveness and it’s confusing.*

Participant 3: *It’s a brick wall, and you’re chipping at concrete.*

Participant 4: *It’s a secret society you can’t get into.*

– Temple

A few parents across the groups had moved or were planning to move to another city that could provide better resources and access to care for their children’s diagnosis. One woman in the Houston group had moved there from Dallas after she found support groups there via online social media sites. Another Houston woman was about to move to Katy, Texas. A parent in Temple was planning a move to Arizona because it ranks number one in a United Cerebral Palsy poll on family support services, whereas Texas ranks number 50 out of 51.

Key Finding: Parents said there isn’t enough communication and publicity about resources and issues in their city pertinent to children with special healthcare needs.

Parents in every focus group said they aren’t being informed or educated enough about the resources, events, research, and legal transition issues that impact their children’s wellbeing. Many also said they think there should be more print and online directories with comprehensive resource listings for children with special healthcare needs.

We need the resources to be within everyone’s reach and view, so everyone finds out about them. We need more publicity and information.

– El Paso (Spanish-dominant)

What I can add to that is, we desperately need a clearinghouse of information where anybody can access that information – because you can call somebody that’s supposed to be helping you coordinate, but they don’t know. They don’t know what is available. They will say to you, “Oh, I’ve never heard of that.”

– Temple

I’d like to know everything that there is to get services for my child at his age; then it turns out the social worker is like, “Oh, why aren’t you getting X services? You should be getting this and such and such.” I’m like, “I can? Then how come I wasn’t getting it two years ago?” It seems like sometimes with the social services, that organizations within themselves have bad communication.

– Houston

We need some type of service that could be the liaison between legislation that's happened on both federal and state levels and to connect that to the parents, because we're so busy doing the things that we do on a daily basis. I have never heard of this Able Act.

– San Antonio

It was only this past spring that I discovered, after several trips down to Houston, that our daughter's insurance would have reimbursed us for mileage, but nobody volunteered that information.

– Jasper

Key Finding: Networking with other parents of children with special healthcare needs emerged as the most valuable way parents learn about resources in their community. Parents in all regions reported that they learn about local resources for their children from a variety of sources, including providers, schools, and friends. Nevertheless, they most frequently learn from other parents of children with special healthcare needs.

I usually learn about resources when you're sitting in the waiting room with other parents in therapy or any facility that you're at where there's other parents of special needs.

– Houston

You leave the doctor's office with a diagnosis, completely lost, and here you find someone who makes you feel better. It's not a doctor. It's a mother just like you, who you can sit down with and cry, talk to, and blow off steam.

– El Paso (Spanish-dominant)

Parents said it is often difficult to find resources that might be able to accommodate their children, and there is no “centralized” source such as a website, listserv, or online directory that can help them in their specific locale.

There's nowhere to find them (resources). We can't just specifically look on a website and say “Okay I need this for Lubbock.” They are spread nationwide. If wanted to go to a bar shop to get my son's haircut, it's not in Lubbock, it's out of town.

– Lubbock

A general database would be great – that has the common illnesses we see in children plus another one for rare cases where you could go and find information, institutions, parents that have kids that's been there longer than you have that can help you through your journey and what to expect.

– Jasper

Parents also described the value of a centralized medical database containing their children's medical records so they don't have to fill out paperwork or present records anew every time they see a different provider. They also see the value of their children's different doctors' being able to access this information to save time and improve efficiency.

I would like to access Sally's medical records anywhere, basically. Say she does have to go to the emergency room. I don't want to have to go through this two hours telling them what's wrong with her, what's going to happen, what could happen. I need to have quick access to those records.

– Jasper

Everybody has their Medicaid number, or some individual number. There should be some uniform system that no matter who you are dealing with, they could plug in that number and have all your information.

– Dallas (English-dominant)

Key Finding: Therapies for their children emerged as one of the resources most valued by parents. Desired modalities include speech, occupational, physical, music, applied behavioral, and food therapy, to name a few. Equine therapy was also mentioned in several of the groups. Parents in all groups extolled the benefits of therapies for their children because they can see how much they improve all facets of their children's functionality – physical, emotional, and relational. They described advancements in their children, such as increased motor function and mobility, improved communication skills, better behavior, greater socialization, and improved diets, as a result of therapy.

I don't remember how [the therapist] phrased it, but in terms of sensory issues, he doesn't do that anymore. If you touched him, he would wipe off your touch. He doesn't do that anymore; I don't really understand why it works, but it did.

– Lubbock

I have heard horseback riding therapy stimulates something in the brain that helps the kids a lot. My mom took my sister there, but it was expensive, too. It was in Mexico.

– Laredo (Spanish-dominant)

Some parents said therapies provide the secondary benefit of offering a social outlet for both their children and themselves. Therapy appointments can help break the social isolation many parents feel as they care for their children 24/7.

More parents in the Laredo Spanish-dominant focus group than in any other mentioned psychological therapy for both children and adults as a high-priority therapy. One parent who is in group therapy with other parents of children with special healthcare needs described it as important to both her mental health and her ability to learn about opportunities for her child in the community.

I relate to the people I go to therapy with. Each tells each other, "Where did you take your kids today? There are classes over there, let's enroll him, how does this work for your child?"

– Laredo (Spanish-dominant)

Jasper parents described a significant lack of therapists in their area. Some of them reported having to drive an hour or more to therapy appointments.

When I say we need therapies here, I mean there is only one speech therapist in Jasper. We've been waiting for over a year now for Medicaid to approve this – I can't get her into the therapy she needs.

– Jasper

Some parents have experienced gaps in therapy coverage because they were waiting for Medicaid to approve a prescription renewal from a provider or had been put on a waiting list. Such delays can take a toll on children's functionality. They said they need better, faster access to both the provider and the Medicaid representative to solve the issue.

I have been put on a waiting list for three years at Therapy 2000. If my daughter would have gotten therapy then, she would be able to eat on her own. Now she can't because she has a lot of movement she can't control. I give it to her, but it's not enough. She's been ten years without any therapy.

– Dallas (Spanish-dominant)

Key Finding: Parents said their communities lack after-school, day care, and sports programs for children with special healthcare needs. Parents in the focus groups often face a lack of school programs and facilities that can accommodate children with special healthcare needs. Consequently, many of them can feel bereft of options for after-school or day care activities for their children, as well as of opportunities for their children to get enough physical exercise. Day programs would also serve a socializing function for their children, many of whom find it difficult to leave their home due to disability.

Parents said a variety of factors make it difficult to find day care for their children. Some day care centers don't offer services for children with special healthcare needs due to concerns about liability or lack of qualified staff. Participants said many schools also are not able to accommodate their children in after-school programs for the same reasons.

I think there's a need for after-school programs because many typically developing after-school programs do not take our children.

– Temple

A lot of people can't handle them [children with special healthcare needs]. They're only used to certain people. I started taking my son to day care, he would get used to it, but it's just if they could handle him. Every autistic child is different – none are the same. Some of them are not trained to take care of special needs children.

– Lubbock

Some parents want these day care centers to offer therapy modalities for their children as well. Others complained about the expense of day care and camps that do accommodate children with special healthcare needs. The cost can be prohibitive.

Summer camp is like \$2,500 per week. It's ridiculous for a special needs child, even one that's not medically fragile.

– Temple

Parents said they particularly need day care and activities for their children during the summer months, when they were not in school.

I live in fear of the summer because the schools do so much during the school year, but when summer comes there's nothing. I don't know what to do with my kids for the whole day. They want to go out and play, but we live in some apartments and they'll jump off the second-storey balcony with some other little kids and then my kids get in trouble because they're older.

– Temple

We need more programs for kids with disabilities in the summer so they can get out of the house. They need more games.

– Laredo (Spanish-dominant)

Key Finding: Medical and therapy appointments are frequently offered only during the standard 9 a.m.-5 p.m. workday. Parents said it is difficult to get to these appointments due to work obligations, the need to take their children out of school, and transportation challenges. Parents talked about the difficulty of taking their children out of school or day care to get to a medical or therapeutic appointment. Most said physicians cannot or will not talk to them over the phone about medical issues, and their offices are open only from 9:00 a.m. to 5:00 p.m., and almost never on the weekends.

Every time I call them, they're like, "Well, you're going to have to bring her out here." You guys realize that you're asking me to take her out of school because of course, there's nothing open when they're out of school. It was to the point that when they told me that, I was just like, "Forget it, I'm not going to even bother."

– Jasper

Some doctors only give you appointments at times during the school day and if you miss the appointment, they complain. We tell the school faculty, "Who am I to tell the doctor I have to come in after he's out of school?"

– El Paso (Spanish-dominant)

Even parents who don't work during the day sometimes have difficulty because they have to take their children out of school to make these appointments.

I'm a stay-at-home mom, so in theory my schedule is wide open and I can go to therapy anytime. But they work from nine to five and the kids are in school. When are they supposed to go? You have to choose between the services the school is providing and the ones you obtain for yourself.

– Lubbock

This situation was exacerbated in Jasper, where parents frequently had to drive an hour or more to medical appointments in nearby cities. Parents who use the Medicaid Medical Transportation Program face another set of challenges with daytime healthcare appointments: They frequently have to catch the van hours prior to their appointments because of other passenger pickups along the way. This further cuts into their day, jeopardizing other plans and activities.

Discussion of the difficulty of getting to healthcare appointments during the day brought up another common barrier for parents: They need someone to stay at home with their other children when they are out, whether the child left at home is typically developing or has special healthcare needs. Many parents described the difficulty of finding childcare with unwilling extended family members or a respite worker they feel they can trust.

I have two other kids. These kids also don't go out. I tell them, "We can't go because of your brother." If I had someone that would stay with my son, then I could go out with the other ones.

– Dallas (Spanish-dominant)

In-home services would be fabulous. Just fabulous.

– Temple

Key Finding: Parents said they would like to see more education about children with special healthcare needs for the community at large. They think mixing children with special healthcare needs and typically developing children would help foster this type of education. Parents said they would like to see more community-wide events, venues, or parks that were inclusive of both children with special healthcare needs and typically developing children. They believe this would improve understanding and acceptance of children with special healthcare needs among those who may currently feel judgmental towards them.

Why don't you make it fun for the whole place, for everybody, free to the public to learn? Like, "This is what this is or this is how it is to have [a special needs child]."

– Lubbock

Luckily, we have a park that's a few minutes down the road that's completely 100% accessible for everybody. It's great because then it mixes in typical children with children with disabilities, so exposing our children both ways.

– Houston

Parents who have had this kind of experience with their children saw the many benefits for both their own children and the people who gained insight into their lives.

Since I learned about the Burkhart Center, he has other interactions with children that are not autistic because they allow you to take your other children that are not autistic. I've seen him open up so much more than just trying to stay in his own world.

– Lubbock

Parents consider education about special healthcare needs in the schools important, including for teachers. Parents worry that their children may be bullied at school.

My daughter used to go to a school, and they used to have an assembly once a year. They would talk about each child [with special healthcare needs] and say, "This is what they'll do, and expect for them to do this." It would decrease bullying so kids expected, "Okay, Bethany is jumping up and down – she does that because that's part of her processing."

– Lubbock

Sports programs offer a particularly great variety of activities, and hence opportunities for children of all abilities to play together. Parents in the focus groups consistently reported that the need for sports programs exceeds the current availability in their area.

We've been taking our kids to go bowling and they have a little rack for my son. He has all these issues carrying – he doesn't grab anything, really. It's like him trying to be out there with all the other kids – we have him in soccer, too. I try to put him in sports so he can get used to the other kids around him.

– Houston

Key Finding: Both parents who have an only child with special healthcare needs and parents who also have typically developing children reported significant challenges. Parents whose only child has special healthcare needs are concerned not only about the social isolation their children experience due to a lack of peers and playmates, but also about the isolation they themselves experience as parents and as a family. Many reported a lack of engagement and connection with other families who have typically developing children; some said they decided not to have any more children after their first child was born with a disability. Some parents said they changed their life or career plans after the child was born because of the enormous amount of time and energy they would need to invest in caretaking.

It's sometimes the lost dreams. I was going to start my last year of law school when I had Marty. I never went back. I should be a judge right now. That's what I wanted to be. My life changed and it's okay. I love her.

– Houston

For us, I created our new normal. It's good and bad at the same time because he's my entire world, so God forbid something ever happens to my kid. I see how special needs kids get treated differently by others, and my son is not going to have that person to grow up with, who's always going to be there for him.

– Temple

I wish I could have had a typically developing child before her because I really got scared to have another child. My child will never get married. I'm never going to be a grandmother. There are some things I'm missing out on. Other people who do have other children, will have those experiences where I won't.

– Houston

Parents with both a typically developing child (or children) and a child (or children) with special healthcare needs reported a different but equally challenging set of parenting issues. They said the typically developing children frequently feel left out or ignored, since so much of the parent's time and attention goes to the child with the special healthcare needs. Parents described the emotional stress that having a sibling with special healthcare needs places on their other children.

The typical child feels isolated because our focus is on the one with special needs. We have to make extra time so they don't feel abandoned.

– El Paso (Spanish-dominant)

It's just a lot of stress, I think, especially for the child without a disability, because they end up having to help take care of the sibling. I try to do it myself, but his sister ends up having to help. It's not fair to her. She resents it. She doesn't understand why he's different and why he gets so much.

– Lubbock

Some parents also talked about the character-building aspects of having a sibling with special healthcare needs, and how they've seen their typically developing children mature as a result.

I see great positive things, like Ross is very protective of Hunter, his twin. It's made my other [typical] children more aware of who they are because of him, in a strange kind of way. We were normal until he came along, and so it shook us out of our normal shell.

– Temple

Parents also talked about the financial cost associated with caring for their children with special healthcare needs and how it can adversely affect the opportunities for their typically developing children, such as higher education and family vacations.

My boys are in their twenties now, but it was hard when she [daughter] was diagnosed because it was like, "You're on your own boys," so they missed out on a lot. Then also the financial track: I lost my home to foreclosure in 2007, because back then I was paying for ADA out of pocket. Like she said, I can't do the things that regular families can, because the child has special needs.

– San Antonio

My nineteen-year-old had the grades, the scholarships to go to Baylor. I had to tell her, "You know what? I spent your entire college fund on your sister's medical bills."

– Houston

Parents said outings that may be routine for other families, such as going to a restaurant or a movie, are more difficult for theirs. They worry about their typically developing children's happiness.

You only have a certain amount of time, so the family has to decide: What are we going to do? Can we go on vacation unless we have help for Carolynn and Adam because it's not safe, or do we leave them behind? We've never been to a movie together. We've never been to a restaurant together. My fifteen-year-old son said to me, "You know, Mom, I don't know half the music that all my friends know." We didn't play music for nine years because of all the sensory issues, and that impacts him in his social development.

– San Antonio

Care Coordination

Key Finding: Most parents have not heard of a care coordinator. Upon learning the definition of "care coordinator," most parents said they are the care coordinator for their child. When the topic of a care coordinator was introduced, only four of the 102 participants knew it was a job and accurately described the services they provide.

Focus group participants were given the following definition of a care coordinator.

A concept of someone working with your family to make sure that your child's health needs are being met and that the right person is delivering the right care at the right time. For example, someone to schedule appointments, share test results between providers, and make referrals.

Typical parent responses include the following.

I didn't even know it [care coordinator role] existed.

– San Antonio

I thought it was just a social worker.

– Temple

Find a care coordinator? That would be like finding another mother.

– El Paso (Spanish-dominant)

Most parents had not sought out a care coordinator per se because they did not know such a role existed. When they learned it actually does exist, a majority of the parents quickly identified themselves as the care coordinator for their child.

Well, I coordinate the care with my husband; coordination with doctors; coordination with family and teaching my family. I have focused on what I do with Andrea, my daughter, so that they can help me when I get sick or when something happens.

– Laredo (Spanish-dominant)

I think of myself as a care coordinator. I'm like, "No." I listen to what everybody says, and then I take the information I think is most relevant, and I find the people that I think are the best and then I go from there.

– Houston

Parents quickly saw the benefits of having a care coordinator: they could work outside the home, spend more time with their children, and generally improve the quality of their lives, both as individuals and as a family. Parents embraced the idea of another advocate for their children, beside themselves, when it comes to communicating with healthcare providers and agencies.

We need a central person that will inform the parent – these are your medical needs NOW. Because when a child is diagnosed or in the school system, at three years old we're not telling the parents that the waiver lists are ten to twelve years long for the HCS [Home and Community-Based Services] and for CLASS [Community Living Assisted and Support Services] and some of the government agencies.

– San Antonio

We have a social worker who would tell us we needed this or that. She would talk to the provider and tell us, "You should do this, this and that. This is what you need to do."

– Dallas (Spanish-dominant)

Parents in all groups talked about how much time they spent on the phone each week talking to insurance carriers and providers. They talked about how a care coordinator would enable them to spend more time with their children and their family, as well as allow them to work outside the home.

My daughter sees about fourteen different specialists and she's got a lot going on. I usually take two to three days of my week, and I know I need to get at my desk and just sit there and call and follow up and call. I have my call days. Two to three days per week, every week.

– Houston

A care coordinator would be able to tell parents whom to call and which services are available for their children, which would be helpful because many do not know what services are available for their children.

Medicaid is all over the place – they're giving wrong numbers; you can never get the right doctor. I wish I could have one person to send me in the right direction for the right answers.

– Dallas (English-dominant)

I guess there needs to be easier access. I can call Medicaid and say, "Well, she needs this." "Well, you've got to call your doctor at Texas Children's." I guess we need somebody who can call and get in directly with the doctor instead of having to go through the nurse, and then somebody that can call Medicaid directly and get straight to what they need.

– Jasper

Many parents think a care coordinator could help educate them in many areas, including medical information. Some feel this type of education can make a significant impact because early intervention is so crucial.

I think care coordination would help us in the sense of teaching us things we don't know. For example, looking back when my child was two and three years old, if someone had said to me, "You should have her hearing tested because she doesn't seem like she's listening," then maybe we would've had her hearing aids ten years ago instead of just two years ago.

– Houston

Parents said it would be helpful if their providers, schools, and other resources told them about care coordinators. One parent in Houston had asked her child's doctor if they offer care coordination. She said specialists are more likely to offer it because they see patients with multiple diagnoses and have to coordinate their care, whereas her family practitioner does not.

Key Finding: Most parents have sought out this type of care coordination for their children among social workers, case managers and nurses, without much success.

Many parents said they have looked for the type of services a care coordinator would provide through a variety of providers, including social workers, case managers, and nurses; some even approached health insurance companies about this type of service. Many had been disappointed with the services they received and, with one exception, nobody described a person they had worked with who was sharing pertinent information, such as test results, with the team of the child's providers.

I have tried to get somebody to help me coordinate anything and have really had no luck trying to get help with coordinating services. As a matter of fact, what I've been told is, "We can give you anything you want if you'll quit your job."

– Temple

I think the most help we've had was from a case worker. It's hard when you have more than one child with disabilities; remembering all the doctor and school appointments, medicines, and monitoring how they feel – it's very hard.

– El Paso (Spanish-dominant)

Yes, we've had several service coordinators, and they would ask me what all I had done [for my child] and I would tell them. I thought they were going to help me. They'd write everything down and tell me they'll get back with me. Finally, they were wasting my time; I just got on the phone [and did it myself].

– Jasper

I have looked for one [care coordinator] a time or two. Once your child is on a waiver, it gets a little complicated. You have a case manager over that, but they don't understand Medicaid. The first thing I'll do is call a Medicaid case manager. Unfortunately, there's two or three that I'll call and usually they say, "You've researched it. You know more about this topic than I do."

– Houston

Some parents thought individual case managers they work with provide a certain amount of helpful care coordination, but the feel these case managers may not be willing or able to provide much information beyond their own specific agency. Others said these case managers have too much on their plates to be of much service to them. Some parents said case managers don't call them back soon enough.

It seems like with the case managers, I've noticed there's been a high turnover of their staff. I've probably had five case workers in two years. It seems like they're understaffed. They're overworked.

– San Antonio

Sometimes I think they [case managers] have a lot of work to do and they are in a hurry. Sometimes I am explaining to them and they say, "No, only answer what I'm asking you, don't tell me anything else." When you keep quiet they don't know what you and your kids need. That's when you start feeling anxious.

– Dallas (Spanish-dominant)

I feel like when I do make a call, they take down information – somebody will call me back two days later. So many changes in our lives – it's not necessarily relevant two days later. I probably could have figured it out on my own.

– Houston

Regardless of how they perceive the role of the care coordinator, many parents emphasized the need for highly personalized attention to their situation rather than a clinical approach to care giving.

Obviously it is a job, but these are our children, these are our lives, these are our hearts that walk outside our bodies, and someone that would be coordinating that would need to be a very special person that wouldn't treat you like a number.

– San Antonio

Key Finding: Some parents expressed concern about trusting their children's healthcare to a care coordinator and said they are the experts on their children's needs. Some parents said they wouldn't entrust this type of responsibility to anyone but themselves. Some expressed doubt that a care coordinator would work on behalf of their children's best interests rather than for their agency of employment.

I have this gut reaction that if I let someone other than myself take charge of that, depending on who they're being paid by, who they work for, that they're going to have more of an interest in deciding that my son doesn't need certain services than actually trying to find the ones I think he needs.

– Lubbock

In addition to trust, some parents feel that a care coordinator couldn't provide the level of care they themselves can because they know their children so well. Others have had experiences with case managers whose caseloads were too heavy to truly provide the level of care for their children that the parents needed and wanted.

I'm the expert about my child. Nobody knows her like I do and nobody knows what her needs are more than I do, so it'd be difficult for me to sit there and explain something to somebody for 20 minutes about what it is that I need to do and how it needs to get done, compared to I just do it and it gets done easily.

– Houston

I felt like her [the social worker's] caseload was too large and we became another number. She gave me a piece of paper and said "Call these people." There was no guidance, no handbook. There was nobody explaining anything to you – I have found through the years that I am more reliable than trusting someone else to depend on for my daughter's care.

– San Antonio

Key Finding: Parents thought that having a care coordinator to help them coordinate their child's medical care would enable them to work outside the home. The inordinate amount of time parents must spend on the phone making medical appointments or trying to get benefits for their children makes it difficult for many to be employed outside the home. This is particularly true of mothers. Many of those who do have a job said they constantly worry about losing their jobs because they must take so much time off to coordinate their children's health and medical needs.

See, I haven't worked in twelve years to manage his care, and the care coordination piece would give the moms an opportunity to not just be moms, but to give them their lives back as far as having jobs or going to school or whatever.

– Temple

I'm the one who helps her with everything. I can't work because I'm the only one who can fill out the paperwork and handle the calls. Only my husband works in order to support the family with the bills, rent, and everything.

– Dallas (Spanish-dominant)

I can't work because I need to go to speech therapy and all these other therapies three times a week and they're not there until 8:00 in the evening. They're there during normal business hours, which is most jobs.

– Houston

I lost my job two years ago and I don't think I could have a job now because of what effort I'd have to put on to show I'm a good employee. I'd get fired within the first month for all the time I have to take off for the boys.

– Temple

Community Support

Key Finding: Most focus group participants said they feel alone and isolated in their journey as parents of children with special healthcare needs, regardless of the resources, accessibility, or activities available to them in their community. Parents were asked, “What’s it like to be a parent of a child with special healthcare needs here?” Most responded that they feel quite alone in spite of varying degrees of local resources and accessibility for their children. Even in large cities such as Houston, where there are so many opportunities to participate in the community, participants still reported a sense of isolation. Parents in multiple focus groups said they their sense of community comes primarily from their own homes and the special healthcare needs community. Most parents feel isolated even within their extended family, receiving little support beyond the immediate family and other parents of children with special healthcare needs.

Participant 1: *I feel isolated. Very isolated.*

Participant 2: *I feel isolated.*

Participant 3: *I’d say I feel I have a community because we have the Spina Bifida Houston, but I went searching for it before I was pregnant.*

– Houston

This finding was equally true in the smaller and more rural communities, such as Jasper and Temple.

Participant 1: *You’re on an island.*

Participant 2: *There’s just not anything. Unless a parent starts a program, like a rec program – it’s the parents going, “We need something for our kids.”*

Participant 3: *The loneliest feeling in the world.*

Participant 4: *There’s not community. Technically, I guess there’s community support, but the truth is that we’re on our own. I’ve been turned away from Easter Seals because my kids are too disabled.*

– Temple

Although they live in such a small town, none of the five participants in the Jasper focus group knew each other. One parent lives in a small trailer with five other people, including her severely disabled daughter who is in a wheelchair. She had moved to Jasper because her husband’s family lives there; she has only two friends in the entire town. At the time of the focus group, she didn’t know any other parents of children with special healthcare needs.

I’d like to see support groups here. Honestly, as far as I know, there are two other special needs kids in Jasper and I’ve never met their parents. I’ve felt alone in this, like I’m in a battle by myself with my husband. My family is nowhere near here and, like I said, I have two very, very good friends. Other than that, I’m alone.

– Jasper

This woman, along with the other parents, eagerly exchanged telephone numbers over lunch after the focus group. They seemed to appreciate the opportunity to talk with other parents like themselves. In fact, *in all the cities* parents lingered together after the focus groups to exchange resources and telephone numbers, and some even went to lunch together. For some parents, the rarity of their children's diagnosis contributed to their sense of isolation because they literally had no one else to talk to who would understand.

My daughter's syndrome is so rare, she's number 43 in the world and most of the syndrome originated in Puerto Rico. When I try to link up with other parents that have similar things, their kids aren't as functioning as her, so it's like we're left in this abyss of "Okay, what do we do?"

– Houston

Parents said that many family activities that other parents take for granted are often difficult for them. This contributes to a sense of isolation from the community at large.

It's hard to do vacations and social outings. I think the biggest thing for us is when people invite us over for dinner and I have to go down the list of what they will eat, what they won't eat, the textures and do you have dogs? Is this okay? As soon as we walk in the house, I've got to scan the entire house – I'll look at the sink, the dish soap, the laundry detergent in her pantry. As the primary caregiver, you're just exhausted.

– San Antonio

A third of the parents in the Dallas Spanish-dominant group said they almost never go out into the community with their children due to a lack of time and transportation. One parent in this group doesn't have a ramp outside her home for her daughter's wheelchair, so she is seldom able to take her anywhere. These types of factors also contribute to a sense of isolation for parents.

Several parents in the focus groups mentioned they had sought counseling for themselves as well as for their children, to help with stress management. A parent in the Dallas Spanish-dominant group said she had considered seeing a therapist. In the end, she decided it would just be another appointment she would have to make, and who has time for that?

Key Finding: Parents in every focus group said they build their community with other parents who have children with special healthcare needs, because they understand each other's world. Parents living in a “world” that is largely devoted to meeting the health and medical needs of their children said they find support and camaraderie in talking with other parents in similar situations. They said only parents who have been what they have been through can truly understand them and provide the kind of emotional support they need.

I think there is a disconnection in your typical community compared to your disability community. We have a better understanding of each other, or compassion or acceptance, than outside of the world. In my neighborhood, I really don't have neighbors that I can go out and do neighborhood stuff with because they don't understand our world.

– Houston

At the day care where I take my daughter – it's like we are a community. I know a lot of the mothers. Sometimes their horror is my pain. I have felt that. It is such a support.

– Dallas (Spanish-dominant)

I think family therapy is great because we can get to know each other and share our stories. Some people feel like they are drowning. To learn how others are overcoming their problems helps us with our own. We can learn from each other.

– Laredo (Spanish-dominant)

Parents in every group identified other parents as their best resource for finding services, doctors, support groups, and activities for their children.

I have to say that really the most helpful thing for me has been the parent networking. That has been the absolute most helpful thing over any agency. It's been the grass roots. That's how I met Norma, and we go to conferences together and we say, “Hey, did you hear about that?”

– San Antonio

Key Finding: Social media and the Internet provide opportunities for parents to build a support community that is not just local but global, as they connect with other parents around the world. Many parents said they use the Internet to find in-person and online support groups as well as resources for their children. Social media emerged as an important source of information for parents. They look for support first and foremost from other parents of children with special healthcare needs, and they are looking online more and more to connect with other parents.

As soon as I got home from the hospital after having my girls, I looked up her syndrome on the Internet and got into a support group immediately.

– Houston

There's an online Meetup group for autism and Asperger's adults. We use it for social opportunities.

– San Antonio

Facebook was mentioned in every group as a valuable online resource for connecting with other parents and joining support groups. In fact, all of the parents in the El Paso Spanish-dominant focus group said they use Facebook to connect with other parents and to find out what is going on in their community for their children.

I found other parents on Facebook – moms there knew other parents, or they knew their patients that had similar issues, and they would give them my phone number and we would talk.

– El Paso (Spanish-dominant)

I look on Facebook groups and I looked out to other moms and things like that. Being medical here and there, they knew parents or they knew their patients that had issues like that, and they would give them my phone number and we would talk.

– Houston

Key Finding: Parents said they feel supported within the special healthcare needs community but experience more judgment outside those enclaves in the public community. They often feel misunderstood by other parents and people because of their children's behavior or appearance. Even in cities where plenty of activities may be available for children with special healthcare needs, some parents do not get out of the house much because they don't want to face the harsh judgment, thoughtless actions, or cruel words of others towards their children.

My daughter is sixteen and practically, we don't do nothing because she don't like to be called stupid or looking wrong. Obviously, she's none of those things, so we just stay home.

– Houston

People are very inconsiderate. They see a child in a wheelchair and they're like, "Oh, well I'm just going to cut right in front of them," like it doesn't matter. She's in a wheelchair so she's not a person; she doesn't matter. It irritates me to death, to the point where I just want to hit them.

– Jasper

Society still looks at them like they are weird kids.

– Laredo (Spanish-dominant)

Parents in all focus groups reported that they sometimes experience judgmental attitudes when they go out to restaurants in their communities. Some of their children are six-foot-tall grown adults with the intellectual capacity of a three-year-old, and people do not understand the disabled person's behavior or need to be fed by a parent at that age.

I've only had a couple of negative experiences. At a restaurant, they had an elderly couple and they were really offended that we were there with her. My husband was getting upset – we just want to have a good dinner. They actually were asked to move.

– Houston

Parents in several groups talked about people who admonish them to spank their children when they are throwing a fit in public. Already under pressure in these situations, parents said they wish people would take a moment to try and be more understanding.

I think I'm on the outside looking in a lot of times, because my family doesn't understand. Everybody thinks when my son is having a meltdown that he is throwing a fit because he is spoiled. There's much more to that. Grocery stores – there'll be cashiers who would see us coming and leave their stations just to get away. They make horrible comments. I think there's a lot of judgmental people that make it very difficult to take your child out in public.

– Lubbock

If she's in the store throwing a fit, people just look at her like she's some bratty child. They go, "Well, she needs to be spanked." She is big for her age; she's 42 pounds to be two years old.

– Jasper

Parents encounter judgmental attitudes and impatience with their children even among educators. One parent in the Dallas Spanish-dominant group said she feels her daughter isn't being treated kindly in the school system.

The school program is not an appropriate program for my daughter. I had to go to school two days all day to teach them how to feed her. It's not that my daughter doesn't eat. She eats very well – they just don't have any patience with her.

– Dallas (Spanish-dominant)

Key Finding: Faith communities can be a significant source of support for many parents of children with special healthcare needs. By and large, faith communities are a source of support for many families, particularly in the smaller communities like Jasper and Temple. El Paso parents also mentioned the support they receive from their faith communities. In Jasper, four of the five participants mentioned their church *first* when asked about community support in their area.

Participant 1: *We have a great church family. I had a great desire to be able to sit in church and not worry about meltdowns or anything, so I would tell the pastor. It was an answered prayer to be able to sit in church.*

Participant 2: *Anytime there is a problem or issue, I send out a message asking for prayer. It spreads; everybody in Jasper knows him and puts him on the prayer lists at church. Parking [at the hospital] is expensive – some of the churches took up collections and sent money down for me to help me cope a little better.*

– Jasper

A number of churches across the state have ministries especially for children with special healthcare needs and their families.

We just started attending church there. They have the STARS program and they are the most amazing people. They started the Buddy Ball program – I have a pretty tightknit group of folks there.

– Temple

However, some parents feel they do not find support in their faith community. One mother in Lubbock went to half a dozen churches before she found one that welcomed her and her autistic son.

We've had trouble with churches. That was the first place we turned for help, and absolutely nothing. They wouldn't let our son go in day care because they considered him too old, and he couldn't sit in the services because he can't sit still and makes too much noise.

– Lubbock

Working with Healthcare Providers

Key Finding: A majority of the parents in all groups have a positive relationship with their children's healthcare providers and said that trust is the number one factor in that relationship. Because so many children with special healthcare needs require extensive medical treatment and therapies, healthcare providers are key. Most parents in all the focus groups said they have good relationships with their children's doctors and feel confident of their ability to treat their children. Parents worked hard to find the right physician and/or specialist for their children, and parents in multiple groups told stories of walking out of a doctor's office if he/she didn't have enough expertise in their child's particular condition and did not care to learn. They left and didn't go back.

I can just tell. If you've never heard of it and I have to teach you, then you're probably not the one. If I'm explaining the disorder to you ...

— San Antonio

The parent's ability to trust a provider emerged as the single greatest factor in the parent-provider relationship. First and foremost, the parent needs to trust the doctor and his/her expertise in treating the child. Parents want to work with doctors who are knowledgeable about the child's specific condition, no matter how rare, and who are willing to educate themselves about it if they are unfamiliar with the condition.

Initially my pediatrician said, "I'm going to be honest, I don't know much about autism." This doctor educated himself so much that now he sees a large number of autistic children. The interest he showed in helping me was very important to me.

— El Paso

Parents said they trust a provider who builds a strong support staff team around himself/herself, consults with other providers and specialists about the child, and is willing to think outside the box in terms of treatment options. Parents trust doctors more if they feel they truly *listen* to them and speak directly to their children while interacting with them as individuals.

They just get down on her level to make it personable. Like she said, just down on her level. She's so excited because they get on the floor with her and do different things.

— Jasper

Generally, her doctor is great, but she needs to learn to talk to the level of the child with special needs.

— Dallas (English-dominant)

I am comfortable with a doctor if they come in to see Rebecca and they address Rebecca instead of talking over her like she's an object. I will always go back to a doctor who believes in her. Don't tell me the negatives about my child – believe in my child. If you believe in my child, then you're part of my team.

— Houston

Trust in a doctor's expertise outweighs a poor bedside manner for most parents. They want to know their child is in the best hands and is receiving care from the most knowledgeable provider.

Participant 1: *We just started seeing a new doctor, but he doesn't have a great bedside manner. When I asked around about him to other professionals, they're like, "Oh yeah, if I had this, I would definitely go to him." That makes me feel a little better. I can deal with he may not be all warm and fuzzy, but if he's good at what he does, then I'm okay with that.*

Participant 2: *He doesn't have to be all warm and fuzzy, but if he's good at what he does, then I'm okay with that.*

– Houston

Parents clearly prioritize trust in their providers, but they also spoke of a number of factors that made them feel *comfortable* with a provider, including the feeling that they genuinely care about them and their child, are willing to be honest with them about difficult topics, and sincerely believe in their child.

Our doctor knew the familiar signs of our child's diagnosis. My husband is the military type, he's like, "Give me the worst-case scenario." I hated him for that, but I appreciated knowing, and the doctor telling me the truth.

– Temple

My daughter told me about her therapist: "She doesn't believe in me." I asked her why she said that, and she said, "Why does she talk to me like that?" I asked for a different therapist, and the other person was completely different. Children feel it.

– El Paso (Spanish-dominant)

Parents said actions speak louder than words when it comes to a provider showing he or she cares for their child. Providing emergency care at 3 a.m., calling parents back late at night – even a simple hug are all interpreted as signs of true concern for the child.

My son's neurologist got up at 3 a.m. to save my son's life. I would say the relationship is very positive. Dr. N saved my son's life – there is no price that can be put on that.

– Lubbock

If she [the doctor] doesn't know the answer, she finds out and calls me back. She will call me at 10 pm at night and say, "This is what I have found out."

– Temple

The oncologist hugged me and tells me my son will be okay and will recover. Just hearing those words meant everything to me. He also believed in God, like me. Just with that, it was the greatest thing because I felt like he gave me moral support.

– Laredo (Spanish-dominant)

In the end, some parents said they think that being able to trust a provider and feeling comfortable with him/her go hand in hand.

I think being comfortable and trusting a doctor go hand in hand; once you are comfortable with them, you have a feeling of trust.

– Houston

Parents don't want a doctor they feel treats their child like an object or textbook case instead of a unique, precious child. Some have had this experience, but fortunately, these instances were not very common.

I had one doctor tell me, "I cannot work with it." I'm like, "My daughter is not an 'it.'" I cussed him out, walked out and made a scene in that office. I never went back. We filed a report against the medical board.

– Lubbock

I once talked to a gastroenterologist about intolerance to gluten and casein, and he told his nurse, "It's another one of those."

– El Paso (Spanish-dominant)

Every child is different. My daughter is not the same as this or that.

– Dallas (Spanish-dominant)

Parents said they want their providers to consider the greater context of their lives with their children outside the office visit. They feel this would foster empathy and a greater understanding of whether they will be able to follow their treatment protocols at home.

Understand it's not just the office visit. That small bit of time they're spending with us, there's a whole dynamic at home for that family as far as nurses, therapists coming in and out your home, respite providers, stress on a marriage, taking care of the other children.

– Temple

The parents in Dallas spoke about a best practice medical education program sponsored by TxP2P. Doctors in residence from Children's Hospital or Texas Scottish Rite Hospital for Children participate in roundtable discussions with parents of children with special healthcare needs to hear what the parents think would make them better doctors. The doctors also visit the parents' homes to better understand their daily routines and what life is like for a family with a special healthcare needs child.

Key Finding: Parents want doctors to know and respect that they are the experts on their own children. Parents in all groups resoundingly stated that they are the experts on their children, even though they may not have the medical expertise doctors have. It was critical to them that their providers acknowledge this and in fact *trust them* to know what is best for their children. They want doctors to work collaboratively with them in treating their children.

They listen and appreciate that we are the experts on our child. They acknowledge that we're the expert on our child and they're the expert in their field.

— San Antonio

The provider I have understands that the parent is the one who knows the most about that child.

— Lubbock

Nobody knows our children better than we do. I don't care if you have a PhD or how many degrees or letters you have behind your name. Listen to me, I know what I am saying. I know my child.

— San Antonio

Parents said that if they were teaching a class for providers about how to help families like theirs feel comfortable and cared for, a significant message they would want to relay would be that they are the experts on their own children. Some of their other responses are listed below (but not identified by city).

I would tell them every child is different. The treatment will be different. They learn by textbooks, but down along the line of years they should have the opportunity to know that every child is not the same.

They have to listen to the parents because doctors do not always know best. They see the child once every couple of months; the parent is there nonstop.

I think that they should be told from the get-go, "If you're not comfortable with special needs, you don't need to go into pediatrics."

Trust the parent. We are the experts about our child.

The nurses need to be very personable because they are a direct representation of the doctor.

What would you do if this was your child?

Put your heart into your work. Do your work out of love, not just to get a check.

Key Finding: Parents frequently complained about medical office staff. They would rather have more direct access to their doctors than spend so much time on the phone with nurses and administrative staff. Although most parents are happy with their children’s providers, some complained about the service they receive from their nursing and administrative staff. They encounter some difficulties when support staff cannot answer their questions quickly and accurately, lose paperwork, or schedule appointments in an untimely manner.

We have a great primary care provider. It’s his office that we have a problem with. They have one secretary for five doctors they have in this pediatric clinic. She is forever losing paperwork, not faxing it on time.

– Temple

Many parents said they need more time to schedule and prepare for appointments of all kinds with their children with special needs, because it can require so much effort and planning. Some said they would like to have greater access to their doctors via the telephone rather than have to visit every time they have a question or need minor medical support. This was particularly true for parents who live in the more rural areas and have to drive further to get to an appointment.

Participant 1: *They [doctors] need to be more willing to talk to us on the phone. They will say, “Well, why don’t you bring her on in?” It’s not as simple as me dropping everything I’m doing. No, I can’t come in in two days; I’ve got to make arrangements.*

Participant 2: *I called my PCP because my daughter had this infection on her arm. They told me to bring her in, but then it started storming. They said, “Send us a picture.” I did and they ordered the antibiotics like that – that was all done over the phone. Stuff like that helps us because we can’t drop everything at the drop of a hat and just take her three hours or an hour away.*

– Jasper

Transportation

Key Finding: Transportation poses a unique challenge to parents of children with special healthcare needs. The myriad factors parents must consider when taking their children to a medical appointment complicate the issue of transportation for them. Many of their children are in wheelchairs, on ventilators, or in need of a special car seat. Others have children with heightened sensory issues or compromised immune systems that make ride-sharing options more problematic.

Luke, because of his trach, couldn't be in the back seat by himself. He also has really low tone through his neck, so there was always fear that he would cut off his airway. Somebody would always have to drive while I sat in the backseat with him to suction him out and keep everything under control.

– Temple

Almost all the parents in the focus groups use their own cars to drive their children to healthcare appointments. Very few use public transportation or the Medicaid Medical Transportation Program vans.

The very few parents who do use public transportation such as city buses or vans said they sometimes encounter other people's negative judgments about their children. Others said the bus system is too slow or cumbersome, and they are sometimes late for their medical appointments.

Before I got my car, I would ride on the city bus. My son doesn't like it because there are so many people and he starts to feel claustrophobic and freaking out. I have been told, "Well, this is where we are going to have to stop – you have to get off here because everybody else is feeling uncomfortable." I'm like, "But I have my kids, I need to ride." Then I'm like, "Okay, it's like all of you against me and my kids; I'm getting off. Fine, whatever."

– Lubbock

I don't have a car and it's very hard. For example, we've had appointments at 7:30 a.m., so we have to leave at 5:45 a.m. so we can take a bus and wait for the next bus and sometimes we're late. I have to call and let them know that I'm going to arrive late.

– El Paso (Spanish-dominant)

Many parents in the focus groups have concerns about their children's being exposed to germs while using public transportation. Parents in most groups talked about their children's compromised immune systems. They also said they need to be able to trust the bus or van drivers to drive safely. These concerns make them less likely to choose ride-sharing options.

I keep him in a bubble. I have to watch where we go and who he's around because he picks up viruses so easily. It could land him in the hospital.

– San Antonio

Hygiene is very important. Our kids get sick very easily, and that's a big deal.

– Temple

A cold to you is pneumonia for us, so we are constantly on the lookout. Even taking him to the park on a nice day, I still have to wipe everything down before we get there.

– Temple

Of all the parents who participated in the focus groups, those in Jasper generally have to drive the farthest to see their children's providers. This further complicates the already challenging task of getting to appointments.

I've never used [the bus] before, but with my daughter the way she is and having the wheelchair and everything, I'm not sure I'd be that comfortable, especially going that far. You are talking an all-day trip. It's not an hour or two hours, it's an all-day trip.

– Jasper

My husband has to take off work to go [to the provider] because he doesn't want me on that long trip and in traffic all by myself.

– Jasper

Additional transportation challenges for parents include accessible parking. Parents in several cities, particularly Jasper and Dallas, spoke about this issue.

They didn't even want to give me a handicapped parking space. They said they have none and there are no ramps either. I talked to the City, and they said they would follow up with me and they never did.

– Dallas (Spanish-dominant)

Parents also talked about how expensive it can be to park in hospital parking lots and provider parking garages. Parents had ideas about how to improve transportation options for their children. These included cab services specifically for children with special healthcare needs, wheelchair storage options on city buses, and driver's ed programs targeted to adolescents with special healthcare needs.

Key Finding: Many parents said the Medicaid Medical Transportation Program service delivery is too slow and time-consuming. Few parents in the focus groups actually use the Medicaid transportation available to them, preferring to drive their own cars. Some said they used it for only a short time. For example one parent in Houston used Medicaid transportation to safely transport her child in an oversized car seat when the child's legs were in casts. It saved her \$250 in special car seat costs.

Other parents, including several in El Paso, have no other option because they don't own a car. Those who do own cars but sometimes use the service said they do so to avoid driving in traffic and expensive parking fees.

The benefit is, I don't have to deal with traffic. I'll be in the backseat and I don't even have to see it and have the anxiety.

– Houston

Most parents had heard from other parents how time-consuming the Medicaid Medical Transportation Program is. Some of the participants had actually tried it a time or two and complained about the lengthy and cumbersome service. Participants described the difficulty associated with having to schedule their provider appointments around van pickup times and spoke at length about how much time pickups and drop-offs take.

You have to plan your whole day for a one-hour appointment. They pick you up two hours early. You go to your appointment and then they pick you back up two hours after your appointment. You're spending most of the day just waiting for them to pick you up and drop you off.

– Houston

It's easy to sign up to get picked up, but with all the other people they have to pick up, there are times when they'll drop us off two hours before the appointment, or we'll have to wait two hours afterward to be picked up.

– El Paso (Spanish-dominant)

I've been told that it takes forever. They'll show up and they'll get you down there, but if they leave for any reason and you call them towards the end of an appointment, there's no telling how long you're going to be waiting for them to come back.

– Jasper

Some parents in Lubbock and Laredo said that the Medicaid program provides transportation for the special healthcare needs child only, not siblings. This makes it difficult for parents to utilize the system because they then have to find separate childcare for their other children.

They have buses where you can get on, but like I said, they only allow you to take that one child. They don't allow you to take the other [children], and you're like, "Well, who's going to take care of them? I have to take them with me."

– Lubbock

They don't want to take two kids – Medicaid doesn't pay for that. What about the other child? How am I going to get her, who is going to pick her up?

– Laredo (Spanish-dominant)

Key Finding: Parents find the Medicaid Medical Transportation Program reimbursement process time-consuming, but most agree it is worth it. Most (but not all) parents in the focus groups had heard of the Medicaid Medical Transportation Program, and not everyone was aware that Medicaid reimburses for mileage, toll, food, and lodging costs associated with travel. The parents who didn't know about reimbursement thought there should be better publicity about the program. Most of the parents who are familiar with the Medicaid reimbursement program utilize it even though they do not use the van service. However, almost half of the parents in the Dallas Spanish-dominant group had never heard of the reimbursement program, and those who had heard of it have not used it. Most of the parents in Laredo who spoke about the Medicaid reimbursement program said they were getting reimbursed in an untimely manner or not at all. This was the only focus group to report significant difficulty in receiving reimbursement.

Most parents complained about the lengthy paperwork associated with getting mileage, toll, food, and lodging reimbursements from Medicaid.

You have to do it [submit paperwork] six weeks prior to the appointment and they have to approve you as driver to drive your own car to the doctor. Then you have to send back a letter to them saying that you took them to the doctor, and it has to be date- and time-stamped, and once you do that you can get reimbursed two to three weeks after the appointment. They make it so difficult you don't even want to do it.

– San Antonio

It's kind of a hassle getting started. They'll mail you a packet that you have to fill out. You have to send it back with your driver's license, insurance card, and let them get you in their system before you can start. Then you have to call [ahead] for each appointment.

– Dallas (English-dominant)

However, some parents had positive experiences with the Medicaid reimbursement program, such as this mother in Jasper:

I don't have a problem with reimbursement. You've got to take your kid to Houston and you've got to eat and all this kind of stuff, and you need that money right up front. They do put it on a card for you. Advance funding.

– Jasper

Some parents also had issues with Medicaid's denying or delaying payment because they weren't able to reach the provider in a timely manner.

Medicaid will not reimburse me for the trip to Baylor unless the doctor sends a referral. You all know what it's like trying get hold of your doctors at Texas Children's Hospital. I send an e-mail, get a reply from the nurse, "Hey, I'll contact you," and I don't hear a word back.

– Jasper

Some parents identified the obstacle of having to pay costs up front that may later be reimbursed through the Medicaid reimbursement program. For example, wheelchair tie-downs for use in a family van can come to \$1,000 out of pocket. However, in spite of these difficulties, most parents did appreciate the Medicaid reimbursements for gas and hotels.

I'm not happy with them right now. I turned in my paperwork and I got a letter in the mail stating that they needed my driver's license and current insurance – I sent that in. They're now saying that they paid me for this appointment that we didn't go to. Yet I haven't gotten paid for October and November yet. They're saying they paid me for something I haven't even gotten paid for.

– San Antonio

It's a lot of paperwork. Like we need more paperwork. It's ridiculous. It's almost not worth it, but it's just this side of "Yeah, it's worth it." I do it.

– Houston

Medical Emergency and Disaster Preparedness

Key Finding: Although they do not have a cohesive disaster plan, most parents have taken some measures to prepare for a natural disaster. Many of them have reached out to 2-1-1, first responders, and utility companies to let them know they have a child with special healthcare needs in the home. Although most parents said they don't have a formal disaster plan in place, they have taken a number of steps to ensure their children and homes would be safe in the event of a natural disaster. Many have registered their home addresses with their city utility office to ensure their homes continue to receive power during a crisis.

I've signed up with the electric and water companies. Depending on who you use, they are really strict about their disability [policies]. They asked if my child was on a ventilator or I wouldn't get approved. So like any vented child, they'll automatically approve for the electricity-type stuff.

– Houston

Many parents had also registered their homes so that first responders will know a child with special healthcare needs is inside should they ever have to come to the house. Some also said they have heard 2-1-1 operators will call and give them advance notice of evacuations.

We were actually in-patient in the hospital, and 2-1-1 works, because they [first responders] came to my home, making sure she was not there, that we needed to get out of there. It works.

– Houston

Before we left the hospital, they had us fill out paperwork that was sent to the fire department, police department, and his doctor. We're still in the system, so if we ever call 9-1-1, they're really there quick.

– Dallas (English-dominant)

A few parents had also taken their children to their local police department or fire station to meet first responders in person. This enabled police and firemen to connect a name with a face should they ever be called upon to respond to a call at that residence.

My husband is a fireman and there are people that will just stop in the fire station and say, "Here's my child. She is hearing impaired. Could you give us some pointers?" They love that kind of stuff. They love to help educate. They love to help teach.

– Dallas (English-dominant)

While parents felt confident in their ability to handle a medical emergency with their children, some said training would help them feel more prepared for a natural disaster.

We need something like a hands-on experience to show us that if this happens, this is how you need to respond. You don't need to freak out. Go over and over it like they do tornado drills or fire drills. Then I'm like, "Okay, if this happens tomorrow, I'm prepared. I know what to do."

– Lubbock

Although they may not have a specific response plan for a tornado, flood, or hurricane, some parents in the focus groups had taken some measures to prepare for a natural disaster. These efforts include having packed bags that contain extra clothing, shoes, prescriptions, bottled water, and extra gas for the car.

I always have at least two weeks of medication. I always have suitcases ready. You always have your vehicle full. I have two five-gallon containers that I can put on top of my vehicle. When you leave, you never know what kind of traffic you're going to be in and how long the gas lines are. I've ten extra gallons of gas.

– Jasper

I have toothbrushes, paper documents in a waterproof bag, like if it's a major disaster. Sometimes I practice with my kids: a fire drill, tornado drill, anything like that. If anything ever were to occur, let's take that and whatever we have in our hands and go.

– Lubbock

Some parents across the groups had even learned how to stockpile medications for their children, in spite of insurance limitations on prescription refills.

Another thing you are always told for disaster: Make sure you have this additional supply of medication. Anybody knows that insurance only gives you a 30-day supply. But there's a trick to that, and the pharmacist knows what the trick is. They're allowed a little bit of leeway, so over time you can build up that supply.

– Jasper

Some parents said they had discussed disaster planning for an in-home fire, while others had generators at their homes for use as a backup source of electricity.

I said, "What if there is a fire and you can't get out of your room?" He said, "Mom, there's a dresser drawer." I said, "Then you got to move that dresser drawer." "The window is locked." "Then you've got to unlock that window and you've got to open." "What if I can't open it?" "Then you've got to break it." That's as far as I got.

– San Antonio

Everyone should have a generator in their house with the 50/50 gas/oil mix, because that's the one I use and it powers my entire house, more or less. Plug in a phone, plug in a TV and it won't have any problems.

– Lubbock

Other parents utilized strategies unique to their situations. For example, a mother who lives alone with her disabled daughter has an iPhone app, Home Solo, which alerts her neighbor to come check on her family if she hasn't pushed a button by a certain time each day. Some parents said they have signed up for emergency and disaster text alerts on their smartphones; others said they also watch the news and weather stations carefully.

I watch the news. I'm just a news geek from my heart. If something gets close to the Gulf of Mexico, I'm always ready.

– Jasper

The parents who do have disaster plans in place said they receive planning support from a variety of resources in their community, including churches, online support groups, and the Boy Scouts.

Participant 1: *Our church was teaching us about how to get prepared, and they told us to get a backpack for each and every one of the family members and to put one pair of pants and shirt and get extra shoes.*

Participant 2: *Disability groups online. I subscribe to a lot of online feeds, and they will often talk about that; the need to plan for your child with special needs during a natural disaster.*

Participant 3: *My oldest son is a Boy Scout. They have an emergency preparedness merit badge. I feel very prepared because that's kind of his interest. He has water and food stored.*

– San Antonio

Parents in the Dallas English-dominant group described concerted efforts by local hospitals, nursing agencies, first responders, and municipalities to help citizens prepare for a disaster. The Denton County Emergency Response Group near Dallas offers weekend disaster preparedness training session to parents of children with special healthcare needs. One parent in the group had spoken at this session and suggested the State offer this type of training statewide.

They had a training session on a weekend. One of their segments was inviting a couple of parents to talk about what to expect in a shelter situation with their child with special needs. And also how they [volunteers] work with a person in an emergency situation like that, which is really great, I thought.

– Dallas (English-dominant)

Other parents in the group agreed that they would like this type of training, and one parent said she thought Medicaid was the best and most likely source of this type of education. One Dallas parent also mentioned a video titled “Be Safe,” which was produced to educate police and parents on effectively managing an autistic child or adult in a threatening situation with the police. Parents in the same group thought facilitated opportunities for first responders to meet local children with special healthcare needs would be a good idea.

Key Finding: Many parents said that although they have not necessarily had conversations with their providers about medical emergency planning, they feel prepared to successfully handle an emergency with their children. Parents said they trust in their ability to galvanize a response to any medical crisis involving their children. Most parents said they feel more confident in their ability to handle a medical emergency with their children than a natural disaster.

I feel prepared now. When I first had my son, I was just like a deer in headlights. I had no idea what to do. But I do now.

– Lubbock

You plan ahead. We’re taking Luke to see the dinosaur train in Dallas. I have to know what doctors are up there, if he does that or this or this – we can stop real quick and say “Okay, we’re popping in here.” You have to plan ahead.

– Temple

Some parents mentioned 24/7 nurse hotlines they know they can call for additional support during an emergency. Others have their doctor’s telephone number on speed dial on their cell phones. Parents in every group mentioned a bracelet that has a USB attached to it that contains medical information about the wearer. Many have heard of parents getting them for their children to help in the event of a medical emergency.

We have the [USB] bracelet. We set that up because the doctor said with a rare condition, you want to make sure the ER understands exactly what needs to be done because when your seizures are not caused by neurotransmitters, they’re caused by glucose, you have a different protocol. I got it from the Epilepsy Foundation.

– San Antonio

I bought her a medical alert bracelet that’s a USB drive, and I put all of her stuff on there. In an emergency, I just grab it and go.

– Houston

Some parents said they have a one-page document written with and by their doctor, which they can take to the emergency room. The document details the child's condition, medications, and other relevant information.

Parents with children who experience seizures seemed more likely than those without to report that they've spoken with their providers about planning for a medical emergency.

We've had a lot of conversations about emergency response for seizures. We went to Cleveland Clinic, and they gave him very specific seizure response meds. When we moved here, the doctor was very reluctant to prescribe those again, so educating providers [is important].

– San Antonio

We had a doctor in Nebraska who sat down and wrote a one-page letter about Jacob. It had all his diagnoses, what seizure meds he needed in case he went into status, et cetera.

– Temple

Most parents said they know when to take their children to the ER as opposed to their doctor; some parents of children with more complex medical situations said their doctors have advised them always to go to the ER if their children become sick.

With our provider, because it's Scott & White Medical Center, and we have such a hard time getting appointments, he basically told us, "If he's running a fever and you can't get in to see me, just go to the emergency room."

– Temple

Several parents in Houston said they would be more comfortable going to the ER if there was a separate waiting room for children with special healthcare needs. They said their children are more susceptible to catching colds and illnesses than are typically developing children. More than one parent said something to the effect of "A cold for you is the ICU for me." Other parents echoed this sentiment during other discussion segments of the focus groups, particularly around public transportation.

Participant 1: *We go to Texas Children's Hospital and I'm going to take him there [to the emergency room]. We avoid the ER at all costs because it's where all the sick kids are.*

Participant 2: *Yes, most of the time when we go to the ER, they automatically just take us back and let us sit in the back because of that.*

– Houston

Another parent in Houston shared a technique she uses with her daughter to avoid the ER waiting room.

The trick at Texas Children's – if you want to be seen quickly – is, Rebecca is deaf/blind so "Oh, she may be having a seizure." Let me tell you, you get immediate assistance if your child might be having a seizure.

– Houston

Key Finding: Spanish-dominant parents are particularly unprepared for a natural disaster or medical emergency. None of the parents in the Dallas Spanish-dominant group said their doctors have discussed emergency or disaster planning with them beyond telling them to call 9-1-1, an ambulance, or take their child to the emergency room. In contrast to parents in the other groups, not a single parent in this group said, when asked, that they feel prepared for a medical emergency with their children. When asked what would make them feel more prepared, most participants mentioned knowledge and more information about what to do.

In Mexico – I'm from Mexico – when there is a national disaster coming, they tell us on the news about this shelter that is available. They tell us where to go. But here, I have never heard anything about where to go.

– Laredo (Spanish-dominant)

None of the parents in the Spanish groups had registered their homes with the city utilities department or with first responders such as the local fire department. No one said they had heard about registering their children with 2-1-1; in fact, one woman seemed to have a misconception about 2-1-1:

The thing about it [2-1-1] is that it only works from a landline, so if you have a cell phone, it doesn't work. I only have a cell phone.

– Dallas (Spanish-dominant)

Even though almost half the parents in El Paso have attended a class on natural disaster, one parent said she felt they were informed but *not prepared*. Several other parents nodded in agreement. None of the parents in this group have a bag packed for their children in case of a disaster.

Similarly, most parents in Laredo were not prepared for a medical emergency beyond calling 9-1-1 or taking their children to the emergency room. Spanish-dominant parents in Laredo, like those in Dallas, also reported that they have done virtually no planning for a disaster and are unfamiliar with the option of registering their homes with 2-1-1. Several said they know they should be prepared, yet they forget to do things such as plan ahead for a disaster.

We should be prepared – sometimes we live day to day and we forget. It is important, but we forget.

– Laredo (Spanish-dominant)

Key Finding: A variety of factors influence whether parents evacuate or shelter in place during a disaster, including their child’s age, disability level, and prior disaster experience. Hurricanes Katrina and Rita were the most top-of-mind natural disasters for these parents, particularly those who had been in the evacuation zone, such as the Houston and Jasper residents. The lengthy traffic lines heading out of town influenced some parents to consider a shelter-in-place response next time there is a disaster, given the dangers associated with running out of generator power for children on respirators. The difficulty of transporting children in wheelchairs and other durable medical equipment also makes evacuation a less desirable choice than sheltering in place.

Most parents in Group 1 in Houston said they would shelter in place in the case of another hurricane or natural disaster. Parents described various preparedness measures that they have in place, such as stocking several weeks’ worth of food and water and having a generator for electricity. In contrast, most parents in Group 2 in Houston said they would evacuate in the event of a disaster.

The children of the Group 1 participants were older than those of the participants in Group 2: Six of the nine participants in Group 1 had teens with special healthcare needs. They had actually lived through a hurricane evacuation with their children, in stop-and-go traffic in hot cars, whereas the parents in Group 2 had younger children and hadn’t had the same experience.

Participant 1: *We would just stay in place. We tried to leave the last time there was a big hurricane and got stuck. I cannot be stuck on the side of the road with a kid in a wheelchair or run out of gas or something. It cannot happen. We’ve decided if there is ever anything like that again, we’d just stay in place.*

Participant 2: *We have, with both hurricanes, evacuated. Yes, I did get stuck on the side of the road with a child having a seizure, hot, and I was told there’s nothing we can do. We don’t even have ice. She just might die. I put her in a car with some strangers who had air conditioning.*

– Houston (Group 1)

By contrast, the dialogue Group 2 played out as exemplified below.

Our thing is, as soon as we get enough of a warning that something is going to happen, we're out of here. We don't wait to the last minute. As soon as you get enough warnings, we're headed north.

We just don't wait. No putting it off to the last minute.

- Houston (Group 2)

Transition

Key Finding: Transition means a variety of things to most parents: it implies not only the transition from childhood to adulthood, but educational, medical, and developmental transitions as well. Parents in all focus groups except the Dallas Spanish-dominant group were familiar with and understood the term *transition*. Parents had a wide range of ideas about when transition planning should start, when transitions actually happen, and how many types of transition their children have ahead of them.

Transition is changing to something else other than what you've been doing, is what I've been told.

– Lubbock

Transition is moving from different agencies that can provide services up until a certain age and then another agency could take over based on that person's age.

– San Antonio

There's so many elements of transition. There's transition in education, transition in healthcare providers, and transition in how they physically grow. There's transition in me and how I am as a parent.

– Houston

I can say for my six-year-old that I don't think we've used the word "transition," but we've started talking about putting down on the paper the things that are working so that each year we can build on it. I think that's a successful long-term plan: to truly start as young as possible, get all those successes that are working and just let it roll from year to year, and then talk about what that transition looks like for the next year.

– San Antonio

Parents in the Dallas Spanish-dominant focus group were the only participants who thought transition planning meant preparing emotionally for the inevitable death of their child.

Transition planning means preparing for the change that is about to happen: what they are living through and will continue to live through. I mean, there is no way out and that moment has to come.

– Dallas (Spanish-dominant)

The parents in that group described the changes in life leading up to that moment, and even described other types of transitions along the way, such as a daughter's first period.

I'm already preparing on my own for the transition when my daughter gets her period. I want to prepare myself to know how to help her. For example, how she needs to behave with other children. I have a cousin with a daughter with Down's syndrome. The day she got her period, she grabbed the bag of pads and gave one to each student in her class because she thought it had happened to everyone.

– Dallas (Spanish-dominant)

When the moderator focused the conversation on transition planning for adulthood, the Dallas Spanish-dominant parents learned what transition planning actually is. They thought they could benefit from it very much. In fact, when the focus group conversation turned to ARD meetings, several women said they now recalled hearing the word "transition" during the meeting but hadn't known what it meant. They felt confused at the time but did not ask questions about it.

Parents in many of the groups talked about the ways they are trying to help prepare their children for the transition to adulthood right now.

To help him live on his own [eventually], I do take him grocery shopping. I will walk out of the produce department and say, "I forgot the bananas. Go back and get the bananas." This is something that I do for him to prepare him to buy groceries.

– Jasper

Most parents in all focus groups other than the Spanish-dominant Dallas group said they had heard the term *transition* from Early Childhood Intervention Services early in their children's lives, or at school meetings when their children reached middle school age. Although many parents agreed that planning for a child's transition into adulthood needs to start as early as possible, there was broad consensus that the timetable for transition planning is actually conditioned on each individual child's unique development, abilities, medical condition, and circumstances.

For those parents who had not yet started transition planning for their children, the reasons frequently included factors such as age (thinking the child is not old enough) or their child's participation in a work program at school. Some have pediatricians who have agreed to see them even after they become adults; parents of these children perceive no need for medical transition. Some parents said they simply don't have time to plan for transition.

It's hard to even think that far in advance. We're just thinking about tomorrow.

– Dallas (English-dominant)

When asked how they might benefit from transition planning services, parents overwhelmingly said it would be helpful.

I'd probably be able to plan for all the stuff that is just at the back of my mind because I'm too busy worrying about the here and now and what needs to be done now.

– Jasper

Several parents in Houston mentioned that they had participated in Person Centered Planning, which is an ongoing problem-solving process used to help people with disabilities plan for their future. This process involves sitting down with the entire group of people who make up a child's community and developing a personal plan for what the child is going to do and how he or she will be supported in this plan.

Medical Transitions

Medical provider transitions are another source of concern for some parents. They aren't sure what to do in terms of medical care once their children transition out of pediatrics, and many of them have good relationships with their pediatricians.

Participant 1: *Pediatric doctors have their cutoff at eighteen, and they're like, "Adios!" Some will see them up to 20, 22.*

Participant 2: *Some of them will just say, "Hey good luck. Hopefully, you find a good doctor after this."*

Participant 3: *That's terrifying.*

– Houston

Legal Guardianship

Many parents mentioned the topic of legal guardianship for their children and said both healthcare providers and the schools have prompted them to consider this option.

Significant life events such as medical emergencies and divorce also cause parents to start thinking about guardianship. Finally, the realization that they themselves may not always be around to care for their children clearly motivates parents to begin to explore legal options.

My son was on hospice. That's when it really hit me, because I had to sign a DNR. They told me, "Well you can leave him on life support and we'll keep him alive as long as you want." I thought to myself, what about his quality of life? What about when I'm not here anymore? That started that for me.

– Lubbock

However, even though parents think legal guardianship is an important issue, many avoid doing anything about it – or even thinking about it – because they believe the legal fees will be prohibitive.

Participant 1: Money is a barrier. The guardianship is very expensive. It was \$2,500 for our attorney.

Participant 2: A special needs trust is another thing I need to do, but we haven't done it because I barely have enough money to make it through all of her medical expenses.

– Houston

Lack of legal action, however, weighs heavily on the parents as well, for they worry about their children becoming wards of the state in their absence. The situation entails a real struggle for some parents.

Our daughter has to have someone take care of her. She can't take care of herself at all, so that's just something I've been struggling with over the years and trying to find someone. Nobody in my family wants to do it, you know? That's way too much for anybody to take on. I have no idea what I'm going to do.

– Houston

Key Finding: Transition planning for adulthood and long-term care for their children triggers anxiety and concern in many parents. The discussion of planning for their children's transition to adulthood, and particularly for their children's care should they die, elicited some of the strongest emotional responses in the focus groups. Parents can feel overwhelmed and sad at the thought of what might happen to their children after they leave their home as adults, or if the parent dies.

Participant 1: *When they talk about transitioning my daughter to group homes, I tell them to stop. She is extremely vulnerable - I'd say she's like a bunny. She has no defense, no language. I'm not going to drop dead until I have someone to take care of her, but then I fear what is going to happen to her, because I'm no spring chicken either.*

Participant 2: *You have to make an effort to let them go. I allow my son to go to the school for the blind in Austin. He is out there. He is in a dorm with other visually impaired kids. He's in Austin for three and a half weeks and that's hard for me, but I have to do it. He said, "We went to Sixth Street." I'm like, Oh, God."*

— San Antonio

Many parents said they feel anxious when they think about what will happen to their children if one or both parents die. This concern is exacerbated when they feel they don't know where to turn for assistance in planning or can't pay for the related legal expenses.

Participant 1: *It's not like having a typical child where you can leave a will. Well, who has the know-how to take care of your child? My parents would love to, but they're also older than me with their own health concerns.*

Participant 2: *I struggle with it all the time. I have no idea what I'm going to do.*

Participant 3: *I have no one. My teenager was like, "I'll take my sister," and I'm like, "No, you've been dealing with this since you were a little kid and once you become an adult I want you to have a normal life." We don't want to burden little Darryl with all that she has going on.*

— Houston

What's going to happen to our children when they turn eighteen? It makes me anxious not knowing if they will have the resources for a job, living independently, or have the doctors they need.

— El Paso (Spanish-dominant)

Some parents expressed concern that their family members may not be willing to take on the responsibility of caring for their child with special healthcare needs should they die.

She can't take care of herself at all, so that's just something that I've been struggling with over the years and trying to find someone – like, nobody in my family wants to do it, you know?

– Houston

Key Finding: Parents aren't sure where to turn for adulthood transition planning.

Many parents said they need assistance in learning how to plan for their children's transition to adulthood but aren't sure whom to talk to. They need someone who can show them the larger picture of possibilities for their children.

I think it [transition planning] would make things go so much smoother. I always feel better if I have a plan and I know what's going to happen. But the school turns to me and says, "What do you want to happen?" like I'm supposed to know. This is your job. I need a professional who's good at this to come in and assess her and say, "Okay, we can make this happen, or this would work, or that would work."

– Houston

Middle schools are mandated to provide transition planning at ARD meetings. This is often the first support or direction many parents have in transition planning for adulthood. In spite of this, many parents feel they are on their own for adulthood transition planning.

Participant 1: *You have to seek it out yourself.*

Participant 2: *When you hit junior high, they start having those conversations in the ARD meetings. What are your plans? Are they college bound? Are they going to get a job?*

Moderator: *Have these conversations been helpful?*

Participant Consensus: *No.*

– Lubbock

I have my caseworker through CSHCN, but she doesn't always know [how to help with transition planning]. She'll try and research, but like I said, the answer comes back "no." I do my own research. Nine out of ten times I hit a brick wall.

– Jasper

Other parents said the fact that the schools initiate transition planning is one of the reasons they haven't looked elsewhere for planning assistance. Many parents work with both the school system and a governmental agency (such as the Department of Assistive and Rehabilitative Services [DARS] or the Health and Human Services Commission) to develop plans for their children's transition into adulthood.

Some of these parents think waiting until their children's junior or senior year in high school is too late to start planning for employment and housing options.

Dayna is fourteen and we just had an ARD meeting. I said, "Is it time to talk about it?" They said, "Next year." DARS asks, "How is she going to be employable?" I was like, "Well, let's face this now. Let's think about this."

– Houston

Other parents said they feel a need to initiate planning for post-secondary education or career transitions for their children because the school systems or governmental agencies aren't helping enough.

It's very difficult to get a job. We ended up having to do it. We did the leg work. We don't live on the bus route; transportation is a huge obstacle for us.

– San Antonio

It's scary because he is so borderline in some cases that people don't understand he might go to college – there is a gap. Just because he is autistic does not mean he cannot go to college.

– San Antonio

Parents expressed concern about the lack of adult services for their children after they transition to adulthood, and also about whether their children will have enough social interaction once they are no longer in school. Many parents expressed concern about the long wait list for Medicaid adult services waivers.

Say she gets to 22 or 23 and graduates high school, then what? We're terrified of that day because she is such a social creature that she needs that interaction, or she's just going to wither and there is nothing. There's actually nothing here [for adults].

– Lubbock

I signed up for every waiver I could at the Burke Center. They said it's a thirteen-year waiting list.

– Jasper

Several parents mentioned the Baylor College of Medicine Transition Clinic as a valuable resource for their families for transition planning and care.

What they do is, this clinic has three specialty doctors that see our kids starting at the age of fourteen. They will see them for the rest of their lives. I was really impressed with them the first time I went.

– Houston

Obesity and Exercise

Key Finding: Parents said their doctors are more likely to discuss obesity, diet, and exercise with them if their child has a specific issue in one of these areas. Although some parents said their doctors talk with them about their children's diet and fitness in general terms, most said these conversations take place because of the child's condition and diagnosis. Most parents said they are careful to monitor their children's weight because extra pounds negatively impact their functional mobility as well as their health.

He has a thyroid disease that's supposed to make him fat, but he's not. We work on trying to figure that out because the tumor sat on his pituitary gland.

– Jasper

I asked about nutrition because my daughter failed to thrive. Now she's the opposite and pre-diabetic, so it was a concern. I put her on a strict diet. They guided me, as far as what to eat and things like that.

– San Antonio

Some parents said they think their physician evaluates their child's weight against a chart or textbook rather than by how the child actually feels and looks. Many parents feel they are the best judge of their children's weight and condition.

To me, she's too thin. But my doctor says she is at an okay weight. She just wants candy and snacks and stuff like that, so lately I've been cutting down on candy and the snacks. If I just let her go, she'll eat candy and stuff all day.

– Dallas (English-dominant)

Weight gain for a child with special healthcare needs can impair his or her mobility, and some parents expressed concern about their children's ability to stand or walk with their extra weight. Impaired mobility can also limit a child's ability to engage in calorie-burning exercise. This made it more difficult for parents to manage their weight. To that end, some parents talked about the lack of insurance reimbursement for adaptive exercise equipment such as bicycles and trampolines.

We have to monitor [food intake] just because the heavier he gets, the more he won't be able to transition and walk, so we talk about the impact of him being able to maintain being on his feet.

– Temple

I'm finding that in order for Rebecca to participate in these [physical exercise activities], it requires equipment that isn't covered by my insurance.

– Houston

Parents often have to lift their children in and out of wheelchairs, beds, etc. They said this can become more difficult as the child gets older, and also if the child is overweight.

We have to lift Grace, so she cannot gain weight. It's hard on me and hard on the nurse. I have to have somebody with me, if we go to doctor appointments, to lift her in and out of the van. That's a major, major focus.

– Houston

Key Finding: When obesity does become an issue, many parents said doctors talk to them about weight loss but don't give them the tools that would really help them help their children lose weight. Parents in the groups said many children with special healthcare needs are picky eaters. They spoke of the limited range of foods that their children will actually eat. Some want only Eggos, noodles, or peanut butter sandwiches.

We're having peanut butter and jelly. You have to pick your battles. What's important to me is that my child is eating.

– Jasper

The fact that many children are obese or that they don't eat what they should is that children with autism don't want to eat anything. They want to eat the same thing every day. We get stressed because we want good nutrition for them.

– El Paso (Spanish-dominant)

Some parents acquiesce to their young children's desire for a limited and sometimes carbohydrate-filled diet, in an attempt to get them to eat anything at all. This pattern, if established early in the child's life, can be very difficult to change as they grow up. This can be especially true for children who are intellectually disabled and do not understand why they cannot eat the foods they have always eaten.

A lot of kids have problems with textures and eating. When they're little, anything they eat, they're happy about, which can then be a problem when they're older.

– Houston

When my daughter went in for her fourteen-year-old check and the doctor wants her on a diet, but she'll only eat certain things, so how do I take that away from her? We've already cut back and limited what she eats, so she can't eat much.

– Lubbock



Many parents said some doctors don't understand how difficult it is to get their children to eat, or not eat, certain foods. They said they want more specific directions from their providers on how to help their children lose weight, rather than just be told that their child needs to lose weight. For example, rather than just telling a parent to quit giving her child a cookie, why not suggest she break it up into smaller portions or give her a healthier, low-calorie recipe?

They tell you, "Your child's metabolism might not be as high as another child." So I'm going to have to think about that. They don't say, "Here. Let me show you this." They just say, "Okay, this is what you need to do."

– Dallas (English-dominant)

Key Finding: Parents want more adaptive physical exercise programs in their communities so their children can get more exercise. Parents in most of the groups said their community does not have enough in-school or after-school exercise and sports programs for children with special healthcare needs. Parents think their children would benefit not only from the physical exercise, but also from social opportunity to play with other children.

The schools have after-school activity clubs – a walk club, a run club. They don't offer that to our children. There's not an adaptive club for our kids after school because that would require so much ...

– Houston

I would love it if there were gyms for special needs kids. I just registered my daughter in a gym, and they kicked her out. She didn't last fifteen days because she is hyperactive. They said, "No, ma'am. Find a special place for her." There aren't that many, and if there are, they are super-expensive.

– Dallas (Spanish-dominant)

Even having sports activities like a really short season of T-ball where kids of all different needs could play. Mix everybody in, and it's good for both [typical children and children with special healthcare needs].

– Houston

Parents in most of the focus groups also said they would like to see more sensory gyms available for children with special healthcare needs, as well as wheelchair-accessible pools. Some wanted their children to receive skills training for basic P.E. exercises so they could better integrate into typical P.E. programs.

I'd love to have the money to open up a sensory gym for kids with special needs that would be able to fill all their senses at every level, whether they are able to walk and talk. Just take a regular clinic, and expand it into a big gym and all for all our kids to come together and safely play while still getting their sensory needs met.

– San Antonio

At least teach them the skills for us to take them to a spin class. If they know how to do something, it's easier to go into a typical program than when you're having to teach it and there's behaviors, and they're not wanting to do it.

– Houston

Parents in some groups said they know of local facilities and gyms that offer fitness options for their children, but most of these are cost prohibitive. Some parents suggested that the YMCA offer free memberships to children with special healthcare needs. Parents in San Antonio mentioned the low cost of participating in the Boerne Special Olympics, but most of the other communities where the focus groups were held don't have Special Olympics.

I think there are a number of programs that do offer exercise, but they are so stinking expensive, especially when it comes to the special needs. What we pay out of pocket already for when they need medical or extra therapies – it just doesn't even make sense to pay \$800 for six weeks.

– San Antonio

She can't come to the gym with me, and that's one of the struggles I have, because her physical therapist has been working with her and says, "I'm just being her personal trainer. We need to transition her into the community, like to a gym." Well, there's not a gym that would take her unless I do a personal trainer, which is \$40 an hour.

– Lubbock

Key Finding: Parents in all regions said their communities need more accessible parks and adaptive playgrounds. Parents said they go to various places so their children can exercise to the best of their ability, whether it involves bowling, visiting a park, or playing at the local playground. Most parents take their children to parks, and participants in almost every group said their city needs more parks, particularly accessible parks with adaptive playgrounds.

Sandy Creek Park is not wheelchair accessible. It has handicap swings, but they've all been torn up.

– Jasper

My aunt, whose son is thirteen and can't speak, would say there are parks where you can take your kids. But they're outside of the city, there aren't any here. Kids who are in a wheelchair can't get on any playground equipment.

– Laredo (Spanish-dominant)

In addition to being accessible, many parents said parks need to be safe and have fences around them to keep children from wandering off or running away.

We need more safe places. My son doesn't have great balance. We need padded playgrounds.

– Lubbock

We have a good park that was put up by the Lion's Club, which is nice and it has a nice, high fence all around it. There's one way in and one way out. Fences are a good thing.

– Jasper

Temple parents in particular said there are limited accessible park options in their community. Some of the parents go to outlying areas such as Belton, Round Rock, and Waco for more parks. Parents in this community also said they have few indoor play and exercise options for their children; some said they walk the mall or walk around the library with their children. In contrast, most parents in the El Paso Spanish-dominant group said they have accessible parks in their community.

Respite Care

Key Finding: Many parents have heard of respite care but aren't always sure where to find it. Parents in the groups unanimously agreed that respite care is very valuable and important to them and their families. The primary barrier is that many parents do not know how or where to access respite care. In fact, some parents had never heard of respite care; awareness of respite care was particularly low in Dallas in both the English- and Spanish-dominant focus groups. Most parents in the larger urban areas had heard of respite care, and about three quarters of the Houston parents have actually used it. San Antonio parents had all heard of respite care, but almost half of the participants in that group rely on family members for respite care rather than agencies. Most of the parents in Laredo also do not receive respite care services, because they don't know where to look for services, don't qualify for services, or have a family member helping them with caregiving.

Parents said respite care offers them the opportunity to spend time with their other children, go grocery shopping, have dates with their spouses, or simply rest.

It gives us our sanity. If we don't have respite, we don't have our sanity. Taking care of your kids 24/7, without sleep 24/7 a lot of times, and you don't have any kind of break, you go a little crazy.

– Houston

I get eight hours of respite a week. He comes and helps, especially in the evenings after school, so I can attend to my other little one and not having to be going back and forth. I pay attention to the little one to really make sure he's taken care of, helping him with his bed, shower, and eat.

– Dallas (English-dominant)

Some parents are in particularly difficult situations in that the need for respite can be profound, as exemplified by the San Antonio woman quoted below.

I use my husband [for respite]. My son that is psychotic and schizophrenic, he wants to kill me, he's literally said it. I don't sleep at night. I take care of my dad, who has ASL. I've gone seven days without sleep because I don't sleep. Once a year my husband sends me to a hotel, he gets me pampered, so that's my respite.

– San Antonio

Key Finding: Parents in every group expressed a strong need to be able to trust the respite care provider who cares for their children in their absence. Many feel there is a lack of qualified respite care providers they can trust. The need for a trustworthy, qualified respite care provider was one of the most unanimous findings across all topics discussed in the focus groups. Parents feel very protective of their children with special healthcare needs, many of whom are quite vulnerable due to their disabilities. Parents don't want just anybody watching their children, and they will go to great lengths to secure a qualified provider.

We haven't used respite care for a long time because they closed the house down where she used to go. But to try to find somebody to come watch her that they would approve and I will approve is hard to find. I don't trust anybody.

– Lubbock

Many parents said the ideal respite care provider would be another parent of a child with special healthcare needs or someone highly trained in caring for children with special healthcare needs.

Participant 1: *You need to understand my child. She is non-verbal, so some of her communication is not as you or I and so she talks very differently. Not anyone off the street can just understand her. Someone who's not going to be able to know what she wants and that's going to cause her more stress and more anxiety not be able to get across what she wants. Why would I do that to my child?*

Participant 2: *I would feel more comfortable if it was someone like another mom who had some experience with a special needs child. She wouldn't feel like a stranger to me upon meeting her because she's lived it and she knows what it's like to live it every day.*

– San Antonio

Some parents said they would like the opportunity to observe, not simply interview, the respite care provider they are considering for their child. They want to see how their child interacts with the caregiver. Several parents raised this issue, but few indicated that they have actually done it, for any number of reasons. Other parents explained that they are reluctant to let others care for their children because they would feel guilty leaving them with someone else.

Most of the parents in El Paso have family members, mostly sisters and grandmothers, provide respite care for their children. They said they do not trust strangers to look after their children. In fact, six of the nine parents in that group said they would not let a non-family member care for their children.

Participant 1: *Aside from the fact that I have my sisters, I'd be afraid to leave my children with a stranger.*

Participant 2: *Yes. With all the news we see about how people hit their children ...*

Participant 3: *So many things we see ...*

– El Paso (Spanish-dominant)

By contrast, only two of the nine parents in the Dallas Spanish-dominant focus group said they have help from family members. The majority said they don't get respite care or any help at all in caring for their children.

They can see me falling down with my daughter – see me not being able to carry her because she's already nineteen years old. My brothers-in-law – not even my brothers get up from their seats to help me out. Not even for a night, because we don't sleep because of her. Sometimes she convulses up to ten times a night. They don't come to help out even one night.

– Dallas (Spanish-dominant)

Key Finding: Parents said some restrictions on respite care providers are a barrier to care. Parents in the focus groups identified a number of regulatory and policy restrictions on respite care offered by the Medically Dependent Children Program (MDCP) or respite agencies. Each of the actual or perceived restrictions mentioned by the parents is discussed in turn below.

Time Limits

Some parents mentioned that the time limit certain providers place on respite care is a barrier to care.

Some people limit you to three hours, or two, or one hour. If it was longer, then you would be able to get more of that time that you need for yourself.

– Lubbock

Perception: Respite Workers Are Not Allowed to Give Medications

Some parents in Temple and Houston are under the impression that respite care providers cannot administer medications. This is a barrier for them because their children need medication. This perception was not noted in other focus groups.

Our problem with respite providers is because our son has seizures, and because he has to take medications with every meal – respite providers can't do medications, which means I can get respite but I have to stay in the home and do stuff at the house, which is fine.

– Temple

My biggest barrier is, my daughter has type 1 diabetes. She can't tell you when her blood sugar is low. She has to have injections, and respite workers aren't allowed to give medications.

– Houston

Some parents said the level of their children's disability and medical care needs makes it more difficult to find qualified respite care providers.

We come across lots of respite programs in the community, but my daughter is trached and vented and needs so much mechanical support. I can't bring her to those volunteers to watch her because they're not clinically trained to take care of her. So we don't qualify for those respite programs.

– Houston

Restrictions on Family Members, Household Members, and People Under Age 18

Parents in several groups said some respite programs will not pay for respite care provided by family members or people under the age of 18. They also said MDCCP will not pay for respite workers who live in the same household with the child. Many parents said these are barriers to care because they limit their pool of trusted respite care providers.

I did use respite services, but there was a change: Before, a member of your family could take care of them, like an aunt, mother, or grandmother. They told me they removed that service and someone else has to come now. I didn't feel as comfortable having someone else come over. I felt more comfortable knowing my children were under the care of my sister.

– El Paso (Spanish-dominant)

It can't be anyone who lives there.

– Houston

My son is on a Medicaid waiver program called Texas Home Living. One of their stipulations is that it can't be a sibling who lives in the home. While I have almost three kids now that are eighteen or over, that would be willing to take my son to go do something, I can't use them. I can pay my son, or my daughter can go get a job and get paid – but I would prefer to pay her to go take him to the zoo or go do something because she knows him. That is a huge barrier, and I don't know why they do it. I feel like I have a resource that I can't use.

– San Antonio

They won't let you use anyone under eighteen. I have lots of people that would do it who are under eighteen and capable of doing it, but they have to be eighteen.

– Houston

However, two parents in the San Antonio group successfully use each other's teenaged daughters to provide respite care for their other siblings. They receive reimbursement from CLASS, a Medicaid waiver program sponsored by DADS and administered through The Arc of San Antonio. Other parents have relatives paid for respite care through the Burke Center.

No Respite Care for Siblings

Some respite benefits and waiver programs do not provide care for the siblings of a child with special healthcare needs; this acts as a barrier for many parents who have more than one child. To truly get away, they need child care for all their children at the same time, as evidenced by the fact that few parents take respite care to spend more time with their typically developing children.

We had signed, and when they [respite worker] was en route, they informed me over the phone they do not care for the sibling. She said "I'm not there to watch the sibling." I said, "Well, never mind then." We just rely on family and friends for her.

– San Antonio

Technically they are only supposed to watch that child – and so he has a twin brother, so really, what kind of break would I get?

– Temple

Key Finding: Parents think the Medicaid respite reimbursement wage is too low to attract qualified respite care providers. The Medicaid reimbursement for respite care is approximately \$9 or \$10 per hour. Many parents feel they cannot find qualified caregivers at this rate.

I've heard the change in personnel is a barrier. Because it doesn't pay what it's supposed to pay, a lot of them [respite care providers] quit and go look somewhere else. You have that revolving door of people. They're barely making minimum wage.

– Houston

Bridget can't go to the restroom by herself. For ten dollars an hour, nobody wants to do it because she's not a baby.

– Houston

Some parents are willing to pay more for a highly qualified respite care provider, bypassing the reimbursement system entirely.

I made a point of hiring someone that was highly qualified, overqualified to be a baby sitter, and paying her a huge amount of money. That made me feel like I had someone who had experience, who had training.

– Lubbock

Conclusion

Topics in the focus groups generated rich discussions among parents and yielded valuable insights into their lives. They appreciated being asked about their experiences as parents of children with special healthcare needs. Hearing the stories of these parents enables one to imagine walking in their shoes for a day as they navigate the healthcare resources necessary to care for their children. Their stories of isolation and the difficulties they face offer a poignant depiction of the lives of Texas children with special healthcare needs and their families.

Woven throughout the focus group transcripts were nuances of the complex social and institutional barriers that can determine what accessibility really means. For these parents, access to respite care is not really access if you cannot trust the respite care worker who shows up at your front door. Access to support groups isn't really access if you have to drive from Jasper to Beaumont just to talk to another parent with a child with autism. Parents in all of the cities lingered after the focus groups were over to exchange resources and telephone numbers, and some even went to lunch together. They share a common bond, so poignantly expressed by a mother in San Antonio: *This [child] is your heart that walks outside your body.*

Appendix A: Parents' Resource Needs Assessment

Parents' Resource Needs Assessment	1
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During the focus groups, parents were asked to list which resources in their community they use most frequently in caring for their children. The resources they mentioned are listed by city below. Where available, resources parents said they find most helpful, as well as those they wish they had in their community, are listed separately.

Lubbock

Resources Used Most Frequently

- Speech therapy
- Occupational therapy
- Physical therapy
- Food therapy
- Sensory therapy
- Music therapy
- Equine therapy
- Burkhart Center at Texas Tech University
- Psychiatry and counseling
- After-school care
- Orientation and mobility therapy
- High Pointe Village
- Family Night Out
- Tutors
- Any Baby Can videos

Least Helpful Resources

- Schools
- Regular day care centers that do not cater to children with special healthcare needs

Desired Additional Resources

- Special needs day care
- Teacher education about special needs
- Student education to decrease bullying
- Greater knowledge of sign language in the general population
- Therapy to help children adjust to change
- After-school care, including during the summer months
- Social activities and sport programs with typically developing children



San Antonio

Resources Used Most Frequently

- Alamo Area Council of Governments (AACOG)
- Northeast Transitional Services
- Department of Assistive and Rehabilitative Services (DARS)
- Nursing services
- Transportation services
- Sports programs for children with special needs
- Applied behavioral therapy
- Occupational therapy
- Sensory integration therapy
- Adaptive physical therapy
- Equine therapy
- Aquatic therapy
- Biomedical therapy
- Homebound services through school district
- Special Olympics
- Homeopathic remedies such as oils
- Eva's Heroes
- Morgan's Wonderland
- Texas Home Living (Medicaid waivers program) funding for respite care
- Dayhab
- TEAMability
- Dietary intervention
- Camp Grace respite care
- Durable medical equipment (DME) companies
- Medical providers
- Attendant care

Most Helpful Resources

- Special Olympics
- DARS
- AACOG (Bexar County Mental Retardation Authority)
- DARS
- Speech and respiratory therapy
- Waiver programs
- Medicaid buy-in
- Variety, the Children's Charity of Texas
- Parent networking



Least Helpful Resources

- Complex and/or slow-moving health insurance practices
- School-provided therapies that are too short in duration
- Slow processing of paperwork at Children with Special Healthcare Needs Services (CSHCN)
- Slow processing of paperwork at DARS
- Medicaid staff who have limited training and limited knowledge about children with special healthcare needs
- Lack of qualified educators at the schools, including teachers, aides, therapists
- Lack of communication between home care and educational institutions

Desired Additional Resources

- Connections to colleges
- Vocational assistance
- Transportation (wheelchair accessible)
- Long-term planning
- Legislation on new kinds of medications
- Better communication to parents about federal and state laws that impact their children

Temple

Resources Used Most Frequently

- Texas Parent to Parent
- Heart of Central Texas Independent Living (HOCTIL)
- Bluebonnet Mental Health Mental Retardation (MHMR)
- Early Childhood Intervention Services (ECI)
- Children with Special Needs Network
- Autism Society
- Angels of Care
- Texas Division of Blind Services
- Physical therapy
- Speech therapy
- Applied behavioral therapy
- Occupational therapy
- Churches
- Other parents
- School district
- Extended Care Health Option (ECHO) program



- Exceptional Family Member Program (EMFP) (military)
- Vision therapy
- Doctors
- Medicaid
- Special Olympics
- Pharmacies
- Medically Dependent Children Program (MDCP)
- Emergency rooms and social services providers
- Every Child, Inc.

Most Helpful Resources

- Children with Special Needs Network
- ECI
- MDCP
- MHMR
- Churches
- Physicians, including primary care and specialists
- Medicaid
- CHIP
- Other parents

Least Helpful Resources

- Schools

Desired Additional Resources

- Recreational resources
- Summer programs
- Day care
- Care coordinators
- Day program for tweens and teens
- Better respite options
- Continuity of care in hospital system
- In-home services
- Faster access to services and DME approval from insurance companies
- Resource network for parents



Jasper

Resources Used Most Frequently

- Social workers
- Social media (online support groups)
- Admission, Review, and Dismissal (ARD) meetings
- Internet/Google
- Foster parent meetings
- Friends, “everyone”
- Spindletop MHMR
- Medicaid
- Arc Autism Support Group of Beaumont
- Autism support group in Lamar
- Specialists
- ECI
- Physical therapy
- Occupational therapy
- Case managers
- Personal care services
- Stephen F. Austin State University (speech therapy services)
- DME
- Assistive technology
- Speech therapy

Most Helpful Resources

- All types of therapies

Least Helpful Resources

- Medicaid prescription-based therapy referral process (too slow)

Desired Additional Resources

- Centralized database listing pediatric special needs conditions and treatments
- Connection to other parents of children with special needs
- Centralized medical records database
- More therapy providers (all types)
- More specialists



Houston

Resources Used Most Frequently

- MDCP waivers
- Texas Children's Hospital Special Needs Primary Care Clinic
- Community sports programs
- Parent support groups
- Association for Retarded Citizens (The Arc)
- Speech therapy
- Occupational therapy
- Physical therapy
- Conferences
- DARS
- Respite care
- Behavioral health
- Easter Seals Respite Camps
- Camps
- Special education at schools
- Transition clinic
- Challenger programs (community sports programs for children with special needs)
- Hospitals
- Great variety of specialists
- DME companies
- Medical transportation and reimbursement
- Ronald McDonald House
- Health insurance
- ECI
- CHIPS
- Supplemental Security Income (SSI)
- Transition planning support
- Health Insurance Premium Program (HIPP)
- Waivers
- Medicaid buy-in program (insurance)
- Respite care
- Camps: Be An Angel, Joni and Friends, Camp Blessing
- Easter Seals
- Expos, Abilities Expos
- Deaf Co-op (HISD)
- University of Houston Nova Clinic (specialized optometry)



- The Center for Hearing & Speech
- Shriners Hospital for Children
- Meyer Center for Developmental Pediatrics
- Department of Aging and Disability Services (DADS)
- 2-1-1

Least Helpful Resources

- Mental Health Mental Retardation Authority (MHMRA) of Harris County
- Medicaid staff who have limited training and limited knowledge about children with special healthcare needs
- Schools
- Therapy services at schools
- Texas Children’s Hospital Spina Bifida Clinic
- Texas Children’s Hospital Neurology Department
- Guidelines for respite care
- DARS
- Health Intervention Program (HIP)

Desired Additional Resources

- Applied behavioral analysis (ABA) for all ages (not just preschool) and across all diagnoses (not just autism)
- Special needs day care and day care for teens and adults
- Greater school compliance vis-à-vis children with special needs
- Greater access to schools that may not have special needs programs but are closer to home
- Social opportunities (e.g., dances) for children and adults with special needs
- Care coordinator
- Outreach programs
- Adaptive play centers
- Greater acceptance and awareness of children with special needs – sensitivity training and education about diagnoses for the larger public/non-special-needs community

El Paso

Resources Used Most Frequently

- Scouts
- Miracle League (baseball)
- Parks
- Church groups, organized dances



- Special Olympics
- Adaptive swimming lessons
- Equine therapy
- Children's Disabilities Information Coalition (CDIC)
- Paso Del Norte Children's Development Center
- Buses
- Medication
- Therapies (all modalities)
- Personal in-home care
- Hearing aids
- Sleeping devices
- Counseling
- Assistive technology
- Support groups
- Classes/courses
- Transportation

Most Helpful Resources

- Therapies of all modalities
- Medication
- Support groups
- Courses/classes
- Respite
- Transportation

Least Helpful Resources

- School-provided therapies that are too short in duration
- Some unhelpful neurologists and a lack of neurologists
- Medicaid income guidelines (too restrictive)

Desired Additional Resources

- More funding for schools, teacher training, and support services
- Money for medication
- More specialists, especially neurologists
- Better communication between schools and doctors
- More therapy sessions covered by insurance



Dallas (English Group)

Resources Used Most Frequently

- Talking Book Club
- Apps, especially educational apps (alphabet, numbers)
- Behavior chart
- Daily schedule
- Good routines
- Assistive technology
- Games
- Medical machines for medically complex children
- Music
- Physical movement in general

Desired Additional Resources

- A place to find more information (online, community-wide)
- Physical exercise programs for children with special needs besides Special Olympics
- Target and ToysRUs stores where parents can sample the special needs equipment

Dallas (Spanish Group)

Resources Used Most Frequently

- Transportation
- Therapies
- Medical supplies
- Schools
- Day care
- Respite care
- Specialists
- Financial assistance

Most Helpful Resources

- Therapies (all modalities)
- Financial assistance for doctors and ambulances
- Ambulances
- Wheelchair maintenance
- Transportation



Desired Additional Resources

- Equine therapy
- Music therapy
- Physical exercise programs for children with special needs
- Aquatic therapy
- Technical communication devices
- Day care
- Participation in stem cell research

Laredo

Resources Used Most Frequently

- Child Adolescent and Parent Services (CAPS)
- Transportation
- Wheelchairs
- Counseling for parents
- Doctors
- Specialists
- Medications
- Special diets
- Health insurance
- Schools

Most Helpful Resources

- Health insurance
- Wheelchairs
- Medication
- Therapies of all modalities

Desired Additional Resources

- More funding for schools
- Longer therapy appointments (physical, occupational)
- Financial assistance with college, scholarships
- Financial assistance for transition-related costs (e.g., adult insurance premiums)
- More family therapy options



Appendix B: Focus Group Guide

Focus Group Guide1
 DSHS Title V CSHCN Research Focus Group Guide1



DSHS Title V CSHCN Research Focus Group Guide

I. Introductions and Icebreaker

Moderator begins by introducing the concept, process, and purpose of the focus group. She will also lay ground rules for the discussion, explain the purpose of the tape recording equipment, and assure participants that their remarks are confidential in the sense their names will never be used. Please remember we are here today to learn from you, we want your honest answers, and no one is being judged – all answers and questions are important.

Introduce purpose of group: *The purpose of this group is to discuss information related to being a parent of a child with special health care needs.*

- ◆ *There are no right or wrong answers.*
- ◆ *Please only talk one at a time so we can hear everyone.*
- ◆ *Do not worry about offending us. We really want to learn from you so please be honest with your thoughts and comments.*
- ◆ *We have a lot to talk about, so sometimes I may move the conversation along.*
- ◆ *It is important for everyone to participate, and don't worry if you disagree with what someone else says.*

Introductions: *Let's start by getting to know each other a little better. One thing you have in common is that you are all parents of at least one child who has a special health care need. Let's go around the table and each of you introduce yourselves, tell us a little bit about your family, how you spend your time, how old your children are, and something about them.*

II. Resources and Access to Care

- *I'd like to continue our discussion by asking about the resources and services that you use for your children with special health care needs and for your family so you can better care for your child. Thinking back over the past few years, how have you found resources for your child with special health care needs?*
- *Think about a typical day from waking up until going to bed and tell me the services and resources that you use and access for your child with special health care needs. I'm going to make a list of them on this flip chart.*
- *Which resource and services are the most helpful to you? **Probe:** Strengths or challenges.*
- *Which resources and services have been the least helpful to you? **Probe:** What made them unhelpful?*

- If you could add any resource or program to this list, what would you want to add? **Probe:** If financial assistance is a response, acknowledge it and then move the conversation to specific services, programs, etc.
- What are the barriers or challenges to receiving the help you need for you and your child(ren) with special health care needs? **Probe:** Communication between the school and your provider, doctors, insurance, transportation to medical appointments, therapists (such as PT and OT), your ability to work outside of the home, others?
- Some of you have more than one child with special health care needs. How would you describe the unique barriers or challenges families like yours face?
- Some of you have children who are typically developing and you have children who have special health care needs. How would you describe the unique barriers or challenges families like yours face?
- We just finished talking about barriers and challenges to services in your community. What are some solutions to these barriers?

III. Care Coordination

- What does the term “care coordination” mean to you?

Moderator explains: *When we talk about it here tonight, think of the concept of someone working with your family to make sure that your child’s health needs are being met and that the right person is delivering the right care at the right time. For example, someone to schedule appointments, share test results between providers, make referrals*

- Have you ever sought assistance to help you coordinate the care that your child receives?
 - If so, what kinds of care coordination assistance have you used?
 - If you have not sought assistance, why?
- How would you imagine your child would benefit from care coordination?
 - If you don’t feel like your child would benefit from care coordination, why?
- What are some of the barriers that you faced when asking for or receiving that assistance?
- How do you think some of those barriers could be overcome?

IV. Working with Providers

Now, let's spend some time speaking specifically about health care providers.

- How would you describe your relationships and experiences with your child's health care providers, either currently or in the past?
- What makes you feel comfortable with a provider? **Probe:** Bedside manner, how they interact with your child, their knowledge and experience in caring for children with special health care needs?
- What makes you trust a provider?
- What makes you feel uncomfortable with a provider?
- If you were teaching a class for health care providers, what would you tell them to do to help families and children with special health care needs feel comfortable and cared for?

V. Community Support

- What is your community like here (moderator name location)?
 - **Probe:** Does your family feel like they are a part of your community?
- How would you describe just generally navigating daily life here in (moderator name location)?
 - **Probe:** Accessibility.
- What community resources do you use to help your child or your family interact with the rest of the community? **Probe:** Are there community activities or resources that you participate in or use?
- How do you create community for your family and your child with special health care needs?
- How do you feel supported by your community in taking care of your child's needs?
- What could be done to help you feel more supported in your community?

VI. Transportation

- What is it like getting your child to appointments?
- How do you take your child to appointments – with doctors, specialists, etc.?
- Which of these that we just listed would you consider reliable transportation services? **Probe:** What about the Medical Transportation Program?

- What are the biggest transportation difficulties that you face getting your child to appointments? **Probe:** Buses, access to a vehicle, language barriers, timing, reliability, vehicle accommodations, etc.
- What could be done to improve transportation? **Probe:** Vouchers, vehicle modifications.

VII. Medical Emergency and Disaster Preparedness

- What kinds of conversations are you having with your child's providers about medical emergencies? Specifically if your child has a medical emergency. **Probe:** Have you discussed when to go to the ER vs. the office? Have you discussed or developed a plan?
- What kinds of plans have you made if a medical emergency were to occur tomorrow? **Probe:** What makes you feel prepared? Unprepared?
- What kind of help do you need to make you feel more prepared for a medical emergency?
- How many of you have thought about what you would do, specifically for your child with special health care needs, in a natural disaster?
- What kinds of plans have you made if a natural disaster were to occur tomorrow?
- How prepared would you feel if a natural disaster occurred tomorrow? **Probe:** What makes you feel prepared? Unprepared?
- What kind of help do you need to make you feel more prepared for a natural disaster?
- Where do you get information about emergency and/or disaster preparedness?

VIII. Transition

- How many of you have heard of the term "transition"? *Moderator notes how many people for the recording.*
- How old was your child when you were introduced to this term?
- What does this term mean to you?
- What does transition planning mean to you?
- At what age or developmental stage do you think transition planning should begin?
- Have you sought assistance for transition planning?

- If so, what kinds of assistance have you used to help you and your child with transition planning?
- If you have not sought assistance, why?
- What are some of the barriers that you faced asking for or receiving that assistance?
- How could some of those barriers be overcome?
- How would you imagine your child would benefit from transition planning?
 - If you don't feel like your child would benefit from transition planning, why?

IX. Obesity

- There has been a lot of talk about obesity in the news lately. How do you think these concerns impact families with children who have special health care needs?
- What kinds of conversation do you have with providers about obesity and physical activity?
- Where do you and your family go together to play or be physically active?
Probe: what are some of the barrier to finding and using a place together?
- Thinking about you and your family and friends, what do you think could be done to help families who have a child with special needs who also has obesity as a health issue?

X. Respite

- How many of you have heard of the term "respite"? *Moderator notes how many people for the recording.*
- What does it mean to you?
- How important is respite care to parents who have children with special health care needs? **Probe:** What makes you think that?
 - Do you feel like you would benefit from respite?
 - If you do not need respite, why not?
- What are some of the barriers to receiving respite care?
- How could those barriers be overcome?
- What kind of respite care do you use? **Probe:** Who provides it? What do you use it for? To spend time with other children or partner?

XI. Closing

I would like to go around the table before we wrap up for the evening and ask you to share the most important information you've heard tonight. Maybe it is something you've learned, or it might be something you knew but now want to share with your family and friends.

Thank you all so much. You have been a great group and we've learned a lot from you.