

Children's Medical Services Network

Family Satisfaction Report

2007-2008



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1 Executive Summary

INTRODUCTION

This report presents the findings of a statewide satisfaction survey of parents and guardians whose children are enrolled in Florida's Children's Medical Services Network (CMSN) program. The CMSN is Florida's Title V program for Children with Special Health Care Needs (CSHCN). Children must be both medically and income eligible to enroll. Medical eligibility mandates that a child have a special health care need which requires extra or specialized care; such as, medical services, therapy, supplies or equipment due to a chronic medical or developmental condition. Children must also meet the income eligibility requirements associated with Medicaid (for children under 21) or the State Children's Health Insurance Program (for children under 19).

All families in this study are eligible for CMSN through Medicaid (Title XIX) and children are nine months to 21 years old. In addition to the criteria for participation being limited to Medicaid eligible CMSN families this study focuses on regional differences across the eight regions of the State. The regions and the counties contained within each region are:

- Northwest Region - Calhoun, Jackson, Holmes Bay, Washington, Walton, Okaloosa, Escambia, Santa Rosa.
- Big Bend Region - Madison, Taylor, Jefferson, Leon, Gulf, Wakulla, Gadsden, Franklin, Liberty.
- North Central Region - Hamilton, Columbia, Baker, Duval, Nassau, Suwanee, Union, Clay, Bradford,

Lafayette, Alachua, Dixie, Gilchrist, St. Johns, Putnam, Flagler, Marion, Levy, Sumter, Citrus, Volusia, Hernando, Lake.

- Central Region - Brevard, Osceola, Orange, Seminole.
- Tampa Bay Region - Highlands, Hardee, Polk, Pasco, Hillsborough, Pinellas.
- Southeast Region - Broward, Palm Beach, Martin, St. Lucie, Okeechobee, Indian River.
- Southwest Region - Sarasota, Collier, Hendry, Charlotte, Glades, DeSoto, Manatee, Lee.
- South Region - Miami-Dade, Monroe.

The CMSN program has a unique delivery system that focuses on providing the highest quality of care for those with special needs. Children in the program receive care from physicians, specialists, and nurse care coordinators (NCC). Each of these individuals plays an important role in the care of the children. The CMSN program has several sub-specialty programs within its domain. Unlike past CMSN satisfaction reports, this report does not delineate across sub-specialty programs, but presents the findings of family attitudes and satisfaction by regions. This is the third CMSN satisfaction report that solely focuses on Medicaid eligible families¹.

At a Glance

This survey presents the results of a survey of parents whose children are enrolled in CMSN and Medicaid.

Survey results are partitioned into 8 regions:

Northwest
Big Bend
North Central
Central
Tampa Bay
Southeast
Southwest
South

At A Glance

Aims

- Describe the results related to parents' experiences with their children's health care as measured by the CAHPS,
- Describe the children's health-related quality of life (HRQOL) as measured by the PedsQL Core questionnaire,
- Describe parents' satisfaction with and reports of availability and knowledge of the CMSN nurse care coordinators,
- Rate the CMSN program overall and describe the best and worst aspects of the program,
- Summarize parental reports of whether or not their children's provider discussed nutrition and exercise with them,
- Describe the results of transition preparedness for children 14 years and older, and
- Compare results of the past four surveys to capture trends during 2004-2005, 2005-2006, 2006-2007, and 2007-2008.

DATA AND EVALUATION INSTRUMENTS

Two data sources are used in the compilation of this report. First, data specialists from the Agency for Health Care Administration (AHCA) provided Title XIX enrollment files which were used to select the sample of families for telephone survey participation. Second, qualitative and quantitative data collected during the telephone surveys are used. Surveys are aimed at describing and quantifying satisfaction and health-related quality of life (HRQOL) for children enrolled in CMSN. The following survey modules are assessed in this report: 1) the Consumer Assessment of Health Plans Survey (CAHPS) Version 4.0, child², Medicaid, 2) Pediatric Quality of Life (PedsQL) Core³, 3) CMSN Program Evaluation, 4) Nurse Care Coordinator Feedback, 5) Healthy Lifestyles and Transition Questions, and 6) Demographics.

In total, 640 surveys were administered to parents and guardians of Title XIX children ages nine months to 21 years old who were enrolled in CMSN for at least six consecutive months. The 640 surveys represent 80 completed surveys in each of the eight regions.

Aims

The aims of this report are to:

- Describe the results related to parents' experiences with their children's health care as measured by the CAHPS,
- Describe the children's HRQOL as measured by the PedsQL Core questionnaire,

- Describe parents' satisfaction with and reports of availability and knowledge of the CMSN nurse care coordinators,
- Rate the CMSN program overall and describe the best and worst aspects of the program,
- Describe the findings for whether or not providers are discussing healthy eating and exercise with children,
- Describe the results of transition preparedness for children 14 years and older, and
- Compare results of the past four surveys to capture trends during 2004-2005, 2005-2006, 2006-2007, and 2007-2008.

FINDINGS

Key findings from this study are:

- Statewide, parents have positive experiences with doctor's communication (91), getting care quickly (89), and getting needed prescriptions (89) as measured by the CAHPS composites (scores based on 100 total possible points with higher scores indicating more positive experiences).
- Statewide, parents report the least positive experiences with specialized services (73), and getting needed care (76) as measured by the CAHPS composites.
- There is wide variation across regions in families' experiences with plan customer service, getting needed information, and specialized services as measured by the CAHPS composites.
- Parents residing in the Northwest and Big Bend regions have

the most positive experiences while parents residing in the North Central region have the least positive experiences as measured by the CAHPS composites. However, after controlling for child functioning level and sociodemographics there were fewer differences across regions.

- Seventy-nine percent of parents report that their children saw a health provider within seven days of making an appointment for routine health care.
- Seventy-nine percent of parents report that the office staff at their children's personal doctor is usually or always helpful and 92% report that the staff is usually or always courteous and respectful.
- One-half of parents tried to make an appointment with a specialist. Twenty-seven percent of those parents found it never or sometimes easy to make an appointment.
- Seventeen percent of parents report that their children's personal doctor is sometimes or never informed or up to date about their children's specialty care.
- Children in the Southeast and Big Bend regions have the highest overall HRQOL as measured by the PedsQL while children in the Tampa Bay and Northwest regions have lowest overall HRQOL as measured by the PedsQL.
- Eighty-one percent of parents report that they know their assigned CMS nurse care coordinator. This varies across the state; more than a third of parents in the South region do not know who their NCC is, compared with 6% of parents in the Southwest region.
- Parents in the South region were least likely to report their NCC as accessible, helpful or knowledgeable.
- Twenty-two percent of parents report that their CMSN nurse care coordinator did not follow-up in a timely manner after their children saw a primary care physician.
- Seventy-six percent of parents are very satisfied with their CMSN doctor. More parents are very satisfied with their CMSN doctor in the Big Bend region (85%) compared with parents in the Tampa Bay region (68%).
- Seventy-five percent of parents rate the quality of care in the CMSN program as excellent to very good. More Tampa Bay and Northwest parents (60% and 62%) rated their children's quality of care as excellent.
- Seventy-five percent of parents rate CMSN overall as excellent to very good. Eight-four percent of parents in the Big Bend and Northwest regions rate CMSN as excellent to very good. Sixteen percent of families in the South region rate the program as fair to poor.
- Eighty-three percent of CMSN parents report that their children's provider has discussed healthy eating and nutrition with them. Fewer parents report that the provider discussed their children's physical activity and exercise (79%) or weight (77%) with them.

At a Glance

KEY FINDINGS

Results from the CAHPS composites show that:

Parents have the most positive experiences with doctor communication and the least positive experiences with specialized services, and getting needed care.

Parents in Northwest and Big Bend regions are most satisfied with CMSN services and parents in the North Central region are least satisfied.

- Seventy-two percent of CMSN parents of children 14 years and older report that their providers have spoken with them and their children about changes that will occur as their children become adults. These changes include transition to the adult health care delivery system.

RECOMMENDATIONS

Primary recommendations for the CMSN program are:

- There are large variations across the state in parental reports of their health care experiences with their children as measured by the CAHPS. Children enrolled in CMSN should receive consistent health care regardless of their region.
- Care coordination is a cornerstone of the CMSN. Currently one-fifth of parents do not know their assigned nurse care coordinator. CMSN should investigate why parents whose children are enrolled in the South are less likely than parents in other regions to find their children's NCC accessible or helpful.
- Half of the CMSN parents report a need for specialist care. However, one-quarter of parents who tried to make a specialist appointment encountered difficulties. Parents' most frequent complaint is that there are not enough specialists in the network to choose from, that they were located too far away or they could not make an appointment at a convenient time.
- Nationally, dental care is the most prevalent unmet health care need for CSHCN. Thirty-nine percent of CMSN children have not seen a dentist in the past year. Further investigation is needed to determine if the low level of compliance is due to lack of access or failure to use dental care even when there is access to an available provider.
- Twenty-seven percent of parents report that their provider has not spoken with them about their children's nutrition and healthy eating. In order to prevent long term health effects and higher costs for the State, providers should be encouraged to address this critical issue.
- One-hundred percent of parents of adolescents should be prepared for transition. Further investigation is needed to determine why adolescent transition is not discussed during outpatient visits and what interventions are needed to foster these discussions.

2 Introduction & Purpose

At A Glance

CMSN provides medical services to children who are financially and medically eligible.

All families in this study are eligible for Medicaid (Title XIX).

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- Rate the CMSN program overall and describe the best and worst aspects of the program,
- Summarize parental reports of whether or not their children's provider discussed nutrition and exercise with them,
- Describe the results of transition preparedness for children 14 years and older, and
- Compare results of the past four surveys to capture trends during 2004-2005, 2005-2006, 2006-2007, and 2007-2008.

3 Data & Evaluation Methods

At a Glance

640 families completed the survey.

48% of the families agreed to complete the survey.

The following survey modules were assessed:

- CAHPS
- PedsQL
- Nurse Care Coordinator Feedback
- Overall Feedback
- Lifestyle and Transition Questions

Two sources of data are used to evaluate the experiences of Title XIX families whose children are enrolled in the CMSN program: enrollment information obtained from AHCA and telephone survey data from interviews conducted with the families.

Using CMSN enrollment files obtained from AHCA data specialists a random sample of children enrolled consecutively in CMSN for at least six of the past 12 months was identified. Using the sample, telephone surveys were conducted with families

from 10 AM to 9 PM, seven days per week from September 2006 to February 2007. Families were contacted a minimum of 30 times and searches were conducted in an attempt to update outdated contact information. Surveys were conducted in both English and Spanish. The respondent was chosen by asking to speak to the individual in the home most familiar with the targeted child's health⁵. Six hundred and forty families completed the CMSN satisfaction survey and 80 families completed the survey in each region. The regions and the counties contained within each region are:

- Northwest Region - Calhoun, Jackson, Holmes Bay, Washington, Walton, Okaloosa, Escambia, Santa Rosa.
- Big Bend Region - Madison, Taylor, Jefferson, Leon, Gulf, Wakulla, Gadsden, Franklin, Liberty.
- North Central Region - Hamilton, Columbia, Baker, Duval, Nassau, Suwanee, Union, Clay, Bradford, Lafayette, Alachua, Dixie, Gilchrist, St. Johns, Putnam, Flagler, Marion, Levy, Sumter, Citrus, Volusia, Hernando, Lake.
- Central Region - Brevard, Osceola, Orange, Seminole.
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- Southwest Region - Sarasota, Collier, Hendry, Charlotte, Glades, DeSoto, Manatee, Lee.
- South Region - Miami-Dade, Monroe.

Of those families with valid contact information (28% did not have valid contact information), 48% of families participated in the survey.

Composite results and major themes are presented in the body of this report. A complete presentation of all questions and responses by region may be found in the technical appendix that accompanies this report.

The 2007-2008 CMSN Family Satisfaction Survey contains the following modules.

CAHPS: The Consumer Assessment of Health Plans Survey (CAHPS), child Medicaid version 4.0⁶ was used to assess several components of the parents' health care experiences with their children. The CAHPS questions related to the following areas:

- 1) Parents' experiences with getting needed care
- 2) Parents' experiences with getting care quickly
- 3) Parents' experiences with doctor's communication
- 4) Parents' experiences with health plan customer service, information, and paperwork
- 5) Parents' experiences with prescription medicine
- 6) Parents' experiences getting specialized services for their children
- 7) Family centered care-experiences with the child's personal doctor

- 8) Family centered care-experiences with shared decision making
- 9) Family centered care-experiences with getting needed information about their child's care

A mean score is calculated for each composite, which ranges from 0 to 100, with 100 being the highest score⁷. Prior to asking all of the CAHPS composite questions, the respondent is asked if he/she had the experience that served as the basis to answer the remaining questions that comprise the composite. For example, respondents are first asked if the parent needed any special medical equipment for their child in the past 6 months, before asking how easy it was to obtain this equipment. If the respondent indicates that they did not have that experience, the interviewer skips to the next question. Therefore, the composite scores represent the experiences of the respondents who had the experience, versus the entire survey pool.

Composite scores are presented for each region graphically within the body of the report. Item responses for the CAHPS questions, again by region, can be found in the technical appendix which accompanies this report. The 2008 Health Plan Employer Data and Information Set (HEDIS) specifications also recommend calculating a composite score between 1 and 3, and these scores are included in the technical appendix for completeness⁸.

It is important to note that the CAHPS module was revised in 2007 by the federal Agency for Healthcare Research Quality (AHRQ). Several of the questions from version 3.0 were either omitted or changed. Therefore, the Institute does not recommend that comparisons be made from CAHPS modules in this report to those from previous reports.

Parents were also asked individual CAHPS questions relating to their experiences accessing dental care, primary care, and specialist care. These questions focus on ease of making appointments and unmet needs.

PEDSQL CORE:

The PedsQL Core Version 4.0⁹ is used to measure health-related quality of life (HRQOL) in children ages two to 18. The PedsQL Core consists of 23 items associated with the following domains: physical, emotional, social, and school functioning. Each set of functioning questions is tailored to the child's age and respondents are asked to answer if their child: Never, Almost Never, Sometimes, Often, or Almost Always had a problem with that functioning element. The items are reverse scored and linearly transformed on a zero to 100 composite score. Higher scores indicate better HRQOL. Composite scores are presented for each region graphically within the body of the report. Item responses for the PedsQL Core are presented, again by region, in the technical appendix which accompanies this report.

NURSE CARE COORDINATOR FEEDBACK:

This survey module asks several questions about the availability, knowledge and satisfaction of the child's nurse care coordinator. Parents are also asked to rate their ability to get help by telephone from the CMSN staff. Item responses are presented in the body of the report by region.

CMSN SATISFACTION QUESTIONS:

Parents are asked about their overall satisfaction and experiences with the CMSN program. Several questions are asked about satisfaction with the benefits, provider, and quality of care as well as the best and worst aspects of the program.

HEALTHY LIFESTYLES AND TRANSITION QUESTIONS:

Finally, parents are asked two series of questions related to the critical issues of healthy lifestyles and transition. Questions focus on gathering information to determine if the child's primary care physician has discussed nutrition and exercise with the family. Transition questions are asked to the parents of children ages 14 and older. Questions focus on determining if the children and their parents have begun to discuss transition issues with their children's primary care physician and if a plan had been developed.

4 Parent Survey Results

At A Glance

Average age of respondents was 41 years.

Forty-nine percent of households are single-parent households.

Forty-one percent of families report that their children are in Excellent to Very Good health.

The telephone surveys collect a variety of information related to health care quality and experiences in obtaining health care for their children. In addition, demographic and socioeconomic characteristics are recorded. Results from the demographics section of the survey follow.

AGE OF CHILDREN AND PARENTS

The average age of children whose parents responded to the survey is 10 years with a standard deviation of 5.6 years. About 55% of the CMSN children whose parents were surveyed are boys. The respondents' average age is 41 years with a standard deviation of 13.3 years.

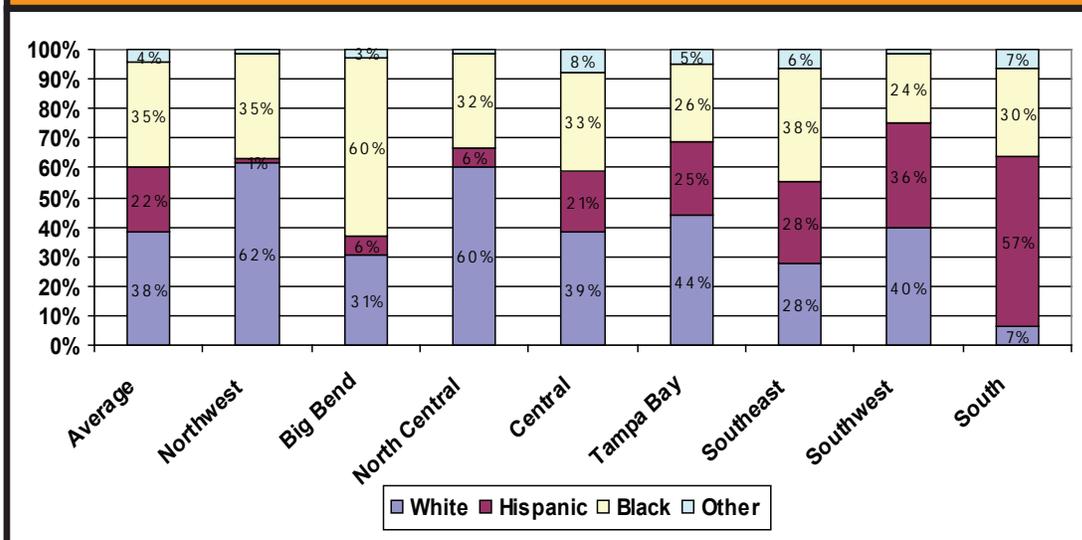
RACE AND ETHNICITY OF CHILDREN AND PARENTS

Figure 1 contains information about the race/ethnicity of the children whose parents responded to the survey from all sites. The race/ethnicity of children are as follows:

- 38% are White non-Hispanic,
- 35% are Black non-Hispanic,
- 22% are Hispanic, and
- 4% from other racial groups.

Of those children who are Hispanic, 23% are of South American descent, 21% are of Puerto Rican descent, 24% are Mexican, 12% are Cuban, and 6% Dominican Republic. Parents had a similar race/ethnicity mix with 40% White non-Hispanic, 32% Black non-Hispanic, 23% Hispanic, and 4% from other racial groups.

Figure 1. Race/Ethnicity of CMSN Children by CMSN Region



NATIVE LANGUAGE OF CHILDREN AND PARENTS

Eighty-one percent of parents speak English, 17% Spanish, and 2% speak other languages in the home. There are geographic differences in the language parents speak at home. There are no Spanish speaking parents in the Northwest region, compared with 48% of Spanish speaking parents in the South region. Twenty nine percent of parents in the Southeast and Southwest regions speak Spanish at home. Children in the program speak English (80%) predominately, Spanish (10%), and other languages (10%).

PARENT EDUCATIONAL ATTAINMENT

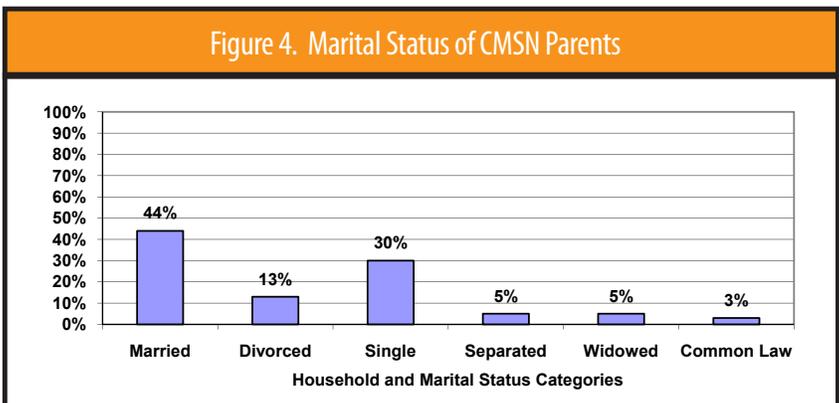
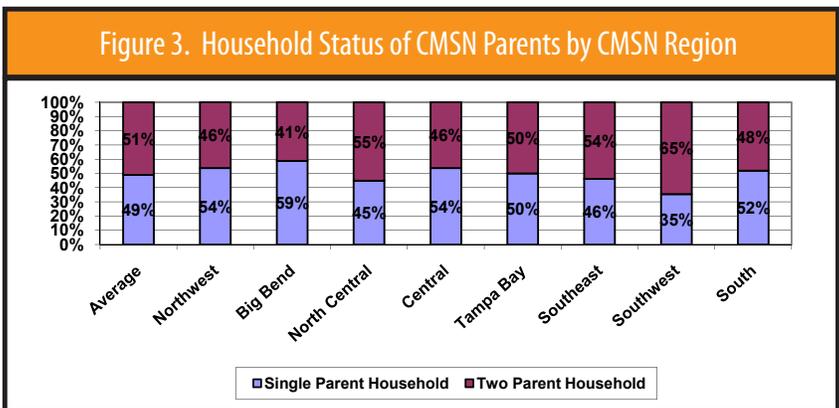
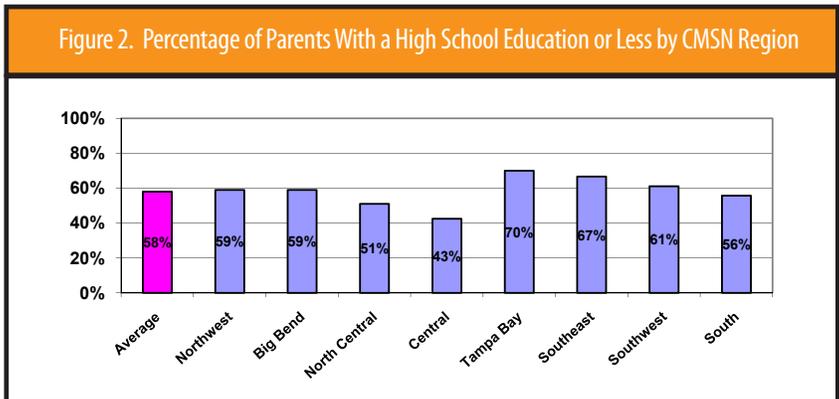
Respondents primarily have a high school education or less. Parental educational attainment is:

- 26% less than high school,
- 32% high school graduate,
- 24% some college or technical school,
- 18% Associates degree or higher.

As seen in **Figure 2**, parents' educational attainment varies between regions. Forty-three percent of parents in the Central region have a high school education or less, compared with 70% of parents in Tampa Bay.

HOUSEHOLD TYPE AND MARITAL STATUS

Finally, respondents are asked two questions about their household type and marital status. As seen in **Figure 3**, forty-nine percent of households are single parent households. As shown in **Figure 4**, forty-four percent of parents are married, 13% divorced, 30% single, 5% separated, 5% widowed, and 3% common law married.



TELEPHONE SERVICE IN THE PAST 6 MONTHS

Families are asked if they had an interruption in their telephone service in the past six months. Seven percent of the families had an interruption, and of those who did, 47% had no service for less than one month and 53% for two to six months. Overwhelmingly, those who did not have telephone service cited cost as the number one reason for loss in service (70%) followed by relocation (18%).

RATING OF CHILD'S HEALTH

Families are asked to rate their child's current health status as Excellent, Very Good, Good, Fair, or Poor. Forty-one percent of families report that their children are in Excellent to Very Good health. Families across the CMSN regions report that their children are in Good health (37%), Fair health (20%) and Poor health (4%).

CHILDREN IN SCHOOL OR DAYCARE

Parents are asked whether their children currently attend school or daycare. Eighty-one percent of families report that their children attend school or daycare. The percentage of children attending school ranges from 73% in the Southeast region to 92% in the Central region.

Finally, 90% of the children in the survey had been enrolled in CMSN for all of the past six months. Four percent were enrolled for three to five months, 3% were enrolled for one to two months, and 3% were enrolled for less than a month.

At A Glance

CMSN families are racially diverse.

Across the State, 17% of parents speak Spanish at home.

In the South region, 48% of parents are Spanish speakers.

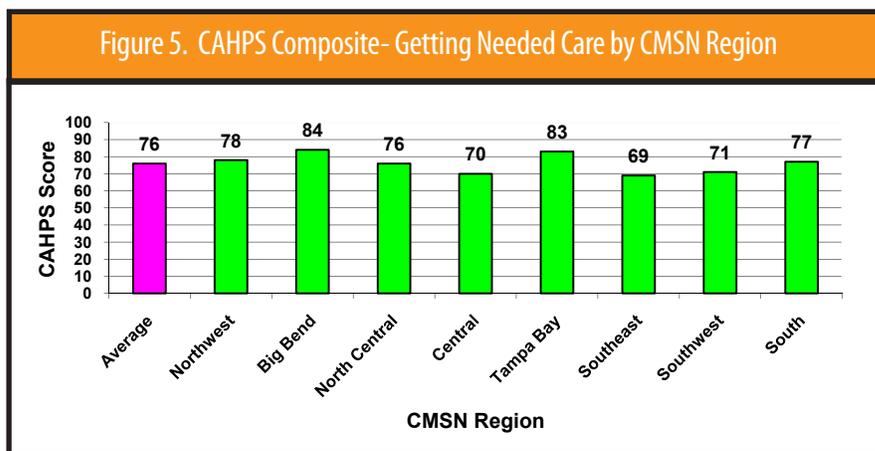
5 CAHPS Composite Scores

The CAHPS version 4.0 is used during the telephone surveys to assess families' experiences in obtaining health care for their children ages nine months to 21 years who had been enrolled for at least six consecutive months in the past year. The National Commission on Quality Assurance recommends using the CAHPS as one measure of quality of care. Questions ask the respondent to think about the health care, health plan, doctor communication, dental care, specialized services, and care from a specialist they received in the past six months. Comparison information specifically for CSHCN programs is not available from the creators of the CAHPS.

Each CAHPS composite score is presented and discussed below. A statewide average for each of the CAHPS composites is shown in pink on the graphs in this section of the report. The range and variance (difference between the minimum and maximum scores) are also reported for all the composites. Composites can not be compared to previous years because of revisions in item wording and composite structure between versions 3.0 and 4.0 of CAHPS. Composite item responses, as well as individual CAHPS questions, may be found in the technical appendix that accompanies this report. Additional CAHPS questions, not included in the composites, may also be found in the technical appendix.

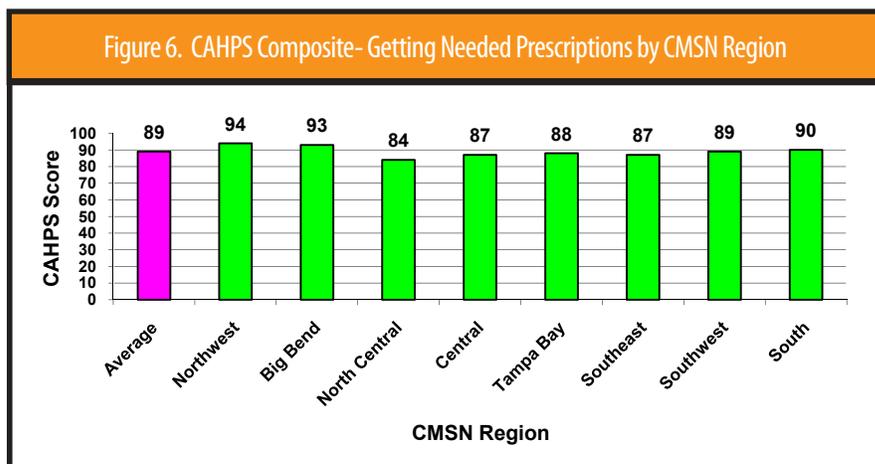
GETTING NEEDED CARE

To measure parents' experiences in getting needed care for their children, two questions are posed to respondents. Thinking about the past six months, parents are asked about how often it was easy to see a specialist, and how often it was easy to get care, treatment or tests. As seen in **Figure 5** below, composite scores ranged from 69 (Southeast) to 84 (Big Bend) indicating a fifteen point variation across regions.



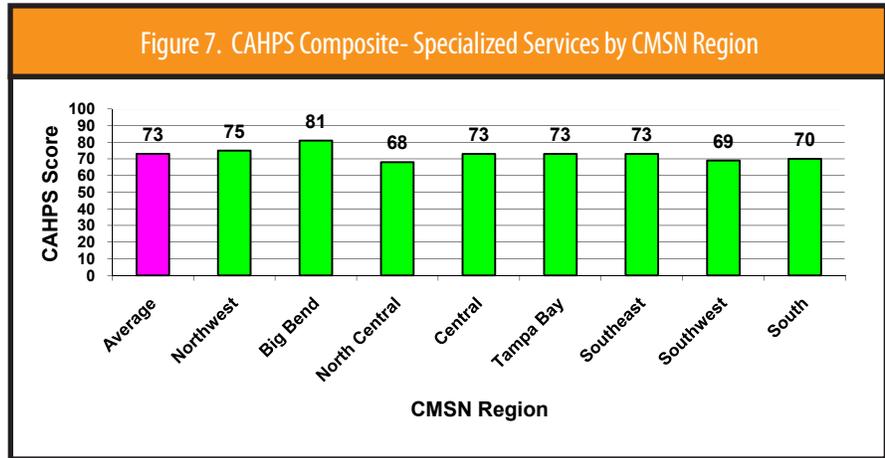
GETTING NEEDED PRESCRIPTIONS

To measure parents' experiences with getting needed prescriptions, only one question is asked: how often was it easy to get your child's prescription. Respondents can choose that it was never, sometimes, usually, or always easy to get your child's prescription. Scores are assigned in descending order for the answer choices of always, usually, sometimes, and never. As shown in **Figure 6** below, scores ranged from 94 (Northwest) to 84 (North Central) across regions. The regional variation in the composite scores was 10 points.



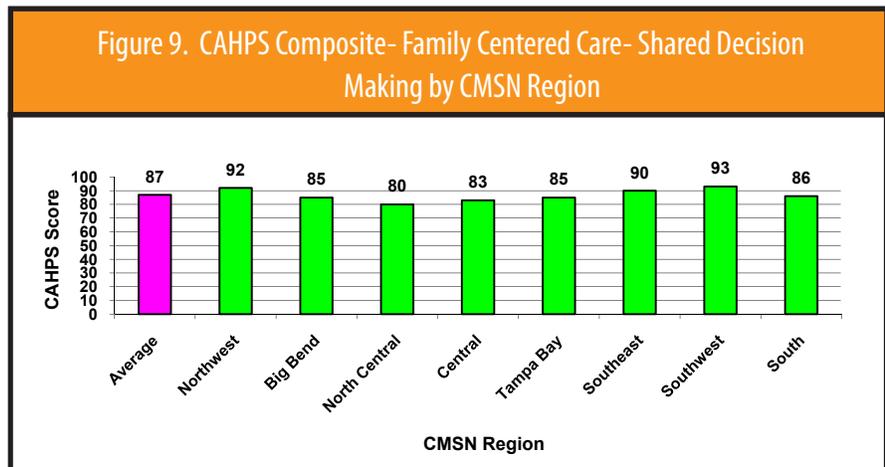
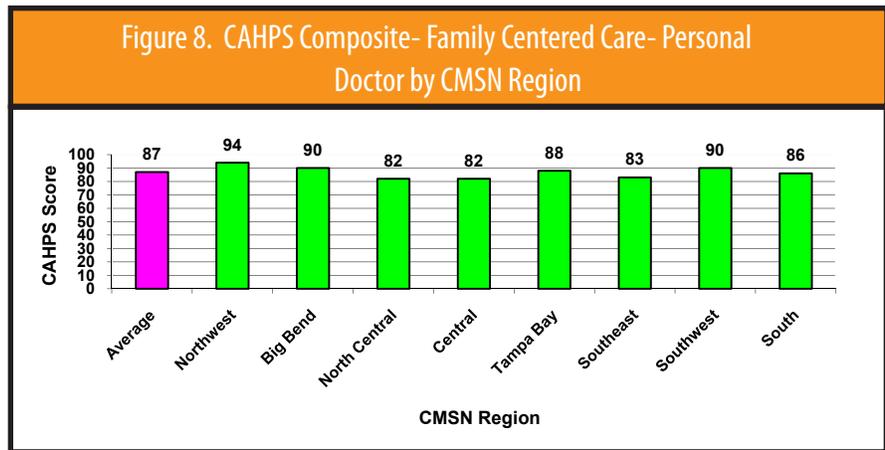
SPECIALIZED SERVICES

Parents are asked three questions related to how often it was easy to get special medical equipment, special therapy, and treatment or counseling. Results seen in **Figure 7** vary widely with the Big Bend region scoring 81 and the North Central region scoring 68. There is wide variation (13 points) across regions. These results indicate inconsistency across the State in the provision and accessibility of specialized services.



Family Centered Care

Family centered care is made up of three separate domains: parents' experiences with the child's personal doctor, parents' experiences with shared decision making, and parents' experiences with getting needed information about their child's care. Each domain focuses on the interactions between the provider and the parent and evaluates how much of a role the parent had in the child's treatment plan. Family centered care also relies on a foundation of understanding between the provider and the parent of how the child's illness affects all parties involved. The Northwest region had the highest scores for two of the three composites (personal doctor and getting needed information) and Southwest had the highest for shared decision making (see **Figures 8 through 10**).



GETTING CARE QUICKLY

Respondents are asked two questions to determine how quickly they are getting the care they need for their children. Questions focus

on whether parents were able to get an appointment as soon as they wanted for non-urgent care, and getting needed care right away when their child had an illness, injury or condition. **Figure 11** shows that all regions scored higher than 81 on this composite. The variance for getting care quickly is 12 points.

DOCTOR COMMUNICATION

This composite has five questions that focus on how well doctors communicate to parents. Parents are asked to evaluate how well doctors listen, show respect and explain things to them and their children. Almost every region scored 90 or better indicating very high levels of satisfaction with provider interactions across the State. Results shown in **Figure 12** are encouraging as parents are very satisfied with their experiences in the past six months. There is small variation (5 points) in the results indicating consistency across the regions.

HEALTH PLAN CUSTOMER SERVICE

The CAHPS includes questions about health plan customer service. In this case, the health plan is CMSN. Three questions are asked of parents in this composite that focus on getting help from customer service and the level of service, and problems with paperwork. Results in **Figure 13** are fairly consistent across the Northwest, Big Bend, and Central regions with scores in the 80s. However, the Southeast region scored the lowest (70) and the overall variance was 17 points.

Figure 10. CAHPS Composite- Family Centered Care- Getting Needed Information by CMSN Region

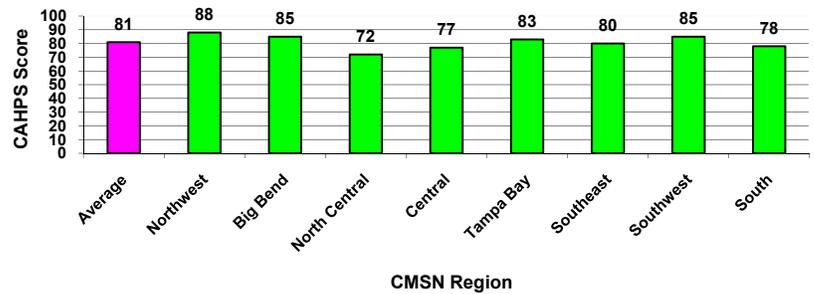


Figure 11. CAHPS Composite- Getting Care Quickly by CMSN Region

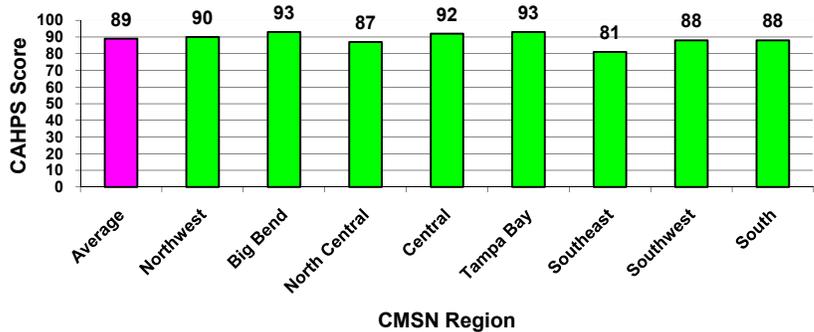
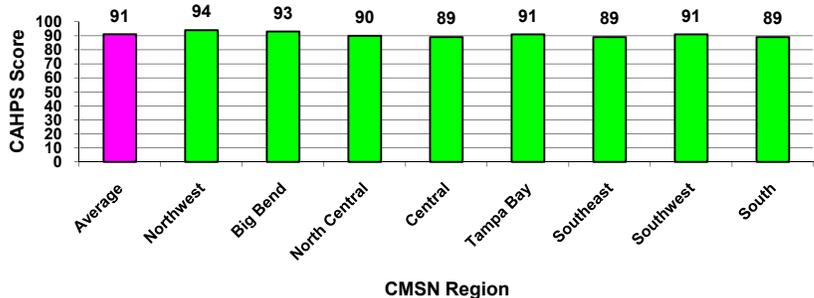


Figure 12. CAHPS Composite- Doctor Communication by CMSN Region



SUMMARY OF CAHPS COMPOSITE SCORES

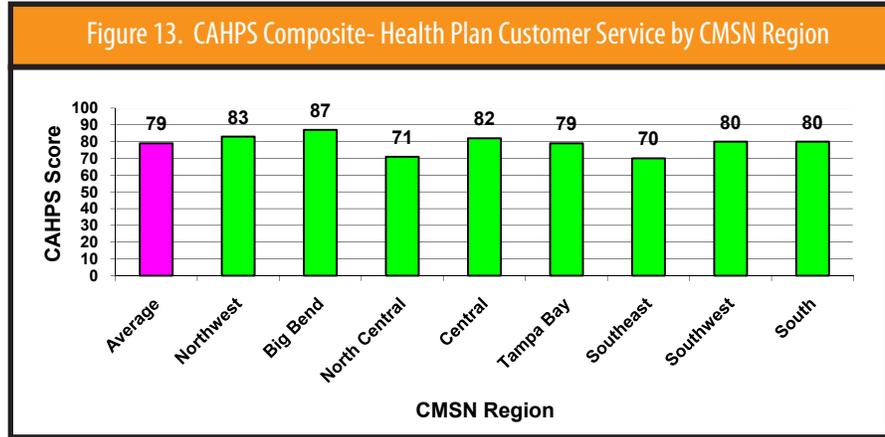
Table 1 below ranks all the CAHPS composites by region to illustrate statewide strengths and weaknesses. Composite scores are ranked from 1 to 8 with 1 being given to the region with the highest score. In the case of a tie, as illustrated in the Getting Care Quickly composite, tied regions are given the same ranking.

With nine CAHPS composite categories and eight regions, the range of possible total rankings is 9 to 72. Results presented in **Table 1** show that the Northwest and Big Bend regions have the most satisfied parents with four number 1 rankings each and the equal lowest total score. The North Central and Southeast regions had the lowest rankings overall indicating that parents have less positive health care experiences in those regions.

Parents with the most positive experiences obtaining health care for their children reside in the following regions (in descending order):

- Northwest and Big Bend
- Tampa Bay
- Southwest
- South
- Central
- Southeast, and
- North Central

The statewide percentage of families reporting satisfaction with the quality of care, obtaining referrals, needed services, and coordination among providers is 77%¹⁰. The statewide percentage of parents who report they are able to access comprehensive services for their child and family is 80%¹¹.



CAHPS Composite	CMSN Region							
	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Getting Needed Care	3	1	5	7	2	8	6	4
Getting Needed Prescriptions	1	2	8	6	5	6	4	3
Getting Care Quickly	4	1	7	3	1	8	5	5
Specialized Services	2	1	8	3	3	3	7	6
Family Centered Care- Personal Doctor	1	2	7	7	4	6	2	5
Family Centered Care- Shared Decision Making	2	5	8	7	5	3	1	4
Family Centered Care- Getting Information	1	2	8	7	4	5	2	6
Doctor Communication	1	2	5	6	3	6	3	6
Health Plan Customer Service	2	1	7	3	6	8	4	4
Total	17	17	63	49	33	53	34	43

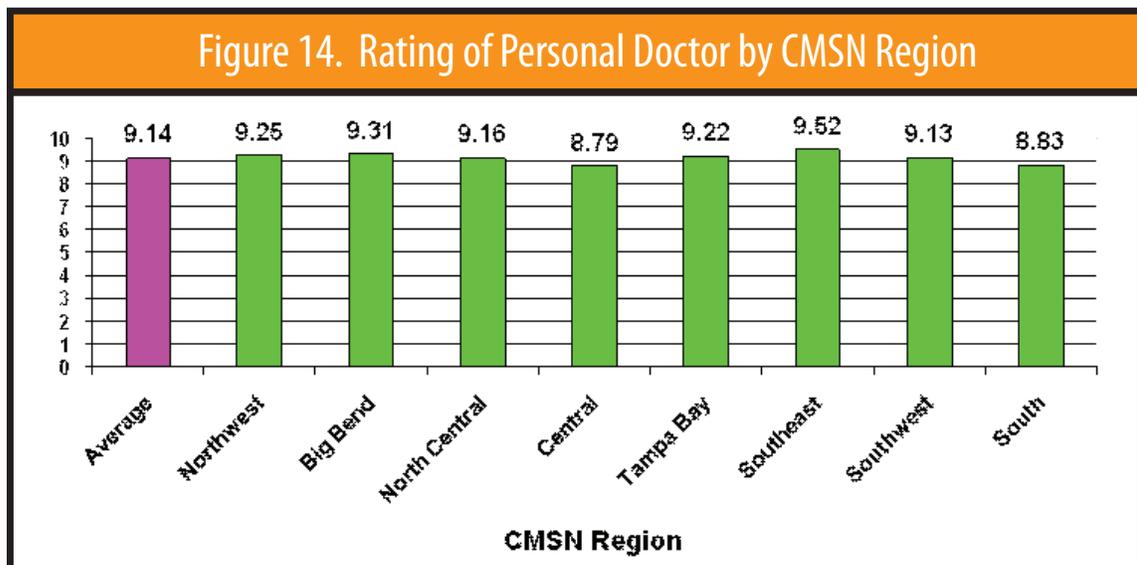
6 Ratings

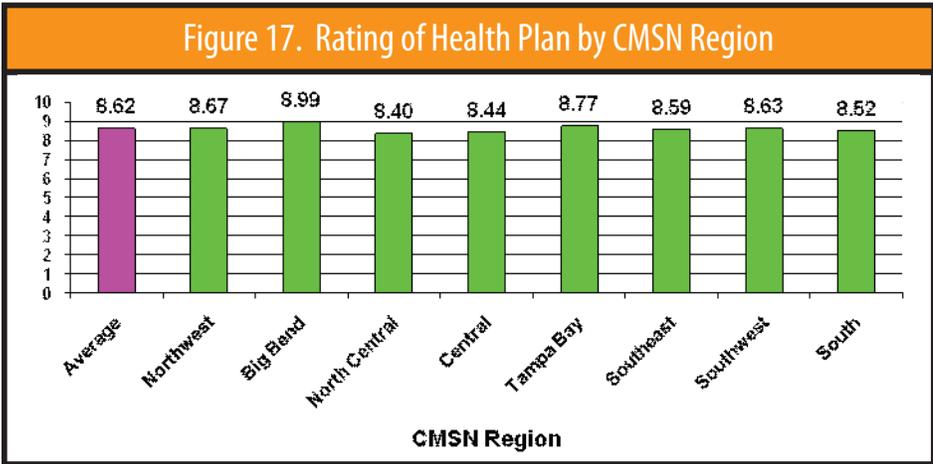
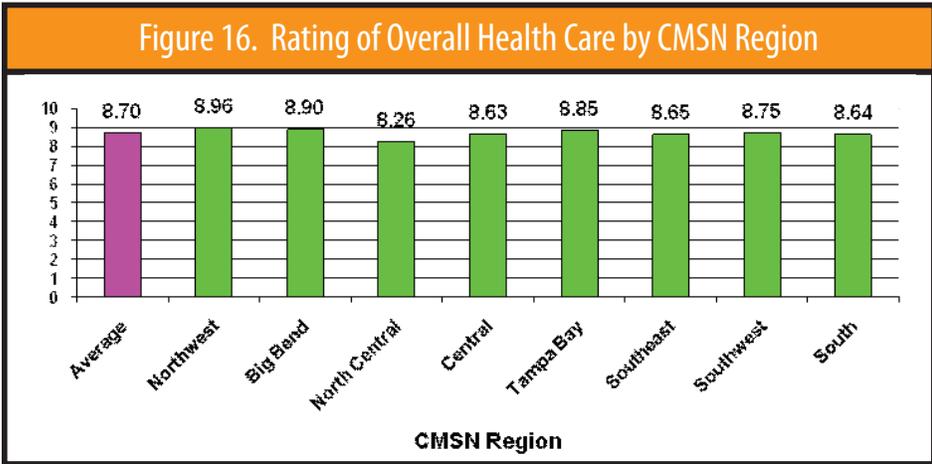
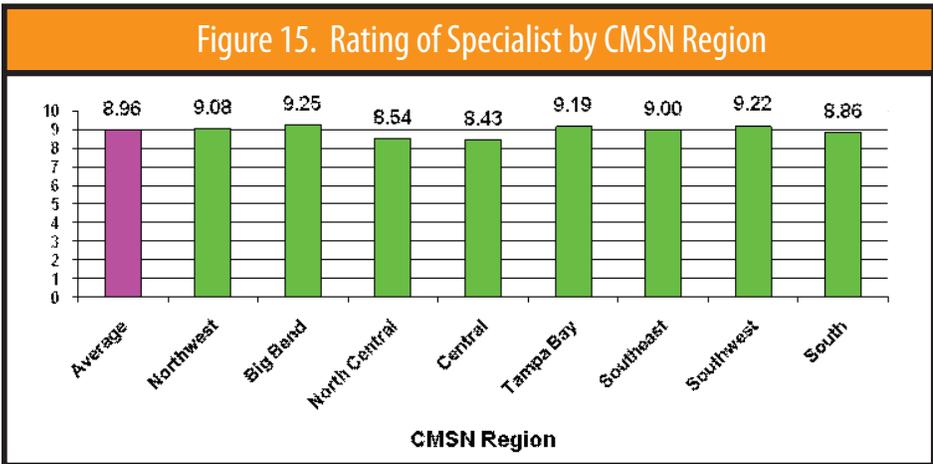
Although not included in the CAHPS composite scores, respondents are asked to assign a rating of zero to 10, with 10 being the highest for several aspects of their child's health care including:

- Personal doctor
- Specialist
- Overall health care, and
- Health plan

Figures 14 through 17 show that for all the respondents in the sample (depicted by the pink Average column in the figures), parents rated their health plan lowest (mean of 8.62) and their child's personal doctor highest (9.14). Compared with responses from 2006-2007, parents rate their personal doctor higher but their overall health care and health plan lower.

By region, rating of personal doctor is highest for Southeast (9.52) and lowest for Central (8.79). For specialist, ratings are highest for the Big Bend (9.25) and lowest for the Central region (8.43). For overall health care, the Northwest region rated highest (8.96) and North Central region rated lowest (8.26). Finally, rating of health plan is highest for Big Bend region (8.99) while North Central region rated lowest (8.40). Compared with responses from 2006-2007, parents rate their overall health care lower in seven regions and their health plan lower in six regions. In contrast, parents rate their personal doctor higher in six regions and their specialist higher in four regions.





7 Dental Care

Oral health is essential to good overall health for children. However, not all children have access to, or receive, needed dental care. In 2000, the Surgeon General published the first report on the nation's oral health. In regard to children, the report found that:

- Tooth decay is the single most common childhood disease, 5 times more common than asthma and 7 times more common than hay fever,
- Over 50% of 5-9 year olds have had at least one cavity or filling and that increases to 78% by age 17,
- Poor children (children below the federal poverty level) have twice as many dental caries than their peers and 25% of poor children have not seen a dentist by Kindergarten,
- Medical insurance is the greatest predictor of dental care, although only one in five Medicaid eligible children received a single dental visit in a one year period, and
- The impact of poor oral health can lead to problems in eating, speaking, and learning¹².

Few studies have focused on the dental care needs and unmet needs for CSHCN. The National Survey of Children with Special Health Care Needs, which

is administered to over 38,000 families in the US, asks questions about dental needs and if they are being met. A 2005 study reported that 78% of all CSHCN reported needing dental care in the past year, and 10% of those who reported needing dental care did not receive it. Children who were uninsured, had more functional limitations, and had lapses in insurance were more likely to have an unmet dental need¹³.

Parents in this survey are asked questions about their children's dental care in the last year. When asked if their child got dental care in the past year the percentages who responded affirmatively by region are:

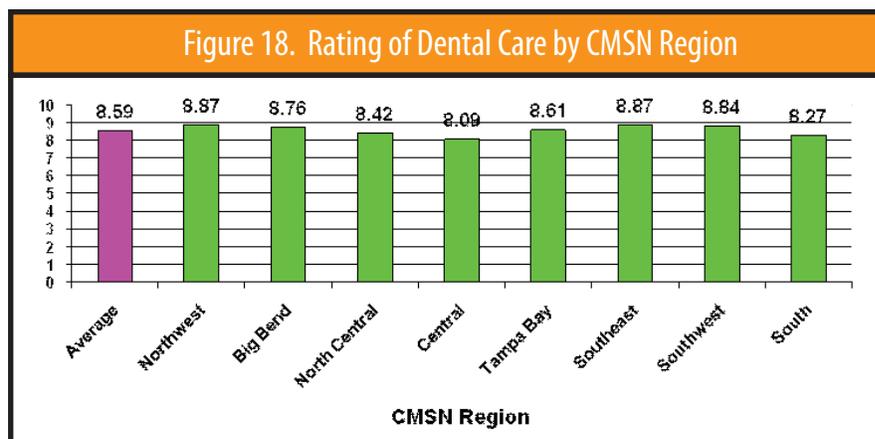
- 56% Northwest
- 58% Big Bend
- 66% North Central
- 56% Central
- 58% Tampa Bay
- 60% Southeast
- 68% Southwest, and
- 69% South.

At A Glance

Between 56% and 69% of CMSN children have seen a dentist in the last year.

Since most children are encouraged to visit a dentist annually, these results indicate moderate levels of compliance with an annual dental check up across the State. When asked to rate their child's dental care, as seen in **Figure 18**, parents in the Northwest and Southeast regions report the highest ratings (8.87) and parents in the Central region report the lowest rating (8.09). Compared with responses from 2006-2007, parents in five regions report lower dental

care ratings and the Statewide average had decreased from 8.70 to 8.59.



8 Access To Primary Care

All children need a consistent source of health care, and none more so than CSHCN. Studies have shown that continuity of children’s care is associated with better coordination of care, greater parent satisfaction with care, and lower emergency department use and costs¹⁴. Nationally, 89% of parents of CSHCN report that their children have a personal doctor, defined as a single health provider who knows their children best¹⁵. Parents in this CMSN satisfaction survey report that 93% of their children have a personal doctor. Furthermore, 73% of respondents report that their children have been seeing their personal doctor for three years or more.

Parents in this survey are asked about their experiences accessing health care from their children’s personal doctor. Parents are asked three questions related to appointment wait time and two questions about accessing after hours care. Parents are also asked to rate the office staff on two qualities: helpfulness and whether the staff is courteous and respectful.

First, parents are asked how often their children are seen by their personal doctor within 15 minutes of their appointment. **Figure 19** shows that between 20% (Northwest) and 46% (Central) of children are always or usually seen within this timeframe. There are wide variations in waiting room time across the regions. Nationally, health plans report that 50% of their patients are usually or always shown to the exam room within 15 minutes or less¹⁶. However, this may not be a realistic goal for CSHCN.

Parents are asked how many days they had to wait between making an appointment and their children seeing their health provider, not including those times where the child needed health care right away. Seventy-nine percent of all parents report that their children saw a health provider within seven days of making an appointment for routine health care. As shown in **Figure 20**, a quarter of parents in North Central and South report having to wait 15 days or more for their children to see a health provider.

Figure 19. Personal Doctor Sees Child Within 15 Minutes of Appointment by CMSN Region

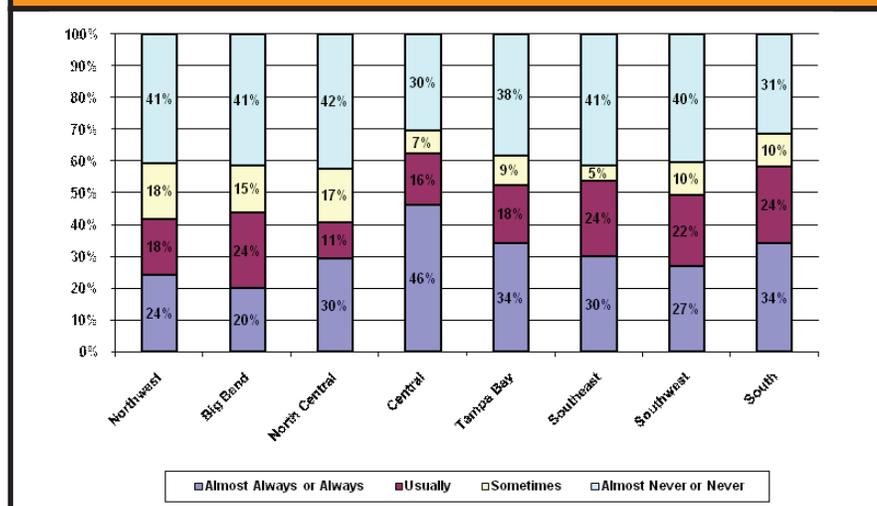
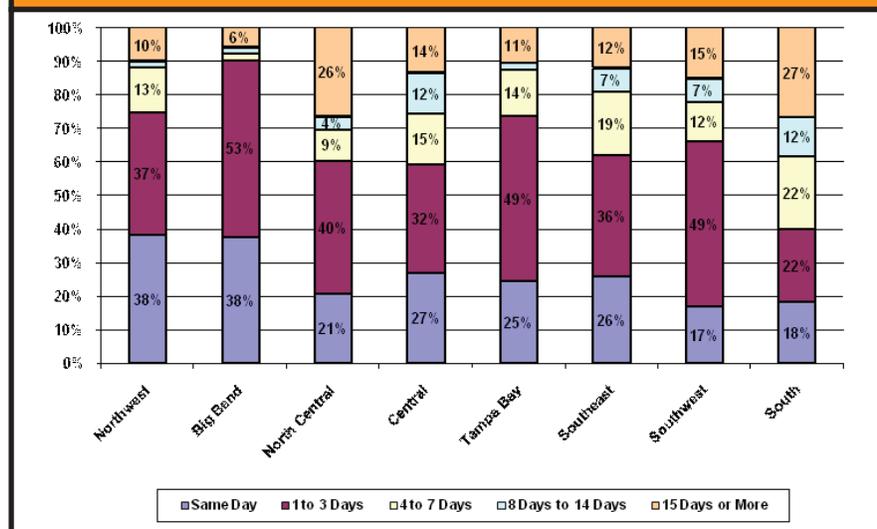
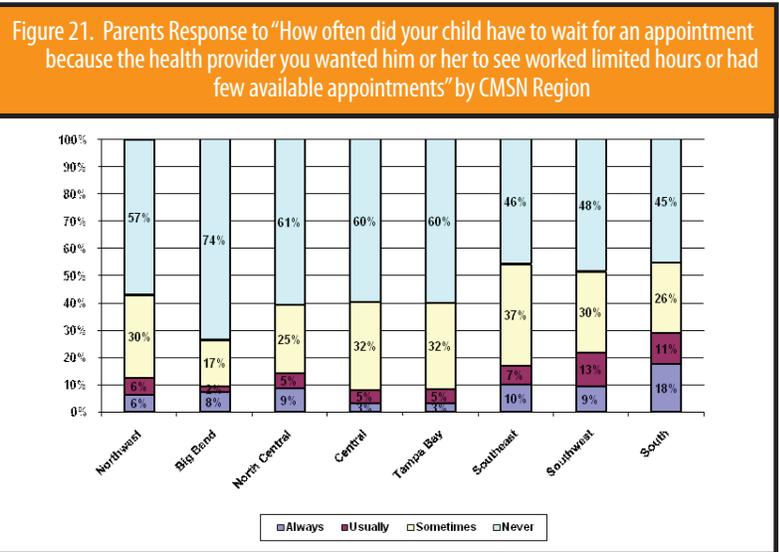


Figure 20. Wait Time to See a Health Provider for Non Urgent Care by CMSN Region

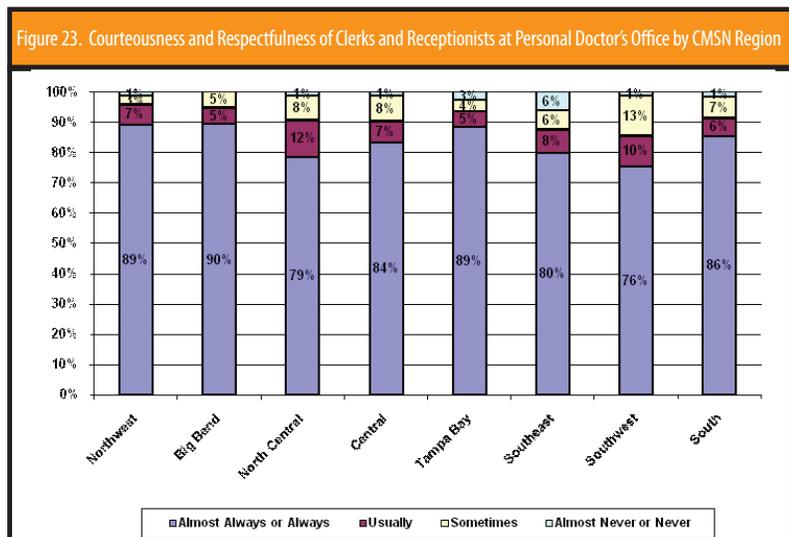
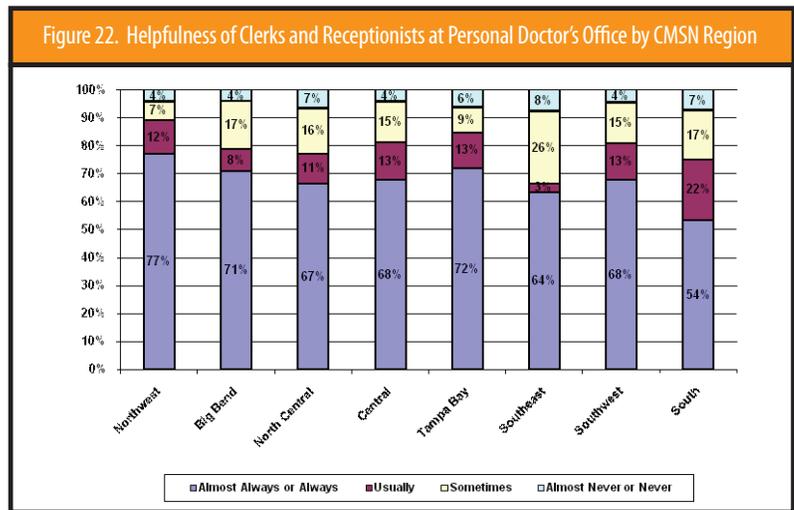


Parents are asked how often their children waited for an appointment because their preferred health provider worked limited hours or had few available appointments. As shown in **Figure 21**, between 8% and 29% of parents usually or always waited for an appointment with their children's preferred health provider because of scarce appointment availability.

Parents are asked whether they tried to get after hours care from their personal doctor's office. Overall, 21% of parents tried to access after hours care. More parents in the South region tried to access after hours care than any other subgroup. Eighty-three percent of parents receiving after hours care report that it met their needs.



Parents are asked to rate the clerks and receptionists at their children's personal doctor's clinic on two qualities: helpfulness, and whether they treat the parent with courtesy and respect. Parent responses by region are shown in **Figures 22 and 23**. Overall, 79% of parents report that the office staff is usually or always helpful and 92% of parents report that the staff is usually or always courteous and respectful. Parents in the Southeast and the Southwest report the lowest scores for helpfulness and courteousness, respectively.



9 Access To Specialty Care

Nationally, 51% of CSHCN require subspecialty physician care¹⁷. According to the National Survey of CSHCN some parents report unmet specialty care needs. Of those survey respondents reporting a need for specialty care, 7.2% did not obtain all necessary specialty care services for their children. Furthermore, 22% of parents of CSHCN requiring a referral for specialty care report a problem obtaining a referral¹⁸. Problems are most commonly reported for low income families or those without insurance.

Parents in this survey are asked about their access to specialist care. First, parents are asked whether they tried to make an appointment for their child to see a specialist in the last 6 months. **Figure 24** shows parents responses by CMSN region.

Overall, 50% of parents tried to make an appointment with a specialist. However, some parents experienced difficulties getting a specialist appointment. As shown in **Figure 25**, between 15% (Tampa Bay) and 47% (Southeast) of parents report that it is never or sometimes easy to make an appointment with their children's specialist.

Parents who found it usually, sometimes or never easy to make a specialist appointment were asked the reasons why they encountered problems, and the responses are given in **Table 2**. Parents' most frequent complaint is that they could not schedule an appointment

at a convenient time. Many parents report that there were not enough accessible specialists in the CMSN network. Parents report less frequently that there were delays with their children's approval or authorization. Eleven percent of parents report that their children's main doctor did not think their child needed to see a specialist.

Parents are asked how often it is easy to get a referral to a specialist. Eighty-three percent of parents find it usually or always easy to obtain a referral. As shown in **Figure 26**, fewer parents reported problems obtaining a referral in the Big Bend region as compared with parents in the Southeast region.

Considering that one-half of parents report that their children require specialist care, parents are asked whether their children's usual source of care is from their specialist. Overall, 35% of parents report that their children's main specialist is also their personal doctor.

In a well coordinated system, primary care physicians and specialists should communicate about all aspects of the child's care. Parents are asked how often their child's personal doctor seemed informed and up to date about their child's specialist care, excluding instances where the provider acts as both the personal doctor and specialist. Parent responses are

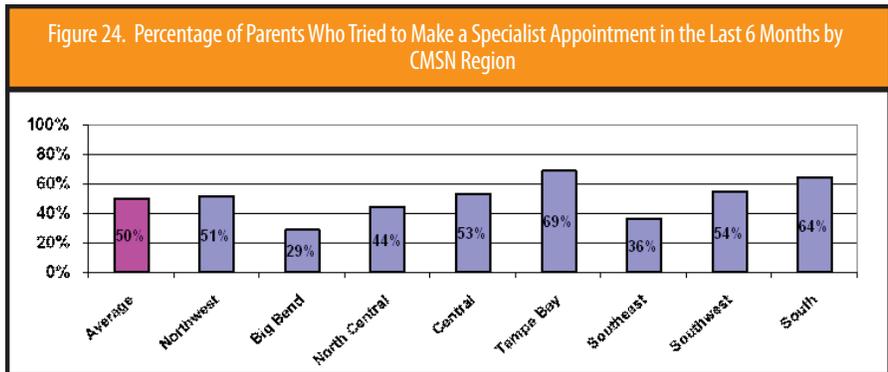


Table 2. Reported Problems Obtaining a Specialist Appointment

Reported Problem	Percentage
Parent could not get an appointment for their child at a time that was convenient	48%
Parent did not have enough specialists to choose from for their child	30%
Specialists to choose from were too far away	32%
Specialist that the parent wanted did not belong to their child's health plan or network	28%
Not sure where to find a list of specialists in child's health plan or network	28%
Child's health plan approval or authorization was delayed	18%
Child's doctor did not think he or she needed to see a specialist	11%

given in **Figure 27**. Parents report that 17% of personal doctors are sometimes or never knowledgeable about the children’s specialist care. Personal doctors in the Central and Southeast regions were least informed or up to date about the children’s specialist care.

Parents are asked if anyone from their child’s health plan or doctor’s office or clinic assisted them to get needed specialized services, such as equipment or therapies. Questions only applied to the sample of parents who sought specialized services. Specifically parents report that they sought the following services:

- Special medical equipment or devices 24%
- Physical, occupational or speech therapy 38%
- Treatment or counseling for child’s emotional, developmental, or behavior problem 28%

As shown in **Figures 28 through 30**, eighty-one percent of parents are helped by their children’s health plan or doctor’s office to get special medical equipment, as compared with 64% of parents trying to get therapies. Parents’ ratings of helpfulness vary widely across the regions. Compared with the other regions, fewer parents in the Southeast region receive help to get specialized medical equipment, or physical, occupational or speech therapies for their children.

Figure 25. Ease of Getting An Appointment with Specialist by CMSN Region

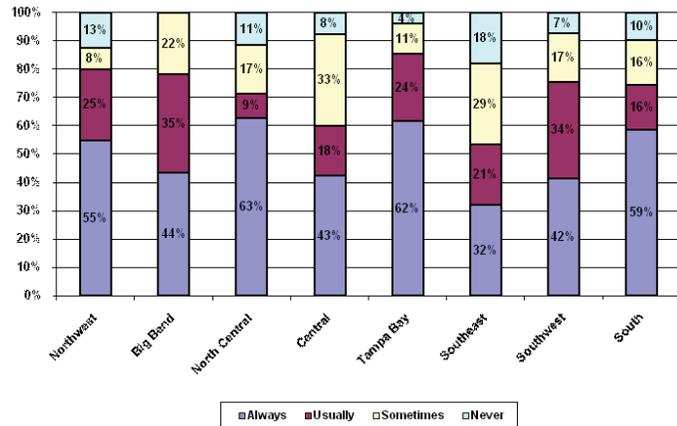


Figure 26. Ease of Getting a Referral to a Specialist by CMSN Region

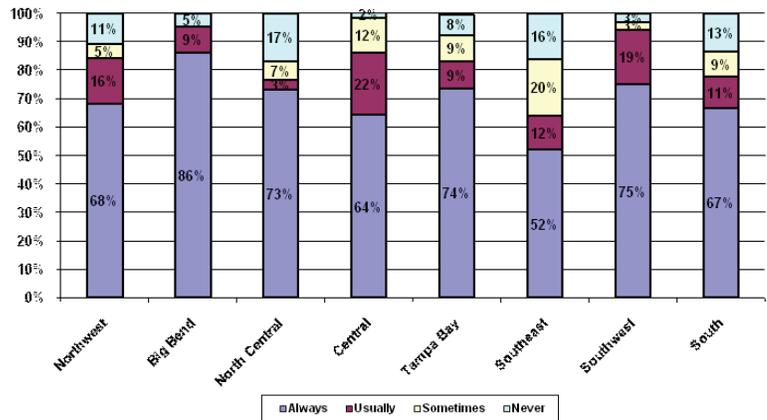
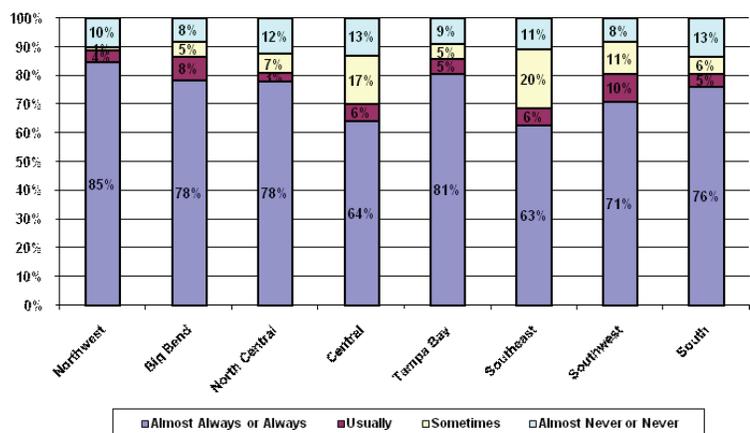
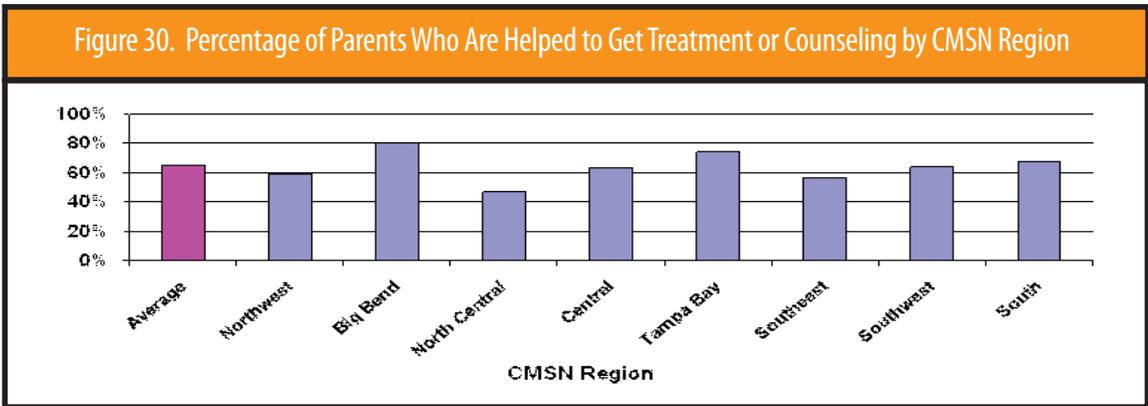
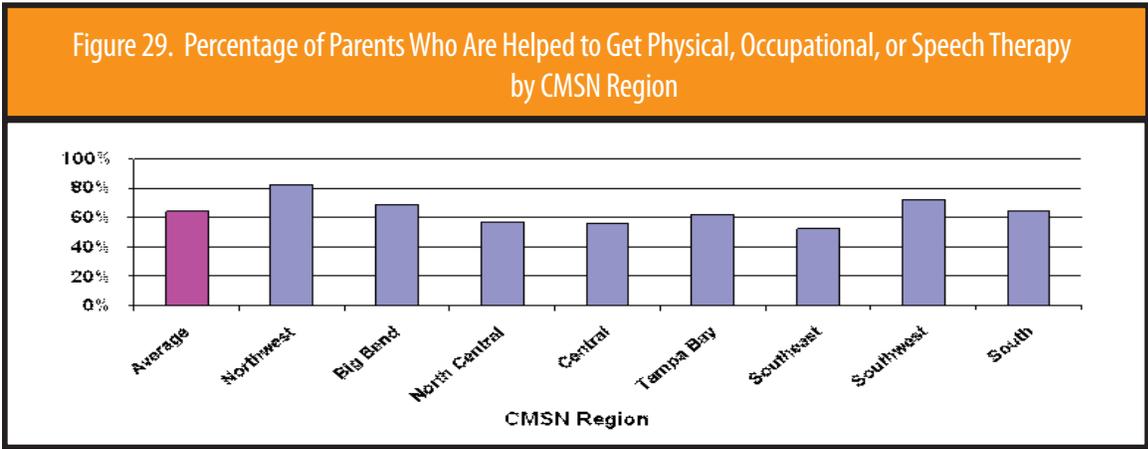
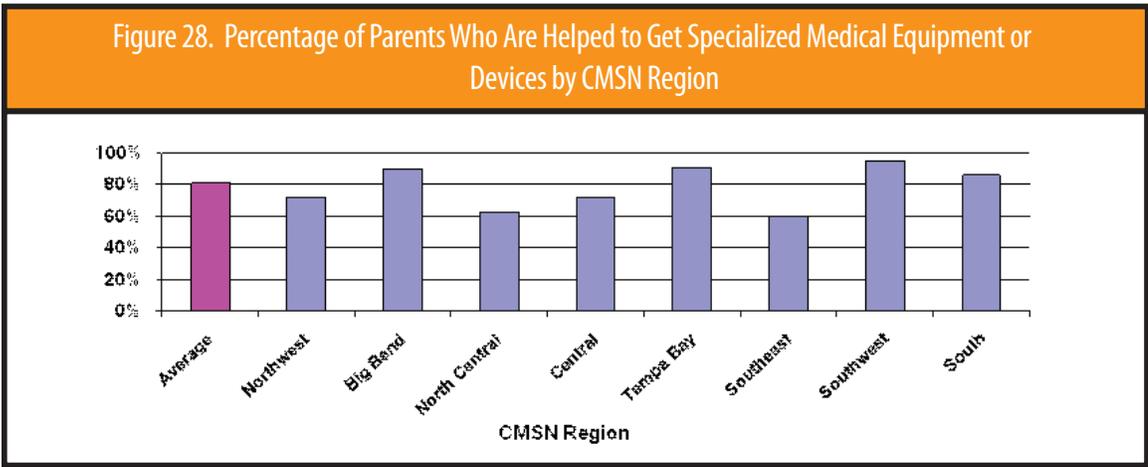


Figure 27. Personal Doctor Is Informed and Up to Date About Child’s Specialist Care by CMSN Region





10 Pediatric Quality of Life Composite Scores

At A Glance

CMSN children had lower functioning scores than a national study of CSHCN.

Children in the Southeast region have the highest functioning levels and children in Tampa Bay the lowest functioning levels.

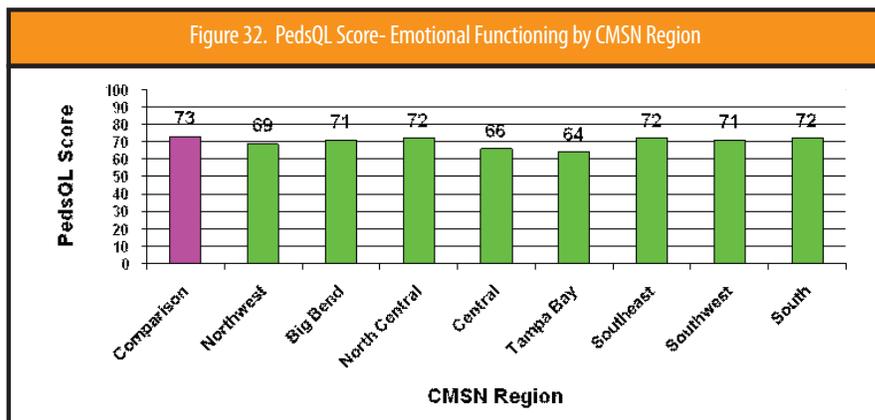
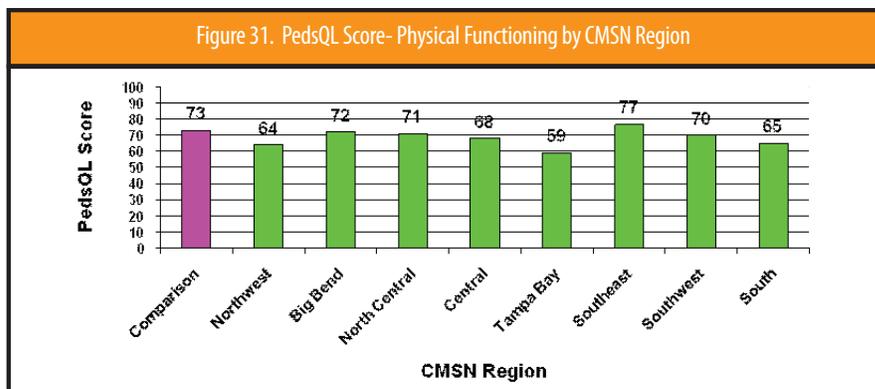
The PedsQL Core questions are scored and averaged to create a health-related quality of life (HRQOL) score for the following areas of functioning: physical, emotional, social, and school. These four domains are scored between 0 and 100, with 100 marking the highest quality of health. Only families who answered the questions are included in the domain scores. Missing responses are not counted as an observation in the mean.

Figures 31 through 34 show the results of the functioning domain scores by region. These figures also present results from a 2001 national study¹⁹ conducted with children with special health care needs by the creator of the instrument to validate and set benchmarks for the scores.

Figure 31 shows that only one region (Southeast) has children who have physical functioning levels higher than the national study. However, three other regions (Southwest, North Central, and Big Bend) are within 3 points of the national study. Children in the South, Northwest, and Tampa Bay regions scored 8-14 points below the national study.

Figure 32 illustrates that emotional functioning in CMSN children is relatively high and almost mirrors the national study in all but three regions (Northwest, Tampa Bay, and Central). There is a smaller amount of variation across the regions for children's emotional functioning (8 points).

Figure 33 shows that CMSN children scored significantly lower than the national study in social functioning. Even the highest functioning children in the Southeast region scored 8 points below the national group. Tampa Bay had the lowest functioning children and scored 21 points below the national study.



Again, the results in **Figure 34** show significantly lower school functioning scores than the national study for all regions. CMSN children scored from 67 (Southeast) to 54 (Tampa Bay) on the school functioning component which asks about the child missing school due to feeling ill, missing school due to hospital or doctor appointments, and keeping up with schoolwork.

As with the CAHPS composites, the scores for the PedsQL composites are ranked from best to worst (1 to 8), with 1 being the region that has the highest functioning composite score.

Table 3 shows that by functioning level, the highest functioning children are located in (in descending order):

- Southeast
- Big Bend
- North Central
- Southwest
- South
- Central
- Northwest, and
- Tampa Bay.

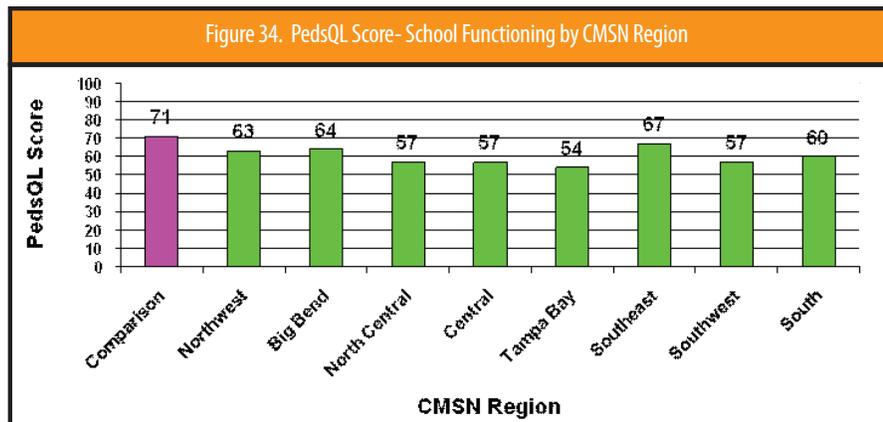
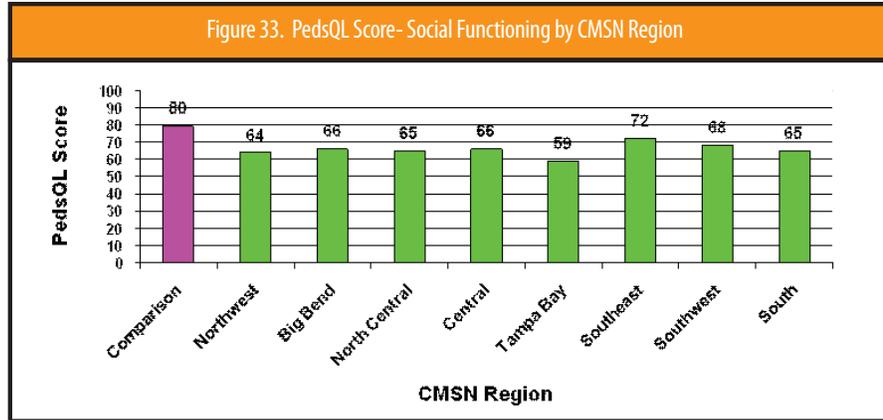


Table 3. Rankings of PedsQL Composites by CMSN Region								
CAHPS Composite	CMSN Region							
	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Physical Functioning	7	2	3	5	8	1	4	6
Emotional Functioning	6	4	1	7	8	1	4	1
Social Functioning	7	3	5	3	8	1	2	5
School Functioning	3	2	5	5	8	1	5	4
Total	23	11	14	20	32	4	15	16

11 Statistical Comparison of the CMSN Regions on the CAHPS Composite Scores

Multivariate regressions are conducted to determine if the differences in CAHPS composite scores between the CMSN regions are significant after controlling for factors known to influence parent-reported health care experiences. These factors include race/ethnicity, parental education, and child functioning level. For example, families whose children have poorer health tend to report less positive health care experiences than families whose children are in better health.

The results of the regression analyses are contained in this section. Each regression uses a logistic functional form where the dependent variable takes on a zero or one value. CAHPS composites are transformed into dichotomous variables by using a cutoff of 75 points. Scores of 75 points or higher indicate that a parent always or most of the time had a positive experience. Scores below 75 indicate a parent sometimes or never had a positive experience. If a parent's CAHPS composite score is 75 or above, the assigned value is one, and zero otherwise. The regressions control for several sociodemographic, regional, and child functioning levels. Child's race (denoted by WHITE, HIS, BLACK, and OTHER), parental educational level (denoted by LESS_THAN_HS, HS, SOME_COLLEGE, and COLLEGE_GRAD), functioning level, and regional indicators variables are included in each regression. Regional indicator variables denote the region where the parent resides. Child functioning level is denoted by TOTPEDS and is the sum of

the child's PedsQL scores. It is important to include the PedsQL scores in each regression to control for the fact that parents of less healthy children tend to report lower CAHPS scores.

Referent groups are chosen for each variable in a logistic regression model. For child's race, the referent group is white and the results on HIS, BLACK, and OTHER should be interpreted as compared to white children. For parental education, the referent group is less than high school education. For the regional indicator variables, the referent region is that region which scored the highest on the CAHPS composite score. For example, Big Bend has the highest CAHPS composite score on getting needed care and is therefore the referent group. Finally, the variable TWOPARENT is included to control for households that have two parents.

A summary of the logistic regression results is contained in **Table 4** and is followed by a discussion. The complete regression results are contained in the Appendix.

At A Glance

There are few regional differences in CAHPS composite scores after controlling for sociodemographic and child functioning level.

- Parents in the Northwest and Central regions have the least positive experiences getting needed care for their children.
- Parents in the Southeast region have the least positive experience getting care quickly, and health plan customer service.

Table 4. Summary of Logistic Regression Results Examining Regional Differences in CAHPS Composite Scores

Region	Getting Needed Care	Getting Need Prescriptions	Getting Care Quickly	Specialized Services	Doctor Communication	Health Plan Customer Service	Family Centered Care- Personal Doctor	Family Centered Care- Shared Decision Making	Family Centered Care- Getting Needed Information
Northwest	.17	NS	NS	NS	Ref	NS	Ref	NS	Ref
Big Bend	Ref*	Ref	Ref	Ref	NS	Ref	NS	NS	NS
North Central	NS**	NS	NS	NS	NS	NS	NS	NS	NS
Central	.20	NS	NS	NS	NS	NS	NS	NS	NS
Tampa Bay	NS	NS	NS	NS	NS	NS	NS	NS	NS
Southeast	NS	NS	.16	NS	NS	.12	NS	NS	NS
Southwest	NS	NS	NS	NS	NS	NS	NS	Ref	NS
South	NS	NS	NS	NS	NS	NS	NS	NS	NS

*Ref = the referent group, NS= not significant, Numerical values significant at p<0.05.

- Getting Needed Care: After controlling for sociodemographic and child functioning variables, parents residing in the Northwest and Central regions are about 80% less likely than parents residing in the Big Bend region to usually or always have positive experiences in getting needed care for their children.
- Getting Care Quickly: Parents residing in the Southeast region are about 84% less likely than parents residing in the Big Bend region to usually or always have positive experiences in getting care quickly.
- Health Plan Customer Service: Parents residing in the Southeast region are about 88% less likely than parents residing in the Big Bend region to usually or always have positive experiences in getting health plan customer service.
- None of the other CAHPS composite scores are significantly different from the referent group.

12 Nurse Care Coordinator Feedback

The CMSN program assigns a nurse care coordinator to each child enrolled in the program. Nurse care coordinators work with families, providers, and other agencies (such as schools and social services programs) to ensure that children receive non-duplicative and comprehensive care. Respondents are asked about their nurse care coordinators' availability and helpfulness. Parents also note whether or not they know where to call to get help for their child during regular office hours. Results for these three questions are presented by region below.

As seen in **Table 5 through 7**, about 80% or more of parents in all regions except South and North Central strongly agree to agree that they know who their nurse care coordinator is. Likewise, all regions but Central, North Central, and South report 82% or higher that parents strongly agree or agree that their nurse care coordinator is available and helpful. Parents in the South, Southeast and Tampa Bay regions disagreed more than any other region that they could reach CMS staff by telephone during office hours (21%, 16% and 15%, respectively).

Compared with responses from 2006-2007, fewer parents in all regions report that their CMSN NCC is available or helpful, or can be easily reached during office hours. Additionally, fewer parents in the Northwest, North Central, and South regions report that they know their NCC. Sixty-two percent of parents in the South do not know their assigned NCC, as compared with 79% of parents responding to the 2006-2007 survey.

Table 5. Parents Agreement for "I know who my CMS Nurse Care Coordinator Is" by CMSN Region

	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Strongly Agree to Agree	81%	86%	77%	80%	82%	88%	91%	62%
Neither	1%	4%	5%	1%	0%	0%	3%	4%
Strongly Disagree to Disagree	17%	10%	18%	19%	18%	12%	6%	34%

Table 6. Parents Agreement with "My CMS Care Coordinator is available and helpful" by CMSN Region

	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Strongly Agree to Agree	85%	89%	78%	75%	82%	78%	87%	65%
Neither	3%	3%	8%	6%	3%	0%	3%	3%
Strongly Disagree to Disagree	9%	6%	9%	9%	13%	16%	5%	21%
I have not needed to get in touch	4%	3%	5%	10%	3%	6%	6%	12%

Table 7. Parents Agreement for "I am able to reach the CMS staff by telephone easily during office hours" by CMSN Region

	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Strongly Agree to Agree	86%	88%	79%	78%	80%	76%	88%	69%
Neither	1%	0%	6%	6%	1%	3%	4%	4%
Strongly Disagree to Disagree	6%	9%	8%	9%	15%	16%	6%	21%
I have not needed to get in touch during office hours	6%	4%	6%	6%	4%	4%	3%	6%

Table 8. Parents Agreement for "I know where to call and what to do when my child needs something" by CMSN Region

	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Strongly Agree to Agree	95%	94%	91%	95%	90%	88%	96%	83%
Neither	1%	1%	1%	1%	0%	3%	1%	1%
Strongly Disagree to Disagree	4%	5%	8%	4%	10%	10%	3%	15%

Table 9. Parents Agreement for "I can get in touch with my CMS Nurse Care Coordinator within 24 hours or less" by CMSN Region

	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Strongly Agree to Agree	80%	88%	75%	76%	80%	77%	86%	57%
Neither	3%	2%	4%	4%	4%	0%	0%	3%
Strongly Disagree to Disagree	8%	8%	9%	14%	13%	16%	9%	25%
I have not needed to get in touch	10%	2%	13%	6%	4%	8%	5%	15%

Parents were asked six additional questions about their children’s NCC and responses are reported in **Tables 8 through 13**. More parents in Northwest, Big Bend and Southwest regions scored their NCC highly on the six measures. Parents in the South region were least likely to agree that their NCC was accessible or helpful.

Table 10. Parents Agreement for “The CMS Nurse Care Coordinator is knowledgeable and helps me obtain answers to questions I have about my child and the CMS program” by CMSN Region

	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Strongly Agree to Agree	84%	85%	77%	75%	81%	75%	86%	65%
Neither Strongly Disagree to Disagree	0%	3%	9%	5%	1%	1%	4%	3%
I have not had any questions	8%	8%	8%	8%	13%	11%	6%	20%
	9%	5%	6%	13%	5%	13%	4%	12%

Table 8 shows that between 83% (South) and 96% (Southwest) of parents know where to call and what to do when their children need something. **Table 9** shows that between 8% (Big Bend) and 25% (South) of parents do not agree that they can get in touch with their CMSN NCC within 24 hours or less. **Table 10** shows that between 65% (South) and 86% (Southwest) of parents agree that their NCC is knowledgeable and responsive.

Table 11. Parents Agreement for “The CMS Nurse Care Coordinator has reviewed with me the services that are available in CMS” by CMSN Region

	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Strongly Agree to Agree	86%	77%	72%	71%	75%	68%	80%	61%
Neither Strongly Disagree to Disagree	3%	6%	5%	6%	1%	4%	5%	3%
I have not needed to get this information	6%	10%	15%	13%	22%	23%	8%	24%
	5%	6%	8%	10%	3%	5%	8%	13%

As shown in **Tables 11 and 12**, 61% to 86% of parents report that their NCC did not review the available CMSN services with them. Across regions, more than 92% of parents who discussed services with their NCC agreed that the information was conveyed in an easily understandable format.

Table 12. Parents Agreement for “When the CMS Nurse Care Coordinator reviewed the services in CMS, the information was easy to understand” by CMSN Region

	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Strongly Agree to Agree	99%	96%	93%	92%	97%	98%	93%	96%
Neither Strongly Disagree to Disagree	1%	3%	3%	7%	0%	2%	4%	0%
I have not needed to get this information	0%	1%	2%	0%	2%	0%	1%	4%
	0%	0%	2%	2%	2%	0%	1%	0%

As shown in **Table 13**, between 16% (Northwest) and 32% (Southeast) of parents report that their NCC did not follow-up in a timely manner after their children saw a primary care physician.

Table 13. Parents Agreement for “After my child is seen by the primary care physician, there is follow up in a timely manner by my CMS Nurse Care Coordinator” by CMSN Region

	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Strongly Agree to Agree	71%	74%	54%	66%	63%	58%	70%	55%
Neither Strongly Disagree to Disagree	5%	1%	5%	5%	6%	0%	4%	9%
My child has not seen his/her PCP	16%	17%	20%	16%	27%	32%	18%	27%
	8%	8%	21%	13%	4%	10%	8%	9%

13 Program Satisfaction

Respondents are asked a series of questions designed to evaluate their overall satisfaction with CMSN, their children's CMSN provider, and the program benefits. Across all regions, CMSN parents respond positively 91% (North Central) to 100% (Northwest) of the time that the CMSN program is right for their children. Likewise, 91% (North Central) to 100% (Northwest) of parents across all regions respond that that they would recommend CMSN to someone they knew whose child had similar needs. By region, the percent of parents who filed a complaint is:

- 8.8% South,
- 5% North Central,
- 3.8% Central,
- 2.5% Northwest,
- 2.5% Big Bend,
- 2.5% Southwest, and
- 1.3% Southeast.

Figure 35 shows the level of satisfaction with CMSN doctor by region. Big Bend and Northwest region parents are most satisfied (86% and 89%, respectively), while 4% of parents residing in the North Central region report that they are very dissatisfied.

Figure 36 shows responses for how parents feel about the quality of care their children receive in CMSN. More Tampa Bay and Northwest parents (60% and 62%) rated their children's quality of care as excellent as any other region. Quality of care was rated as poor by 5% of parents in North Central region.

Finally, parents are asked to rate the overall CMSN program as excellent, very good, good, fair, or poor (**Figure 37**). About 84% of parents in the Big Bend and Northwest regions rate the CMSN program as excellent or very good. About 7% of parents in the South rate CMSN as poor.

Compared with responses from 2006-2007, parents in the Central region rate all three aspects of care lower. More parents rate the quality of care as excellent in six regions, and more parents rate the overall program as excellent in five regions. Compared with responses from 2006-2007, fewer parents in the three Southern regions are very satisfied with their personal doctor.

Figure 35. Satisfaction with Doctor by CMSN Region

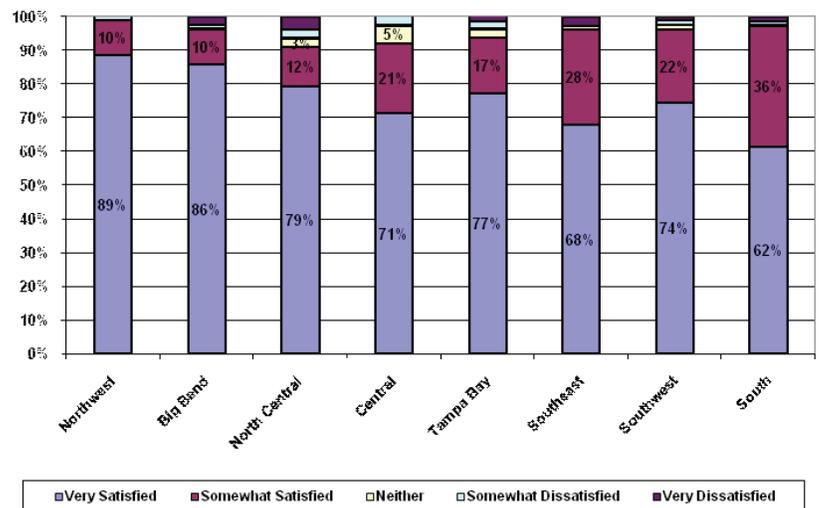
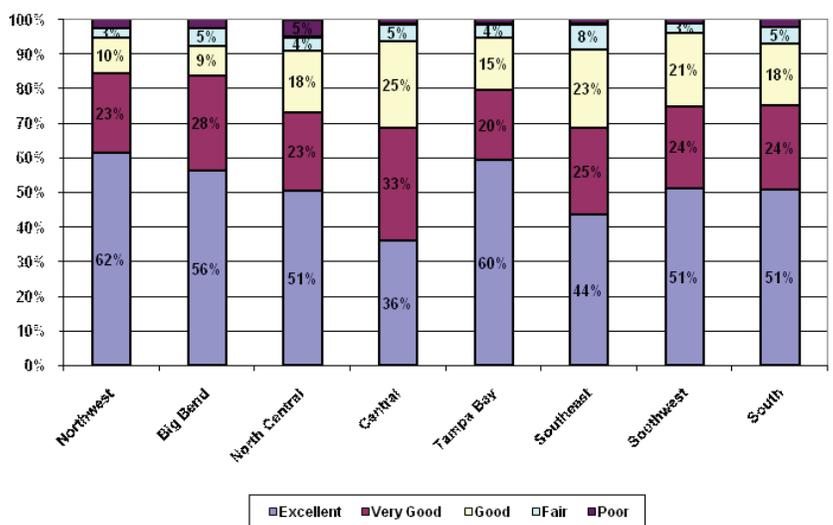
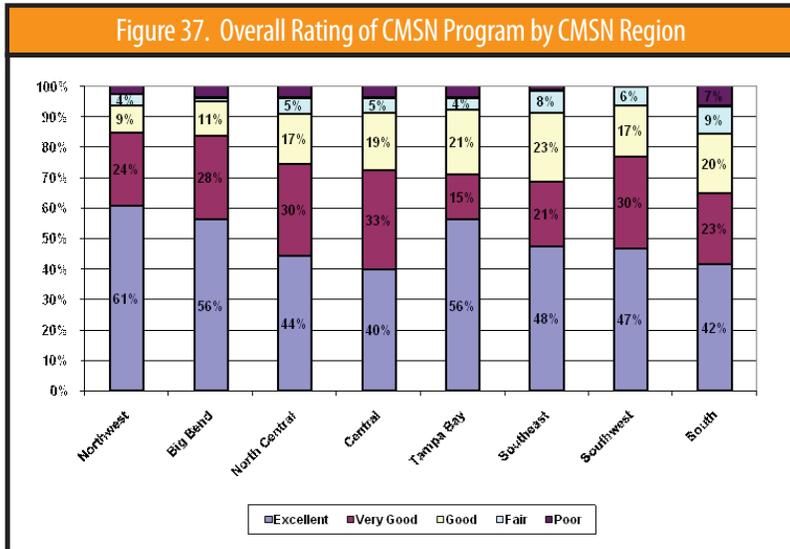


Figure 36. Quality of Care in CMSN by CMSN Region





Respondents feel that the three best aspects of CMSN are:

- Good doctors/medical care,
- Access to doctors and specialists, and
- Good coverage

The three worst aspects of CMSN are:

- Bad communication,
- Program is disorganized, and
- Too complicated

When asked what other benefits parents would like to see added to the benefit package, the primary benefits are:

- Vision,
- Substance abuse counseling, and
- Coverage for other family members.

At a Glance

Three-quarters of parents are very satisfied with their CMSN doctor, and rate the quality of care in the CMSN program, and the program overall, as excellent to very good.

Parents in the Northwest and Big Bend regions have the highest levels of program satisfaction.

14 Healthy Lifestyles and Transition

Two areas of special interest are investigated in this report: healthy lifestyles and adolescent transition.

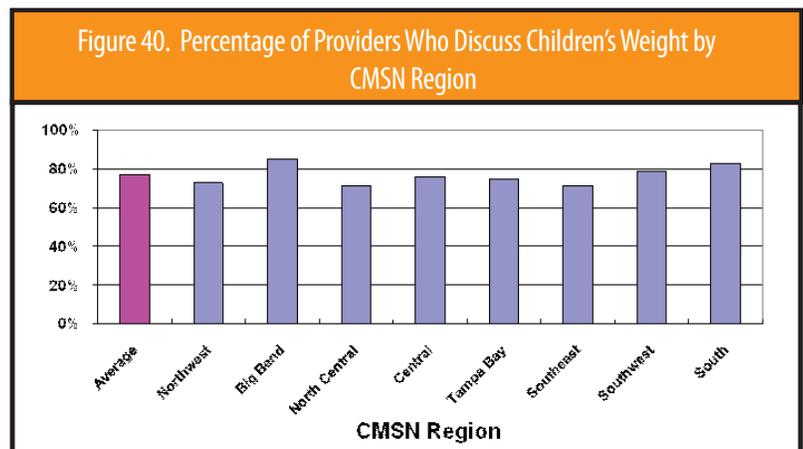
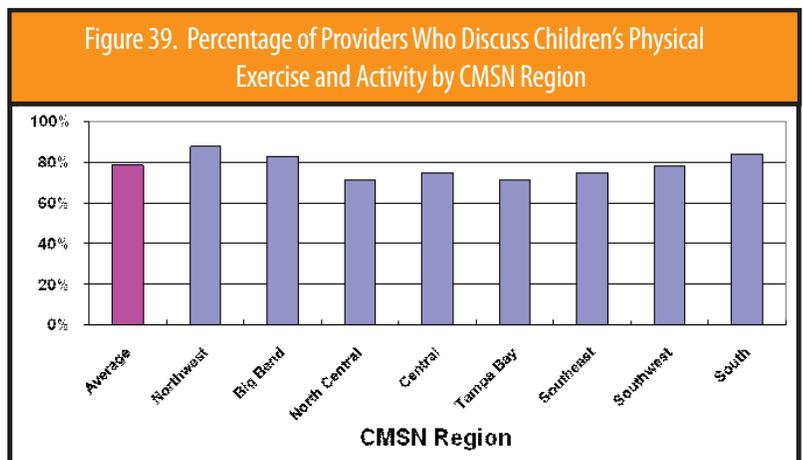
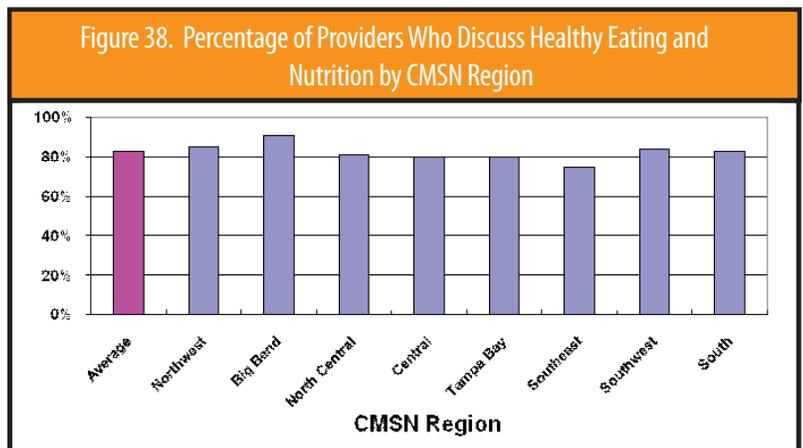
HEALTHY LIFESTYLES

The National Health and Nutrition Examination Survey is a national longitudinal survey that studies the prevalence of overweight and obese children and adults in the United States. Results from two of the longitudinal studies (1976-1980 and 2003-2004) show that the prevalence of being overweight for children has increased across all age strata²⁰. Overweight and obese children are at risk for developing high blood pressure, high cholesterol, and Type 2 diabetes. Overweight and obesity can have a negative health impact on all children, including those with special health care needs who already have chronic health conditions. Given the importance of identifying and treating overweight and obese children, this survey includes a section of questions related to whether or not the provider discussed proper nutrition and exercise with the children and parents. Parents are asked three questions to determine if their children's providers are discussing issues of nutrition and exercise with them.

The findings show:

- Eighty-three percent of parents respond that their children's health care providers discussed healthy eating and nutrition with the parent and child. As shown in **Figure 38**, seventy-five percent of Southeast parents respond positively.
- Seventy-nine percent of parents report that their providers discussed their children's physical activity and exercise with them. As shown in **Figure 39**, seventy-one percent of parents in North Central and Tampa Bay respond positively, and

- Seventy-seven percent of parents respond that their children's provider had discussed their children's weight with them. As shown in **Figure 40**, seventy-one percent of parents in North Central and Southeast respond positively.



Compared with responses in 2006-2007, there is a 4% increase in the number of parents who report that their children's provider discusses their children's weight with them. There is a 2% increase in the number of parents who report discussing healthy eating and nutrition.

TRANSITION

As the number of CSHCN that survive to adulthood rises, due to advances in technology and improved screening procedures, addressing adolescent health care needs as they transition to the adult health care system becomes increasingly important. Several national agencies and government organizations have emphasized the need for transition planning standards and widespread implementation. Healthy People 2010, an initiative from the U.S. Surgeon General, have 207 objectives for people with disabilities, one of which is to improve adolescent transition to the adult health care system²¹. Maternal Child Health Bureau (MCHB) cites a plan to, "achieve appropriate community-based services for children and youth with special health care needs including their families", with improvements in transition as one of their four objectives. The American Academy of Pediatrics (AAP) and the American Academy of Family Physicians (AAFP) have also called for written transition plans for each CSHCN to be established by the age of 14²².

Implementing these standards can be complicated since barriers to successful transition exist for many

participants in the process. From the perspective of the adolescent there are three primary barriers to transition: service needs, structural issues, and personal preferences²³.²⁴ Service needs might impede transition since certain treatment services might not be available in the adult health care system and if they are, they might not be comparable to the pediatric services. Structural barriers such as age limits for public health insurance and charitable hospitals oftentimes exist. Finally, adolescents might be hesitant to abruptly end well developed relationships with their pediatric providers. Adolescents entering adulthood find themselves newly charged with making decisions about their own health care, and they might not be comfortable or confident about doing so.

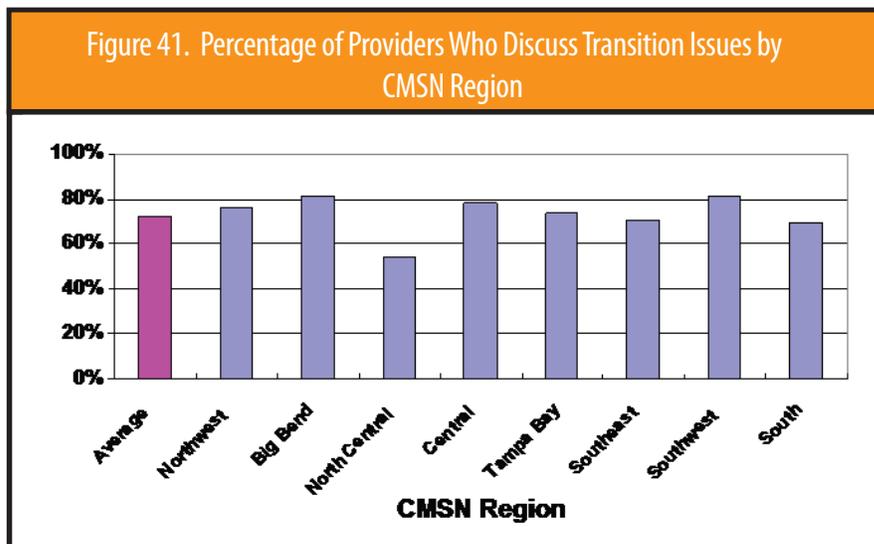
Perhaps less emphasized in the literature is that parents might play an important role in the transition of their adolescent to the adult health care system. Especially, parents must understand and stress the importance of successful transition to their adolescent and act as an intermediary between the adolescent and physician. Two recent studies that used the 2001 National Survey of Children with Special Health Care Needs data showed that about 50% of parents or guardians of adolescents aged 14 to 17 years had discussed their child's changing health care needs with their doctor. Of those who had this discussion with their doctor, 60% reported that they had a plan in place to address these needs and 42% reported that they had discussed the plan with providers in the adult health

care system^{25, 26}. Results from these national studies indicate low levels of compliance (about 15%) with the recent MCHB transition guidelines as reported by parents. More importantly, adolescents' own perspectives regarding preparedness for transition planning were not investigated in these studies.

To assess the amount of transition preparedness that is occurring between CMSN adolescents and their parents, three transition questions are asked.

For parents whose children are 14 or older (n=134) the results show **(Figure 41)**:

- Seventy-two percent indicated that their children’s doctor had talked to them or their children about how their children’s health care needs might change when he/she becomes an adult,
- Of those parents, 59% of parents indicated that a plan for addressing those changes had been developed, and
- Of those parents, 56% of parents indicated that their children’s doctors had discussed the need to eventually see an adult provider.



The percentage of parents who report that their provider discusses their children’s future health care needs varies widely between regions, from 54% in the North Central region to 81% in the Big Bend region. Compared with responses in 2006-2007, there has been no improvement in the percentage of parents statewide who report that their provider discusses these transition issues with them.

15 Comparing Results Over Time

In 2007-2008, the CAHPS survey was revised to version 4.0. **Table 14** lists the recent changes made to the CAHPS composites by the AHRQ. As a result of these changes, comparisons cannot be made from Version 3.0 to Version 4.0²⁷. However, Figure 30 from the previous year's report is included again for the reader's reference.

COMPARISON OF CAHPS COMPOSITES

Figure 42 compares the CAHPS composite scores across time for the three contract years; 2004-2005, 2005-2006, and 2006-2007. Results from the comparisons show that families consistently have positive experiences with the components of the CMSN program. Regardless of sampling strategy and time, families have the most positive experiences with office staff and doctor communication. Families have the least positive experiences over time and sampling strategies with specialized services. Improvements over time are seen in specialized services and health plan customer service; whereas less positive experiences are reported over time in family centered care and getting needed care.

COMPARISON OF CMSN SATISFACTION

During each of the four survey years parents were asked about the satisfaction level with the CMSN

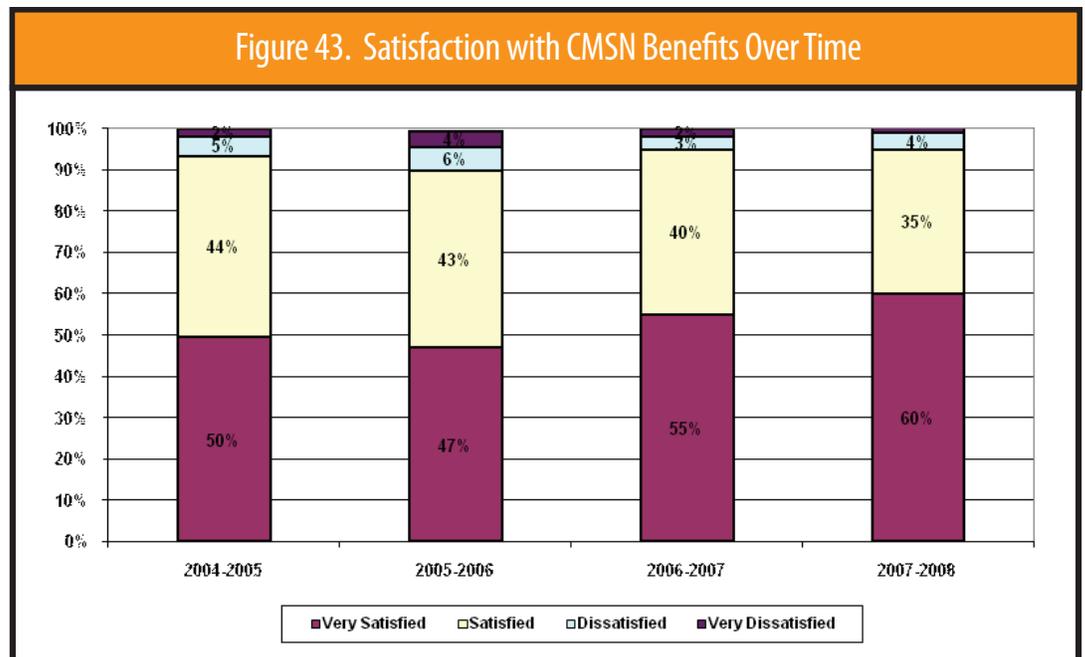
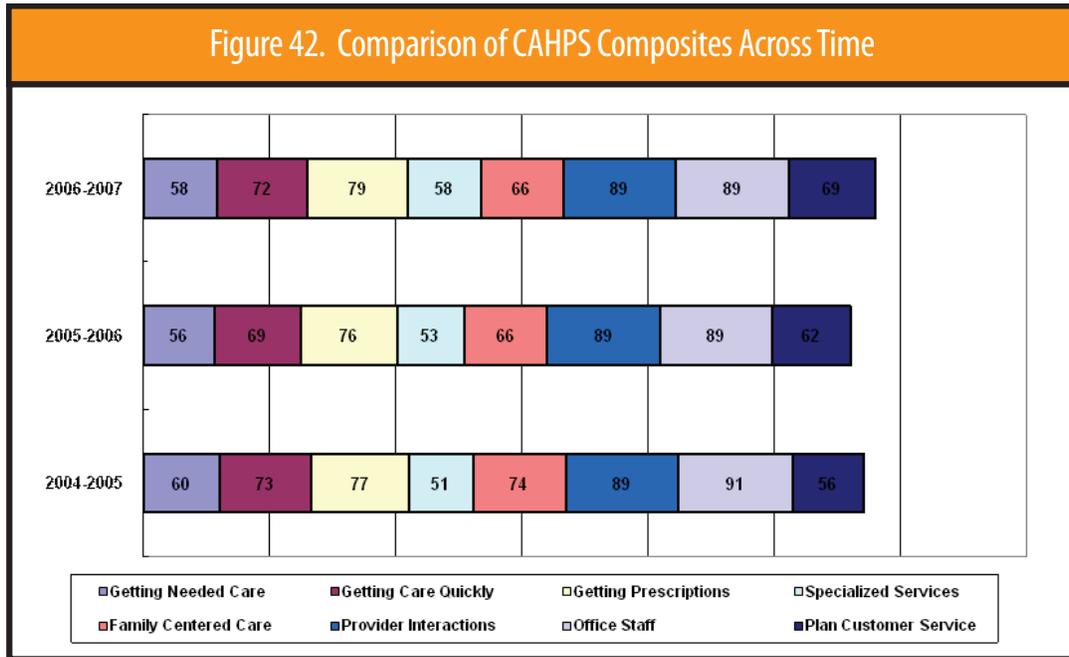
benefits and those results are presented in **Figure 43**. The figure shows that over time the relative levels of satisfaction have slightly risen. The majority of parents in 2004-2005 and 2006-2007 were very satisfied (50% and 55%) while 2005-2006 had slightly fewer very satisfied parents (47%). In 2007-2008 the percentage of very satisfied parents reached 60%.

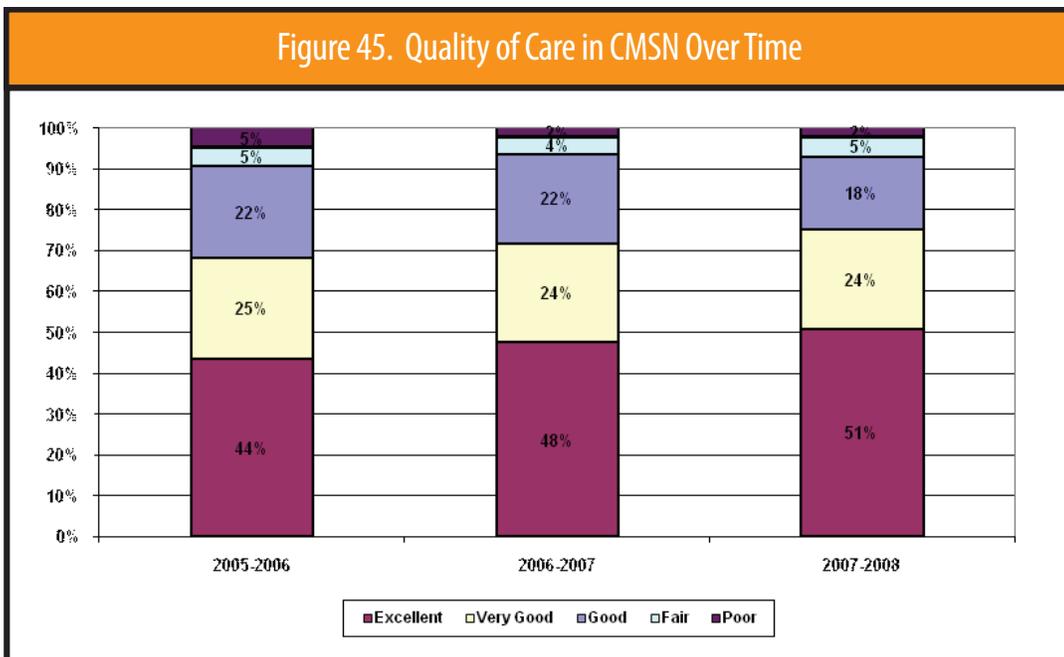
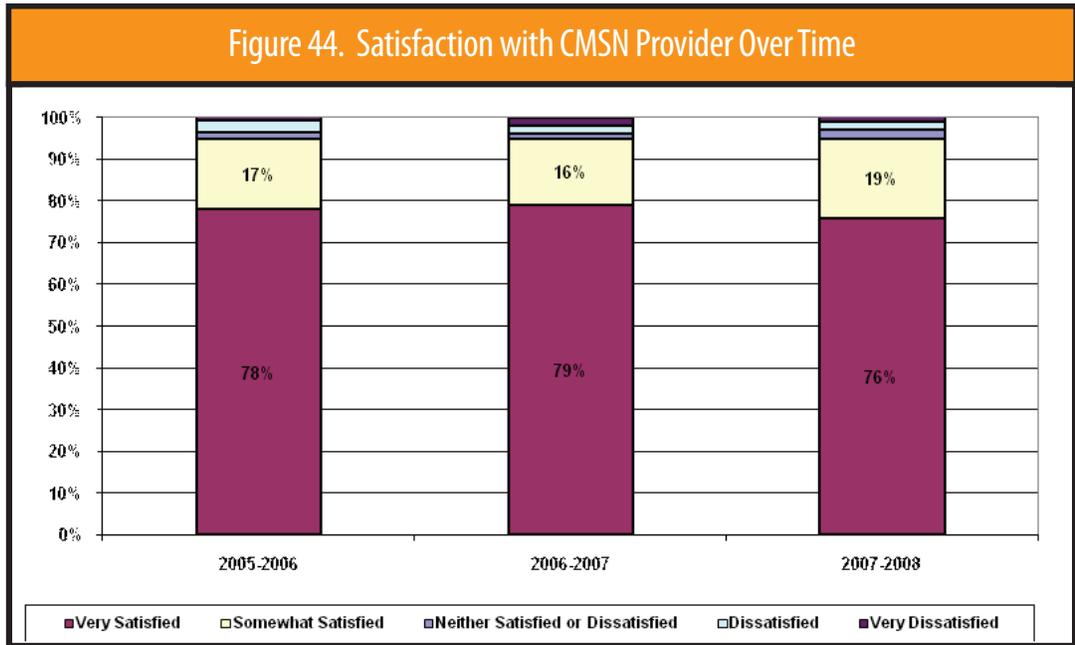
Figures 44 and 45 show the results of satisfaction with the CMSN provider and the quality of care for 2005-2006 and 2006-2007. These questions were not asked in the 2004-2005 survey because

questions specifically related to the Children's Multidisciplinary Assessment Teams, Primary Care Case Management, and Medical Foster Care programs were substituted. However, over the three-year period, parents report about the same satisfaction levels with their CMSN provider (76% to 79% very satisfied). The percentage of parents who report that their children's quality of care is excellent has risen steadily from 44% to 51%.

Table 14. Changes Between Versions 3.0 and 4.0 of the CAHPS Composites

Composite	Changes
Getting Needed Care	<ul style="list-style-type: none"> Two items deleted Item wording changed Scale changed
Getting Care Quickly	<ul style="list-style-type: none"> Two items deleted One item wording changed
Doctor Communication	<ul style="list-style-type: none"> One item deleted Item wording changed Focus has moved from "child's doctors or other health providers" to "child's personal doctor."
Health Plan Customer Service, Information, and Paperwork	<ul style="list-style-type: none"> Item wording changed Scale changed
Courtesy, Respect, and Helpfulness of the Office Staff	<ul style="list-style-type: none"> Composite dropped
Prescription Medicine	<ul style="list-style-type: none"> Item wording changed Scale changed
Getting Specialized Services	<ul style="list-style-type: none"> Item wording changed Scale changed
Family Centered Care- Personal Doctor	<ul style="list-style-type: none"> No longer asks about experiences with the child's nurse, only their personal doctor
Family Centered Care- Shared Decision Making	<ul style="list-style-type: none"> One item deleted Item wording changed Scale changed
Family Centered Care- Getting Needed Information	<ul style="list-style-type: none"> Two items deleted





16 Summary and Recommendations

CMSN serves a diverse population of Medicaid eligible children up to 21 years old. Thirty-eight percent are White non-Hispanic, 35% Black non-Hispanic, and 22% Hispanic. Regions with the most Hispanic respondents are the South (57%), Southwest (36%), Southeast (28%), Tampa Bay (25%), and Central (21%). Fifty-eight percent of respondents have a high school education or less, while 44% are married and 51 percent live in a two-parent household.

Using the CAHPS composite scores, families in the Northwest and Big Bend regions have the most positive experiences obtaining health care for their children and the North Central region the lowest. Parents are more satisfied with doctor's communication, getting care quickly and getting needed prescriptions but are least satisfied with getting needed care, and specialized services.

Using the PedsQL as a measurement for functioning ability of the CMSN children, overall CMSN children had lower functioning levels than CSHCN in a national study. Children residing in the Southeast and Big Bend regions had the highest level of functioning while children in the Tampa Bay and Northwest regions had the lowest.

This report demonstrates high levels of provider and program satisfaction. Three quarters of parents report that they are very satisfied with their CMSN doctor,

and rate the quality of care in the program and the program overall as excellent to very good.

Based on the results from this survey, several recommendations are made for the CMSN program:

- There is wide variation in satisfaction across regions. Several aspects of the CMSN program seem to be inconsistent: rated high in the Northern part of the State and low in the Southern part. It is recommended that a follow up evaluation occur. The CMSN regional nursing directors should be surveyed to document their operational and quality improvement practices. Lessons and experiences from the highly satisfied regions should be documented and shared with the lesser satisfied regions to increase statewide satisfaction. This information can be used to develop best practices.
- Care coordination is a cornerstone of CMSN. Currently one-fifth of parents do not know their assigned NCC. CMSN needs to determine the reasons behind the large regional discrepancies in NCC ratings.
- One-half of CMSN parents report a need for specialty care. However, one-quarter of parents found it never or sometimes easy to make a specialty appointment. Parents' most frequent complaints are not enough network specialty providers to choose from, and many are not easily accessible. CMSN should evaluate whether

provider recruitment can be improved.

- Sixty-one percent of CMSN parents report that their child had a dental visit in the past year. It is unclear if children are not visiting the dentist because of limited access or other reasons.
- Because obese and overweight children are at a high risk for many long term illnesses, providers should be encouraged to discuss healthy lifestyle habits with CMSN children and their parents.
- Lack of transition preparedness has been an ongoing problem for CSHCN. All children ages 14 and older should have a written care plan for transition that takes into account the needs and desires of the child, parent, and provider.

Table 17. Logistic Regression for Specialized Services

```

logistic GETTING_SPECIAL_LOG HIS BLACK OTHER HS SOME_COLLEGE COLLEGE_GRAD
TWO_PAREN_TOTPEDS Northwest North_Central Central Tampa_Bay Southeast
Southwest South, robust

Logistic regression                               Number of obs =          336
                                                  Wald chi2(15) =         44.73
                                                  Prob > chi2 =           0.0001
Log pseudo-likelihood = -150.80912                Pseudo R2 =            0.1487
    
```

GETTING_SP~G	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]	
HIS	.8049672	.3684292	-0.47	0.635	.3282371	1.974098
BLACK	1.071085	.4003654	0.18	0.854	.5148132	2.228426
OTHER	.4397971	.3126717	-1.16	0.248	.1091678	1.771781
HS	.668395	.2870042	-0.94	0.348	.2880933	1.550719
SOME_COLLEGE	.4529347	.2079362	-1.73	0.084	.1841876	1.113809
COLLEGE_GRAD	.1816666	.0847635	-3.66	0.000	.0727972	.453352
TWO_PAREN_TOTPEDS	.9593261	.2912667	-0.14	0.891	.529088	1.739421
TOTPEDS	1.009516	.0020621	4.64	0.000	1.005482	1.013565
Northwest	.3765577	.2074176	-1.77	0.076	.1279287	1.108397
North_Cent~l	.4747129	.2744544	-1.29	0.198	.1528658	1.474184
Central	.6866872	.3737305	-0.69	0.490	.236315	1.995385
Tampa_Bay	.5221893	.3243188	-1.05	0.296	.1545852	1.763957
Southeast	.8240189	.5081206	-0.31	0.754	.2460678	2.759431
Southwest	.3849855	.2466638	-1.49	0.136	.1096659	1.351504
South	.3127963	.2074615	-1.75	0.080	.0852519	1.147676

Table 18. Logistic Regression for Doctor Communication

```

logistic DOCTORS_COM_LOG HIS BLACK OTHER HS SOME_COLLEGE COLLEGE_GRAD
TWO_PAREN_TOTPEDS Big_Bend North_Central Central Tampa_Bay Southeast Southwest
South, robust

Logistic regression                               Number of obs =          336
                                                  Wald chi2(15) =         48.54
                                                  Prob > chi2 =           0.0000
Log pseudo-likelihood = -65.746874                Pseudo R2 =            0.2161
    
```

DOCTORS_C~G	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]	
HIS	.6980539	.4046043	-0.62	0.535	.2241391	2.174004
BLACK	2.399506	2.159419	0.97	0.331	.4112339	14.00086
OTHER	.19996	.1973127	-1.63	0.103	.0289075	1.38317
HS	10.8313	7.132145	3.62	0.000	2.97979	39.37094
SOME_COLLEGE	3.224548	2.46548	1.53	0.126	.7205145	14.43095
COLLEGE_GRAD	5.595403	3.962708	2.43	0.015	1.396381	22.4212
TWO_PAREN_TOTPEDS	.8725307	.4853524	-0.25	0.806	.293287	2.595784
TOTPEDS	1.008928	.0034227	2.62	0.009	1.002242	1.015659
Big_Bend	1.327042	2.048713	0.18	0.855	.0643848	27.3518
North_Cent~l	.5363566	.5100427	-0.66	0.512	.0831787	3.458557
Central	.4037426	.3987826	-0.92	0.358	.0582586	2.798008
Tampa_Bay	.29392	.2853684	-1.26	0.207	.0438322	1.970902
Southeast	1.350049	1.83866	0.22	0.826	.0935579	19.48134
Southwest	.9315023	.9517982	-0.07	0.945	.1257292	6.901314
South	.1605458	.1616213	-1.82	0.069	.0223201	1.154789

Table 19. Logistic Regression for Getting Care Quickly

```

logistic GETTING_CARE_QUICKLY_LOG HIS BLACK OTHER HS SOME_COLLEGE
COLLEGE_GRAD TWOPARENT TOTPEDS Northwest North_Central Central Tampa_Bay
Southeast Southwest South, robust

Logistic regression                               Number of obs   =       336
                                                    Wald chi2(15)   =       22.69
                                                    Prob > chi2     =       0.0909
Log pseudo-likelihood = -104.10805                Pseudo R2      =       0.0727
    
```

GETTING_C-G	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]	
HIS	.751134	.4567045	-0.47	0.638	.2281234	2.473232
BLACK	.6223344	.2915544	-1.01	0.311	.2484555	1.558831
OTHER	.7468359	.7665606	-0.28	0.776	.0998947	5.583516
HS	2.030325	1.066688	1.35	0.178	.7250419	5.685494
SOME_COLLEGE	1.927408	1.074773	1.18	0.239	.646132	5.749445
COLLEGE_GRAD	.9819238	.5367811	-0.03	0.973	.3363239	2.866803
TWOPARENT	1.509489	.6319562	0.98	0.325	.6644611	3.429181
TOTPEDS	.9996914	.0031531	-0.10	0.922	.9935305	1.005891
Northwest	.24672	.2101202	-1.64	0.100	.0464809	1.309587
North_Cent-l	.4719762	.4417596	-0.80	0.422	.0753726	2.95547
Central	.5937659	.5494935	-0.56	0.573	.0968012	3.64208
Tampa_Bay	.4383848	.436459	-0.83	0.408	.0622864	3.085444
Southeast	.1646867	.1387045	-2.14	0.032	.0316045	.8581603
Southwest	.2301438	.2210381	-1.53	0.126	.0350329	1.5119
South	.3916109	.3739744	-0.98	0.326	.0602542	2.5452

Table 20. Logistic Regression for Health Plan Customer Service

```

logistic CUSTOMER_SERVICE_LOG HIS BLACK OTHER HS SOME_COLLEGE COLLEGE_GRAD
TWOPARENT TOTPEDS Northwest North_Central Central Tampa_Bay Southeast
Southwest South, robust

Logistic regression                               Number of obs   =       336
                                                    Wald chi2(15)   =       22.28
                                                    Prob > chi2     =       0.1006
Log pseudo-likelihood = -118.13676                Pseudo R2      =       0.1071
    
```

CUSTOMER_S-G	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]	
HIS	1.191676	.6199335	0.34	0.736	.4298791	3.303468
BLACK	1.949457	.9326295	1.40	0.163	.7632989	4.97889
OTHER	.357263	.2770515	-1.33	0.184	.0781439	1.633356
HS	2.279678	1.062207	1.77	0.077	.9146596	5.681818
SOME_COLLEGE	1.268885	.617168	0.49	0.624	.4891135	3.29181
COLLEGE_GRAD	1.234316	.6047079	0.43	0.667	.4725104	3.224344
TWOPARENT	.5224232	.186837	-1.82	0.069	.2591808	1.053033
TOTPEDS	1.005326	.0026686	2.00	0.045	1.00011	1.01057
Northwest	.3376061	.3077121	-1.19	0.234	.0565692	2.01484
North_Cent-l	.2650466	.2255602	-1.56	0.119	.0499956	1.405117
Central	.5987028	.5514346	-0.56	0.578	.0984494	3.640907
Tampa_Bay	.2702026	.2450229	-1.44	0.149	.0456888	1.597972
Southeast	.1235756	.1068172	-2.42	0.016	.0227073	.6725132
Southwest	.6151383	.6567142	-0.46	0.649	.0758998	4.98546
South	.2298847	.221643	-1.52	0.127	.0347396	1.52123

Table 21. Logistic Regression for Family Centered Care- Personal Doctor

logistic PERSONAL_DR_LOG HIS BLACK OTHER HS SOME_COLLEGE COLLEGE_GRAD TWOPA
 RENT TOPPEDS Big_Bend North_Central Central Tampa_Bay Southeast Southwest
 South, robust

Logistic regression Number of obs = 1201
Wald chi2(15) = 35.68
Prob > chi2 = 0.0020
 Log pseudo-likelihood = -536.48854 Pseudo R2 = 0.0308

PERSONAL_D-G	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]	
HIS	.6830606	.1296495	-2.01	0.045	.470864	.9908844
BLACK	1.091339	.2298622	0.41	0.678	.7222307	1.649085
OTHER	1.605127	.6664611	1.14	0.254	.7113511	3.621887
HS	1.014973	.2361003	0.06	0.949	.643354	1.601248
SOME_COLLEGE	.8056271	.1865808	-0.93	0.351	.5116799	1.26844
COLLEGE_GRAD	.741274	.177325	-1.25	0.211	.4638283	1.184678
TWOPARENT	.9984331	.1608366	-0.01	0.992	.7281147	1.369109
TOPPEDS	1.004575	.0011001	4.17	0.000	1.002421	1.006734
Big_Bend	1.033422	.4510395	0.08	0.940	.439308	2.43101
North_Cent-l	.5432261	.1941191	-1.71	0.088	.2696548	1.094342
Central	.6309984	.2397349	-1.21	0.226	.299662	1.328694
Tampa_Bay	1.204177	.5650863	0.40	0.692	.4800043	3.020892
Southeast	.9677734	.4044803	-0.08	0.938	.4265938	2.195497
Southwest	1.715713	.910209	1.02	0.309	.6065558	4.853093
South	.7835497	.3618952	-0.53	0.597	.3169022	1.937349

Table 22. Logistic Regression for Family Centered Care- Shared Decision Making

logistic SDM_LOG HIS BLACK OTHER HS SOME_COLLEGE COLLEGE_GRAD TWOPARENT
 TOPPEDS Northwest Big_Bend North_Central Central Tampa_Bay Southeast
 South, robust

Logistic regression Number of obs = 336
Wald chi2(15) = 28.04
Prob > chi2 = 0.0213
 Log pseudo-likelihood = -90.088784 Pseudo R2 = 0.1089

SDM_LOG	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]	
HIS	1.820668	1.285808	0.85	0.396	.4561291	7.267309
BLACK	1.795375	.9675659	1.09	0.278	.6243447	5.162807
OTHER	.6251866	.5809293	-0.51	0.613	.1011731	3.863263
HS	1.761736	.9822751	1.02	0.310	.5906691	5.254574
SOME_COLLEGE	1.478311	.7875551	0.73	0.463	.5203512	4.19986
COLLEGE_GRAD	1.309106	.8138868	0.43	0.665	.3870551	4.427687
TWOPARENT	2.385305	1.118439	1.85	0.064	.9515387	5.979453
TOPPEDS	1.007835	.0030076	2.62	0.009	1.001957	1.013747
Northwest	1.143215	1.085164	0.14	0.888	.1778888	7.346948
Big_Bend	.4579429	.4058713	-0.88	0.378	.0806117	2.601506
North_Cent-l	.6323552	.5707025	-0.51	0.612	.1078323	3.708285
Central	.7957772	.7170257	-0.25	0.800	.13609	4.653253
Tampa_Bay	.310402	.2665384	-1.36	0.173	.0576778	1.670478
Southeast	.7366292	.6909173	-0.33	0.745	.1171842	4.630509
South	.7169151	.7186907	-0.33	0.740	.1004981	5.114197

Footnotes

1. Children's Medical Services: Family Satisfaction Report 2006-2007, also focused on Medicaid eligible children and is available upon request.
2. Agency for Healthcare Research and Quality. CAHPS Health Plan Survey 4.0: Child Medicaid Questionnaire. Washington, DC: August 2007. Available at: <https://www.cahps.ahrq.gov/default.asp>. Accessed: February 2008.
3. Varni JW, Seid M, Rode C. The PedsQL: Measurement Model for the Pediatric Quality of Life. *Med Care*. 1999 Feb; 37(2):126-39.
4. Children's Medical Services: Family Satisfaction Report 2006-2007 and Children's Medical Services: Family Satisfaction Report 2006-2007, also focused on Medicaid eligible children and are available upon request.
5. Surveys were targeted to one child in the household even if the household had two or more children enrolled in the CMSN.
6. Agency for Healthcare Research and Quality. CAHPS Health Plan Survey 4.0: Child Medicaid Questionnaire. Washington, DC: August 2007. Available at: <https://www.cahps.ahrq.gov/default.asp>. Accessed: February 2008.
7. Composite scores are normalized to a 100 point scale for ease of interpretation.
8. National Commission on Quality Assurance. HEDIS 2008: Specifications for Survey Measures. Washington, D.C.:2007.
9. Varni JW, Seid M, Rode C. The PedsQL: Measurement Model for the Pediatric Quality of Life. *Med Care*. 1999 Feb; 37(2):126-39.
10. This measure is referred to as CM28 and is reported to CMSN for the purposes of internal reporting requirements. The composite is equal to the average of CAHPS composites Getting Needed Care, Getting Specialized Services, Prescriptions, and CAHPS question cc18. Question cc18 asks if anyone helped to coordinate the child's care. If the parent answered 'Yes' the score was adjusted to 100, if 'No' 50. The 3 composite scores plus the score for cc18 are averaged and reported for CM28.
11. This measure is referred to as CM31 and is reported to CMSN for the purposes of internal reporting requirements. The composite is equal to the average of CAHPS composites Getting Needed Care, Getting Specialized Services, Prescriptions, Getting Care Quickly, Doctor Communication and CAHPS question cc18. Question cc18 asks if anyone helped to coordinate the child's care. If the parent answered 'Yes' the score was adjusted to 100, if 'No' 50. The 3 composite scores plus the score for cc18 are averaged and reported for CM31.
12. Oral Health in America: A Report of the Surgeon General. Rockville, MD: US Dept of Health and Human Services, National Institutes of Health, National Institute of Dental and Craniofacial Research; 2000:2.
13. Lewis C, Robertson A, Phelps S. Unmet Dental Care Needs Among Children with Special Health Care Needs: Implications for the Medical Home. *Pediatrics*.2005; 116(3):426-431.
14. O'Malley AS. Current Evidence on the Impact of Continuity of Care. *Curr Opin Pediatr*. 2004 Dec; 16(6): 693-9.

Footnotes

15. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2001. Rockville, Maryland: U.S. Department of Health and Human Services, 2004.
16. The 2007 National CAHPS Benchmarking Database. Available at: https://www.cahps.ahrq.gov/content/NCBD/Chartbook/2007_CAHPs_HealthPlanChartbook.pdf. Accessed: Feb 2008.
17. Mayer ML, Skinner AC, Slifkin RT. Unmet Need for Routine and Specialty Care: Data From the National Survey of Children With Special Health Care Needs. *Pediatrics*. 2004; 113:e109-15.
18. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2001. Rockville, Maryland: U.S. Department of Health and Human Services, 2004.
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20. Centers for Disease Control and Prevention. Overweight and Obesity: Childhood Overweight. Available at: <http://www.cdc.gov/nccdphp/dnpa/obesity/childhood/index.htm>. Accessed March 30, 2007.
21. US Department of Health and Human Services, Maternal Child Health Bureau. All Aboard the 2010 Express: A 10-Year Plan to Achieve Community-Based Services for Children and Youth With Special Health Care Needs and Their Families. Washington, DC: Maternal and Child Health Bureau; 2001.
22. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110:1304-06.
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25. Lotstein D, MacPherson M, Strickland B, Newacheck P. Transition Planning for Youth with Special Health Care Needs from the National Survey of Children with Special Health Care Needs. *Pediatrics*. 2005;115:1562-68.
26. Scal P, Ireland M. Addressing Transition to Adult Health Care for Adolescents With Special Health Care Needs. *Pediatrics*. 2005;115:1607-12.
27. At the time of writing, the CAHPS policy documents do not recommend comparing any composites longitudinally. The CAHPS Consortium is waiting on national data and analysis before deciding whether some composites (Getting Care Quickly, Doctor Communication, and Personal Doctor) may be comparable across years.