

Children's Medical Services Network

# Family Satisfaction Report

2006 - 2007





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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. 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 second CMSN satisfaction report that solely focuses on Medicaid eligible families<sup>1</sup>.

## At a Glance

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

Survey results are partitioned into 8 regions:

Northwest  
Big Bend  
North Central  
Central  
Tampa Bay  
Southeast  
Southwest  
South

## At A Glance

### 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 three surveys to capture trends during 2004-2005, 2005-2006, and 2006-2007.

### 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 3.0, child<sup>2</sup>, Medicaid, 2) Pediatric Quality of Life (PedsQL) Core<sup>3</sup>, 3) CMSN Program Evaluation, 4) Nurse Care Coordinator Feedback, 5) Obesity and Transition Questions, and 5) 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 approximately 80 completed surveys in each of the eight regions.

### FINDINGS

Key findings from this study are:

- Statewide, parents have positive experiences with doctor's communication (89) and office staff courtesy, respect, and helpfulness (93) 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 (58) and getting needed care (58) as measured by the CAHPS composites.
- There is wide variation across regions in families' experiences with plan customer service, family centered care, and specialized services as measured by the CAHPS composites.
- Parents residing in the Northwest region have the most positive experiences while parents residing in the 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.
- Children in the Northwest and North Central regions have the highest overall HRQOL as measured by the PedsQL while

children in the South and Central regions have lowest overall HRQOL as measured by the PedsQL.

- Parents are most satisfied with their CMSN doctor in the Big Bend region (85%) and least satisfied with their CMSN doctor 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 in four regions: Southwest, Southeast, North Central, and Big Bend.
- Eight-five percent of Big Bend and Northwest region parents rate CMSN overall as excellent to very good while 67% of Tampa Bay parents report those ratings.
- Eighty percent of CMSN parents report that their children's provider has discussed nutrition and exercise with them.
- 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.
- About 50% of CMSN children have seen a dentist in the past six months. Further investigation is needed to determine if the low level of compliance is due to access or uptake.
- About 20% of parents report that their provider has not spoken with them about nutrition and exercise. In order to prevent long term health effects and higher costs for the State, providers should 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.

## At a Glance

### Key Findings

Parents have the most positive experiences with doctor communication and office staff courtesy and respect.

Parents have the least positive experiences with specialized services and getting needed care.

Parents in Big bend are most satisfied with CMSN and parents in Tampa Bay are least satisfied.

# 2 Introduction & Purpose

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:

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- Central Region - Brevard, Osceola, Orange, Seminole.
- Tampa Bay Region - Highlands, Hardee, Polk, Pasco, Hillsborough, Pinellas.
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The CMSN program has a unique delivery system that focuses on providing the highest quality of care. Children in the program receive care from physicians, specialists, and nurse care coordinators. 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 second CMSN satisfaction report that solely focuses on Medicaid eligible families<sup>4</sup>.

## 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 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 three surveys to capture trends during 2004-2005, 2005-2006, and 2006-2007.

## 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).

# 3 Data & Evaluation Methods

## At a Glance

640 parents completed the survey.

51% of the families agreed to complete the survey.

The following survey modules were assessed:

- CAHPS
- PedsQL
- Nure Care Coordinator Feedback
- Overall Feedback
- Lifestyle 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 health<sup>5</sup>. Six hundred and forty families completed the CMSN satisfaction survey and approximately 80 families completed the survey in each region<sup>6</sup>. 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 -

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- Southwest Region - Sarasota, Collier, Hendry, Charlotte, Glades, DeSoto, Manatee, Lee.
- South Region - Miami-Dade, Monroe.

Using the contact information in the enrollment files, 51% of families agreed to participate 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 2006-2007 CMSN Family Satisfaction Survey contains the following modules.

**CAHPS:** The Consumer Assessment of Health Plans Survey (CAHPS), child Medicaid version 3.0<sup>7</sup> 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 the courtesy, respect, and helpfulness of the office staff
- 5) Parents' experiences with health plan customer service, information, and paperwork
- 6) Parents' experiences with prescription medicine
- 7) Parents' experiences getting specialized services for their children
- 8) Family centered care-experiences with the child's personal doctor or nurse
- 9) Family centered care-experiences with shared decision making
- 10) Family centered care-experiences with getting needed information about their child's care
- 11) Parents' experiences with coordination of their child's care

A mean score is calculated for each composite, which ranges from 0 to 100, with 100 being the highest score. It should be noted that prior to all the CAHPS composite questions, the respondent is asked if he/she had

the experience that served as the basis to answer the question. For example, the respondent is first asked if they had called their doctor's office for help in the past six months before asking them if they were satisfied with the help they had received. 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.

**PedsQL Core:** The PedsQL Core Version 4.0<sup>8</sup> 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

Parents average age was 40 years

CMSN surveyed families are racially diverse

80% of parents speak English

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 CMSN children in the survey is 13 years with a standard deviation of 15.5 years. The respondents' average age is 40 years with a standard deviation of 12.6 years.

### RACE AND ETHNICITY OF CHILDREN AND PARENTS

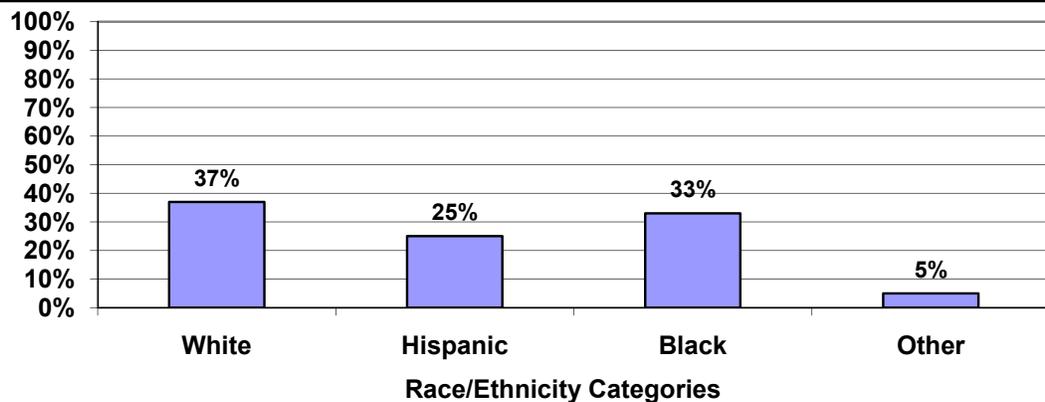
Figure 1 contains information about the race/ethnicity of the CMSN children whose parents responded to the survey. Thirty-seven percent are White non-Hispanic, 33% are Black non-Hispanic, and 25% are Hispanic.

Of those CMSN children who are Hispanic, 30% are of Puerto Rican descent, about 23% are Mexican, and 21% are of South American descent. Parents had a similar race/ethnicity mix with 40% White non-Hispanic, 31% Black non-Hispanic, 25% Hispanic, and 4% from other racial groups.

### NATIVE LANGUAGE OF CHILDREN AND PARENTS

Eighty percent of parents speak English, 18% Spanish, and 3% speak other languages in the home. Children in the program speak English (83%) predominately, Spanish (12%), and other languages (5%).

Figure 1. Race/Ethnicity of CMSN Children



### PARENT EDUCATIONAL ATTAINMENT

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

- 30% less than high school,
- 33% high school graduate,
- 23% some college or technical school,
- 15% Associates degree or higher.

### HOUSEHOLD TYPE AND MARITAL STATUS

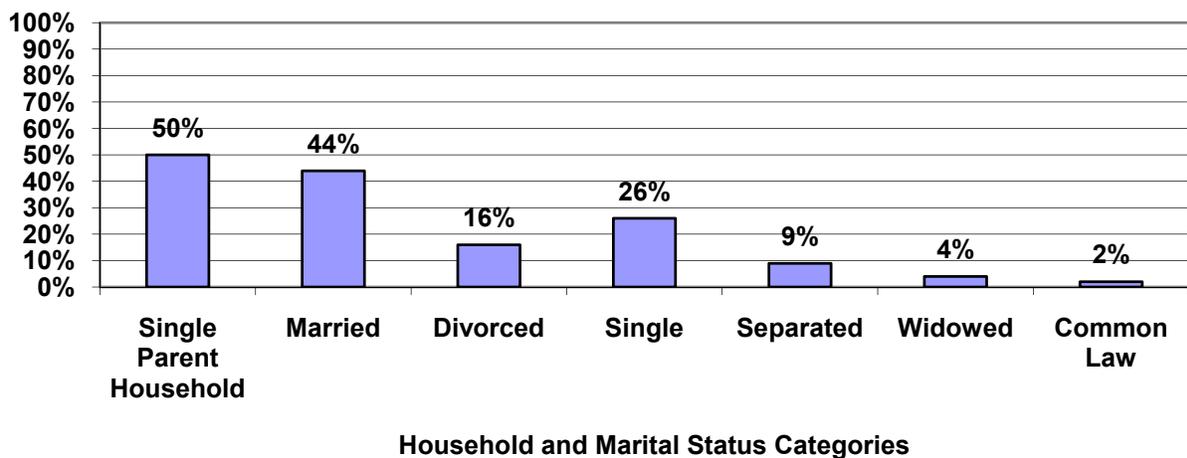
Finally, respondents are asked two questions about their household type and marital status. As seen in **Figure 2**, one-half of households are single parent households, 44% of parents are married, 16% divorced, 26% single, 9% separated, 4% widowed, and 2% common law married.

### TELEPHONE SERVICE IN THE PAST 6 MONTHS

Families are asked if they had an interruption in their telephone service in the past six months. Three percent of the families had an interruption, and of those who did, 40% had no service for less than one month and 60% 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 personal preference (20%).

Finally, 87% of the children in the survey had been enrolled in CMSN for all of the past six months. Six percent were enrolled for three to five months, 3% were enrolled for one to two months, and 5% were enrolled for less than a month.

Figure 2. Household and Marital Status of CMSN Parents



# 5 CAHPS Composite Scores

The CAHPS version 3.0 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. 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, four questions are posed to respondents. Thinking about

the past six months, parents are asked about how much of a problem it was to see a doctor or nurse, how much of a problem it was to see a specialist, how much of a problem it was to get care, treatment or tests, and how much of a problem delays were while waiting for the health plan to approve needed services. As seen in **Figure 3**, composite scores ranged from 49 (Southeast) to 69 (Big Bend) indicating a twenty point variation across regions.

## GETTING NEEDED PRESCRIPTIONS

To measure parents' experiences with getting needed prescriptions, only one question is asked: how much of a problem was it to get your child's prescription. As shown in **Figure 4**, scores ranged from 91 (Northwest) to 69 (Southeast) across regions. The regional variation in the composite scores was 22 points.

Figure 3. CAHPS Composite- Getting Needed Care by CMSN Region

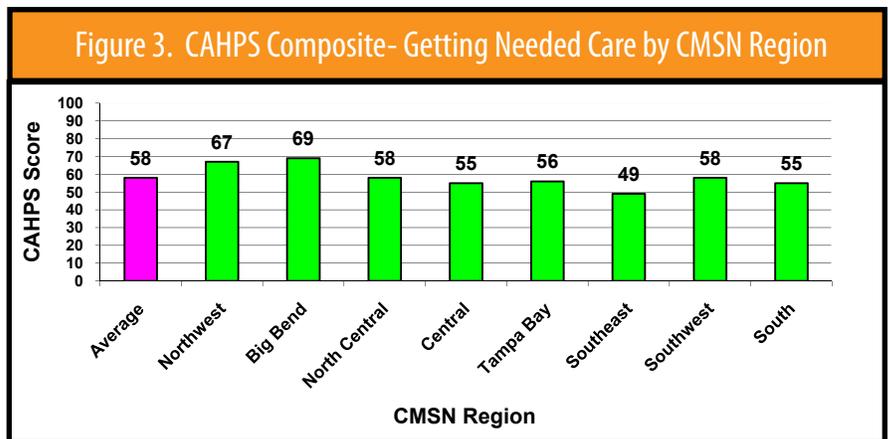
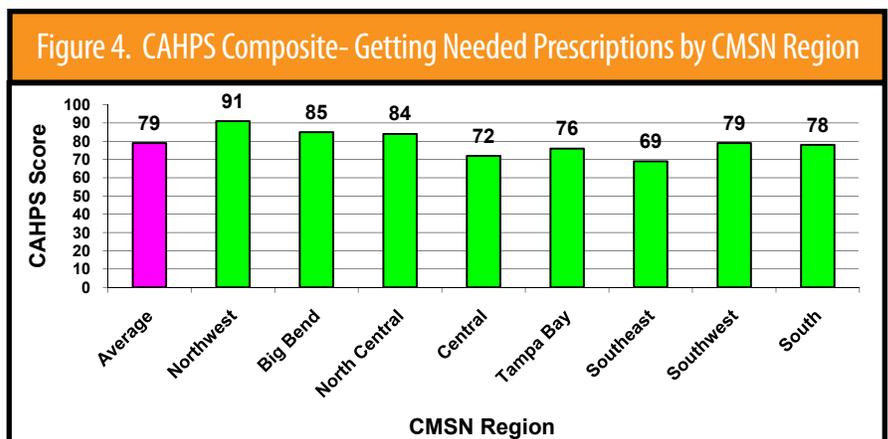
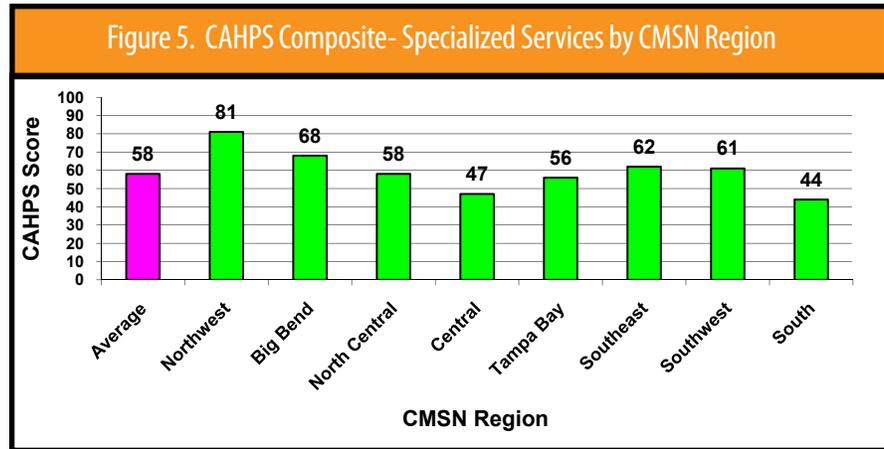


Figure 4. CAHPS Composite- Getting Needed Prescriptions by CMSN Region



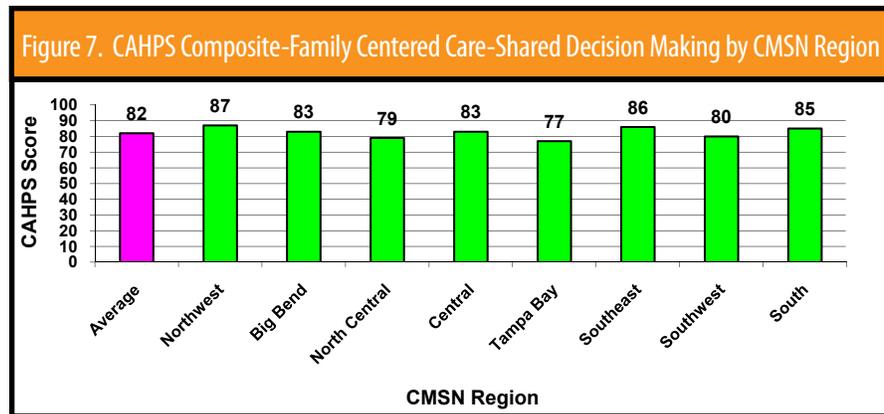
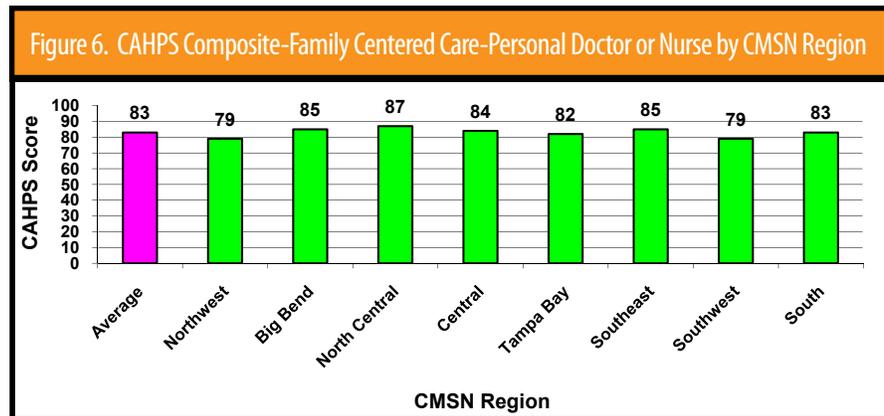
## SPECIALIZED SERVICES

Parents are asked three questions related to how much of a problem it was to get special equipment, special therapy, and treatment or counseling. Results seen in **Figure 5** widely vary with the Northwest region scoring 81 and the South and Central regions scoring in the 40s (44 and 47, respectively). There is wide variation (37 points) across regions within a range from 81 to 44. 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 or nurse, 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. Again, the Northwest region had the highest scores for two of the composites (shared decision making and getting needed information) and North Central had the highest for personal doctor or nurse (see **Figures 6 through 8**).

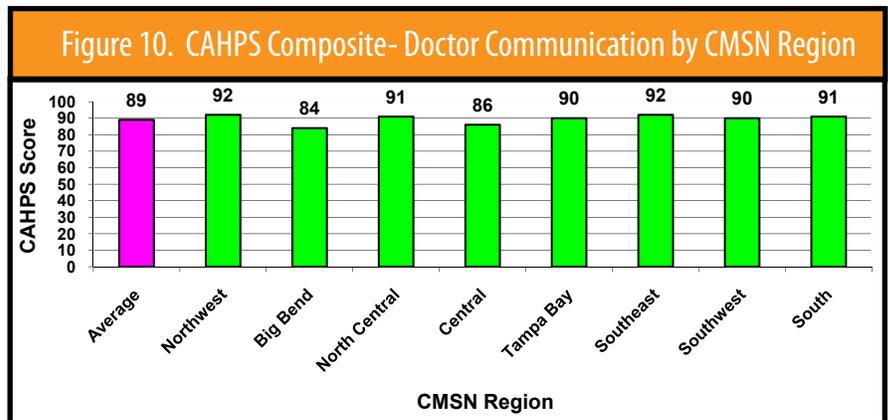
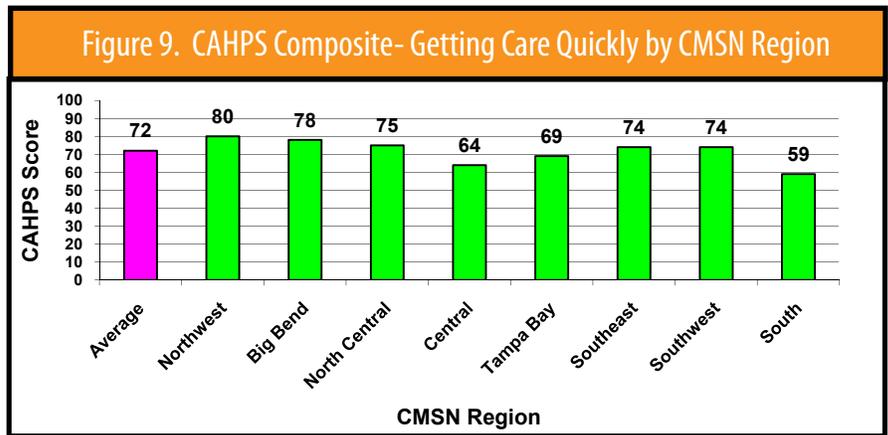
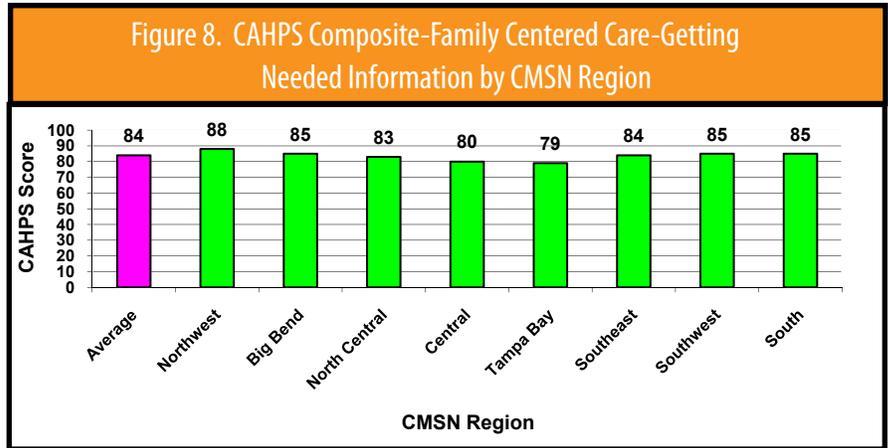


### GETTING CARE QUICKLY

Respondents are asked four questions to determine how quickly they are getting the care they need for their children. Questions focus on the experiences when parents called the office for help, getting an appointment as soon as they wanted, getting taken into an exam room within 15 minutes, and getting care right away. **Figure 9** shows that all regions but the South (59) scored higher than 60 on this composite. While there is still room for improvement, parents in all regions but the South seem to have consistent levels of satisfaction across the State in getting care quickly. The variance for getting care quickly is 21 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 10** are encouraging as parents are very satisfied with their experiences in the past six months. There is small variation (8 points) in the results indicating consistency across the regions.



### OFFICE STAFF

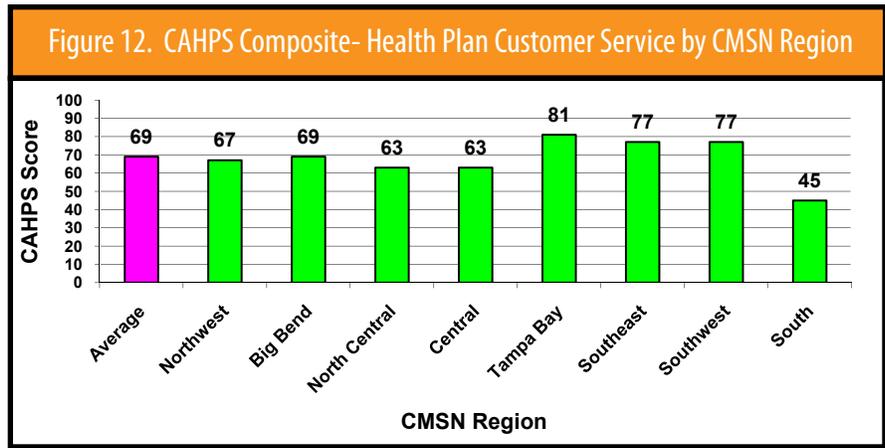
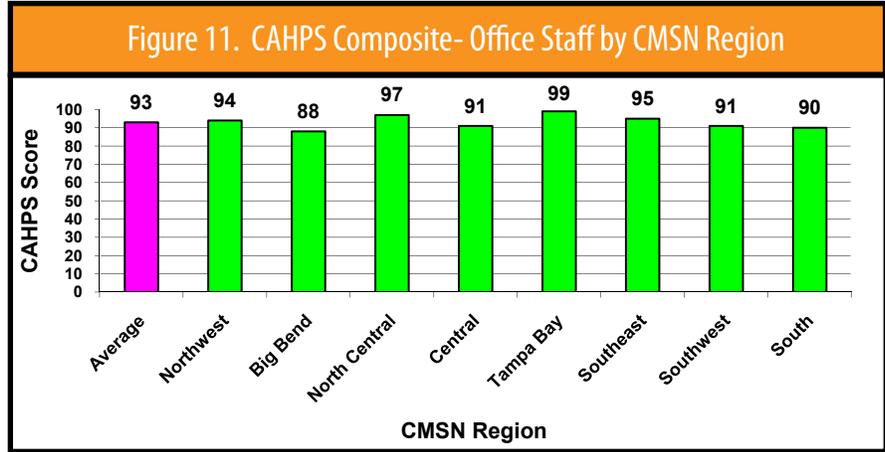
Parents were asked two questions related to how helpful and how courteous and respectful the doctor’s office staff are. Again, the results in **Figure 11** show high levels of satisfaction across the State and very little variation (11 points).

### 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 understanding information from the health plan, getting help from customer service, and problems with paperwork. Results in **Figure 12** are fairly consistent across the Northwest, Big Bend, North Central, and Central regions with scores in the 60s. However, the South region scored the lowest (45) and the Tampa Bay region the highest (81) with an overall variance of 36 points.

### SUMMARY OF CAHPS COMPOSITE SCORES

**Table 1** 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 ten CAHPS composite categories and eight regions, the range of possible total rankings is 10 to 80. Results presented in Table 1 show that the Northwest region has the most satisfied parents with five out of nine number 1 rankings and the lowest total score. Northwest parents gave their lowest ranking (7) for family centered care- personal doctor or nurse. The Central region had the lowest rankings overall indicating that parents have less positive health care experiences in that region. Parents with the most positive experiences obtaining health care for their children reside in the following regions (in descending order):

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

The statewide percentage of families reporting satisfaction with the quality of care, obtaining referrals, needed services, and coordination among providers is 70%. The statewide percentage of parents who report they are able to access comprehensive services for their child and family is 77%.

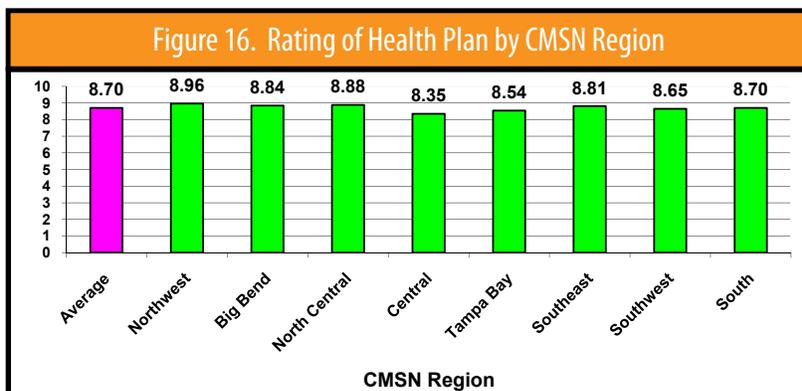
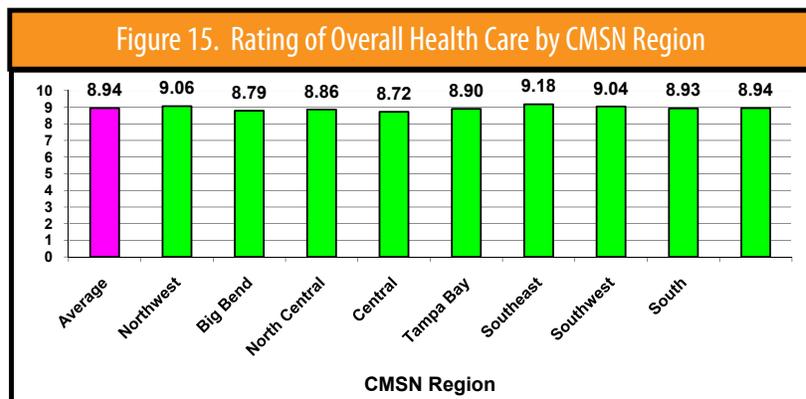
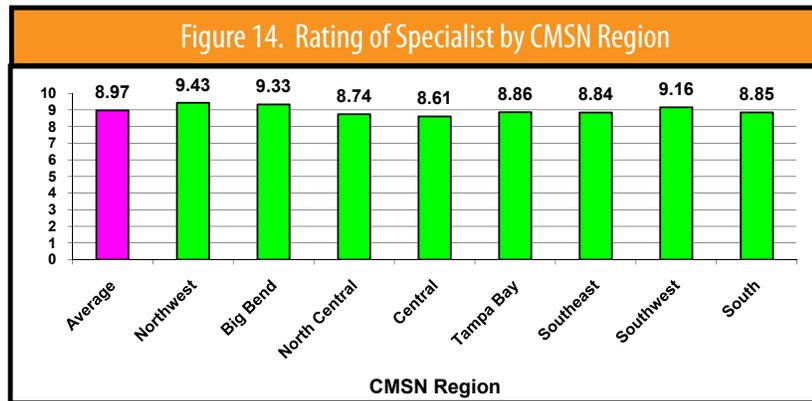
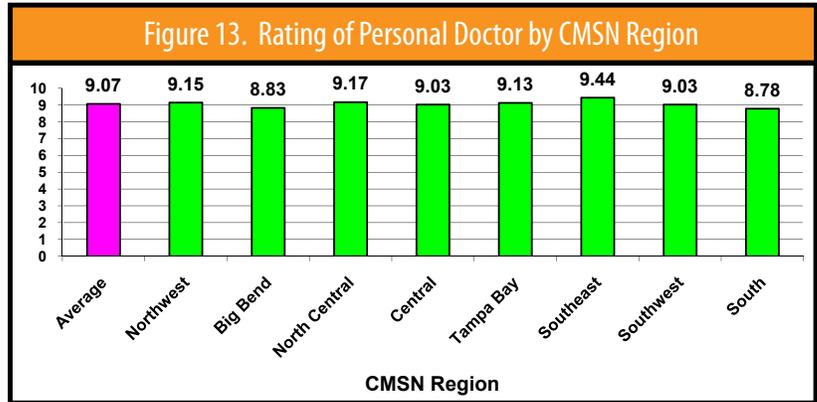
Table 1. Rankings of CAHPS Composites by CMSN Region								
CAHPS Composite	CMSN Region							
	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Getting Needed Care	2	1	3	6	5	8	3	6
Getting Needed Prescriptions	1	2	3	7	6	8	5	4
Getting Care Quickly	1	2	3	7	6	4	4	8
Specialized Services	1	2	5	7	6	3	4	8
Family Centered Care- Personal Doctor or Nurse	7	2	1	4	6	2	7	5
Family Centered Care- Shared Decision Making	1	4	7	4	8	2	6	3
Family Centered Care- Getting Information	1	2	6	7	8	5	2	2
Doctor Communication	1	8	3	7	5	1	5	3
Office Staff	3	8	1	5	3	2	5	7
Health Plan Customer Service	5	4	6	6	1	2	2	8
<b>Total</b>	<b>23</b>	<b>35</b>	<b>38</b>	<b>60</b>	<b>54</b>	<b>37</b>	<b>43</b>	<b>54</b>

# 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 13 through 16 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 8.70) and their child's personal doctor highest (9.07). By region, rating of personal doctor is highest for Southeast (9.44) and lowest for South (8.78). For specialist, ratings are highest for the Northwest (9.43) and lowest for the Central region (8.61). For overall health care, the Southeast region again rated highest (9.18) and Central region rated lowest (8.72). Finally, rating of health plan is highest for Northwest region (8.96) while Tampa Bay region rated lowest (8.35).



# 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 learning<sup>9</sup>.

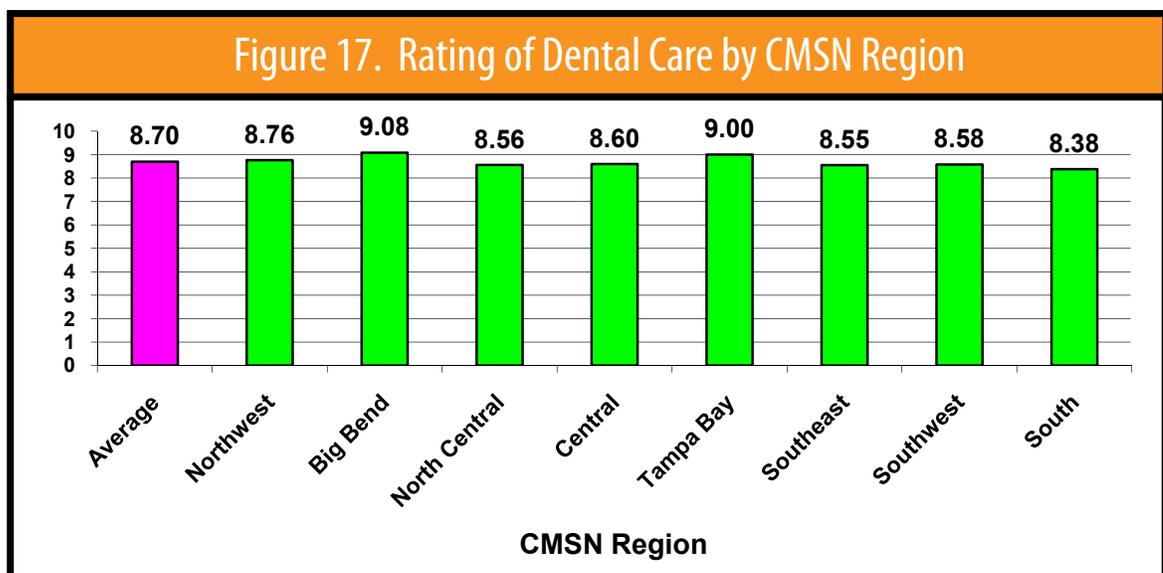
Few studies have focused on the dental care needs and unmet needs for CSHCN. The National Survey of Children with Special Health Care Needs, which is administered to over 38,000 families in the US, asks questions about dental needs and if they are being met. A 2005 study reported that 78% of all CSHCN 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 need<sup>10</sup>.

Parents in this survey are asked questions about their children's dental care in the last six months.

When asked if their child got dental care in the past six months the percentages who responded affirmatively by region are:

- 48% Northwest
- 59% Big Bend
- 55% North Central
- 53% Central
- 43% Tampa Bay
- 48% Southeast
- 54% Southwest, and
- 43% South.

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 17**, parents in the Big Bend region report the highest ratings (9.08) and parents in the South region report the lowest rating (8.38).



# 9 Transportation

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This series of survey questions asks about whether or not a child got help with transportation, how often they were able to get help when they needed it, and did the transportation they received meet their needs. By region, the percentage of parents who report they got help with transportation is:

- 5% Northwest
- 7% Big Bend
- 3% North Central
- 5% Central
- 5% Tampa Bay
- 14% Southeast
- 10% Southwest, and
- 7% South.

When asked how often they were able to get the transportation they needed, the percentage of parents who report they always get transportation is:

- 25% Northwest
- 50% Big Bend
- 50% North Central
- 25% Central
- 25% Tampa Bay
- 67% Southeast
- 38% Southwest, and
- 40% South.

Finally, when asked if the transportation received met their needs, the percentage of parents who report they always have their needs met are:

- 100% Northwest
- 60% Big Bend
- 50% North Central
- 50% Central
- 33% Tampa Bay
- 90% Southeast
- 67% Southwest, and
- 100% South.

# 10 Preventive Care Compliance

Access to preventive care visits is a fundamental component of pediatric health care for all children including those with special health care needs. Preventive care visits that meet the American Academy of Pediatrics periodicity schedule are associated with a decrease in avoidable inpatient admissions for infants, across various racial and ethnic groups, income levels, and health status<sup>11</sup>. Preventive care visits are also critically important given the marked increase in the incidence of learning difficulties, accidents, and violence among children – a cluster of conditions that are called the “new morbidities” of childhood. These visits provide an opportunity for anticipatory guidance to parents about issues such as home safety, seat belt and car seat use, and normal developmental changes. Such interventions have been shown to increase

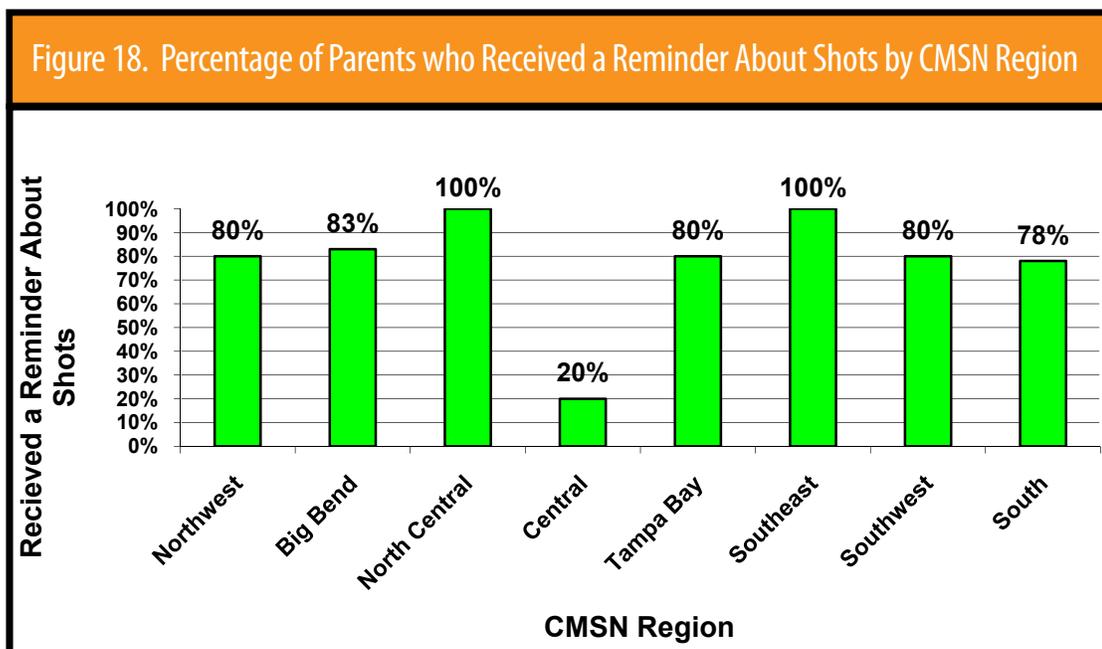
parents’ awareness of important developmental milestones and to reduce injury. Moreover, preventive care visits may be especially important for low-income children who are more likely than their more affluent counterparts to have these “new morbidities”<sup>12</sup>. In addition, preventive care visits are a critical time to provide immunizations and to screen for anemia and lead poisoning.

CAHPS questions aimed at assessing preventive care for children focus on those children two years old and under. A parent with a child two years old or under is asked if they received a reminder about getting the child’s first shots, if they brought the child in for a check up, and if they were able to receive an appointment for that check up as soon as they wanted.

With the exception of Tampa Bay, Southeast, and Southwest 100% of parents with children two years and under report that they brought their child in for a check up. Eighty-three percent of parents in Tampa Bay, 73% in Southeast, and 60% in Southwest brought their child in for a check up.

With the exception of Northwest and Tampa Bay, 100% of parents with children two years and under report that they got an appointment for their child’s check up as soon as they wanted. Northwest parents report 83% and Tampa Bay parents 80%.

**Figure 18** below shows that all regions except the Central region had high percentages of parents who received a reminder about getting their children’s first shots. Twenty percent of the Central region parents indicate that they received a reminder.



# 11 Pediatric Quality of Life Composite Scores

## At A Glance

Children in North Central have the highest physical functioning levels.

Emotional functioning is high and has little variation statewide.

Children in Tampa Bay have the lowest social functioning levels.

Children in Tampa Bay have the highest school 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 19 through 22** show the results of the functioning domain scores by region. These figures also present results from a 2001 national study<sup>13</sup> conducted with children with special health care needs by the creator of the instrument to validate and set benchmarks for the scores.

**Figure 19** shows that only one region (North Central) has children who have physical functioning levels higher than the national study. However, three other regions (Southeast, Northwest, and Big Bend) are within 3 points of the national study. Children in the South, Central, and Southwest regions scored 8-10 points below the national study.

**Figure 20** illustrates that emotional functioning in CMSN children is relatively high and almost mirrors the national study in all but three regions (Central, Tampa Bay, and South). There is a smaller amount of variation across the regions for children's emotional functioning (11 points).

**Figure 21** shows that CMSN children scored significantly lower than the national study in social functioning. Even the highest functioning children in the Northwest and North Central regions scored 10 points below the national group. Tampa Bay had the lowest functioning children and scored 22 points below the national study.

Again, the results in **Figure 22** show significantly lower school functioning scores than the national study for all but Tampa Bay. CMSN children scored from 72 (Tampa Bay) to 52 (South) 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.

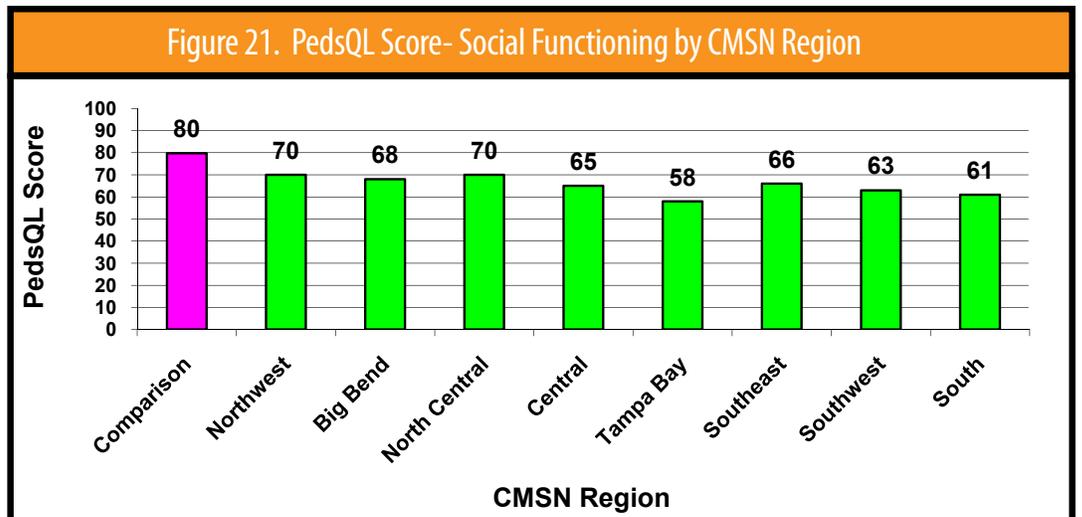
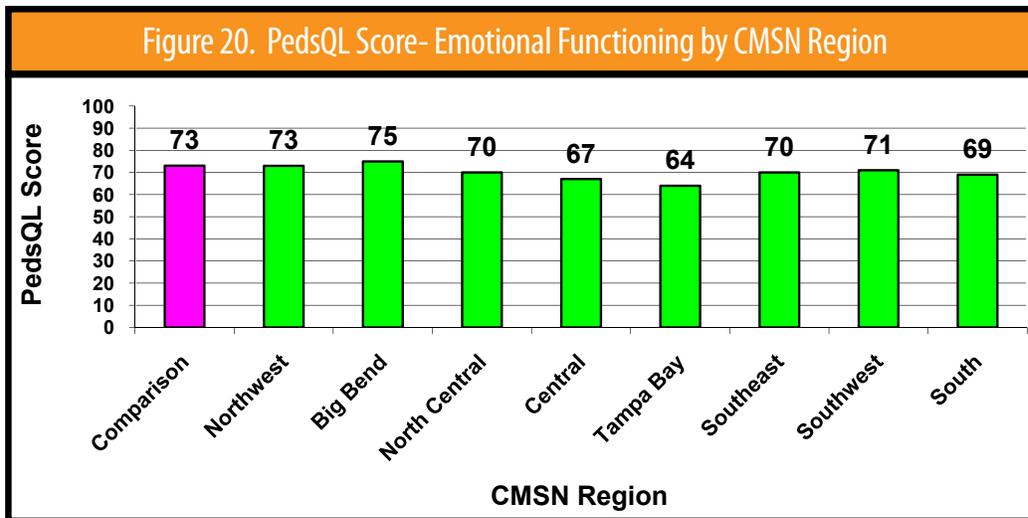
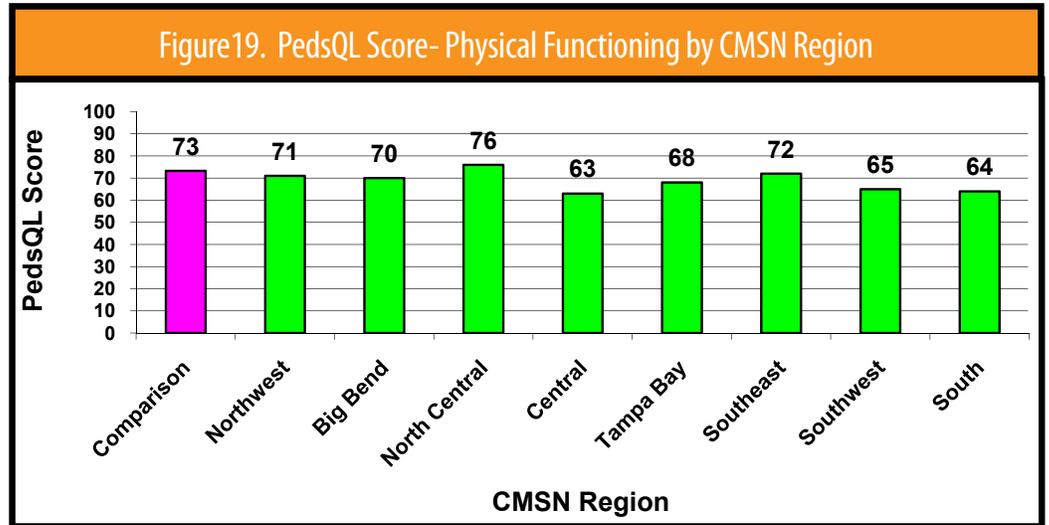


Table 2. Rankings of PedsQL Composites by CMSN Region								
CAHPS Composite	CMSN Region							
	Northwest	Big Bend	North Central	Central	Tampa Bay	Southeast	Southwest	South
Physical Functioning	3	4	1	8	5	2	6	7
Emotional Functioning	2	1	4	7	8	4	3	6
Social Functioning	1	3	1	5	8	4	6	7
School Functioning	4	3	2	7	1	5	5	8
<b>Total</b>	<b>10</b>	<b>11</b>	<b>8</b>	<b>27</b>	<b>22</b>	<b>15</b>	<b>20</b>	<b>28</b>

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

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

# 12 Statistical Comparison of the CMSN Regions on the CAHPS Composite Scores

Family Satisfaction Report | 2006-2007

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 indicator 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 3** and is followed by a discussion. The complete regression results are contained in the Appendix.

Table 3. Summary of Logistic Regression Results Examining Regional Differences in CAHPS Composite Scores<sup>14</sup>

Region	Getting Needed Care	Getting Need Prescriptions	Specialized Services	Doctor Communication	Office Staff	Health Plan Customer Service	Family Centered Care- Personal Doctor or Nurse	Family Centered Care- Shared Decision-Making	Family Centered Care- Getting Needed Information
Northwest	NS**	Ref	Ref	Ref	NS	NS	NS	Ref	Ref
Big Bend	Ref*	.10	NS	NS	NS	NS	NS	NS	NS
North Central	NS	NS	NS	NS	Ref	NS	Ref	NS	NS
Central	.34	.16	.23	NS	NS	NS	NS	NS	NS
Tampa Bay	.34	.08	NS	NS	NS	Ref	NS	NS	NS
Southeast	NS	.05	NS	NS	NS	NS	NS	NS	NS
Southwest	NS	NS	NS	NS	NS	NS	NS	NS	NS
South	NS	.06	.18	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 Central and Tampa Bay regions are 66% 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 Needed Prescriptions: Parents residing in the Big Bend, Central, Tampa Bay, Southeast, and South regions are about 90 to 84 percent less likely than parents residing in the Northwest region to usually to always have positive experiences in getting needed prescriptions.
- Specialized Services: Parents residing in the Central and South regions are about 80 percent less likely than parents residing in the Northwest region to usually or always have positive experiences in getting specialized services.
- None of the other CAHPS composite scores are significantly different from the referent group.

# 13 Nurse Care Coordinator Feedback

## At A Glance

The majority (80%) of parents know who their nurse care coordinator is.

About three-fourths of parents indicate that their nurse care coordinator is available and helpful.

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 and after hours. Results for these four questions are presented by region below.

As seen in **Figures 23 through 26**, about 80% or more of parents in the Northwest, Big Bend, Tampa Bay, Southwest regions strongly agree to agree that they know who their nurse care coordinator is. Likewise, about 74% to 89% strongly agree or agree that their nurse care

coordinator is available and helpful. Parents in the South, Southwest, and Central regions strongly disagreed more than any other region that they knew where to call during office hours. Finally, large percentages of parents did not need to call after hours to get help for their children (19% to 46%).

Figure 23. CMSN Parents Agreement for "I know who my CMS Nurse Care Coordinator Is" by CMSN Region

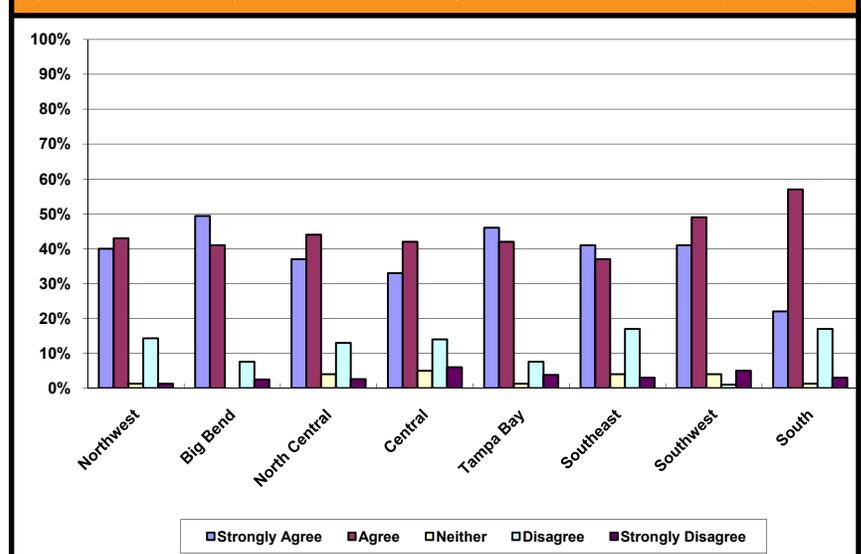
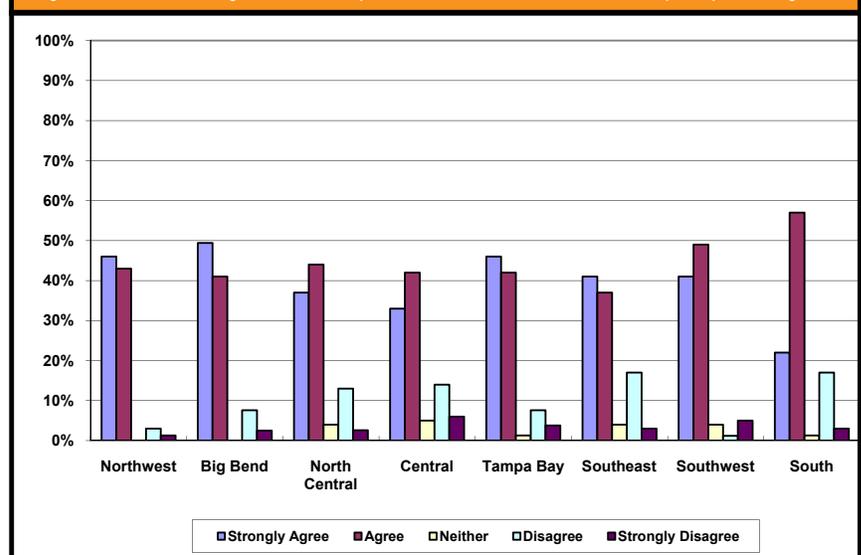
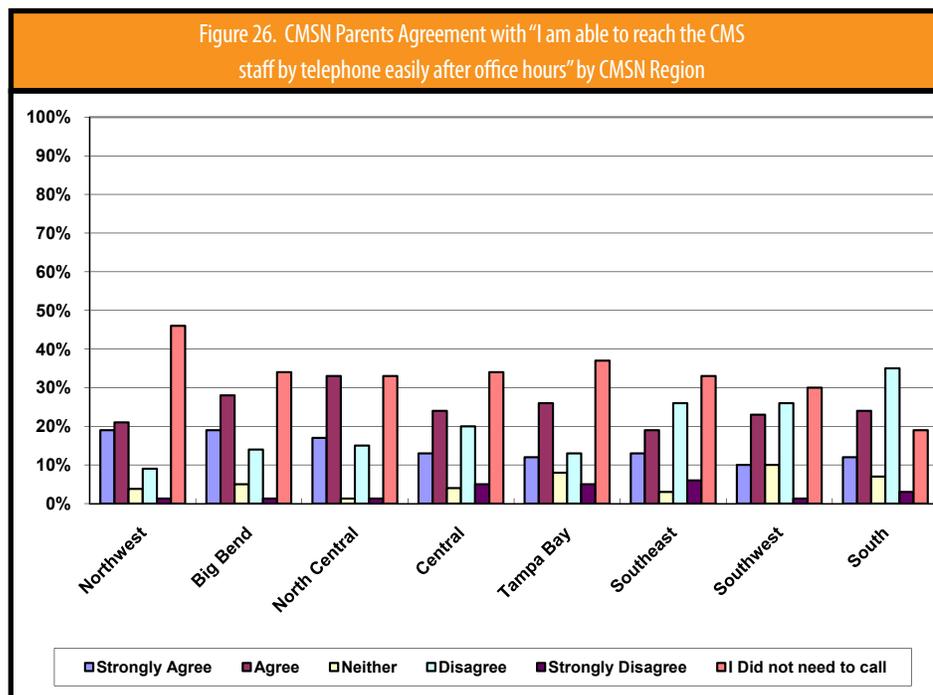
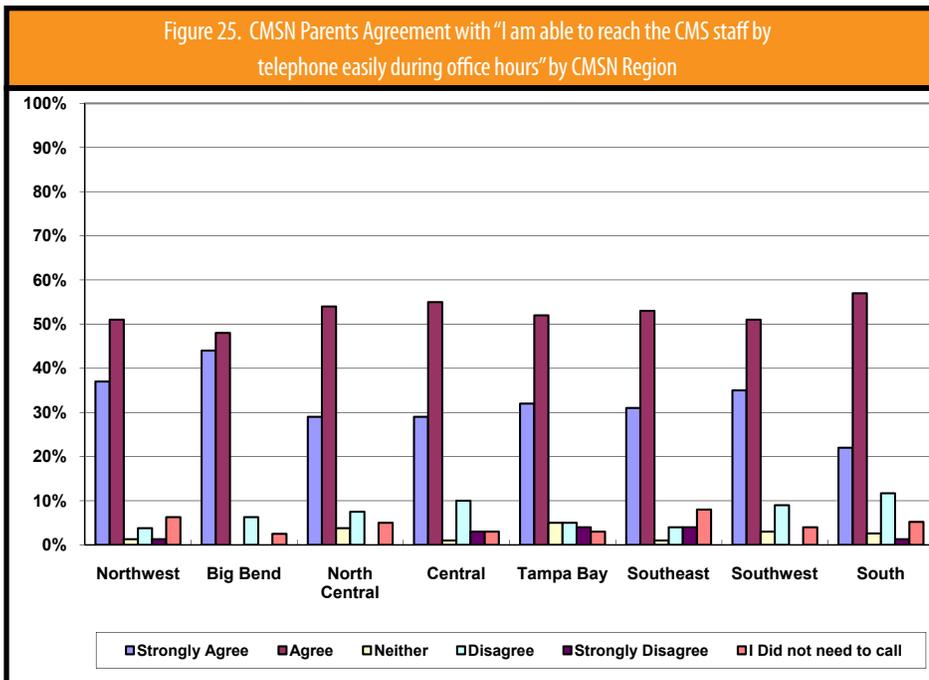


Figure 24. CMSN Parents Agreement with "My CMS Care Coordinator is available and helpful" by CMSN Region





# 14 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 96% to 99% of the time that the CMSN program is right for their children. Likewise, 93% to 99% of parents across all regions respond that they would recommend CMSN to someone they knew whose child had similar needs. Parents in two regions report never having filed a complaint (Northwest and North Central). By region, the percent of parents who filed a complaint is:

- 2.5% Big Bend
- 5% Central
- 2.5% Southeast
- 7.4% Southwest, and
- 2.6% South.

**Figure 27** shows the level of satisfaction with CMSN doctor by region. Big Bend and Southeast region parents are most satisfied (86% and 85%), while 3% of parents residing in the Southwest, Central, Big Bend, and Northwest regions report that they are very dissatisfied.

**Figure 28** shows responses for how parents feel about the quality of care their children receive in CMSN. More Tampa Bay and Big Bend parents (55% and 50%) rated their children's quality of care as excellent than any other region. Quality of care was consistently rated excellent across regions, varying from 44% to 55%.

Finally, parents are asked to rate the overall CMSN program as excellent, very good, good, fair, or poor (**Figure 29**). About 85% of parents in the Big Bend and Northwest regions rate the CMSN program as excellent or very good. Fewer than 70% of parents in the South and Tampa Bay regions rate CMSN as excellent or very good.

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:

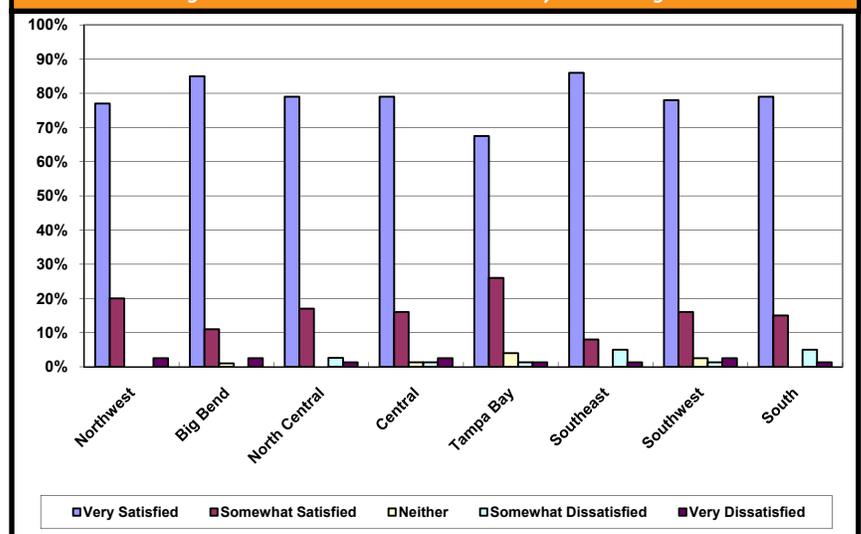
- Bad communication,
- Program is disorganized, and
- Too complicated

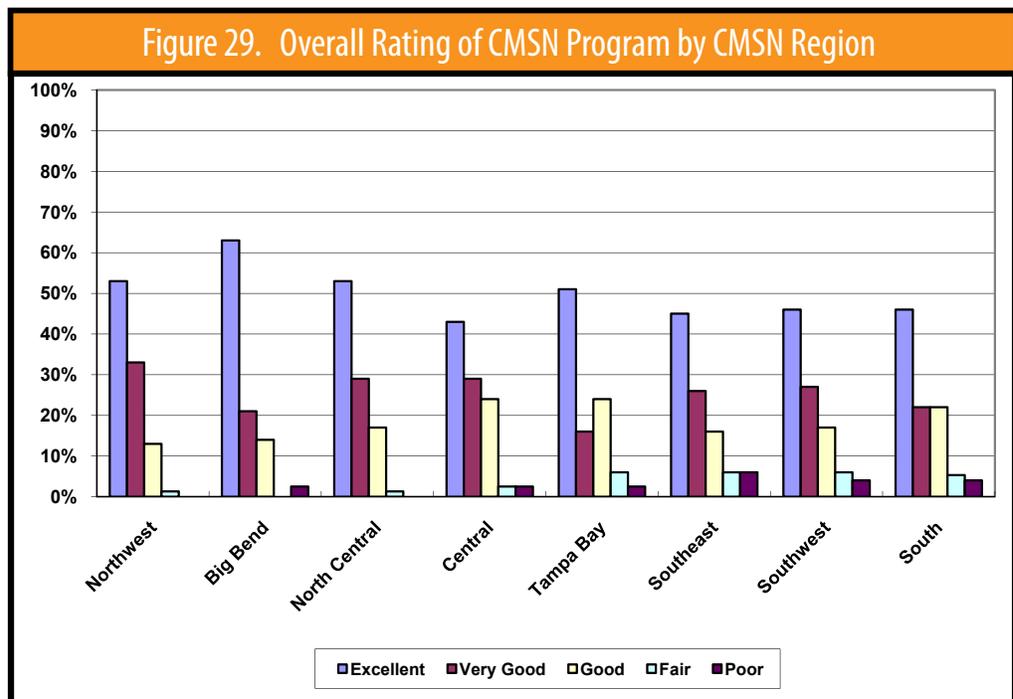
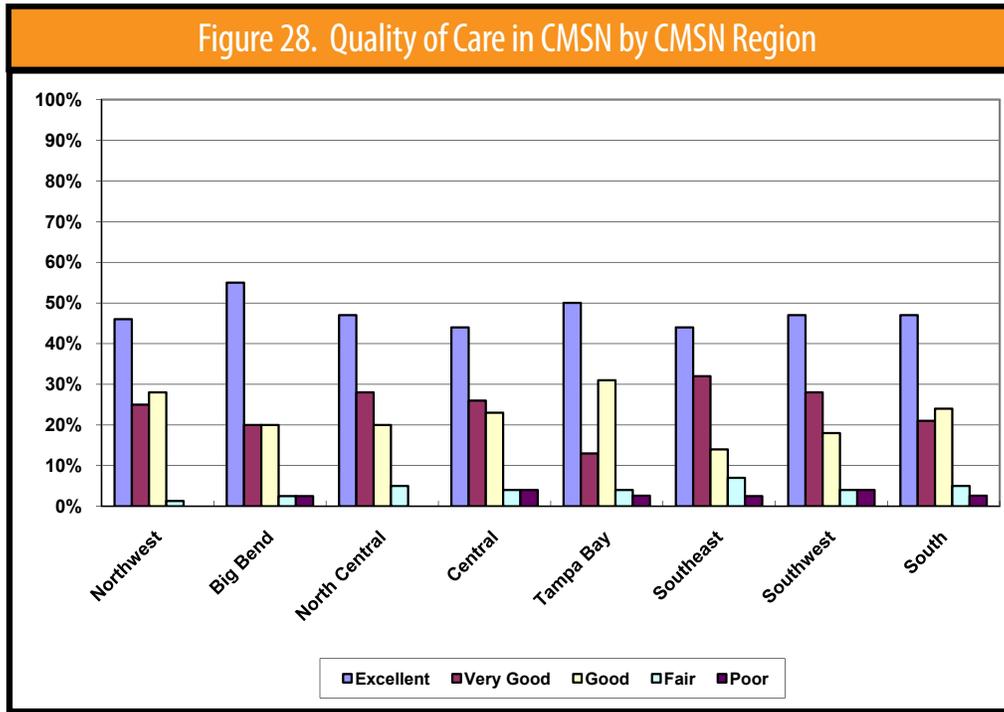
## At A Glance

About 50% of parents rate their children's quality of care in CMSN as Excellent.

About 70% - 88% of parents rate the CMSN program as Excellent or Very Good.

Figure 27. Satisfaction with Doctor by CMSN Region





# 15 Healthy Lifestyles and Transition

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

- 75% responded that their children's provider had discussed their children's weight with them.

## 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 strata<sup>15</sup>. 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:

- 81% responded that their children's health care provider had discussed healthy eating and nutrition with the parent and child,
- 80% responded that their provider discussed their children's physical activity and exercise with them, and

## 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, has 207 objectives for people with disabilities, one of which is to improve adolescent transition to the adult health care system<sup>16</sup>. 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 in established by the age of 14<sup>17</sup>.

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,

## At a Glance

80% of CMSN doctors have discussed nutrition and exercise with families.

72% of parents whose children are 14 and older report that their children's doctor has talked to them about changing needs as they age.

and personal preferences<sup>18, 19</sup>. Service needs might impede transition since certain treatment services might not be available in the adult health care system<sup>20, 21</sup> 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<sup>20, 21</sup>. 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=235), the results show:

- Seventy-two percent (n=167) 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 167 parents, 60% indicated that a plan for addressing those changes had been developed, and
- Of those 167 parents, 55% indicated that their children's doctors had discussed having their child eventually see an adult provider.

When the sample is restricted to children ages 18 and older, the results show:

- Seventy-five percent (n=82) indicated that their children's doctor had talked to them or their children about how their child's health care needs might change when he/she becomes an adult,

- Of those 82 parents, 70% indicated that a plan for addressing those changes had been developed, and
- Of those 82 parents, 55% indicated that their children's doctors had discussed having their child eventually see an adult provider.

The results indicate that three-fourths of the parents have talked to their children's doctors about how their children's health care needs will change as they become adults. However, that percentage does not increase when the sample is reduced only to children ages 18 and older.

Results from the 2005-2006 CMSN Family Satisfaction Report showed that more parents thought that transition planning had occurred than their children. Further research is needed to determine if transition planning is adequate and universal for CMSN children ages 14 and older.

# 16 Comparing Results Over Time

Over the past three years the Institute for Child Health Policy has evaluated family satisfaction in the CMSN program. Evaluations conducted in 2004-2005, 2005-2006, and 2006-2007 are compared and contrasted in this section<sup>22</sup>. However, the reader should note that the surveys conducted during the three evaluations years differed in the following ways:

- The 2005-2006 and 2006-2007 evaluations focused solely on Title XIX enrollees, the 2004-2005 evaluation focused on both Title XIX and Title XXI enrollees,
- The 2004-2005 evaluation was administered to parents of children ages nine months to 21 years and was separated into sub-specialty programs such as; Medical Foster Care (MFC), Children's Medical Assessment Team (CMAT), and Primary Care Case Management (PCCM),
- The 2005-2006 evaluation was administered to two groups of parents: those with children nine months to 15 years old and those with children 16 years and older,
- The 2006-2007 evaluation is administered to parents of children ages nine months to 21 years and is separated by region.

Keeping in mind the different constructs of the sampling methodologies, it is still possible to compare and contrast certain survey questions that were asked in each of the three years. This report compares the results from the CAHPS composites (which were asked in all three years) and the overall CMSN satisfaction questions (which were asked in two of the three years).

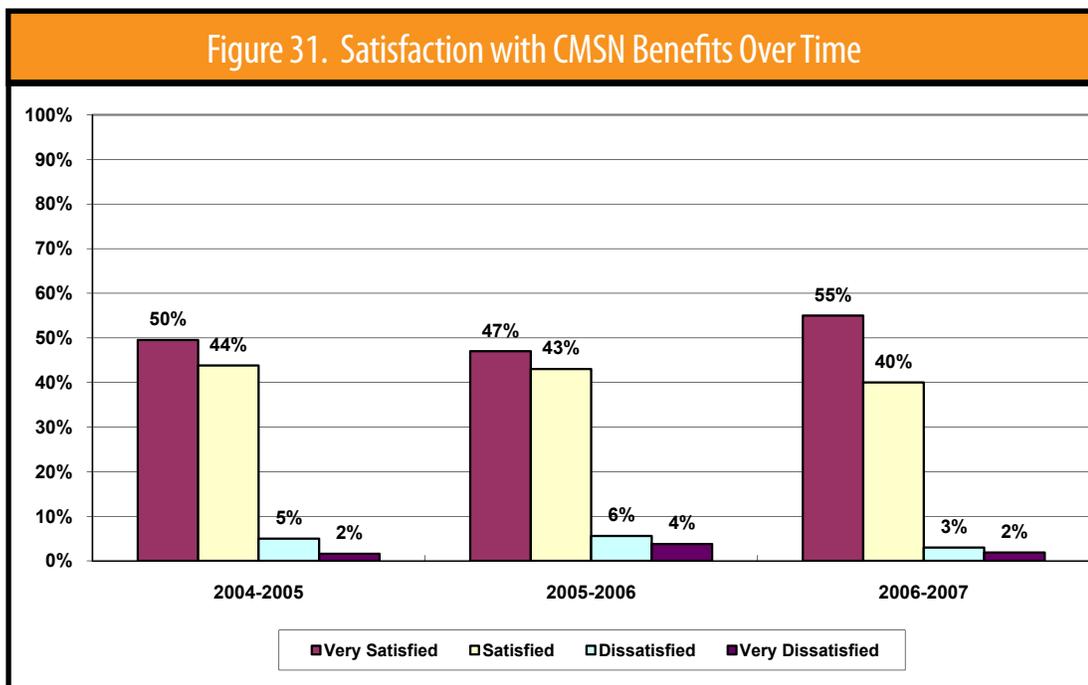
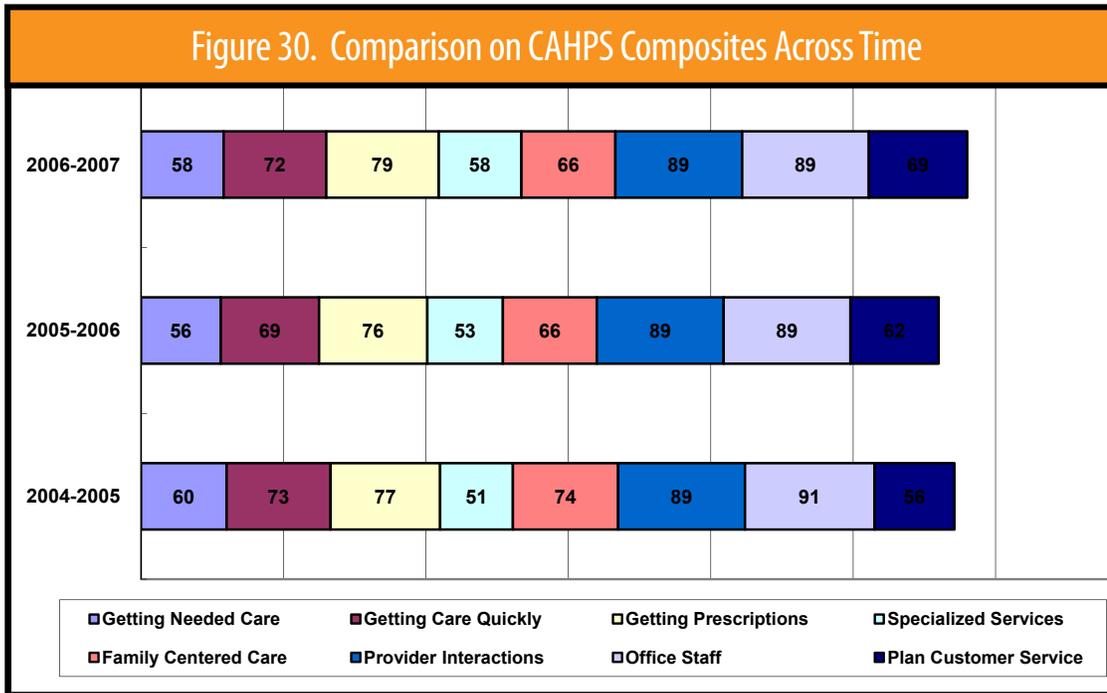
## COMPARISON OF CAHPS COMPOSITES

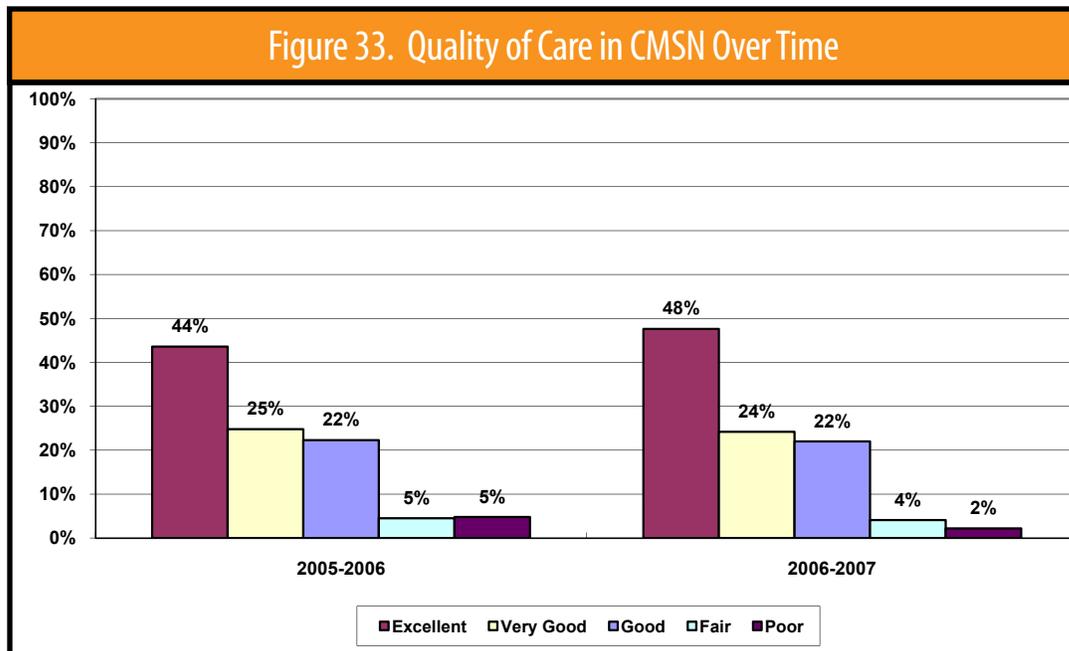
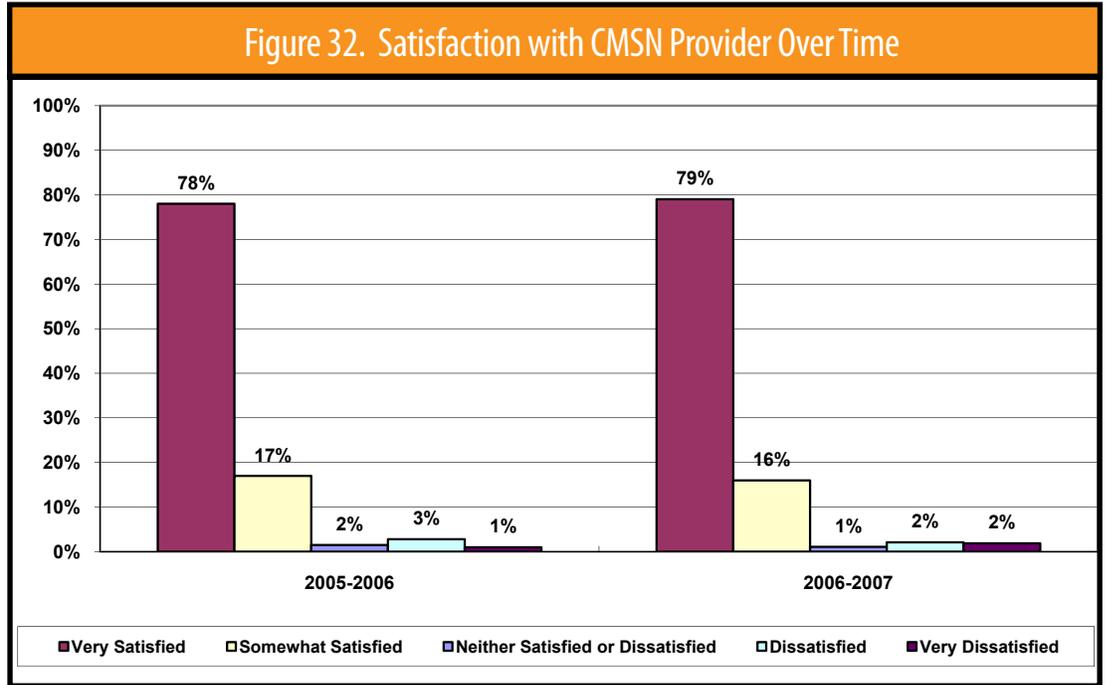
**Figure 30** below compares the CAHPS composite scores across time for the three contract years; 2004-2005, 2005-2006, and 2006-2007. Results from the comparisons show that families consistently have positive experiences with the components of the CMSN program. Regardless of sampling strategy and time, 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 three survey years parents were asked about the satisfaction level with the CMSN benefits and those results are presented in **Figure 31**. The figure shows that over time the relative levels of satisfaction were about the same. 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%).

**Figures 32 and 33** 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 CMAT, PCCM, and MFC programs were substituted. However, over the two-year period, parents report about the same satisfaction levels in 2006-2007 with their CMSN provider (79% versus 78% were very satisfied) and the quality of care their children receive (43% and 47% said the care was excellent).





# 17 Summary and Recommendations

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CMSN serves a diverse population of Medicaid eligible children up to 21 years old. Thirty-seven percent are White non-Hispanic, 33% Black non-Hispanic, and 25% Hispanic. One-third of the respondents have a high school education, while 44% are married and 50 percent live in a two-parent household.

Using the CAHPS composite scores, families in the Northwest region has the most positive experiences obtaining health care for their children and the Central region the lowest. Parents are more satisfied with the office staff and provider interactions indicating a satisfactory health care infrastructure. Parents 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 that CSHCN in a national study. Children residing in the Northwest and North Central regions had the highest level of functioning while children in the South and Central had the lowest.

This report demonstrates high levels of provider and program satisfaction. About 75% of parents in four of the CMSN regions feel that their quality of care is excellent to very good.

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

**First**, 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.

**Second**, about 50% of CMSN parents report that their child had a dental visit in the past six months. It is unclear if children

are not visiting the dentist because of limited access or other reasons. CMSN should investigate why dental uptake is below the recommended levels.

**Third**, 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. Medical record reviews can be used to quantify the level of compliance.

**Fourth**, lack of transition preparedness has been an ongoing problem for CSHCN. All children ages 14 and older should have a written care plan that takes into account the needs and desires of the child, parent, and provider. Providers should discuss these upcoming changes and guide families through the process. Medical record reviews can be used to determine if transition preparedness is occurring. Also, CMSN should consider developing alternative interventions that might increase levels of preparedness.

# 18 Appendix

**Table 4. Logistic Regression for Getting Needed Care**

Logistic regression		Number of obs =		356	
		Wald chi2(15) =		35.77	
		Prob > chi2 =		0.0019	
Log pseudo-likelihood = -203.55821		Pseudo R2 =		0.0970	

NEED	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]	
HIS	.6988793	.2286616	-1.10	0.274	.368047	1.327092
BLACK	1.142915	.353956	0.43	0.666	.6228742	2.09714
OTHER	.8996076	.6800463	-0.14	0.889	.2044554	3.958289
HS	2.177619	.6659578	2.54	0.011	1.195827	3.96548
SOMECOLLEGE	.9709369	.3257604	-0.09	0.930	.5030408	1.87404
COLLEGEGRAD	.9752362	.3828885	-0.06	0.949	.4517713	2.105237
northwest	.7056051	.4029127	-0.61	0.541	.2304151	2.16079
northcentral	.3835445	.1914687	-1.92	0.055	.1441746	1.020335
central	.3370005	.1766048	-2.08	0.038	.1206588	.9412435
tampa	.3370596	.1816602	-2.02	0.044	.1172051	.969319
southeast	.3615597	.1953968	-1.88	0.060	.1253624	1.04278
southwest	.8421221	.4734212	-0.31	0.760	.2798013	2.534548
south	.4173353	.2481655	-1.47	0.142	.130114	1.338586
totpeds	1.006172	.0016351	3.79	0.000	1.002973	1.009382
TWOPARENT	.7596392	.1938257	-1.08	0.281	.460701	1.252552

**Table 5. Logistic Regression for Getting Needed Prescriptions**

Logistic regression		Number of obs =		343	
		Wald chi2(14) =		28.86	
		Prob > chi2 =		0.0109	
Log pseudo-likelihood = -138.30381		Pseudo R2 =		0.1035	

SCRIPT	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]	
HIS	1.309289	.5316919	0.66	0.507	.5907032	2.902029
BLACK	1.548364	.6077482	1.11	0.265	.7174111	3.341782
HS	.8173128	.3378704	-0.49	0.626	.3635035	1.837672
SOMECOLLEGE	.4091453	.1779221	-2.06	0.040	.1744703	.9594746
COLLEGEGRAD	.4170431	.2080126	-1.75	0.080	.1568986	1.108518
bigbend	.1055275	.1130593	-2.10	0.036	.0129244	.8616288
northcentral	.1641675	.1776814	-1.67	0.095	.0196796	1.369486
central	.1084677	.1170059	-2.06	0.039	.0130947	.8984736
tampa	.0806716	.0861882	-2.36	0.018	.0099383	.6548332
southeast	.0515268	.0549386	-2.78	0.005	.0063749	.4164816
southwest	.1308889	.1435721	-1.85	0.064	.0152482	1.123534
south	.0613941	.0663089	-2.58	0.010	.0073923	.5098826
totpeds	1.00515	.0019614	2.63	0.008	1.001313	1.009001
TWOPARENT	1.088695	.3738459	0.25	0.805	.555409	2.134025

**Table 6. Logistic Regression for Specialized Services**

Logistic regression		Number of obs =		356	
		Wald chi2(15) =		55.65	
		Prob > chi2 =		0.0000	
Log pseudo-likelihood = -153.39253		Pseudo R2 =		0.1570	

SPECIAL	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]	
HIS	2.168983	.903913	1.86	0.063	.9583457	4.908968
BLACK	1.809287	.6734034	1.59	0.111	.8723618	3.752481
OTHER	1.36204	1.08614	0.39	0.698	.285372	6.500826
HS	.8997189	.3367854	-0.28	0.778	.4319988	1.873834
SOMECOLLEGE	.8569352	.3638532	-0.36	0.716	.3728458	1.969549
COLLEGEGRAD	.5206757	.2379701	-1.43	0.153	.2125854	1.275267
bigbend	.2897661	.2017824	-1.78	0.075	.074012	1.13447
northcentral	.3566551	.2406449	-1.53	0.127	.0950429	1.338373
central	.2375937	.1638911	-2.08	0.037	.0614724	.9183113
tampa	.4611101	.3461479	-1.03	0.302	.1058818	2.008112
southeast	.3730234	.2705692	-1.36	0.174	.090017	1.54578
southwest	.3782086	.2779499	-1.32	0.186	.0895722	1.596943
south	.1796716	.1317172	-2.34	0.019	.0427036	.7559533
totpeds	1.01171	.0020134	5.85	0.000	1.007771	1.015664
TWOPARENT	1.137024	.3798396	0.38	0.701	.5907633	2.188397

**Table 7. Logistic Regression for Doctor Communication**

Logistic regression		Number of obs =		356	
		Wald chi2(15) =		19.99	
		Prob > chi2 =		0.1721	
Log pseudo-likelihood = -99.271058		Pseudo R2 =		0.0775	

DOCTOR	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]	
HIS	.2769657	.1545202	-2.30	0.021	.0927977	.8266365
BLACK	.286803	.1555095	-2.30	0.021	.099094	.8300799
OTHER	.3312308	.3944013	-0.93	0.353	.0321065	3.417187
HS	1.405443	.6618497	0.72	0.470	.5584271	3.537204
SOMECOLLEGE	1.150317	.6126367	0.26	0.793	.4050269	3.267015
COLLEGEGRAD	2.0765	1.384899	1.10	0.273	.5618655	7.674172
bigbend	.6326105	.4770531	-0.61	0.544	.1442923	2.773509
northcentral	.5614328	.4209792	-0.77	0.441	.1291342	2.440924
central	.7436083	.605627	-0.36	0.716	.1506914	3.669441
tampa	1.594607	1.496037	0.50	0.619	.2535531	10.02855
southeast	.9341228	.8242086	-0.08	0.938	.1657142	5.265605
southwest	1.276332	1.102562	0.28	0.778	.2347746	6.938668
south	1.388642	1.339625	0.34	0.734	.2096213	9.199102
totpeds	1.00477	.0026658	1.79	0.073	.9995586	1.010008
TWOPARENT	1.054772	.5098755	0.11	0.912	.4089678	2.720373

**Table 8. Logistic Regression for Office Staff**

Logistic regression		Number of obs = 356					
		Wald chi2(15) = 12.73					
		Prob > chi2 = 0.6231					
Log pseudo-likelihood = -81.727411		Pseudo R2 = 0.0413					
-----							
OFFICE	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]		
-----							
HIS	.990108	.6763758	-0.01	0.988	.2595365	3.777172	
BLACK	.9182114	.5355201	-0.15	0.884	.2927549	2.879926	
OTHER	.5520307	.664248	-0.49	0.621	.052207	5.837108	
HS	.9370833	.5245442	-0.12	0.908	.3128293	2.807043	
SOMECOLLEGE	.99139	.6494447	-0.01	0.989	.2745587	3.57976	
COLLEGEGRAD	1.171278	.857087	0.22	0.829	.2791197	4.915071	
bigbend	.6460988	.5179523	-0.54	0.586	.1342529	3.109383	
northcentral	2.100882	1.958763	0.80	0.426	.3378947	13.06237	
central	1.250833	1.055726	0.27	0.791	.2392046	6.540771	
northwest	1.134119	.9779881	0.15	0.884	.2092376	6.147204	
southeast	3.828338	4.340521	1.18	0.236	.414886	35.32578	
southwest	1.213337	.9853095	0.24	0.812	.2470299	5.959546	
south	.9260369	.8881728	-0.08	0.936	.1413289	6.067721	
totpeds	1.004627	.0028453	1.63	0.103	.9990656	1.010219	
TWOPARENT	.7785612	.3827966	-0.51	0.611	.2970168	2.040819	

**Table 9. Logistic Regression for Health Plan Customer Service**

Logistic regression		Number of obs = 343					
		Wald chi2(14) = 20.39					
		Prob > chi2 = 0.1184					
Log pseudo-likelihood = -52.171441		Pseudo R2 = 0.0565					
-----							
CUSTSERV	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]		
-----							
HIS	.4607691	.3771269	-0.95	0.344	.0926399	2.291757	
BLACK	.570805	.4235132	-0.76	0.450	.1333313	2.443674	
HS	.4337348	.412364	-0.88	0.380	.0672919	2.795669	
SOMECOLLEGE	.2005421	.1913603	-1.68	0.092	.0309013	1.301472	
COLLEGEGRAD	.3559554	.3702482	-0.99	0.321	.0463463	2.733856	
bigbend	.4233776	.5322788	-0.68	0.494	.036023	4.975945	
northcentral	.5622467	.6956696	-0.47	0.642	.0497431	6.355083	
central	1.049611	1.586413	0.03	0.974	.0542622	20.30296	
northwest	.9076442	1.270953	-0.07	0.945	.0583443	14.11994	
southeast	.361078	.429571	-0.86	0.392	.0350699	3.717638	
southwest	.3841175	.5320399	-0.69	0.490	.0254371	5.800435	
south	.3726432	.5651393	-0.65	0.515	.0190716	7.281143	
totpeds	1.001075	.0035771	0.30	0.764	.9940884	1.008111	
TWOPARENT	.8462318	.5023709	-0.28	0.779	.2643432	2.70901	

**Table 10. Logistic Regression for Family Centered Care- Personal Doctor or Nurse**

Logistic regression		Number of obs	=	356
		Wald chi2 (15)	=	14.80
		Prob > chi2	=	0.4656
Log pseudo-likelihood = -190.00931		Pseudo R2	=	0.0402

FAMILYDR	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]
HIS	.9379151	.334196	-0.18	0.857	.4665145 1.885654
BLACK	1.607533	.5431155	1.41	0.160	.8290408 3.117051
OTHER	.6553958	.4154728	-0.67	0.505	.1891927 2.270403
HS	.6954913	.2287062	-1.10	0.269	.3650746 1.324957
SOMECOLLEGE	.6848529	.2479123	-1.05	0.296	.3368743 1.392281
COLLEGEGRAD	1.18651	.5375474	0.38	0.706	.4882422 2.883418
TWOPARENT	2.01092	.5840799	2.41	0.016	1.138046 3.553283
totpeds	.9991492	.0017518	-0.49	0.627	.9957216 1.002589
northwest	.5951	.2922259	-1.06	0.291	.2273026 1.558029
bigbend	.701068	.3538963	-0.70	0.482	.2606617 1.885572
central	.8266419	.419176	-0.38	0.707	.3059762 2.2333
tampa	.5510589	.2703252	-1.21	0.224	.2106862 1.441319
southeast	1.064138	.5781291	0.11	0.909	.3669049 3.086328
southwest	.4768237	.2282919	-1.55	0.122	.1865618 1.218689
south	.4949938	.2746838	-1.27	0.205	.1668199 1.468763

**Table 11. Logistic Regression for Family Centered Care- Shared Decision Making**

Logistic regression		Number of obs	=	356
		Wald chi2 (15)	=	26.48
		Prob > chi2	=	0.0333
Log pseudo-likelihood = -103.51896		Pseudo R2	=	0.1122

FAMILYDEC	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]
HIS	2.598921	1.396763	1.78	0.076	.9064076 7.451824
BLACK	6.010396	3.249454	3.32	0.001	2.083102 17.34186
OTHER	1.463788	1.521708	0.37	0.714	.1908076 11.22951
HS	1.731463	.8092925	1.17	0.240	.6927212 4.327809
SOMECOLLEGE	1.106191	.5200865	0.21	0.830	.4401793 2.779911
COLLEGEGRAD	2.101032	1.273013	1.23	0.220	.6407529 6.889292
TWOPARENT	2.253614	.9577683	1.91	0.056	.9797734 5.183624
totpeds	1.002881	.0021597	1.34	0.182	.9986567 1.007122
northcentral	.7320088	.5755569	-0.40	0.692	.1567624 3.418148
bigbend	.6446167	.5676427	-0.50	0.618	.1147473 3.621268
central	.3741387	.3040825	-1.21	0.226	.0760704 1.840135
tampa	.520866	.4168393	-0.82	0.415	.1085239 2.499924
southeast	2.614428	3.148072	0.80	0.425	.2468495 27.68989
southwest	.4560017	.3637499	-0.98	0.325	.0954922 2.177534
south	.4422263	.3824339	-0.94	0.345	.0811955 2.408558

**Table 12. Logistic Regression for Family Centered Care- Getting Needed Information**

Logistic regression		Number of obs	=	356
Log pseudo-likelihood = -92.767366		Wald chi2(15)	=	25.26
		Prob > chi2	=	0.0466
		Pseudo R2	=	0.0986

FAMILYINFO	Odds Ratio	Robust Std. Err.	z	P> z	[95% Conf. Interval]	
HIS	.5138279	.2853653	-1.20	0.231	.1730154	1.525987
BLACK	.5957352	.3620574	-0.85	0.394	.1810241	1.960514
OTHER	.5460906	.5982846	-0.55	0.581	.0637834	4.675434
HS	.5803148	.321645	-0.98	0.326	.195829	1.71969
SOMECOLLEGE	.5038718	.307026	-1.12	0.261	.1526351	1.663358
COLLEGEGRAD	.611688	.3633576	-0.83	0.408	.1909393	1.959587
TWOPARENT	1.572433	.8258881	0.86	0.389	.561689	4.401982
totpeds	1.008208	.0026725	3.08	0.002	1.002983	1.013459
northcentral	.3484831	.3036616	-1.21	0.226	.0631627	1.922661
bigbend	1.184664	1.253313	0.16	0.873	.1489593	9.421555
central	.8411607	.8121365	-0.18	0.858	.1267792	5.580972
tampa	.4719797	.4116489	-0.86	0.389	.0854135	2.608074
southeast	.4785052	.4910179	-0.72	0.473	.0640364	3.575582
southwest	.5148379	.5064073	-0.67	0.500	.0748872	3.53943
south	.4610038	.4743194	-0.75	0.452	.0613645	3.463316

# Footnotes

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1. Children's Medical Services: Family Satisfaction Report 2005-2006, also focused on Medicaid eligible children and is available upon request.
2. National Commission on Quality Assurance. HEDIS 2003: Specifications for Survey Measures. Washington, D.C.: 2002.
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 2005-2006, also focused on Medicaid eligible children and is 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. One region had 77 completes and three regions had 81 completes.
7. National Commission on Quality Assurance. HEDIS 2003: Specifications for Survey Measures. Washington, D.C.: 2002.
8. Varni JW, Seid M, Rode C. The PedsQL: Measurement Model for the Pediatric Quality of Life. *Med Care*. 1999 Feb; 37(2):126-39.
9. 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.
10. 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.
11. Hakim RB, Bye BV. Effectiveness of Compliance with Pediatric Preventive Care Guidelines among Medicaid Beneficiaries. *Pediatrics*. 2001;108:90-97.
12. Busey S, Schum TR, Meurer JR. Parental Perceptions of Well-Child Care Visits in an Inner-city Clinic. *Arch Pediatr Adolesc Med*. 2002; 156:62-66.
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14. The CAHPS Composite "Getting Care Quickly" could not be analyzed due to lack of variation in the dependent variable.
15. 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.
16. 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.
17. 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.

18. Reiss J, Gibson R, Walker L. Health Care Transition: Youth, Family, and Provider Perspectives. *Pediatrics*. 2005;115:112-20.
19. Reiss J, Gibson R. Health Care Transition: Destination Unknown. *Pediatrics*. 2002;110:1307-14.
20. 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.
21. Scal P, Ireland M. Addressing Transition to Adult Health Care for Adolescents With Special Health Care Needs. *Pediatrics*. 2005;115:1607-12.
22. Data earlier than 2004-2005 cannot be used for comparison due to the nature of the sampling methodology. The Institute did not have access to the State's enrollment data during that time period so CMSN area offices were contacted and asked to supply a list of names and contact information of parents who they thought should be contacted for the survey. Not having the ability to pull an independent, random sample skews the survey results and therefore, none are presented in this section of the report.