Maternal Child Health (MCH) Title V
2015 Needs Assessment Findings
Stakeholder Feedback Pertaining to Selection of National Performance Measures

Office of Title V and Family Health
Division for Family and Community Services
What we’ll cover today:

• Purpose of the webinar
• Title V Framework & Transformation
• National Performance Measures
• Needs Assessment Process
• Needs Assessment Data
  • General Population
  • Maternal & Women’s Health
  • Perinatal Health
  • Children with Special Health Care Needs Health
  • Child Health
  • Adolescent Health
• Feedback for Selection of National Performance Measures
Purpose

- Discuss Texas Needs Assessment findings and obtain Stakeholder feedback for selection of new National Performance Measures (NPM)
TITLE V FRAMEWORK AND TRANSFORMATION
Title V Framework

• Three legislatively defined Maternal and Child Health populations:
  • Preventive and primary care services for pregnant women, mothers, and infants up to age one
  • Preventive and primary care services for children
  • Preventive and primary care services for children with special health care needs

• Assure access to quality care, especially for those with low-incomes or limited availability of care;

• Reduce infant mortality;

• Provide and ensure access to comprehensive prenatal and postnatal care to women (especially low-income and at risk pregnant women);

• Increase the number of children receiving health assessments and follow-up diagnostic and treatment services;

• Provide and ensure access to preventive and child care services as well as rehabilitative services for certain children;

• Implement family-centered, community-based, systems of coordinated care for children with special healthcare needs; and

• Provide toll-free hotlines and assistance in applying for services to pregnant women with infants and children who are eligible for Title XIX (Medicaid).
Title V Transformation

• The Life Course Model’s influence on the transformation of the Title V Block Grant started many years ago.
• The National MCH Life Course Meeting in 2008 discussed promoting a new direction for the field of MCH that lead to increased efforts focused on social determinants of health.
• Personal behavior is strongly influenced by the social, economic, and physical environmental factors that are major determinants of health.
• The pathways to better health do not generally depend on better health care so much as on improvements in personal behavior.
Title V Transformation

• In order to improve maternal and child health in America:
  • we must close the gaps in access, quality, and prevention in our maternal and child healthcare system
  • we must also carve out a role for MCH in sectors other than healthcare to ensure that all mothers and children can be healthy.
• We must not only optimize the health arena, we must also attend to the educational, economic, family, community, and physical environment arenas as well.
NATIONAL PERFORMANCE MEASURES
New NPM by 6 Population Domains

Maternal & Women’s Health
• 1  Well woman care
• 2  Low risk cesarean deliveries

Perinatal Health
• 3  Perinatal regionalization
• 4  Breastfeeding
• 5  Safe sleep

Child Health
• 5  Developmental screening
• 6  Child safety/Injury
• 7  Physical activity

Adolescent Health
• 7  Child safety/Injury
• 8  Physical activity
• 9  Bullying
• 10  Adolescent well-visit

CSHCN
• 11  Medical home
• 12  Transition

Crosscutting or Life Course
• 13  Oral Health
• 14  Smoking
• 15  Adequate insurance coverage
NEEDS ASSESSMENT PROCESS
Processes for the Assessment of Need In MCH Population

• Stakeholder Meetings
• Focus Groups
• Surveys
• Data systems
STAKEHOLDER MEETINGS
## Stakeholder Participation

### Table 3

<table>
<thead>
<tr>
<th>Location</th>
<th>Total Stakeholders</th>
<th>Stakeholders Working with Children with Special Health Care Needs and Their Families</th>
</tr>
</thead>
<tbody>
<tr>
<td>San Antonio</td>
<td>26</td>
<td>8</td>
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<tr>
<td>Laredo</td>
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</tr>
<tr>
<td>Arlington</td>
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<td>1</td>
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<td>Tyler</td>
<td>11</td>
<td>2</td>
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<td>Houston</td>
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<td>0</td>
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<tr>
<td>Lubbock</td>
<td>15</td>
<td>5</td>
</tr>
<tr>
<td>Waco</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>El Paso</td>
<td>14</td>
<td>4</td>
</tr>
</tbody>
</table>
Process for Identifying Needs

• 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
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.
Areas Identified to 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
  • A shift to a focus on the whole person across the life course.
MCH Focus Groups

Nacogdoches, Houston, Amarillo, Killeen, Ft. Worth, Brownsville, San Antonio, San Angelo

Lines of Inquiry

• General health concerns
• Eating behaviors
• Physical activity
• Medical and behavioral health care
• Child health and safety at different ages
• Females: prenatal, pregnancy, and post-partum experiences and health care provided
• Males: health at work, especially concerns about exposure to chemicals and toxins
Top Health Concerns

Females
• Weight/obesity
  • Nutritional concerns
  • Children’s lack of exercise
• Chronic disease: diabetes, heart problems, hypertension, asthma
• Cancer
• Access to health care/insurance coverage
  • Oral health
  • Mental health
• Knowledge/education about parenting and raising children

Males
• Obesity
• Chronic disease: diabetes, heart problems, hypertension, asthma, Alzheimer’s
• Cancer
• Heat exhaustion/dehydration
• Access to health care/insurance coverage
• Poverty/paying bills
• Stress
NEEDS ASSESSMENT DATA
Geography

- Texas accounts for 7.4 percent of the total U.S. land area
- Equal to the land area of all six New England states, Ohio, New York, Pennsylvania, and North Carolina combined
- 254 urban and rural counties
- 88.5 percent of the population concentrated in urban areas
- The five largest metropolitan areas are centered around the cities of Houston, San Antonio, Dallas, Austin, and Fort Worth and encompass multiple counties.
Population

• Texas Population is over 26 million.
• Will exceed 31 million by 2050.
• Second fastest growing state in the nation since 2010
• Population Distribution on Figure 2.2
Race/Ethnicity

Hispanic

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

Legend
- <= 24.9%
- 25.0% - 49.9%
- 50.0% - 74.9%
- >= 75.0%

Source: Texas State Data Center, 2014 Projections, Full 2000-10 Migration Rate
Prepared by: Office of Program Decision Support

Black

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

Legend
- <= 0.9%
- 1.0% - 4.9%
- 5.0% - 9.9%
- >= 10.0%

Source: Texas State Data Center, 2014 Projections, Full 2000-10 Migration Rate
Prepared by: Office of Program Decision Support
Crime

Property Crime

Violent Crime

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

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

Legend

Source: Texas Department of Public Safety,
The Texas Crime Report 2012
Prepared by: Office of Program Decision Support
Income and Poverty

Adult Below 200% FPL  Adult Female Below 200% FPL

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

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

Legend
- <= 34.3% (State Average)
- 34.4% - 37.7%
- 37.8% - 41.2%
- > 41.2%

Source: U.S. Census Bureau, American Community Survey, 2008-2012
Prepared by: Office of Program Decision Support

Legend
- <= 28.4%
- 28.5% - 37.7%
- 37.8% - 46.8%
- > 46.8%
- No Women Below 200% FPL

Source: Texas State Data Center, 2014 Projections, Full 2000-10 Migration Rate American Community Survey
Prepared by: Office of Program Decision Support
Health Insurance

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

Legend
- <= 10.9% (State Average)
- 11.0% - 12.0%
- 12.1% - 13.1%
- > 13.1%

Source: U.S Census Bureau, American Community Survey, Table B27001
Prepared by: Office of Program Decision Support
Access to Health Care

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

Legend
- None
- 0.1 - 35.3
- 35.4 - 70.6
- > 70.6

Source: Texas Health Professions Resource Center September 2013
Prepared by: Office of Program Decision Support

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

Legend
- None
- Clinic Only
- Partial County
- Whole County

Source: U.S. Health Resources and Services Administration, December 2014
Prepared by: Office of Program Decision Support
MATERNAL AND WOMEN’S HEALTH

Women of Child Bearing Age (WCBA), Texas Women Aged 18-44
Demographics, Women Aged 18-44 ("Women of Childbearing Age"), Texas

There are an estimated 5.2 million women in Texas, aged 18-44.

Source: Texas Population Projections Program, Texas State Data Center

Racial/Ethnic Distribution 2015, projected
- Anglo: 37%
- Black: 7%
- Hispanic: 44%
- Other: 12%

Educational Attainment, 2013 Estimate
- >HS Grad: 33%
- HS Grad: 15%
- Some College: 29%
- College Grad: 23%

On average, 14.7% of Texas women aged 18-44 reported their health status as fair or poor in 2013.

On average, 61.5% of Texas women aged 18-44 reported having a routine checkup within the past year in 2013.
33.6% of Texas women aged 18 to 44 were uninsured from 2009-2013 compared to 21.3 % nationally.

- Limited Access:
  - Inadequate insurance coverage and inability to pay
  - Lack of transportation
  - Undocumented status prevents access
  - Shortage of primary care providers and specialists
  - Limited number of Medicaid providers
- Lack of coordination between providers
- Lack of continuity across the life span
- Access to mental health services, early prenatal care, preventive health services (e.g. obesity) and oral health services are priorities
Proportion of Women Aged ≥18 Years Old, With Normal Weight, Overweight, or Obesity, Texas, 2002-2010

Source: Texas BRFSS, 2002-2010
Diet & Exercise Among Women Aged >18 Texas BRFSS, 2009

- Few women (28.2%) ate the recommended number (5 or more) of fruits and vegetables per day.
- Most women (54.6%) did not meet recommendations for moderate or vigorous physical activity.
  - 40.6% of women did not have sufficient or any aerobic exercise.
  - 30.5% of women had no physical activity in their leisure time.
Texas Title V Focus Group Findings, 2014

• Participants (women and men) consistently identified obesity, diabetes, and access to health care as top health care concerns.

• Participants reported knowing what constitutes a healthy meal and understanding importance of regular physical activity.

• Participants find it challenging to adopt healthy lifestyles because of time constraints and perception that healthy foods are more expensive than less nutritious foods.
2.9% of Texas women 18-44 reported they have been diagnosed with diabetes by a doctor or other health professional.

12.5% of Texas women 18-44 reported they have been diagnosed with hypertension by a doctor or other health professional.
Texas Chlamydia Case Rates among Texans by Sex (all ages) by Year of Report 2006-2013

Cases per 100,000 population

<table>
<thead>
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<th>Year</th>
<th>Female</th>
<th>Male</th>
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<tbody>
<tr>
<td>2006</td>
<td>503</td>
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<td>722</td>
<td>231</td>
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<tr>
<td>2013</td>
<td>701</td>
<td>235</td>
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</tbody>
</table>


Texas Gonorrhea Case Rates among Texans by Sex (all ages) by Year of Report 2006-2013

Cases per 100,000 population

<table>
<thead>
<tr>
<th>Year</th>
<th>Female</th>
<th>Male</th>
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<tr>
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<tr>
<td>2012</td>
<td>130</td>
<td>117</td>
</tr>
<tr>
<td>2013</td>
<td>126</td>
<td>122</td>
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MATERNAL AND WOMEN’S HEALTH

Pregnant Women
Women Reporting Existing Pregnancy Was Intended by Race/Ethnicity, Texas

Reported pregnancy was Intended (%)

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<thead>
<tr>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White/Other</td>
<td>61.6</td>
<td>61.3</td>
<td>62.8</td>
<td>59.3</td>
<td>61.9</td>
<td>60.7</td>
<td>62.0</td>
<td>59.6</td>
<td>62.3</td>
<td>65.2</td>
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<tr>
<td>Black</td>
<td>53.5</td>
<td>56.8</td>
<td>53.8</td>
<td>54.9</td>
<td>54.8</td>
<td>50.4</td>
<td>55.1</td>
<td>51.8</td>
<td>49.2</td>
<td>54.0</td>
</tr>
<tr>
<td>Hispanic</td>
<td>39.2</td>
<td>34.1</td>
<td>32.7</td>
<td>32.4</td>
<td>32.7</td>
<td>36.8</td>
<td>38.3</td>
<td>34.4</td>
<td>39.1</td>
<td>40.7</td>
</tr>
</tbody>
</table>

Source: DSHS. Texas PRAMS 2002-2011.
Late Entry into Prenatal Care Texas, 2012 Live Births

No Entry into Prenatal Care Texas, 2012 Live Births

Source: 2012 Birth File
Prepared by: Office of Program Decision Support
First Trimester Entry into Prenatal Care by Race/Ethnicity, Texas, 2005-2013 Births

Percent of Mothers with No Prenatal Care by Race/Ethnicity, Texas, 2008-2012 Births

- White
- Black
- Hispanic
- Other
- Texas Average

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

Source: DSHS. 2008-2012 Birth Files.
Oral Health Care Utilization Before and During Pregnancy, Texas PRAMS, 2009-2011

- Only 40.9 percent had a dental cleaning one year before becoming pregnant.
- Only 29 percent of pregnant women had a dental cleaning during pregnancy.
- There was a strong and positive association between receiving care before becoming pregnant and having a dental check-up during pregnancy.

Factors Associated with an Increased Odds of Receiving Dental Care During Pregnancy
Texas PRAMS 2009-2011


Model adjusted for race/ethnicity, socioeconomic status, education, maternal age, obesity status, & smoking during pregnancy.
Texas Women who Reported Smoking During Pregnancy by Race/Ethnicity, 2008-2013 Births

Smoking During Pregnancy Title V Focus Group Findings, 2014

- Women reported receiving information about the dangers of smoking but received little help or support to quit smoking during pregnancy.
- Women reported it was hard to quit smoking because smoking was everywhere.
- Even when successful quitting, staying away from tobacco exposure from partners and family members that still smoked was a challenge.

Source: DSHS. 2009-2013 Birth Files. 2013 data are preliminary. Prepared by OPDS.
Women Reporting Experiencing Abuse and also Reporting Discussions of Physical Abuse with Provider During Prenatal Care
Texas PRAMS, 2002-2011

Source: DSHS. Texas PRAMS 2002-2011. Prepared by OPDS.
Women having Hypertension and/or Diabetes During Pregnancy by Race/Ethnicity Texas 2009-2013 Births

Source: DSHS. 2009-2013 Birth Files. *2013 data are preliminary. Prepared by OPDS.
Most Prevalent Causes of Death, Texas Maternal Death Cohort, 2011-2012

Source: DSHS Vital Statistics Birth Matched Death Files. Prepared by OPDS.
National Performance Measures
Maternal & Women’s Health

1 Well-woman care
2 Low risk cesarean deliveries
INFANT HEALTH
Low Birth Weight by Race/Ethnicity, Texas, 2004-2013 Live Births

Preterm Births by Race/Ethnicity, Texas, 2004-2013 Live Births

Rate of Deaths Due to Preterm-Related Causes, Texas Residents, 2008-2012

Number of deaths for preterm-related causes per 1,000 live births

- White
- Black
- Hispanic
- Other
- Average, All R/E

Source: DSHS. 2008-2012 Death Files.
Infant Mortality Rate by Race/Ethnicity, Texas Residents, 2004-2013 Live Births

Source: DSHS. 2004-2012 Birth and Death Files. Prepared by OPDS.
Rates of Sudden Infant Deaths and Other Sudden Unexplained Infant Deaths by Race/Ethnicity, Texas Residents, 2012

Note: The rates are not reported for other race/ethnicities because of few deaths.

Source: DSHS. 2012 Birth and Death Files.
Infants Placed on Back to Sleep by Race/Ethnicity, Texas 2004-2011

Source: DSHS. 2002-2011 Texas PRAMS. Error Bars: 95% Confidence Interval. Prepared by OPDS.
Breastfeeding Outcomes, Texas, 2004-2011 Births

Ever breastfed: 77.2%, Exclusively breastfed through 6 months: 77.2%, Breastfed at 12 months: 78.4%

Texas WIC, Did you breastfeed for as long as you wanted? No (52.8%)

- Breastfed < 3 months: 63.9% No, 36.1% Yes
- Breastfed 3-5 months: 46.4% No, 52.7% Yes
- Breastfed 6-8 months: 27.5% No, 72.5% Yes
- Breastfed ≥ 9 months: 16.2% No, 83.8% Yes

Percent of Women Who Recently Gave Birth and Who Reported that Smoking is Allowed in Their Homes Race/Ethnicity, Texas, 2009-2011

Linear (White/Other)
Linear (Black)
Linear (Hispanic)
Linear (Average, All R/E)

Source: DSHS. 2009-2011 Texas PRAMS.
National Performance Measures
Infant and Perinatal Health

• 3 Perinatal regionalization
• 4 Breastfeeding
• 5 Safe sleep
Title V Five Year Needs Assessment: Children and Youth with Special Health Care Needs

Manda Hall, MD
Title V Children with Special Health Care Needs Director
Assistant Medical Director, Purchased Health Services Unit

Rachel Jew, MPAff
Systems Development Group
Outline

• Background
• Core Systems Indicator
  • Transition
  • Medical Home
  • Community Inclusion
• Conclusions
BACKGROUND
Definition of Children and with Special Health Care Needs (CSHCN)

“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”

Maternal and Child Health Bureau (MCHB)
Children with Special Health Care Needs (CSHCN) Services Program

• Administered by the Texas Department of State Health Services (DSHS)

• Focus is improving the lives of people with disabilities & children with chronic health conditions

• Goals based on Title V and state performance measures

• Components/Services: Health Care Benefits, Case Management, Family Support and Community Resources, other statewide initiatives and activities
Six Core System Outcomes

- Families of CYSHCN partner in decision-making regarding the child’s health
- CSHCN 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.
Lifecourse

• Definition: An approach that examines how early life events or circumstances influence future life events or circumstances.

• Needs Assessment:
  • All system and individual level indicators are inter-connected
  • 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.”
CORE SYSTEMS INDICATORS
# 2009/10 National Survey of Children with Special Health Care Needs (2009/10 NS-CSHCN)

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Texas</th>
<th>Nation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children receiving their care within a medical home</td>
<td>40.1%</td>
<td>43%</td>
</tr>
<tr>
<td>Children receiving the services necessary to make the transition to adult health care</td>
<td>35.4%</td>
<td>40%</td>
</tr>
<tr>
<td>Families of CYSHCN have adequate private and/or public insurance to pay for the needed services</td>
<td>57.9%</td>
<td>60.6%</td>
</tr>
<tr>
<td>Children are screened early and continuously for special health care needs</td>
<td>76.8%</td>
<td>78.6%</td>
</tr>
<tr>
<td>Community-based services are organized so families can use them easily</td>
<td>56.6%</td>
<td>65.1%</td>
</tr>
<tr>
<td>CYSHCN whose families partner in decision making</td>
<td>70.3%</td>
<td>70.3%</td>
</tr>
</tbody>
</table>
What is Transition?

• “dynamic, LIFELONG PROCESS that seeks to meet [youths’] individual needs as they move from childhood to adulthood. The goal is to MAXIMIZE LIFELONG FUNCTIONING and potential through the provision of high-quality, developmentally appropriate health care SERVICES THAT CONTINUE UNINTERRUPTED as the individual moves from adolescence to adulthood. It is PATIENT CENTERED, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination”
Transition

CYSHCN Outreach Survey

• Average age of children of respondents: 12.4 years
• 20% felt prepared for their child to transition to adulthood
• 40% had prepared for transition
• Most respondents have prepared for transition by themselves
Help Preparing for Transition

Who Has Helped You Prepare for Your Child's Transition to Adulthood, by Topic

<table>
<thead>
<tr>
<th>Topic</th>
<th>By Myself</th>
<th>By Myself &amp; With a Professional</th>
<th>With a Professional</th>
<th>Have Not Prepared</th>
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<tbody>
<tr>
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<td>33.5%</td>
<td>26.2%</td>
<td>13.1%</td>
<td>8.6%</td>
<td></td>
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<tr>
<td>Educational plans</td>
<td>41.0%</td>
<td>16.5%</td>
<td>11.9%</td>
<td>10.1%</td>
<td></td>
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<tr>
<td>Independent living</td>
<td>44.4%</td>
<td>14.7%</td>
<td>7.5%</td>
<td>15.0%</td>
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<tr>
<td>Financial needs</td>
<td>48.6%</td>
<td>12.4%</td>
<td>7.8%</td>
<td>11.9%</td>
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<tr>
<td>Social needs</td>
<td>43.4%</td>
<td>19.5%</td>
<td>6.2%</td>
<td>12.7%</td>
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<tr>
<td>Employment</td>
<td>46.5%</td>
<td>11.4%</td>
<td>5.4%</td>
<td>16.9%</td>
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<tr>
<td>Legal needs</td>
<td>42.0%</td>
<td>12.0%</td>
<td>9.1%</td>
<td>14.1%</td>
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Transition – Parent Focus Groups

CYSHCN Parent Focus Groups

• Wide range of ideas about transition planning

• Awareness of the term *transition* and perceived need to consider transition planning

• Unsure where to go for assistance with transition planning
“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.”

“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.”
Transition – Stakeholder Meetings

Stakeholder Meetings

• Few doctors to help plan for transition
• Lack of information, services, or support needed by families
• Lack of written transition plans
• Arlington: unmet needs due to lack of coordination and continuity among health care providers
CYSHCN Transitioning in a Medical Home

Texas Data from 2009/10 NS-CSH CN

Unsuccessful Transition
- With Medical Home: 39.4%
- Without Medical Home: 78.1%

Successful Transition
- With Medical Home: 60.6%
- Without Medical Home: 21.9%
What is a Medical Home?

• Approach to providing comprehensive primary care that facilitates partnership between patients, physicians, and families
• Care should be:
  • Accessible
  • Family-centered
  • Continuous
  • Comprehensive
  • Coordinated
  • Compassionate
  • Culturally effective
Providers

- **CYSHCN Outreach Survey:**
  - 77% indicated a usual source of sick care
  - 54.8% cited lack of a medical provider where the family lives as a barrier to care

- **Stakeholder Meetings:**
  - Provider shortages and a lack of willingness by providers to work with CYSHCN
  - San Antonio: need for more case managers to help with access to care for CYSHCN
Providers – Focus Groups

• **Focus Groups:**
  • Report a positive relationship with their child’s health care providers & indicate trust as the number one factor in the relationship
  
  • Parents trust doctors if they feel they are truly listened to & the provider relates directly to their children while treating them as individuals
  
  • Parents want doctors to know & respect that they are the experts on their own child
Providers – Family Quote

“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.”
Care Coordination

- **2009/10 NS-CSHCN**: 22% of CYSHCN in Texas received any help in arranging or coordinating care

- **CYSHCN Outreach Survey:**

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**Who Ensures Your Child Receives the Care He/She Needs**

- **71.6%**: I do it myself
- **26.5%**: Someone at my child’s doctor’s office
- **19.9%**: A case manager or a social worker
- **7.9%**: Someone at my child’s school
- **1.7%**: Someone in our community
- **2.8%**: Another parent of a child with disabilities or special health care needs
- **16.4%**: Family members and/or friends
Care Coordination – Stakeholder Meetings

- **Stakeholder Meetings**
  - Gaps in care exist when care is not coordinated among providers, including specialists leading to delay in referral & lack of continuity of care.

- Tyler: collaboration & coordination were a regional priority & that coordination was needed at several levels:
  - Among local health care providers and social service organizations
  - Across state and federal partners
  - Between specialists and social service providers for CYSHCN
Care Coordination – Parent Focus Groups

• **Parent Focus Groups**
  - Care coordination is performed by the parent
  - Many not familiar with the term *care coordinator*
  - Most who have sought care coordination for their children were not successful
  - Some said that they would not entrust this type of responsibility to anyone but themselves
  - 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.”

“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.”
Access to Resources

• ~25% nationally did not receive at least one of the services needed\(^1\)
• General lack of access was a significant finding for all focus groups
• Families most frequently learn about resources from other parents
• Barriers:
  • Lack of specific therapies
  • Limited access to services
  • Lack of awareness of resources by both families and providers
  • Lack of communication of available resources
  • Difficulties in finding a trustworthy caregiver
  • Lack of extended family support
  • Bias toward their children in public
  • Unaffordability
  • Services offered during the standard workday

\(^1\)2009/10 NS-CSHCN
Access to Resources: Transportation

• **CYSHCN Outreach Survey**: 57.3% noted lack of transportation as an obstacle to seeking care

• **Stakeholder groups**:  
  • Rural areas may not have access to public transportation and have to travel hundreds of miles for health care  
  • Urban areas may have limited public transportation and costly fares

• **Focus groups**:  
  • Exposure to germs while ride-sharing  
  • Expenses  
  • Slow public transportation systems
Access to resources: Health Care Coverage

- 53.5% identify not having health insurance as a barrier to accessing care

- 3.1% of respondents 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

- 40.1% of families reporting that insurance covers all of their child’s medical needs.

\(^1\)CYSHCN Outreach Survey
Access to Resources: Respite

- 6.7% of parents nationwide report a need for respite\(^1\)

**CYSHCN Outreach Survey:**
- 52% of parents indicated a need for respite
- 34% of families had received respite

**Focus groups:**
- Provides an opportunity to spend time with their other children, go grocery shopping, have dates with their spouses or simply rest

**Barriers:**
- Financial, lack of knowledge of respite, provider restrictions, difficulty finding providers and lack of qualified providers, trust

\(^1\) 2009/10 NS-CSHCN
Family Quote - Respite

“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.”
Specific Topics: Emergency Preparedness

• **CYSHCN Outreach Survey:**
  • 34.5% have prepared
  • 15% indicated assistance in making a plan
    • Majority received help from family members

• **Focus Groups:**
  • Most have not spoken to a provider
  • Most have taken measures to prepare and felt prepared to handle an emergency
Specific Topics: Obesity & Exercise

- Top health concern of CYSHCN Outreach Survey

- **Focus Groups:**
  - Doctors to discuss if the child has a specific issue
  - Preventative care not addressed in the visit
  - Not provided tools & resources
    - Children fixated on a type of food or have sensory issues that make changing food difficult
Specific Topics: Mental & Dental Health

- **Mental Health**
  - Access to providers & services identified as priority needs
  - Majority of counties have too few school psychologists & psychiatrists
  - Most border counties are mental health professional shortage areas
  - Parents in the southern border region indicated the importance & need for mental health support for their children & themselves

- **Dental Health**
  - Limited number of dental providers
  - 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
Community Inclusion

• Feelings of isolation, exclusion from community
• Parents look for support from other parents of CYSHCN
• Desire for more education about CYSHCN for the community at large
Community Inclusion – cont’d

• Accessibility at home a barrier to community engagement
• Lack of programs and facilities that are able to accommodate CYSHCN
• Need for the community to be physically accessible so that their children could fully participate alongside typically developing peers
• Need to create accessible parks and recreation centers, adaptive playgrounds, and inclusive sports programs and community-wide events
CONCLUSIONS
Central Themes

• Access
• Education
• Coordination of resources and services
ACKNOWLEDGEMENTS

• The CSHCN Services Program would like to acknowledge our partners and stakeholders for their support and work in this project. Most importantly, we would like to thank the CYSHCN and their families in Texas that we partner with for their knowledge, insight and willingness to give of their time and expertise to this work. As one of our focus group parents stated:

“This [child] is your heart that walks outside of your body.”
National Performance Measures

CSHCN

- 11 Medical home
- 12 Transition
Early Childhood 1-12 years of Age

CHILD HEALTH
Poverty

- 25% of Texas children live in poverty.
- Low unemployment + high poverty = Texas working families do not earn enough to keep their children out of poverty.
- Poorer children are at greater risk for:
  - food insecurity
  - poor academic achievement
  - school dropout
  - abuse and neglect
  - behavioral and socio-emotional problems
  - physical health problems
  - developmental delays
Early Education (Pre-K)-School Readiness

- Texas is ranked last in the nation in terms of pre-k quality.
- Characteristics of quality pre-k include:
  - trained teachers with expertise in early childhood education
  - learning goals tied to K–12 standards
  - low child/staff ratios
  - small class size
- Benefits to children who receive high-quality pre-k:
  - enter school more ready to learn
  - improved (social-emotional, language and communication, early literacy, and mathematics) that define kindergarten school readiness.
  - gives our most vulnerable kids a greater chance to succeed
Health Care

- Texas is ranked 49th nationally for the percentage of children with health insurance.
- In Texas (2011-2012), 51.8% of children received coordinated, continuous, compassionate, ongoing, comprehensive care within a Medical Home.
- Children without health insurance are more likely to be in poorer health, experience higher rates of hospitalization, miss regular checkups, go without diagnostic screenings, critical preventative care and have greater unmet mental health needs than children with insurance.

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

Prepared by: Office of Program Decision Support
Dental Health

- 77.8% of Texas children are receiving preventative dental care; national average 77.1%
- 66.3% of children in Texas have very good or excellent dental health; 71.3% nationally.
- Children enrolled in Medicaid in Texas have higher oral health care utilization than children not enrolled in Medicaid, including those children with private insurance.

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
Obesity

• Within the state, WIC provides the only viable surveillance of obesity among toddlers.
• Toddler data is important for assessing the overall health of children.
• Obesity among toddlers can lead to later health issues and long-term problems with weight.
• State Needs Assessment (2014) Parent perception barriers:
  • Feel helpless to get child to eat healthy
  • Feel neighborhoods not safe for outdoor physical activity
  • Perceive their child to be a healthy weight

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

* represents a significant change from the previous year

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

- Asthma is the most common chronic condition among children.
- In 2014, it was estimated that 9.1% of Texas children 0-17 years had asthma.
- Children 0-4 years have the lowest prevalence of asthma but the highest hospitalization rate.
- Of asthma-related Medicaid claims, hospitalizations account for less than 1% of the number of claims, but 24% of expenditures for children.
- Asthma is the #1 chronic cause of school absenteeism accounting for more than 13 million total missed days of school.
Child Maltreatment

- Texas Department of Family and Protective Services (DFPS) found 66,572 children were confirmed victims of maltreatment in 2014.
- 76% due to neglectful supervision, medical or physical neglect
- 23% due to physical, sexual or emotional abuse.
- 1% falling in the “other” category.
Child maltreatment (Homicide) – FY2014

DFPS Child Abuse/Neglect Related Fatalities
Fiscal Year 2014

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Texas Child Population*</td>
<td>6,584,709</td>
<td>6,663,942</td>
<td>7,054,634</td>
<td>7,159,172</td>
<td>7,266,760</td>
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<tr>
<td><strong>DFPS Child Abuse/Neglect Related Fatalities</strong></td>
<td><strong>227</strong></td>
<td><strong>231</strong></td>
<td><strong>212</strong></td>
<td><strong>156</strong></td>
<td><strong>151</strong></td>
</tr>
<tr>
<td>Confirmed Child Abuse/Neglect Related Fatalities per 100,000 Texas children</td>
<td><strong>3.4</strong></td>
<td><strong>3.5</strong></td>
<td><strong>3.0</strong></td>
<td><strong>2.2</strong></td>
<td><strong>2.1</strong></td>
</tr>
</tbody>
</table>
Child maltreatment (Homicide)

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

- Percent below 185 FPL
- Percent below 150 FPL
- Percent below 125 FPL
- Percent not speaking English at home
- Percent with more than a bachelor's degree
- Percent younger than 18 years old
- Percent in census not moved in past year
- Percent of 18-34 year olds with no health Insurance
- Percent of 18-24 year olds with no health Insurance

*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
Unintentional injuries

• Unintentional injuries are the leading cause of death for children 1-14 years of age in Texas.

• The unintentional mortality rate from 2006 to 2012 for:
  • Children one to four years of age = 11.1 per 100,000 population
  • Children five to fourteen years of age = 5.1 per 100,000 population

• The motor vehicle mortality rate from 2006 to 2012:
  • Children aged one to four = 4.3 per 100,000 population
  • Children aged five to fourteen = 3.3 per 100,000 population

• The drowning mortality rate from 2006 to 2012 for:
  • Children aged one to four = 3.5 per 100,000 population
  • Children aged five to fourteen = 0.7 per 100,000 population
National Performance Measures
Child Health

• 5 Developmental screening
• 6 Child safety/Injury
• 7 Physical activity
ADOLESCENT HEALTH
Weight Status - Children 10-17

Children 10-17, based on BMI

- Healthy weight: 59.3%
- Overweight / obese: 36.6%
- Underweight: 4.1%
Focus Group Findings

• 54% of focus group parents indicated that “overweight/obesity among children and adults” was one of their top five health concerns.

• 40.5% of the respondents indicated that “the lack of exercise/physical activity” was one of their top five health concerns as well.
Weight and Bullying

• Only 59% of 8th grade students were healthy weight based on SPAN survey.
• For some students, there are gaps between their perceived weight and actual weight at both the low and high end of the BMI scale.
• The gap between perceived body weight and actual BMI can be related to the child’s history of being bullied.
• Students that perceived themselves as weighing too little had three times the risk of being bullied than those who reported that they weighed the right amount.
• Students who perceived themselves as weighing too much had a risk more than twice as high as those who perceived themselves as weighing the right amount.
Bullying

• 19% of Texas youth experienced bullying on school property.
• 13% of Texas youth had experienced cyberbullying.

Source: 2013 YRBSS
Dating Violence

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
Substance Abuse

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

Figure 7.9
Percent of 10-12th Grade Students Reporting Ever Trying Tobacco or Alcohol by Grade and Race/Ethnicity, Texas 2012

Source: Texas Student Survey of Substance Use, 2012
Prepared by: Office of Program Decision Support
Teen Contraception Use

Figure 7.14
Percent of Teens Who Used No Method to Prevent Pregnancy

Source: 2006-2013 Youth Risk Behavior Surveillance System
Prepared by: Office of Program Decision Support
HIV/STDs

- 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.
- The rate of Syphilis among youth has also increased since 2005.

![Graph showing Chlamydia and Gonorrhea Rates for Youth 15-19 Years Old, Texas, 2005-2013](image)
Adolescent Mortality

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

Prepared by: Office of Program Decision Support
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
Suicide

Figure 7.8
Percent of Teens Who Had Attempted Suicide in the Past Year

Source: 2006-2012 Youth Risk Behavior Surveillance System
Prepared by: Office of Program Decision Support
Homicide

• In 2011, Texas child fatality review teams reviewed 114 of the 138 (82.6 percent) homicide deaths to children less than seventeen years of age in Texas.
  • Twenty-six percent of the deaths reviewed were caused by assault.
• According to the Youth Risk Behavior Surveillance-United States 2013:
  • 18.4 percent of youth and 27 percent of males carried a weapon during the last 30 days
  • One-fourth of youth were in a physical fight during the previous 12 months.
  • 5.5% of the high school students surveyed indicated that they had carried a firearm within the previous 30 days. The prevalence was higher among boys than girls and among white students than black students
National Performance Measures
Adolescent Health

7  Child safety/Injury
8  Physical activity
9  Bullying
10 Adolescent well-visit
National Performance Measures
Crosscutting or Lifecourse

13 Oral Health
14 Smoking
15 Adequate insurance coverage
POLL RESULTS
Select 8 NPM

- One from each of the 6 Domains
- 2 remaining NPM with highest percentage in poll
Stakeholder Feedback

- April webinars for Regional, Central Office, and External Stakeholders
- **MCH Home Page** - http://www.dshs.state.tx.us/mch/default.shtm
- PowerPoint presentation posted April 13th
  - Email feedback to: **TitleV@dshs.state.tx.us**
  - Survey to choose NPM