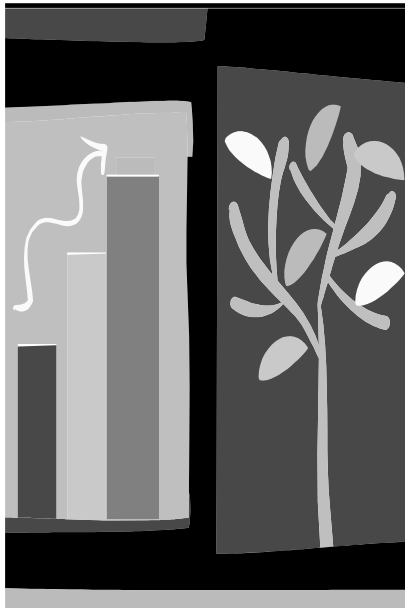


# Specialty Health Care for Children in the Los Angeles California Children's Services Program (CCS)



R E P O R T

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# Acknowledgements

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# Executive Summary

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## Introduction

Understanding the health care needs of children with chronic conditions is a statewide policy issue in California. Policy concerns for public insurance programs include low reimbursement rates and complicated delivery systems and benefit rules in Medi-Cal as well as the volume and access of pediatric specialists. The 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN) showed poorer experiences with care for CSHCN in California compared to nationally, and large disparities between Medi-Cal and private insurance (Inkelas, Ahn, Larson 2003).

Until now, there has been little information on experiences with care for children with the most intensive health care needs. This report provides new data on specialty care for children in the Los Angeles County California Children's Services (CCS) program. CCS pays for specialty health care services for children from birth through age 21 years with serious and/or chronic medical conditions such as birth defects, HIV/AIDS, cerebral palsy, blood disorders, heart disease, cancer, and endocrine and metabolic disorders. CCS also provides school-based physical and occupational therapy, and follow-up for high risk infants, without regard to income. Nearly 175,000 children annually (about 15% of California's CSHCN) receive care through the CCS program, and most (nearly 80%) are in Medi-Cal.

This report describes experiences with care for children in the Los Angeles CCS program, which serves one-third of CCS children statewide. Information on the Los Angeles CCS population comes from a survey conducted in 2005. The survey profiles current needs and unmet needs and examines factors that may improve access, such as having a medical home, care coordination, and support from CCS. Selected comparisons are made with findings from the NS-CSHCN, although that survey included a younger age group (0-17 years) statewide in 2001.

## Highlights

### Specialty Care

Difficulty accessing needed specialty care may result from inadequate pediatric subspecialty supply, poor provider participation in public insurance programs, long waits due to limited specialist availability, problems with transportation, and difficulty obtaining referrals due to cost containment or other insurance restrictions (Hansel and Reifman 2000). For children in CCS, authorization problems may rest with CCS or with other insurance or a health plan.

- About 23.6% of children in Los Angeles CCS have difficulty with authorization, with half of these children (11.6%) experiencing a big problem.
- Authorization problems affect twice as many children in Healthy Families (42.1%) as in Medi-Cal (21.7%) or private insurance (20.3%). This difference is largely due to high rates of problems experienced by Spanish-speaking parents with lower educational attainment within Healthy Families.

- Comparison to the broader population of CSHCN statewide shows that (1) children in Los Angeles CCS have similar rates of authorization problems (23.6%) as CSHCN statewide (21.0%), and (2) the identical rates for Medi-Cal and private insurance in Los Angeles CCS are somewhat reflected for CSHCN statewide. Among CSHCN, problem rates are similar for Medi-Cal (34.9%) and for privately insured children in lower income households (below 200% FPL) (30.3%), but substantially lower for higher income privately insured children (15.7%). Income was not determined in the Los Angeles CCS survey which prevents stratification of the privately insured group by income level.
- As with specialty authorization problems, unmet needs for specialty care are highest in Healthy Families (16.6%). Children with exclusively Medi-Cal coverage have nearly twice the rate of unmet specialty care need (8.5%) than children with both Medi-Cal and private coverage (5.0%) and exclusively private coverage (5.8%). In contrast, among the general population of CSHCN in 2001, unmet specialty care need was similar (at 5%) for Medi-Cal and private insurance.
- Unmet need for specialty care is higher among those in fee-for-service Medi-Cal (10.4%) than among those in managed health plans (6.6%), with greater condition severity among the fee-for-service group a likely contributing factor.
- Of those children with a problem obtaining authorization, the type of provider was most often a cardiologist, neurologist, orthopedist, or orthodontist. For needed care not received, the specialty type is most often neurology, orthodontia, dental care, or endocrinology.

Mental health services are another type of specialized services that are reimbursable through CCS for children whose emotional or behavioral problem relates to a CCS condition (e.g., depression, coping, behavioral issues affecting adherence to a treatment plan).

- Rates of need and unmet need, for both the child and family members, are higher for children experiencing greater impact from their medical condition.
- Unmet need for counseling is more common among children in Medi-Cal (33.0% of those needing care) than among children with exclusively private coverage (17.0%).
- Among those needing but not receiving counseling, the most frequent barrier is finding a provider who could treat the child or knowing where to go (46.4%). Finding a provider is more frequently a problem for children age 0-5 years (72.2%) than for older children age 6-21 years (40.5%).

### **Delayed and Foregone Care**

Delays in care may affect severity of the disease, lead to more urgent care contacts and greater emergency department utilization, and ultimately reduce children's physical and mental well-being.

- About 18.4% of children had delayed or missed care that was needed in the past year. This rate of delayed or missed care in the Los Angeles CCS program is slightly lower than the rate for the larger population of CSHCN in California in 2001 (23.2%).

- About half of delays are due to obtaining approval and/or inability to get a timely appointment.
- A health insurance plan problem is a more frequent reason for delay among children with Medi-Cal (75.2%) than among privately insured children (55.2%).
- Cost is a more common cause of delay among children in Healthy Families than in Medi-Cal. Cost contributed to twice as many delays among those in fee-for-service than in managed care Medi-Cal.

## **Medical Home**

Continuity of care is thought to improve health care quality through the relationship that develops between the provider and patient, based on provider knowledge about the patient. The American Academy of Pediatrics (AAP) promotes the medical home concept as a means of enabling access and coordinating care.

- About 85% of children in CCS have personal providers. For those in Medi-Cal or lacking insurance, children in Los Angeles CCS are more likely than CSHCN statewide to have a personal doctor.
- Receiving needed information is the lowest rated family-centered care measure. About two-thirds of parents (64.9%) report always receiving the specific information they need from the child's providers about topics such as the causes of any health problems, how to care for the child, and what changes to expect in the future.
- Parents of children in Medi-Cal report the lowest use of friends/relatives and children under age 18 years to translate medical information, and are mostly likely to always receive interpreter services when needed.

## **Family-Centered Care, Care Coordination, and Communication Among Providers**

Care coordination involves sharing of medical information between providers as well as helping parents navigate service systems. The health needs of CSHCN can affect their ability to attend school or child care, the need to arrange medical treatment or special accommodations in these settings, and their need for referral to and coordination with public programs such as early intervention and Regional Centers. Although interpretations of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) have increased the difficulty in care coordination, CCS is able to exchange medical information needed to coordinate care for the CCS condition.

- Parents give higher ratings for communication among medical providers than for communication between the medical system and other community programs/providers.
- Fewer parents reporting a personal provider say they often need to go back and forth between agencies to get needed services.
- Most parents (83.2%) say that the child's medical services are always or usually organized in a way that made them easy to use. These perceptions of service organization are considerably higher than those reported by parents of the broader population of CSHCN in 2001.

- Most parents who report needing care coordination in the past year say that they received all of the coordination they needed. About 13 percent of all parents (one-quarter of those needing coordination) did not receive all of the coordination needed. The most common reasons are that help was not offered to them (10 percent of all children in Los Angeles CCS), not knowing that coordination was available, a language or translation barrier, and being unable to find help with coordination.

### **Self-Management and Transition Support for Adolescents**

An increasingly important need for children in CCS is self-management of conditions, particularly as medical advances improve life expectancy. Recent expansion of CCS to income-eligible children with diabetes has also increased the program's role for children with chronic conditions for which self-management is key to future health status. Another emerging issue is planning the transition from pediatric to adult systems of care, given the CCS supports that are lost at age 21, and the shortage of physicians able and willing to provide quality care to young adults with congenital or severe chronic conditions.

- Most but not all young adults age 18-21 are always encouraged in self-management (69.8%). This is an increase from 53.5% of those age 13-17 years.
- Most parents (77.0%) of those age 13-21 who are never encouraged in self-management say they would find this helpful.
- About 50.0% of adolescents and young adults are not yet seeing an adult physician and have not discussed future changes with their doctor or any other provider or care coordinator. More than half of their parents say that such discussion would be helpful.

### **Experiences with CCS**

It is increasingly important for parents to be aware of CCS program resources. All children receiving medical services through Los Angeles CCS, or therapy services through the Medical Therapy Program (MTP), have an assigned nurse case manager. Within the complicated and often under-resourced service systems for CSHCN, efforts by CCS staff to identify and address needs of the child and family can be vital to the child and family's well-being.

- About two-thirds of parents report knowing the name of the child's nurse case manager at Los Angeles CCS.
- Parents are generally satisfied with their experiences with CCS. Using the parents preferred language, responding to requests, and helping to find needed services receive the highest parent ratings.
- The fewest parents (just over half) say that CCS staff usually ask if they need additional help (52.1%) or share the child's information with providers (52.2%).
- Parents enthusiastically support several hypothetical improvements to the system of care for children in CCS. The largest proportion of parents endorse the ideas of (1) having a single care coordinator, chosen by the family, who would help coordinate all of the child's services across programs and providers, and (2) providing more information and help to parents.



## **Conclusions**

CCS was created to reduce financial barriers to quality medical care. For most enrolled children, CCS appears to be serving its intended purpose. However, a minority of enrollees experience problems in getting needed care. Given the nature of the survey, it is not clear if the challenges families are facing are related to care for the child's CCS eligible medical condition or care for their other health related needs. The division of responsibility between CCS, health plans, and other public programs makes it difficult to know the specific causes of problems reported by families. Regardless, the survey provides additional evidence to those involved in providing care to these children of the need for a more coordinated system of care with fewer barriers to accessing high quality care in a timely way.

The Los Angeles CCS survey shows that the most frequent causes of delays are authorization problems and the timeliness of specialty appointments rather than cost concerns. Parents clearly identify neurology, orthopedics, and orthodontics/dental care as the most problematic areas of specialty care availability.

Patterns by insurance type suggest possible coordination or coverage problems for certain insured groups. Parents of children in Healthy Families report the highest rates of problems with authorizations and receiving needed specialty care. It appears that cost is a larger barrier for children in Healthy Families than in Medi-Cal, with children in managed Medi-Cal plans having the fewest cost-related delays among publicly insured children. Given the complexity of the system for children in CCS, the survey did not ascertain the proportion of authorization problems and delays that rest with CCS or with other insurance or a health plan.

One particularly positive area for children in Medi-Cal is much greater access to interpreter services, among those with a need. Yet unmet specialty and mental health/counseling needs in Medi-Cal still exceed the rates for privately insured children. The greatest population burden for most access concerns is in Medi-Cal, given that children in Medi-Cal are the majority of children in Los Angeles CCS. More than half of the children with delays (53%), problems with specialty care authorization (52%), and unmet specialty care need (59%) have exclusively Medi-Cal coverage.

The findings from this study suggest several strategies for improvement.

### **Addressing the supply of pediatric subspecialists**

There is a role for Children's Medical Services, possibly in partnership with the Medi-Cal Managed Care Division (MMCD) and the Managed Risk Medical Insurance Board (MRMIB) and commercial health plans, to better understand the supply of pediatric specialists in California. Given the standards in MMCD for time to appointment to primary care and specialty care, establishing expectations or norms for selected specialties used by CCS might enable California to continuously improve access to these providers using incentives and other strategies. While, the current supply might be improved by more efficient use of existing pediatric subspecialists and by payment rate changes, current information on these topics is limited. A comprehensive analysis of this problem is needed given the dynamic and complicated

nature of California's health care system and the potential for unintended consequences of new incentives.

### **Addressing pressures for cost reduction**

These survey findings show that caution in cost reduction for specialized services and chronically ill populations is warranted. For many with ongoing chronic conditions, childhood and young adulthood are the period of time when disease management skills develop, with important implications for the disease trajectory over the life course. There are significant potential cost implications for California if management of conditions such as diabetes and severe asthma is poor, in terms of workforce participation, productivity, and health expenditures (particularly for Medi-Cal).

### **Improving pathways to mental health/counseling services**

The survey showed that accessing mental health services was problematic, and the estimates in this survey likely underestimate need for mental health services/counseling. Lack of parent knowledge about where to get these services prevented about half of children with a need from obtaining needed care. Outlining the respective responsibilities and interfaces of public programs providing services for developmental, emotional, and behavioral concerns could help address informational barriers faced by providers. A statewide question is the extent to which CCS special care centers can improve any elements of the pathways to services through screening, referral, and billing changes.

### **Expanded transition support for adolescents and young adults with chronic conditions**

There is almost no information within the state about the effectiveness of current transition support and the health status and well-being of young adults who have graduated from CCS. This is an opportune time to evaluate transition support given plans within Medi-Cal Redesign to expand Medi-Cal managed care to the aged, blind, and disabled (ABD) population receiving Supplemental Security Income benefits.

### **Extending access to interpreter services across all insurance groups**

In Los Angeles CCS, children in Medi-Cal appear to have better access to interpreter services and much lower use of children under age 18 for translation. The current gap between Medi-Cal and both Healthy Families and private insurance may stem from different standards and expectations for provision of professional translation. This is an important issue for all children in CCS since there are substantial numbers of Spanish-speaking parents of children with private coverage and Healthy Families.

### **Ongoing needs assessment for CSHCN**

Ongoing assessment of needs, and information on any regional differences in parent experiences, would be very useful to the CCS program. In particular, further exploration is needed of the needs and unmet needs for parents of different educational backgrounds and language.

### **Supporting local stakeholder groups focusing on CSHCN**

Several of the health care disparities identified in this survey—such as information needs of parents, problems with specialty care authorization, lack of a personal provider, and communication gaps between physicians and community programs—have been the target of

California's Medical Home Project, created in 2001. An essential area is working with pediatric practices to be better organized around the needs of CSHCN by providing extra time and the information that parents need, among other practice improvements. Some elements of coordination between physicians and programs such as schools, and the back and forth between community agencies for services, deserve statewide solutions but can be initially tackled at the local level if financial support is provided.

**Taking advantage of statewide CMS information systems**

The new statewide Children's Medical Services information system (CMS-Net) created particular opportunities to improve information about the "medical home" for children in CCS. It is important to evaluate how this information system, and the associated changes to authorization procedures, may influence access. As counties begin to more routinely collect information about children's medical home, developing meaningful measures of this concept is vital. There is also an opportunity to more systematically assess parents' needs for information and assistance.

# Introduction

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This report profiles access to health care for children in California's CCS program. Data from a new parent survey show how well children with chronic illness are accessing primary and specialty health care services.

## **California Children's Services (CCS)**

The CCS program is administered by Children's Medical Services in the Department of Health Services. This medical care program pays for specialty services to children with complex and severe medical conditions. Providers must be approved by the State CCS program to be CCS paneled providers. There were 172,340 children in the statewide CCS program in fiscal year 2002-03, an increase of 4 percent from 2001-02. About 27,197 children were enrolled in the CCS Medical Therapy Program in 2003-03, an increase of 2 percent from the prior year.

The program is open to children from birth to age 21 years who have a CCS-eligible medical condition and meet financial eligibility.

- All medically eligible children in Medi-Cal automatically qualify. This includes the majority who have Medi-Cal due to low income as well as those who have higher income, with share-of-cost Medi-Cal or special Medicaid waivers. Medically eligible children in Healthy Families also are deemed eligible.
- Uninsured and privately insured children are eligible with household income below \$40,000 annually or when projected to spend more than 20% of annual family income on treatment of the CCS-eligible condition.
- For a narrower population of children with neuromuscular and orthopedic problems (predominantly cerebral palsy), therapy services are provided through Medical Therapy Units (MTUs) located in selected public schools. There are no financial eligibility requirements to receive therapy in MTUs.
- CCS pays for periodic assessments of children with risk of developmental and/or medical problems due to prematurity/low birthweight through the high risk infant follow-up program, irrespective of income.

Both diagnostic and treatment services are covered. For certain CCS diagnoses, children receive care through a hospital Special Care Center. In Los Angeles County, children in the CCS medical program as well as those in MTUs have an assigned nurse case manager.

The relationship between Medi-Cal and Healthy Families managed health plans and CCS varies by counties. In California's "Two Plan Model" counties such as Los Angeles County, CCS determines medical eligibility and authorizes payment of eligible specialty services for children in Medi-Cal who have CCS conditions. The role is similar for Healthy Families enrollees in health plans who have CCS eligible conditions. Under this "carve-out" model for CCS, other specialty care and primary care remains the responsibility of the health plan.

## **Meeting Health Care Needs of CSHCN**

Developing effective systems of care for children with special health care needs in California is a challenge to Medi-Cal, health care professionals, managed care organizations, and other public agencies providing services to this population. For children with chronic conditions, having a source of ongoing care and obtaining timely specialty care that is coordinated among providers requires a well organized system. Yet the health system for children is complex and fragmented. Many means-tested public programs have been developed specifically for children to complement private or public health insurance, but require separate applications and operate their own case management systems.

In recent years, the nature of special needs in children has changed. Advances in neonatal care are improving the survival of low birthweight infants. These improvements have led to an increased number of “medically fragile” children who need intensive monitoring and special services to thrive. Other advances in medical care are improving the life expectancy among children with conditions such as cystic fibrosis. As a result, many more children are surviving into adolescence and adulthood and need preparation for disease self-management as adults.

California’s Medi-Cal program faces particular challenges in assuring primary care, referrals, and specialty care. California has relatively generous Medi-Cal eligibility for children but nearly the lowest provider reimbursement rates among all state Medicaid programs. The statewide-adjusted monthly Medi-Cal managed care rate is among the lowest as well. Lower income households may have more difficulty with transportation and the ability to pay for needed care.

A recent Senate Office of Research report summarizes current policy challenges for improving access for children in CCS including reimbursement, workable models of care coordination, timely access to pediatric specialty care, having a “medical home,” and gaps in care in rural and medically underserved communities (Hansel and Reifman 2000). Developing systems of care for children with special health care needs has become increasingly difficult given the complexity of programs and service models.

### **The Los Angeles CCS Survey**

In 2001, the first statewide information in California on access for CSHCN became available through the National Survey of Children with Special Health Care Needs (NS-CSHCN). This survey used a broad definition of special needs that includes complex medical diagnoses as well as moderate conditions and emotional or behavioral disorders. The NS-CSHCN did not include diagnostic information and did not identify CCS eligible children among respondents.

In contrast, the 2005 Los Angeles CCS survey was specifically designed to inform the CCS program and profiles access to services that are targeted to special needs populations, such as care coordination and specialty services.

# Methodology

## Survey Design

This survey provides data on access, utilization, care coordination, and satisfaction with care for 2,000 randomly sampled children in the Los Angeles CCS program. The survey reflects parent perceptions of child health need and health care access. The specialty access survey was developed in 2003 by the UCLA Center for Healthier Children, Families and Communities. Input on the questionnaire design and content was provided by the Los Angeles CCS program and by parent advisors convened by the Family Centered Care Committee of the Los Angeles CCS program. Selected measures are drawn from or adapted from the 2001 National Survey of Children with Special Health Care Needs to permit comparisons with the 10% of California children identified in that survey as CSHCN.

The CCS survey includes information on key questions about health care for CCS enrollees:

- Are the special health care needs and the concerns of parents being addressed?
- What is the quality of primary, specialty, and ancillary care that children receive?
- Are children receiving comprehensive care in a medical home?
- Do children in Medicaid and children with private insurance appear to receive services of similar quality and comprehensiveness?
- Are children receiving the care coordination that they need?

Survey content is summarized in **Exhibit 1**.

<b>Exhibit 1</b>	
<b>Indicators of Health Care Access in Los Angeles CCS Survey</b>	
<b>Access to Specialty Care</b>	<b>Health Insurance</b>
Problems obtaining authorization for specialty care Unmet specialty care need Type of unmet specialty care need	Type of insurance Medi-Cal managed care
	<b>Access to Transition Services for Adolescents</b>
<b>Delays and Missed Care</b>	Planning for child's changing needs Transition from pediatric to adult providers
Unmet health care needs Type of access barriers Received assistance in accessing services	
	<b>Delays and Missed Care</b>
<b>Access to a Medical Home</b>	Unmet health care needs Type of access barriers Received assistance in accessing services
Usual source of care for condition Types of settings for care Having a personal doctor or nurse Access to preventive services	
	<b>Family Centered Care</b>
<b>Care Coordination</b>	Adequacy of information provided, providers listen carefully, parent treated as partner, spend enough time, sensitive to family values Access to interpreter services
How well medical providers communicate/coordinate How well medical providers communicate with other How well specialized services are organized Coordination from CCS	
	<b>Experiences with CCS</b>
	Current experiences and potential improvements

The questionnaires were translated into Spanish in two independent translations. Survey content and contact materials were reviewed by the Los Angeles CCS Family Centered Care Committee for comprehension and cultural appropriateness to improve the validity of reports. The survey protocol and materials were reviewed and approved by the Institutional Review Boards (IRB) of the Los Angeles Department of Health Services and UCLA. Survey findings are based on parent report from telephone interviews.

## **Sampling**

A total of 4,000 letters were mailed to a random sample of parents of children active in the Los Angeles County CCS program. Activity in the CCS program was defined as having a service authorized or denied within the 12 months preceding the sampling. Parents received introductory letters from UCLA and CCS along with a research information sheet describing the study and their rights. No incentives for participation were provided. About 120 children (3.0%) were excluded due to returned mail, and another 877 children (21.9%) were excluded due to a disconnected telephone number. A total of 1.6% were contacted but declined to be interviewed. The response rate was 71.9% using standard definitions of the American Association for Public Opinion Research and the Council of American Survey Research Organizations (CASRO).

Interviews were conducted with 2,000 parents of children age 0-22 years. Interviews were conducted in English (62.8%) or in Spanish (37.2%). Most parents (78.6%) recalled receiving this letter. About 8.7% reported that at any time in the past year their household had been without telephone service.

The child's mother or father was the respondent in 91.0% of interviews. The child's mother was the respondent in most interviews (78.8%), while the father was the respondent in 12.2% of interviews. The remaining 9.0% of interviews were completed by someone other than the parent. These respondents were another relative (6.0%), grandparent (2.0%), or foster parent (0.8%).

## **Analysis**

Comparisons are statistically significant ( $p < 0.05$ ) unless otherwise indicated. Chi square tests of independence are used to compare percentages across subgroups.

Some comparisons contrast children in Medi-Cal to those with private health insurance, Healthy Families coverage, and no insurance. Medi-Cal is the sole source of coverage for many low-income children but a partial coverage or supplemental payment program for others. Children with dual coverage (Medi-Cal as well as private coverage) primarily use their private health insurance and utilize Medicaid as a secondary payer for those services that are not covered by their private insurance. In this survey, about 24.1% of parents report that their child has both Medi-Cal and private coverage.

Because understanding the experiences of children with Medi-Cal coverage is important, some comparisons combine children with exclusively Medi-Cal coverage and children with both Medi-Cal and employer-based coverage. In other comparisons, estimates for children with both

Medi-Cal and private coverage are compared with estimates for children with exclusively Medi-Cal coverage.

About 11.5% of children are reported to have both Healthy Families and employer-based coverage. Having both is permitted on only a temporary basis by the Managed Risk Medical Insurance Board (MRMIB), which administers the Healthy Families program. In this report, these children are classified as having Healthy Families coverage.

Despite substantial differences between children in CCS and the broader population of CSHCN, selected comparisons are made in this report to show where experiences with access are similar and where patterns differ. Other than the fact that children in CCS have greater severity conditions and comprise a small subgroup of CSHCN generally, comparisons in this report between CCS and the general population of CSHCN statewide have the following limitations: (1) the CCS survey includes children 0-22 years while the CSHCN estimates include children 0-17 years, (2) the CCS survey was conducted in 2005 while data for CSHCN were collected in 2001, and (3) the CCS survey is limited to Los Angeles while the CSHCN data are statewide.

To achieve comparability on age, the **Appendix** shows how CCS and NS-CSHCN populations compare, using the full sample from the NS-CSHCN and the subsample of children age 0-17 years from the CCS survey.



## Part I

# Characteristics of Children in CCS

**C**haracteristics of Children in CCS provides basic information about children in the Los Angeles CCS program. It compares these children with characteristics of CSHCN in California. These characteristics provide an important context for understanding the key indicators of health care access. Severity and impact of condition provide basic information about the impact of health conditions on children's daily activities.

- ❖ Sociodemographic Characteristics of Children in CCS
  - ❖ Condition Severity and Impact
  - ❖ Type of Conditions

## Sociodemographic Characteristics of Children in CCS

**Exhibit 2** presents the sociodemographics of children in the Los Angeles CCS program and the larger population of CSHCN statewide.

- While the prevalence of chronic health conditions in the general population increases with age, the age distribution within CCS is more evenly distributed between early childhood, middle childhood, and adolescence.
- Parent educational levels show the lower socioeconomic status of children in CCS compared to CSHCN generally. Nearly half of parents of children in CCS have less than a high school education compared to about 19% of parents of CSHCN statewide.
- The racial/ethnic distribution also reveals differences between Los Angeles CCS and CSHCN children statewide, with Latino children comprising about 80% of children in CCS and only about one-third (31%) of CSHCN statewide.

<b>Exhibit 2</b>		
<b>Sociodemographic Characteristics of Children in Los Angeles CCS and CSHCN in California</b>		
	<b>Los Angeles CCS (2005)</b>	<b>Statewide CSHCN (2001)*</b>
	<b>%</b>	<b>%</b>
<i>Age</i>		
< 5 years	34.8	18.2
6-11 years	25.7	35.8
12-17 years	30.0	46.0
18-21 years	9.2	---
<i>Parental Education</i>		
Less than high school	44.2	19.2
High school diploma or GED	30.4	23.8
Some college	19.1	37.0
College graduate or higher	6.3	20.0
<i>Child Race/Ethnicity</i>		
Non-Hispanic White	5.8	49.1
Hispanic	80.2	31.0
African-American	8.3	10.0
Asian/Pacific-Islander**	4.5	2.3
Multiracial or Other	1.2	7.6
<i>Health Insurance***</i>		
Private coverage	34.3	78.8
Medi-Cal only	56.1	15.2
Healthy Families	8.0	1.7
Uninsured	1.6	4.4

Sources: Los Angeles CCS Survey (2005) for children age 0-21 years and the National Survey of Children with Special Health Care Needs (2001) for children 0-17 years

\*\* For the NS-CSHCN, Pacific-Islander children are classified as "Other" or "Multiracial".

\*\*\* Percentages for Medi-Cal include only children reported to have exclusively Medi-Cal coverage. The private coverage category includes children reported to have both private employer-based coverage and Medi-Cal coverage.

More CSHCN statewide in 2001 (78.8%) than children in Los Angeles CCS (34.3%) have private insurance. About 15.2% of all CSHCN, and 56% of children in CCS, are solely covered by Medi-Cal, according to their parent.

- Fewer children in CCS than CSHCN statewide are uninsured. This is expected given higher likelihood of Medi-Cal eligibility for low-income children with high medical need.

**Exhibit 3** compares demographic factors of CCS children with different insurance coverage.

- Parents of children with exclusively Medi-Cal coverage have the lowest education. More in Medi-Cal and Healthy Families are Latino, and Latino with Spanish-speaking parent.
- Children with Medi-Cal coverage—with or without private coverage—have greater condition impact on daily activities. Condition severity is highest for children with Medi-Cal only and with Healthy Families coverage. This may reflect greater use of the CCS program among privately insured children for physically disabling conditions.
- Children in Medi-Cal are younger, with 32.5% of dual Medi-Cal/private coverage and 41.9% of Medi-Cal only age 0-5 years, compared to 17.9% of privately insured children.

<b>Exhibit 3</b>					
<b>Characteristics of Children in Los Angeles CCS, by Insurance Type</b>					
	Private (n=190)	Medi-Cal & private (n=482)	Medi-Cal only (n=1,099)	Healthy Families (n=157)	Uninsured (n=32)
	%	%	%	%	%
<b>Parent education</b>					
Less than high school	32.1	35.1	***51.2	35.7	40.6
High school	36.8	29.9	29.6	31.2	21.9
More than high school	31.0	35.1	19.2	33.1	37.5
<b>Child race/ethnicity</b>					
Latino-English	67.2	***54.5	***37.0	***40.5	***50.0
Latino-Spanish	8.1	20.2	46.9	47.1	36.7
Non-Hispanic White	13.2	5.9	5.1	3.2	3.1
African American	4.8	13.3	7.4	3.8	3.1
Asian/Pacific Islander	6.4	5.7	3.5	5.1	0.0
<b>Activities affected often/always</b>					
Severity (mean, 0-10)	25.8	**38.5	***47.9	23.6	15.6
	6.1	5.7	*6.6	***7.2	5.8
<b>Child age</b>					
Less than 12 months	5.8	**12.0	***9.3	***0.0	18.8
1-5 years	12.1	20.5	32.6	13.4	12.5
6-12 years	42.6	30.3	29.9	20.4	31.2
13-17 years	31.0	26.1	20.3	52.9	28.1
18-22 years	8.4	11.0	7.9	13.4	9.4
Two parents in household	78.4	**65.0	*71.1	80.8	86.2

Source: Los Angeles CCS Survey, 2005

Note: Percentages are calculated from the total base of children in the insurance category. The private insurance category is limited to children with exclusively private coverage. Latino children are classified as Latino-English or Latino-Spanish based on the language of the interview.

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$  for comparison to privately insured (chi square)

## Condition Severity and Impact

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### Severity of Condition

Parents reported severity of the child's current medical conditions, using a scale of 0 to 10, with 10 indicating greatest severity. **Exhibit 4** shows that parents most often report moderate severity (rating of 5) (16.3%) or the highest severity (rating of 10) (23.3%). As expected, average severity is higher among children in CCS (mean of 6.3) than among the general population of CSHCN in California (4.2) as measured in the 2001 NS-CSHCN.

About 6.5% of parents give the lowest rating. Of these parents, about one-third report that their child currently has no medical condition. More of these children had been premature or low birthweight. About 32.8% are under the age of one year, compared to only 7.5% of other CCS children. These low severity ratings within the CCS population are likely due to children in the CCS high risk infant follow-up program and children receiving diagnostic/evaluation through CCS.

### Changing Needs

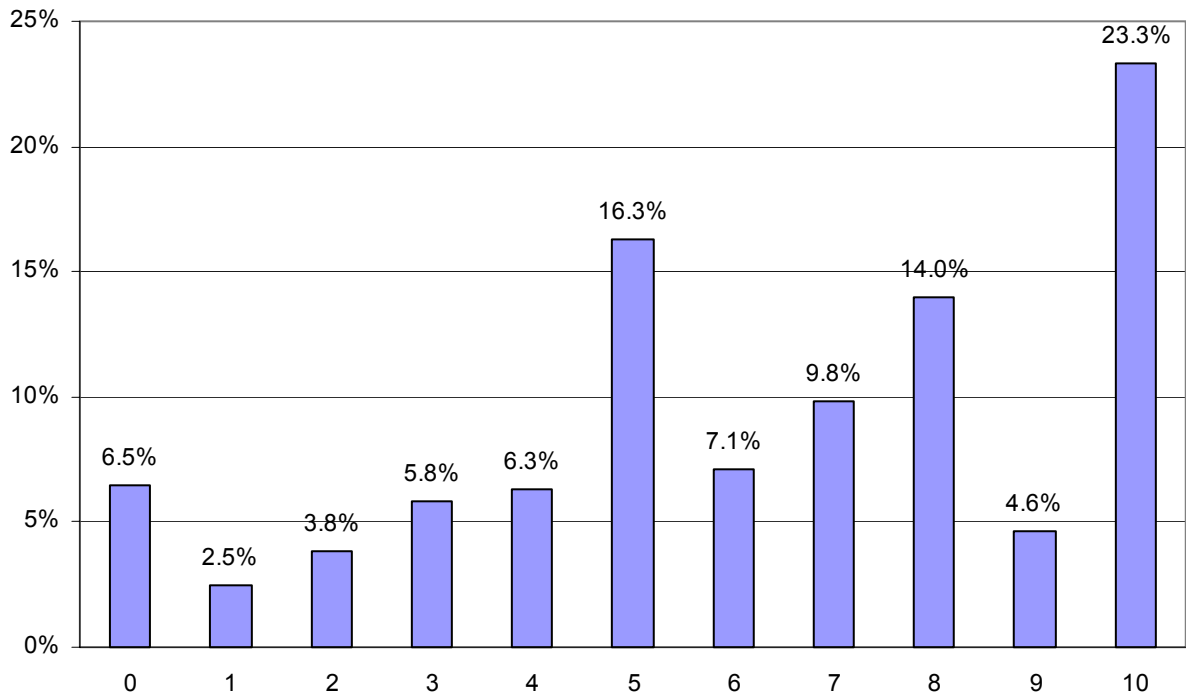
Not all CSHCN are affected in the same way by their health condition(s). Some chronic conditions, such as sickle cell anemia and asthma, are episodic and do not always affect the child in the same way each day. Other chronic conditions such as cerebral palsy tend to have the same impact on the child on an average day. The majority of parents (59.6%) say that their child's health care needs are usually stable. For about 24.8%, needs sometimes change. For about 15.6%, the child's needs are changing all of the time. Changing needs are associated with higher severity conditions; about half of children whose needs change all of the time have the highest severity rating (10).

### Impact on Activities

Most children are at least sometimes affected in their daily activities (69.2%). About 40.5% of children in CCS are reported to be "always" or "usually" affected by their condition.

Nearly one-third of parents (32.9%) report that the medical condition never affected the child's regular activities over the past year. For some of these children, the condition may be managed so well that symptoms do not interfere with daily activities. Others may not be impaired in daily activities but are awaiting further treatment for a significant problem (e.g., for a congenital heart condition). For example, 38.6% with diabetes, 39.0% with a heart condition, and 46.9% with prematurity/low birthweight were unaffected in their regular activities over the past year. Finally, this group includes those children whose CCS eligible condition was resolved during the past year.

**Exhibit 4**  
**Parent Rating of Severity of Condition**



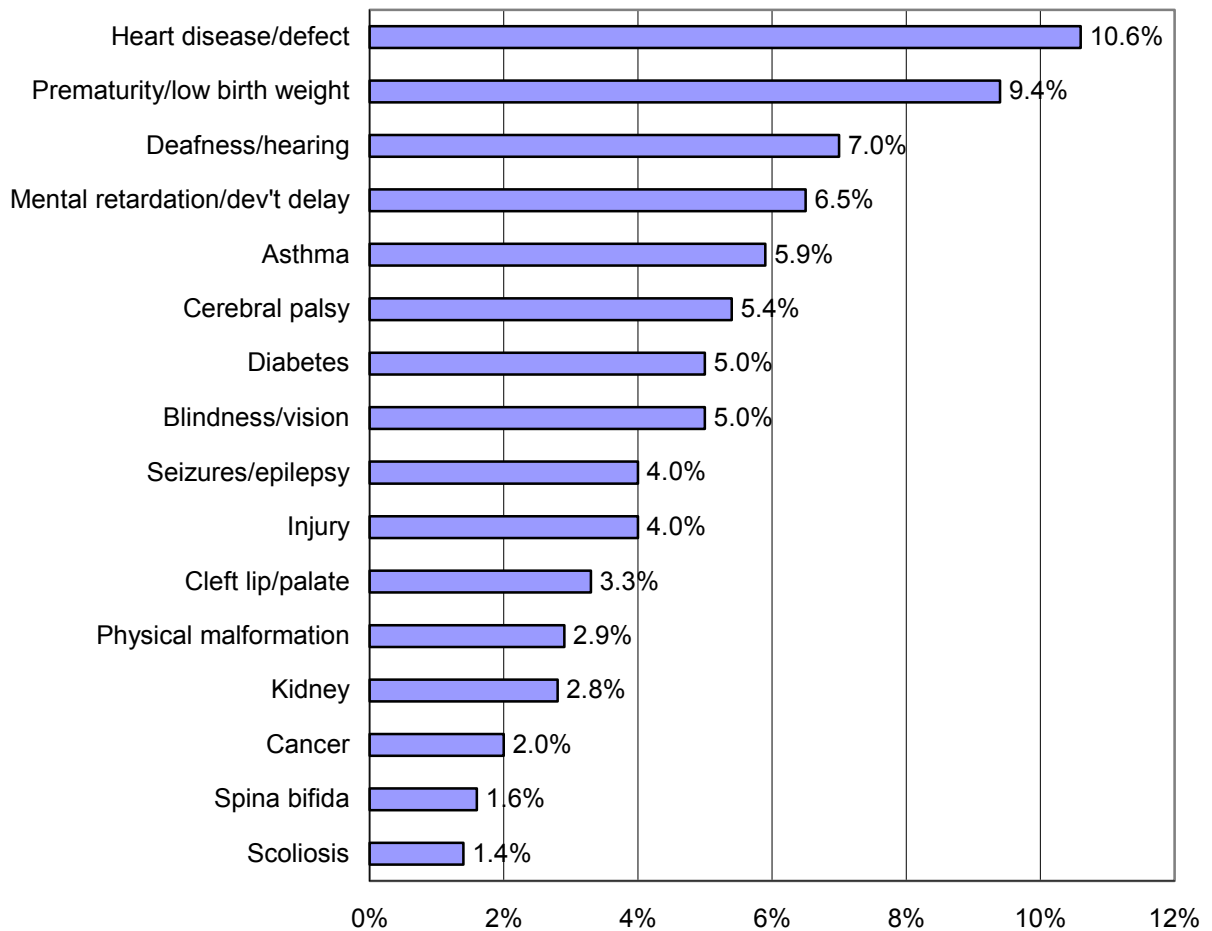
*Note: Parents rated severity of the child's condition(s) using a scale of 0-10, with 10 indicating greatest severity.  
Source: Los Angeles CCS Survey, 2005*

**Types of Conditions**

Medical conditions identified by the parent are provided in **Exhibit 5**. Parents were asked about the child's health conditions and not specifically about the condition(s) for which the child qualified for CCS. This was done in part because the study examines care for children in CCS, not care for specific diagnoses. In addition, parents of children with multiple problems may not always be able to identify the specific condition(s) that qualified the child for CCS. As a result, not all conditions identified by the parent are CCS eligible conditions.

Given the broad range of conditions covered by CCS, the percentage of children with any particular diagnosis is relatively small. The most commonly reported conditions are heart disease/congenital heart defect (10.6% of all children), prematurity or low birth weight (9.4%), asthma (5.9%), deafness/hearing (7.0%), vision (5.0%), cerebral palsy (5.4%), diabetes (5.0%), and injury (4.0%). Although statewide rates of CCS conditions are not available, these conditions reflect some of the most common reasons for receiving services through CCS.

**Exhibit 5**  
**Medical Conditions of Children in CCS**



*Note: Some children have more than one condition. For these children, parents rated the severity of the condition that causes the most problems for the child. Other conditions with low frequency are not listed here. About 3.7% of parents did not identify a current condition or a condition for which CCS services had been provided.*

*Source: Los Angeles CCS Survey, 2005*

**Exhibit 6** shows that some types of conditions are associated with insurance type.

- Conditions that are more common for children in Medi-Cal than for privately insured children include heart conditions, cerebral palsy, developmental delay, and hearing and vision problems.
- In contrast, more privately insured children than children in Medi-Cal or in Healthy Families were low birthweight/premature. This may be due in part to high risk infant follow-up as a means of including privately insured children in CCS. For example, 55.9% of privately insured children age 0-5 years, compared to 21.0% with private/Medi-Cal and 19.1% with Medi-Cal only, are reported with a medical condition of prematurity/low birthweight.

- More children in Healthy Families than with Medi-Cal have diabetes, although there are no differences between children with Medi-Cal and with private coverage. Due to recent legislation, all income eligible children with diabetes now qualify for CCS.
- More children with private insurance, or with private and Medi-Cal coverage, have no condition reported (nearly 10%) in comparison to children with exclusively Medi-Cal or Healthy Families coverage.

<b>Exhibit 6</b>				
<b>Frequencies of Conditions, by Insurance Type</b>				
	Private (n=190)	Medi-Cal & private (n=482)	Medi-Cal only (n=1,099)	Healthy Families (n=157)
	%	%	%	%
Heart condition	5.8	9.8	**12.2	8.3
Prematurity/low birthweight	15.3	11.6	*8.3	(a) ***3.8
Deafness/hearing	(a) 1.0	**6.0	***9.4	0.0
Developmental delay	(a) 2.1	*6.6	**8.0	(a) 3.8
Asthma	4.7	4.8	6.6	(a) 5.1
Cerebral palsy	1.6	7.9	5.7	1.9
Diabetes	5.8	6.0	4.1	§10.2
Vision	(a) 0.5	5.4	6.0	(a) 1.9
Seizures/epilepsy	5.7	2.7	4.1	(a) 6.4
Injury	5.8	*2.5	4.1	(a) 6.4
Cancer	(a) 2.6	2.9	2.0	0.0
No condition	9.5	8.9	(a) ***0.2	(a) **1.3

Source: Los Angeles CCS Survey, 2005

Note: Percentages are calculated from the total base of children in the insurance category. The private insurance category is limited to children with exclusively private coverage. \* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$  for comparison to privately insured (chi square). § $p < 0.01$  for comparison to Medi-Cal (chi square). Some children have more than one condition and are included in more than one category in the Exhibit.

(a) denotes percentage does not meet standard criterion for precision.

## Summary

Parent educational levels show the lower socioeconomic status of children in the Los Angeles CCS program. Nearly half of parents of children in CCS have less than a high school education, including 51.2% of children with exclusively Medi-Cal, compared to 19% of the broader population of CSHCN.

Reflecting the general statewide pattern, the most commonly reported conditions reported by parents were heart disease/congenital heart defect (10.6%) and prematurity or low birth weight (9.4%). The survey also shows that just under half of children in CCS (40.5%) are reported to be “always” or “usually” affected by their condition. For others, the condition may be managed so well that symptoms do not interfere with daily activities, or they may be awaiting further treatment for a significant problem.

## Part II Specialty Care

**S**pecialty Care describes children's experiences with obtaining specialty health care. It includes specialty medical care as well as experiences obtaining particular types of specialized services.

- ❖ Specialty Care
- ❖ Delayed and Foregone Care
- ❖ Mental Health Services



## Specialty Care

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Being able to see the health care providers that the child needs is a critical access indicator. Availability of pediatric sub-specialists, such as pediatric neurologists, and willingness to participate in public insurance programs is a statewide policy concern. There are concerns that children have difficulty accessing some specialty care due to inadequate pediatric subspecialty supply, provider participation in public insurance programs, waits imposed by limited provider availability, and problems obtaining authorization from the CCS program or from their private insurance plan's restrictions (Hansel and Reifman 2000). Health plan network restrictions and out-of-pocket cost for non-network providers may pose barriers. Area of residence may impair parents' ability to get the child to the providers needed.

This study examines both problems with authorization and the actual outcome of receiving the needed specialized services. Children may have problems obtaining referrals for specialty care, finding a provider who accepts the child's insurance or getting timely care, or both. The survey did not identify the source of the difficulties (e.g., CCS or the child's health plan) or the nature of the care (i.e., needed for the child's CCS condition or for another medical problem). Even without this important detail, information about authorization problems is still useful because irrespective of source, such problems are affecting children within the CCS program.

### Difficulty with Referrals or Authorization

About three-quarters of children in CCS (72.0%) required an authorization or referral for specialty care in the past year. About 23.5% of these children experienced a problem with authorization, including 11.6% with a big problem and 11.9% with a small problem. In 2001, a similar proportion of parents of CSHCN in California (21.1%) reported having a problem obtaining a needed referral.

Of those children with a problem obtaining authorization, the type of provider was most often a cardiologist, neurologist, or orthopedist. The most frequently mentioned specialty types were a cardiologist (11.0%), neurologist (10.1%), orthopedist (9.1%), and orthodontist (12.8%).

Authorization problems for specialty care differed with the child's insurance coverage. The survey did not specify CCS or another entity in asking about authorization problems so it is not known if the parent believed the specialty care authorization problem rested with CCS or another entity, such as a health plan or another public program.

- Problems obtaining referral or authorization for needed specialty care were most frequent among children in Healthy Families, affecting nearly one-third (30.6%) compared to about 15% of children with private insurance or with Medi-Cal (**Exhibit 7**).
- Children in Healthy Families had the highest rate of big problems with authorization (19.7%).
- Overall rates for Medi-Cal and privately insured children were similar within Los Angeles CCS. The broader population of CSHCN statewide had lower overall rates of problems, but also showed similar rates for Medi-Cal (34.9%) and for privately insured children in lower income households (below 200% FPL) (30.3%); rates for higher income privately insured children were much lower (15.7%).

<b>Exhibit 7</b>						
<b>Problems with Specialty Care Authorization and Unmet Need, by Insurance Type</b>						
	Private	Medi-Cal		Healthy Families	Uninsured	
		All	Medi-Cal & private	Medi-Cal only		
	(n=190)	(n=1,568)	(n=482)	(n=1,099)	(n=157)	(n=32)
Needed specialty care referral	85.8	86.7	82.4	87.6	86.6	81.2
Any problem obtaining referral	15.3	15.8	16.0	15.6	***30.6	21.9
Big problem obtaining referral	4.2	7.7	6.0	*8.4	***19.7	*15.6
Unmet need for specialty care	5.8	7.5	5.0	8.5	**16.6	(a) 9.4
Unmet need due to cost	(a) 0.5	2.2	1.9	2.3	**11.5	0
Unmet need due to health plan	(a) 1.0	3.1	(a) 0.9	4.0	***14.6	0

Source: Los Angeles CCS Survey, 2005

Note: Percentages are calculated from the total base of children in the insurance category. The private insurance category is limited to children with exclusively private coverage. Problems obtaining referral are due to referral or authorization. \* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$  for comparison to privately insured (chi square). § $p < 0.01$  for comparison to Medi-Cal (chi square).

(a) denotes percentage does not meet standard criterion for precision.

- Three rates for Medi-Cal are provided in **Exhibit 7**: (1) the overall rate, (2) those with both private and Medi-Cal coverage, and (3) those with exclusively Medi-Cal. More children with exclusively Medi-Cal coverage had big problems (8%) than children with both Medi-Cal and private coverage (6%) or exclusively private coverage (about 4%).
- Among those exclusively in Medi-Cal, rates of authorization problems were similar for children reported to be in managed health plans and those in fee-for-service.

These insurance patterns are concentrated in certain demographic groups.

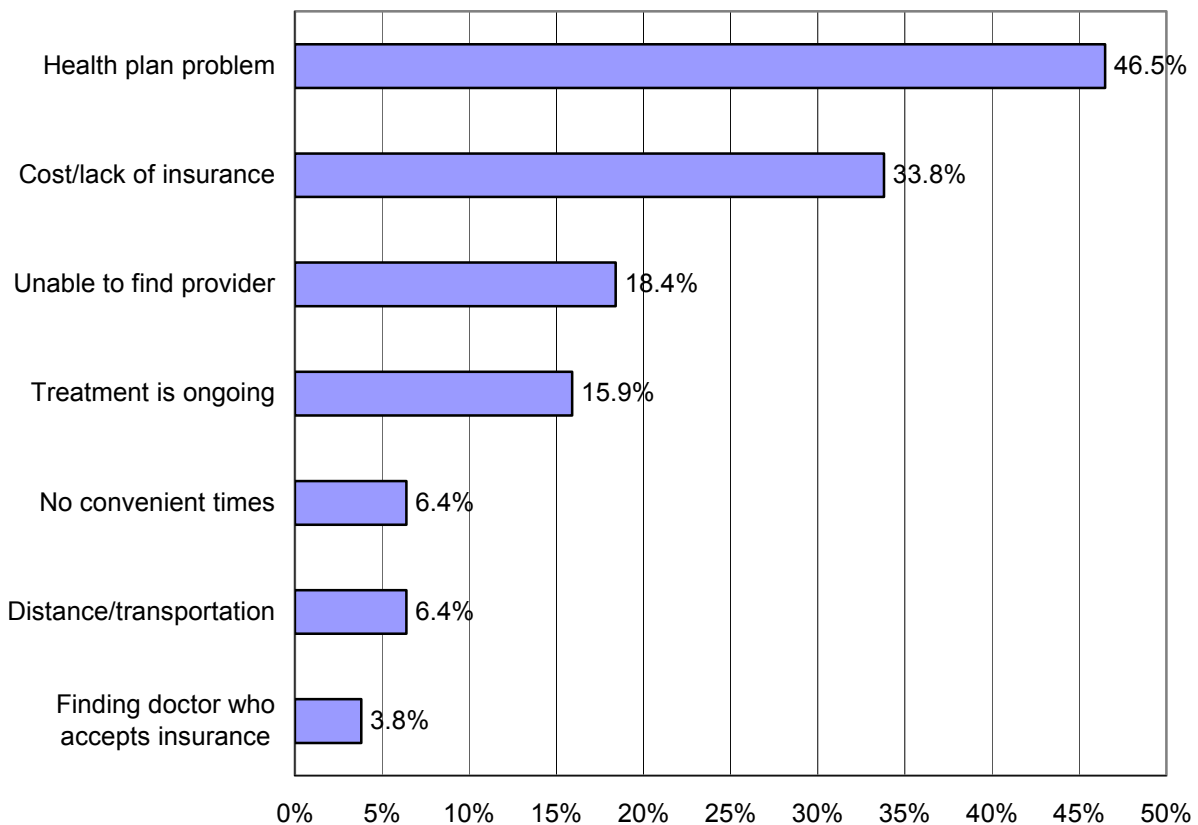
- Parents with lower educational attainment (less than high school, and high school only) reported at least twice the rate of specialty authorization problems when their child is in Healthy Families. For example, among parents with less than high school, 34.0% with a child in Healthy Families and only 16.7% with a child in Medi-Cal reported an authorization problem.
- Parents of Latino children who interviewed in Spanish also reported much higher rates of authorization problems in Healthy Families. For example, among this demographic group, parents of 52.6% with a child in Healthy Families and only 19.2% with a child in Medi-Cal reported an authorization problem. There was no insurance-related difference for parents of Latino children who interviewed in English.

## Unmet Need for Specialty Care

Problems obtaining authorization did not always prevent children from getting needed specialty care. Most children ultimately received the needed specialty care. However, about 7.9% of children in CCS did not obtain all of the specialty care needed in the past year. This is about one-quarter (26.0%) of those experiencing an authorization problem. Comparison to CSHCN statewide in California in 2001 shows that children in CCS have twice the rate of needed specialty care not received (7.9% compared to 4.5%).

- Children with unmet needs for specialized care had higher severity conditions than those receiving all needed care. Severity ratings were higher among children experiencing delay due to cost, authorization, or getting a timely appointment, compared to others.
- Care from an orthodontist, neurology, dental care, and endocrinology were the most frequently identified types of specialized care not received.

**Exhibit 8**  
**Reasons for Not Receiving Needed Specialty Care**



Source: Los Angeles CCS Survey, 2005

Note: Shows reasons among children who did not receive all specialty care needed. Parents may cite multiple reasons.

## Reasons that Specialized Care was not Received

**Exhibit 8** shows the reasons that children who needed specialty care did not receive services. About one-half (46.5%) of unmet specialty care needs were attributed to a problem obtaining care through the health plan. Cost of the care was identified for 33.8% of children. About 18.4% were unable to find a provider who could treat the problem. A relatively small percentage (about 3.8%) were unable to find a provider who accepted the child's insurance (whether private, Medi-Cal, CCS, or some other payment type). About 15.9% of parents reporting an unmet need said that treatment was ongoing. For these children, the unmet need may not indicate an access problem and instead indicate an ongoing treatment process.

Cost should not be a major barrier to care for the CCS condition for children in the CCS program. However, parents can encounter uncovered costs for the child's care or equipment in certain circumstances. These include when CCS determines that the care is not required specifically for the CCS eligible condition; when parents seek care although CCS has determined that the care is not medically necessary for the condition, or a benefit of CCS, for medical reasons; when the expense is part of the monthly "share of cost" for children in this Medi-Cal coverage category; or when private insurance cost-sharing (co-payments or deductibles) apply.

## Child Characteristics Associated with Authorization Difficulties and Unmet Specialty Need

Patterns of referral problems, unmet specialty care need, and reasons for unmet specialty care needs show the following (**Exhibit 7**):

- Unmet needs for specialty care were highest for children in Healthy Families.
- Children with exclusively Medi-Cal coverage were more likely to have an unmet need than children with both Medi-Cal and private coverage, or exclusively private coverage.
- Unmet need due to a health plan problem was highest for children in Healthy Families (about 12%), followed by children with exclusively Medi-Cal coverage (about 4%).

Among those with unmet needs for specialty care, comparison of Medi-Cal with Healthy Families shows that cost and health plan problems were more common among Healthy Families enrollees.

- Among children with an unmet need for specialty care, parents of children in Healthy Families were more likely to report the cost of care as a problem than children in Medi-Cal (69.2% vs. 29.1%).
- Unmet specialty care needs due to a problem with the health plan were also more frequently reported for children in Healthy Families (88.5%) than for children in Medi-Cal (41.0%).

Comparison of children with Medi-Cal coverage only, and children with any private coverage (with or without Medi-Cal coverage) shows several patterns.

- Unmet need for specialty care was less common among children with any private coverage (5.3%) than among children with Medi-Cal (8.5%).

- Reasons of authorization requirements and inability to find a provider were equally common among privately insured and Medi-Cal insured children.

Among children with exclusively Medi-Cal coverage, comparison of children reported to be in a managed health plan with those reported to be in fee-for-service Medi-Cal shows the following.

- As noted earlier, problems with authorization occurred at the same rate for both groups.
- Unmet need for specialty care was higher among those in fee-for-service (10.4%) than among those in managed health plans (6.6%).
- Among those with unmet need, cost was just as often a reason for managed care as for fee-for-service Medi-Cal (29.4% vs. 21.8%). Inability to find a provider accepting the child's insurance also occurred at similar rates (14.7% vs. 21.8%).

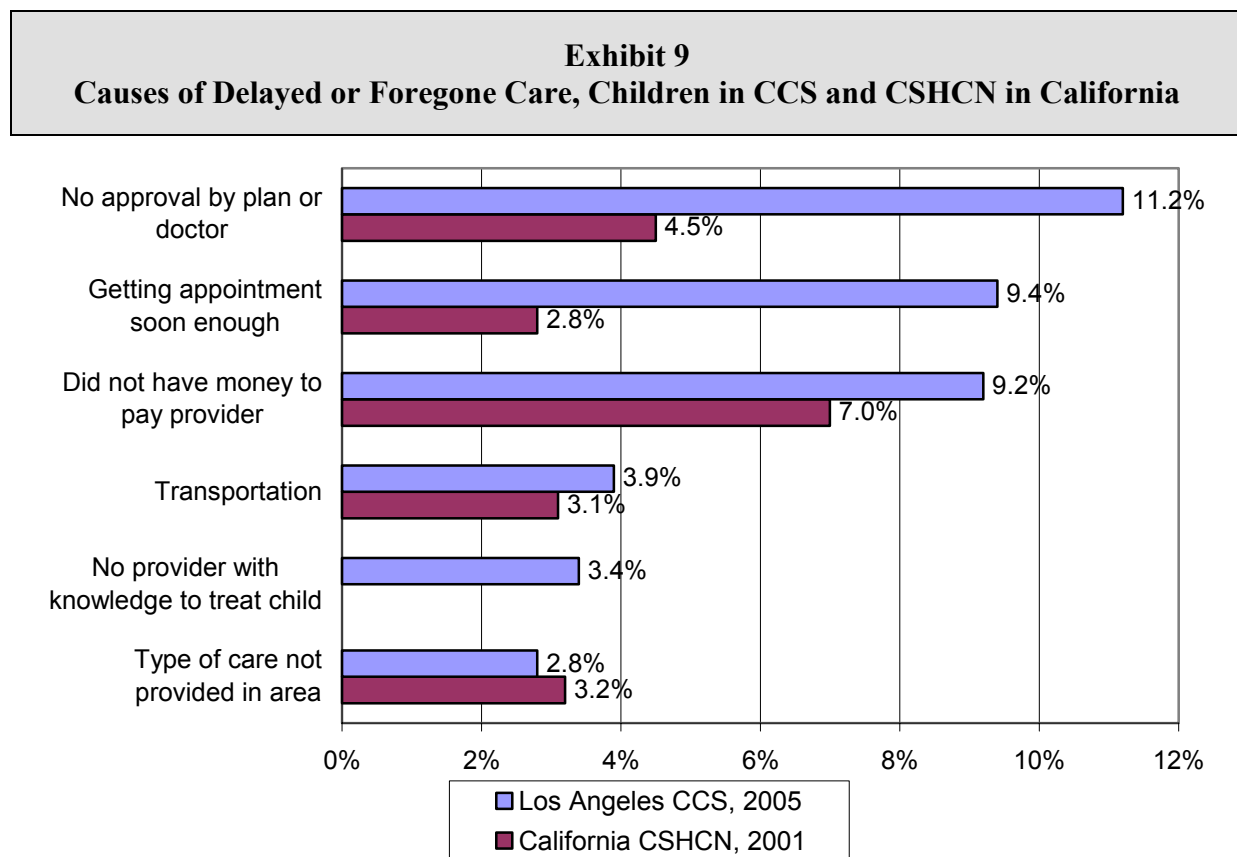
Factors other than the child's insurance coverage could influence these apparent differences. For example, parent educational attainment varies with the child's health insurance coverage and might itself influence perception of need and care-seeking, and therefore influence perceptions of needed care not received. Comparing children by insurance coverage and parent education shows the following:

- Reports of specialty care problems were higher among more educated parents. Authorization problems were reported by 18.7% of parents with less than high school, 27.6% of those with high school only, and 28.1% of parents with more than high school. Unmet specialty care needs also increased with education level at 6.6%, 8.0%, and 10.3% respectively.
- Both authorization problems and unmet specialty care needs were twice as high for children in Healthy Families than for other children. Among parents with more than a high school education, however, there were no differences in either outcome by insurance type.
- The substantially higher rates of authorization problems and unmet specialty care needs for children in Healthy Families compared to children with other coverage appears concentrated in the poorer experiences of a specific subgroup. There were much higher unmet needs reported by less educated, Spanish-speaking parents of Latino children in Healthy Families. For others in this demographic group who have private insurance or Medi-Cal, rates of unmet need were much lower.

## Delayed and Foregone Care

Children in CCS may require a range of services. Examples include preventive care, specialty care, mental health care, physical/occupational/speech therapy, dental care, vision/hearing care, and respite care. About 18.4% of parents in CCS reported that in the past year, their child had delayed or missed care that they needed. The rate of delayed or missed care in CCS is slightly lower than the rate for the larger population of CSHCN in California in 2001 (23.2%).

Reasons that children may not receive needed care include cost of the care for the family, problems getting referral or authorization, transportation to the provider, and the ability to get appointments at times that are convenient to the family. **Exhibit 9** shows the rates among all children in CCS, not only those with any delay. As with barriers for specialty care, a common reason is obtaining authorization or approval, which was a reported barrier for half of children (49.6%) with a delay, comprising 11.2% of all children in Los Angeles CCS. A similar proportion of parents reported inability to get an appointment as a contributing factor (51.2%). About half identify cost as a barrier (50.6%). About one-quarter (21.0%) could not obtain the type of care needed in their area, while somewhat fewer (18.3%) had been unable to find a provider who could treat the child's problem.



*Source: Los Angeles CCS Survey, 2005 and National Survey of Children with Special Health Care Needs, 2001*  
*Note: Percentages are the proportion of all children in the survey with delayed or foregone care due to the specific reason. Parents may give more than one reason.*

Rates of delayed or foregone care due to lack of authorization were the highest (with 11.2% of all children in Los Angeles CCS experiencing a delay due to an approval process), followed by getting an appointment soon enough (9.4%). The cost of services was also frequently reported (affecting 9.2% of children). As noted earlier, although in principle cost should not be a major barrier for needed care for the CCS condition, parents can encounter costs for care or equipment in several circumstances. These include when the care is not considered to be required for the CCS eligible condition; when the care is not authorized by CCS for the condition for medical reasons; when the cost is part of the child's Medi-Cal "share of cost"; when the child has private insurance and cost-sharing associated with this coverage applies (e.g., co-payments or deductibles).

Other reasons for delayed or foregone care were less frequently reported by parents: finding care in the area, finding a provider at all, and securing transportation. Comparison to California CSHCN in 2001 shows that the major cause of delayed care for CSHCN statewide was the cost of care. As might be expected given the greater severity of conditions in CCS compared to the broader population of CSHCN, problems with authorization and the timeliness of appointments were much less frequent for CSHCN statewide in 2001 than for children in Los Angeles CCS in 2005. Other reasons for foregone or delayed care, such as ability to find the type of care locally and transportation, appear to occur just as often for children in CCS as for CSHCN statewide.

### **Association of Insurance with Delayed Care and Reasons for Delay**

**Exhibit 10** shows rates and reasons for delay among subgroups of children in CCS. Comparing rates of delays by insurance type shows the following patterns.

- Delayed care was more frequent among children in private insurance than in Medi-Cal (21.6% vs. 16.2%) and most frequent among children in Healthy Families (37.2%).
- Parents of children in Healthy Families were more likely to report the cost of care as contributing to a delay (25.2%) than parents of children in Medi-Cal (8.8%) or with private insurance (9.5%).
- While cost contributed to more delays among children in Healthy Families than in Medi-Cal, authorization problems caused a similar proportion of delays in Medi-Cal (12.4%), Healthy Families (16.2%), and private insurance (12.1%).
- Among those with a delay, parents of privately insured children were more likely to say that competing demands on their time or resources contributed to the delay (29.3%), in comparison to children with Medi-Cal (14.6%) or with Healthy Families (0.0%). Competing demands refer to situations in which the needed care was not as important as other things that the family was taking care of. Examples may include work demands, care of other children in the household, meeting other basic needs of the family, or obtaining other kinds of services needed by the child.

Among children with exclusively Medi-Cal coverage, comparison of children reported to be in a managed health plan with those reported to be in fee-for-service Medi-Cal shows the following.

- Delayed or foregone care is slightly less frequent for children in managed care (14.9%) than in fee-for-service (20.6%).

<b>Exhibit 10</b>				
<b>Having Delay/Foregone Care by Child Characteristics</b>				
	Delay	Delay due to cost	Delay due to approval	Delay due to getting appointment
	%	%	%	%
Total	18.4	9.3	11.3	9.4
Activities affected by condition				
Always/usually	***23.4	***12.1	***14.5	***14.5
Sometimes/never	15.4	7.5	9.4	6.2
Parent education				
Less than high school	**19.6	***12.6	***13.3	**12.3
High school	13.9	5.6	6.3	7.0
More than high school	22.2	7.9	14.3	7.7
Child race/ethnicity				
Latino-English	***13.0	***4.3	**8.7	***5.1
Latino-Spanish	24.4	16.8	15.0	15.6
Non-Hispanic White	20.7	7.8	12.1	5.2
African American	23.0	6.7	13.3	10.9
Child age				
Less than 12 months	**9.5	***2.2	**2.8	***1.7
1-5 years	19.6	12.6	12.4	8.0
6-12 years	19.5	7.6	13.2	11.4
13-17 years	21.2	11.9	12.3	13.7
18-22 years	13.0	5.2	8.3	3.1
Health insurance				
Private	***21.6	***9.5	**12.1	***11.0
Medi-Cal & private	13.3	4.8	7.3	8.1
Medi-Cal	17.5	8.8	12.4	8.4
Healthy Families	37.2	25.2	16.2	19.9
Uninsured	21.9	(a) 15.6	(a) 6.2	---
Medi-Cal arrangement				
Managed care	*14.9	**5.8	11.6	**5.2
Fee-for-service	20.6	11.3	14.3	11.2

Source: Los Angeles CCS Survey, 2005

Note: Percentages for each type of delay include all children (with and without delays) in the denominator.

Percentages for Medi-Cal arrangement include only children with exclusively Medi-Cal coverage.

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$  for each comparison (chi square)

- Cost and the time to appointment less frequently cause delays among those reported to be in Medi-Cal managed health plans (5.8% and 5.2% respectively) than among those in fee-for-service Medi-Cal (11.3% and 11.2% respectively).
- Approval problems and inability to find a provider cause the same proportion of delays for children in managed and in fee-for-service Medi-Cal.



## **Association of Child and Family Characteristics with Delayed Care and Reasons for Delay**

**Exhibit 10** also shows that need and demographic factors were associated with delays.

- Greater condition impact was associated with nearly twice the rate of delayed/foregone care, and delays associated with cost, authorization problems, and time to appointment.
- Parents with the lowest educational attainment were no more likely than other parents to report a delay. However, they were more likely to report delays associated with the specific causes of cost and time to appointment (but not authorization problems).
- Spanish-speaking parents of Latino children reported the highest rates of delays due to cost and time to appointment, but were no more likely than most other parents to report delays overall, and delays due to authorization. In contrast, parents of Latino children interviewed in English reported the lowest rates of delayed and foregone care.
- Infants and young adults had the lowest rate of delays.

**Exhibit 11** compares delays by insurance type, and by need and demographic factors within insurance groups.

- In all insurance groups but Healthy Families, delays were more frequent among children with greater condition impact.
- Spanish-speaking parents of Latino children reported the highest rates of delays in Healthy Families and in combined Medi-Cal/private insurance groups.
- Among privately insured children, parents with less than a high school education reported higher rates of delayed/foregone care than parents with greater educational attainment. This difference between parents with different educational attainment generally was not found for children with other types of insurance coverage.

<b>Exhibit 11</b>				
<b>Having Delay/Foregone Care by Child Characteristics, Within Insurance Type</b>				
	Private (n=190)	Medi-Cal & private (n=482)	Medi-Cal only (n=1,099)	Healthy Families (n=157)
	% with delay	% with delay	% with delay	% with delay
Total	21.6	13.3	17.5	37.2
Activities affected by condition				
Always/usually	*34.7	*17.9	**21.9	40.5
Sometimes/never	17.0	10.6	13.9	36.1
Parent education				
Less than high school	**34.4	17.4	**18.2	29.1
High school	8.6	10.5	12.0	40.8
More than high school	23.7	11.9	24.3	42.3
Child race/ethnicity				
Latino-English	23.2	***9.4	**11.7	***12.9
Latino-Spanish	(a) 20.0	23.7	21.4	56.3
Non-Hispanic White	(a) 20.0	(a) 14.3	23.2	(a) 20.0
African American	(a) 22.2	17.4	19.8	83.3
Child age				
0-5 years	20.6	**10.2	**17.2	**42.9
6-12 years	25.9	9.6	22.3	29.0
13-17 years	15.2	22.0	12.6	44.6
18-22 years	(a) 25.0	(a) 11.3	14.0	(a) 14.3

Source: Los Angeles CCS Survey, 2005

Note: Percentages are calculated from the total base of children in the insurance category. The private insurance category is limited to children with exclusively private coverage.

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$  for comparison within each insurance type (chi square)

(a) denotes percentage does not meet standard criterion for precision.

## Mental Health Services

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### Counseling for the Child

Mental health services are reimbursable through CCS for children whose emotional or behavioral problem relates to a CCS condition (e.g., depression, behavioral issues relating to adherence with a treatment plan). However, there is concern that not all providers routinely screen and refer for psychological issues despite risk for depression and other treatable behavioral problems associated with some chronic conditions. An inadequate supply of pediatric mental health providers exacerbates the challenges for all children. Given the stigma of mental health problems, actual need may be under-reported.

There are other barriers for services that CCS cannot authorize for children in the program. Public mental health services have often been limited to children with severe emotional disturbance (SED) and are not offered for children who need mental health care for depression or moderate emotional or behavioral problems associated with chronic illness. Many children in Medi-Cal now receive certain mental health services (such as for attention deficit disorder) through managed care plans. Privately insured children may not be covered for mental health services or may encounter limits on outpatient or inpatient services.

### *Need for Care*

**Exhibit 12** shows that about 18.0% of children in CCS were reported by their parents as needing care or counseling for an emotional or behavioral problem. About 3% of parents were not sure if their child needed counseling or not.

Comparison of children in Los Angeles CCS to CSHCN statewide shows higher parental perceived need for counseling among the general population of CSHCN (25.9%) than among children in CCS (18.0%). A similar proportion of CSHCN and children in CCS received needed counseling. Although rates were relatively low among both populations, and reported need was greater among CSHCN statewide, the proportion not receiving counseling among those with a need was twice as high for children in CCS (about 28.0%) than for CSHCN generally statewide (about 14.3%).

**Exhibit 13** shows that need was most common among the age group of 13-17 years (27.9%); rates of need were lower in middle-childhood (18.7%) and young adulthood (16.1%). Reported need increased with condition impact, affecting 19.1% of those sometimes limited by the condition and 25.8% of those often or always limited.

### *Obtaining Needed Care*

About three-quarters (72.0%) of children received the care they needed. In total, about 4.8% of all children in CCS had an unmet need for counseling for a behavioral or emotional problem.

Among those who needed but did not receive counseling, the most frequent barrier was finding a provider who could treat the child, or knowing where to go (46.4%).

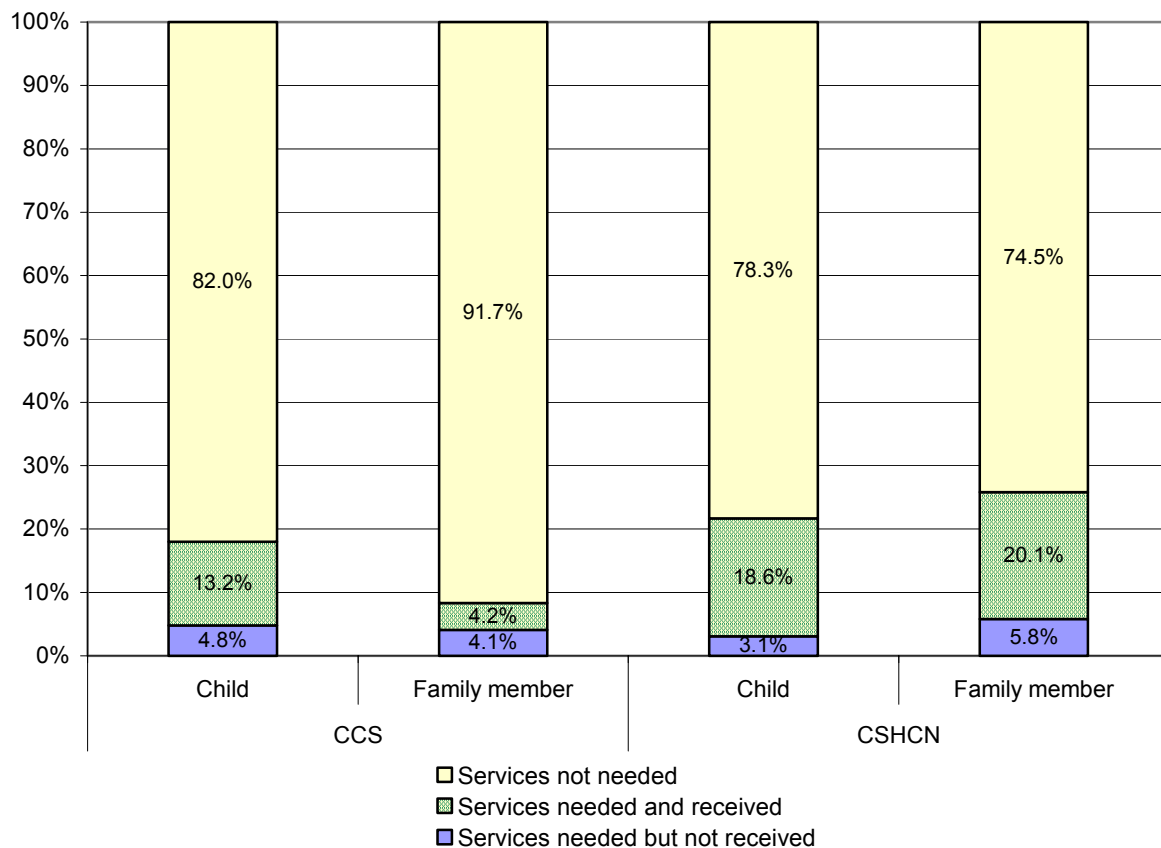
- Finding a provider was more frequently a problem for children age 0-5 years (72.2%) than for older children age 6-21 years (40.5%).
- Finding a provider or knowing where to go was much more common among children in Medi-Cal (57.4%) than among children with private coverage (17.4%).

Parents of 6.4% said that the child did not want the care, while another 6.2% had not yet sought any care.

Other causes of delay included health plan problems (10.3%) and insurance coverage for or cost of the services (14.4%).

- Cost was a smaller barrier among children in Medi-Cal needing care (9.8%) than among children with exclusively private coverage (34.8%).

**Exhibit 12**  
**Access to Mental Health Services**



Source: Los Angeles CCS Survey, 2005 and National Survey of Children with Special Health Care Needs, 2001

<b>Exhibit 13</b>				
<b>Counseling/Mental Health Needs and Unmet Need, for Child and Family</b>				
	Child		Family	
	Need	Unmet need	Need	Unmet need
	%	%	%	%
<b>Activities affected by condition</b>				
Always/usually	***25.9	***8.0	***12.8	***6.8
Sometimes/never	13.0	3.1	5.4	2.3
<b>Parent education</b>				
Less than high school	**21.3	*3.6	8.3	*5.1
High school	12.6	6.5	7.1	4.3
More than high school	19.2	5.8	9.7	2.2
<b>Child race/ethnicity</b>				
Latino-English	***13.6	*3.9	**5.9	***1.5
Latino-Spanish	21.6	5.3	9.6	7.0
Non-Hispanic White	24.1	(a) 2.6	15.5	2.6
African American	19.4	6.7	9.7	4.8
Asian/Pacific Islander	21.6	10.2	8.0	(a) 5.7
<b>Child age</b>				
1-5 years	***12.1	**3.8	7.6	***6.4
6-12 years	18.7	4.0	7.6	1.8
13-17 years	27.9	8.5	10.5	5.2
18-22 years	16.1	6.2	5.2	(a) 1.6
<b>Health insurance</b>				
Private	20.0	(a) *2.1	***7.9	(a) *1.0
Medi-Cal & private	19.7	3.9	12.5	4.6
Medi-Cal	18.1	6.0	7.5	5.1
Healthy Families	13.4	6.4	(a) 2.5	(a) 1.3
Uninsured	15.6	(a) 9.4	(a) 12.5	(a) 0.0

Source: Los Angeles CCS Survey, 2005

Note: Percentages for each type of delay include all children (with or without delays) in the denominator.

Percentages for Medi-Cal include only children with exclusively Medi-Cal coverage.

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$  for each comparison (chi square)

(a) denotes percentage does not meet standard criterion for precision.

## Counseling for the Family

For about 8.7% of children in CCS, the parent or another family member needed counseling or mental health services because of the child's condition. About two-thirds received the needed care. Thus a total of 5.8% of children in CCS had a parent or family member who needed but did not receive counseling associated with the condition.

In comparison, of the 13.8% of CSHCN in California with a family member or sibling needing mental health care/counseling due to the child's condition, about one-third had not received it, comprising 3.2% of all CSHCN.

The most common reasons for unmet need among family members were similar to those for children: inability to find a provider who could treat the problem, and the cost or a lack of insurance. Cost/insurance coverage was a more significant problem for family members, affecting 27.2% with a need compared to 14.4% for the child in CCS.

### **Summary of Factors Associated with Need and Unmet Need for Mental Health**

A summary of factors associated with needs and unmet needs for counseling shows that:

- Rates of need and unmet need, for both the child and family members, were higher for children with greater condition impact. Children age 13-17, and their families, had higher rates of need and unmet need.
- More Asian/Pacific Islander than Latino children had an unmet need for counseling. About half of the 21.6% of Asian/Pacific Islander children with a counseling need did not receive the care needed.
- While reported need did not differ, unmet need was higher among publicly insured and uninsured children than among privately insured children.
- The rate of family need was similar for families of children in Medi-Cal and families of children with private coverage.
- Unmet need is more common among children in Medi-Cal needing care (33.0%) than among children with exclusively private coverage (17.0%). Unmet need also affects a larger proportion of families with a need when the child is in Medi-Cal (more than half).

### **Summary**

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Parents identify neurology, orthopedics, and orthodontics/dental care as the most problematic areas of specialty care availability in Los Angeles CCS. Parents cite difficulties with authorization and timeliness of specialty appointments more frequently than cost barriers. Parents of children in Healthy Families reported the highest rates of problems with authorizations and receiving needed specialty care, which may reflect differences in the Healthy Families population or more difficulty in how the CCS carve-out works for Healthy Families compared to Medi-Cal. The higher rate of unmet specialty care needs in fee-for-service Medi-Cal compared to managed health plans is partly influenced by greater condition severity among the fee-for-service group. Among publicly insured children, cost-related delays and foregone care are highest in Healthy Families and lowest in Medi-Cal health plans.

Mental health services are another type of specialized services that are reimbursable through CCS for children whose emotional or behavioral problem relates to a CCS condition (e.g., depression, coping, behavioral issues affecting adherence to a treatment plan). Rates of need and unmet need, for both the child and family members, are higher for children with greater condition impact. Unmet need for counseling is more common among children in Medi-Cal. The most frequently cited reason for unmet need is finding a provider who could treat the child or knowing where to go. Finding a provider is more frequently a problem for children age 0-5 years than for older children.

## Part III

### Medical Home

**M**edical Home provides basic information about access to a medical home as defined for children with special health care needs. It compares health care access for children with different types of health insurance.

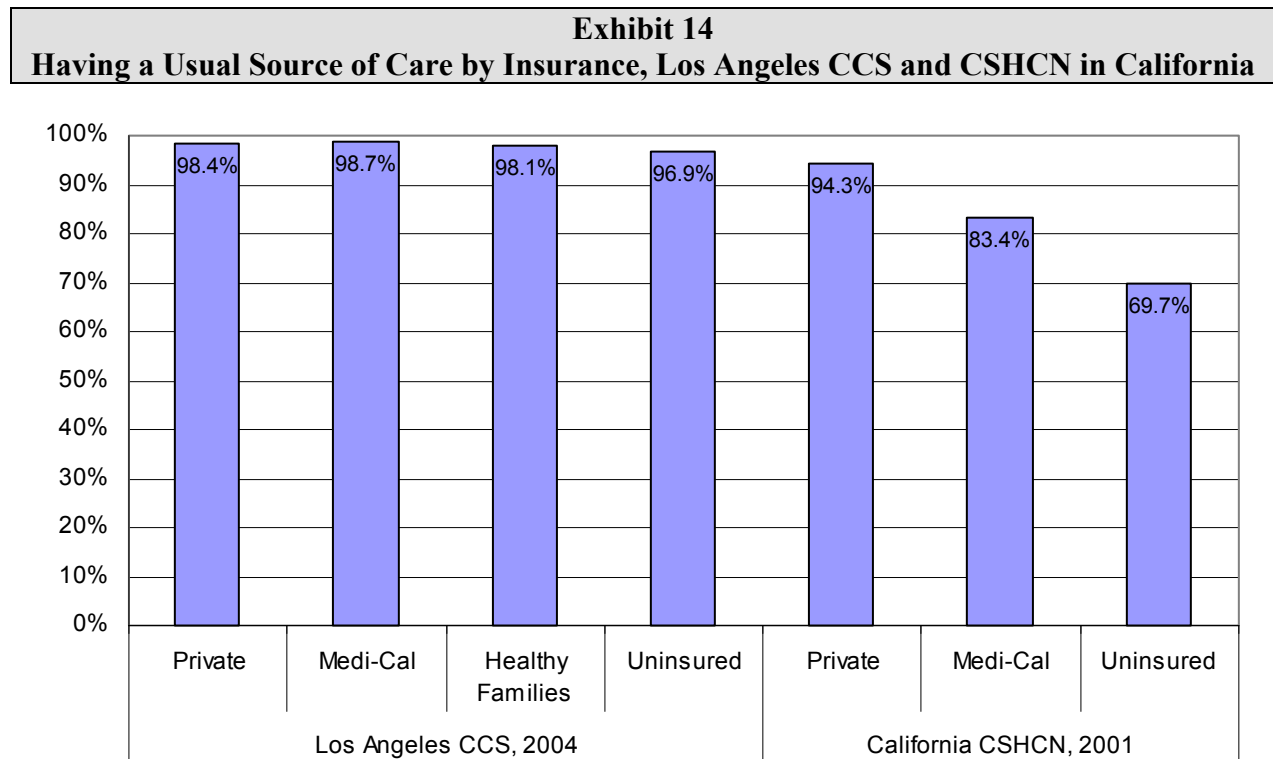
- ❖ The Medical Home Concept
  - ❖ Setting of Health Care
  - ❖ Having a Personal Health Care Provider
    - ❖ Interpreter Services
- ❖ Family Centered Care/Quality of Interpersonal Relationship
  - ❖ Coordination Among Physicians and Programs
- ❖ Health Care Self-Management and Transitions for Adolescents and Young Adults

## The Medical Home Concept

The U.S. Department of Health and Human Services' *Healthy People 2010* goals and objectives, as well as national Title V performance objectives for CSHCN, state that all children with special health care needs will receive regular ongoing comprehensive care within a medical home. The purpose of the medical home is to provide a continuous source of coordinated health care for children. Health care professionals help children to access all medical and non-medical services needed to help them reach their maximum health potential. The American Academy of Pediatrics (AAP) has built on this concept in promoting the “medical home” most simply as a place that promotes access and coordinates care.

Having a regular source of care—usually defined as a regular place to go when the child is sick or when advice is needed about the child’s health—provides the foundation for a medical home. Continuity is needed for appropriate diagnosis, for quality treatment plans, and for follow-up and monitoring. It can be more difficult to coordinate care when children are using multiple sources of care.

**Exhibit 14** shows that nearly all children in CCS have a usual source of health care, irrespective of the type of health insurance coverage. The difference between children in CCS and CSHCN generally is large for children in Medi-Cal (98.7% vs. 83.4%) and for uninsured children (96.9% vs. 69.7%).



Source: Los Angeles CCS Survey (2005) and National Survey of Children with Special Health Care Needs (2001)



## Setting of Health Care

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CSHCN may receive care in multiple places due to the specialized nature of their care. It is useful to know which setting the parents considers to be the child's usual source, as well as the proportion of children whose specialty location is also their usual source of care for general primary care problems and preventive care.

About 60.8% of children in Los Angeles CCS receive most of the care for their condition in their usual source of care. The most common usual source of care for the child's medical condition(s) is a hospital outpatient clinic (41.7%). This is expected given the types of diagnoses of children in CCS. About one-third (30.6%) receive care for their condition in a physician's office, with the remainder going to community health clinics/centers (21.0%), an emergency room (5.2%), or another setting.

An important question relating to a child's medical home is where children are getting care for their condition, when it is not the same place as their usual source of care. **Exhibit 15** shows the usual sources of care for children based on which setting type they use for specialty care. The first bar shows that about half (55.0%) of children receiving specialty care in a hospital outpatient clinic received their usual care in a hospital setting, with most others going to a physician's office or community clinic. **Exhibit 15** also shows that the majority of children receiving specialty care in a physician's office or in a community clinic also receive their usual care in that type of setting: 94.0% of those in physician's offices and 72.2% of those in clinics.

## Having a Personal Health Care Provider

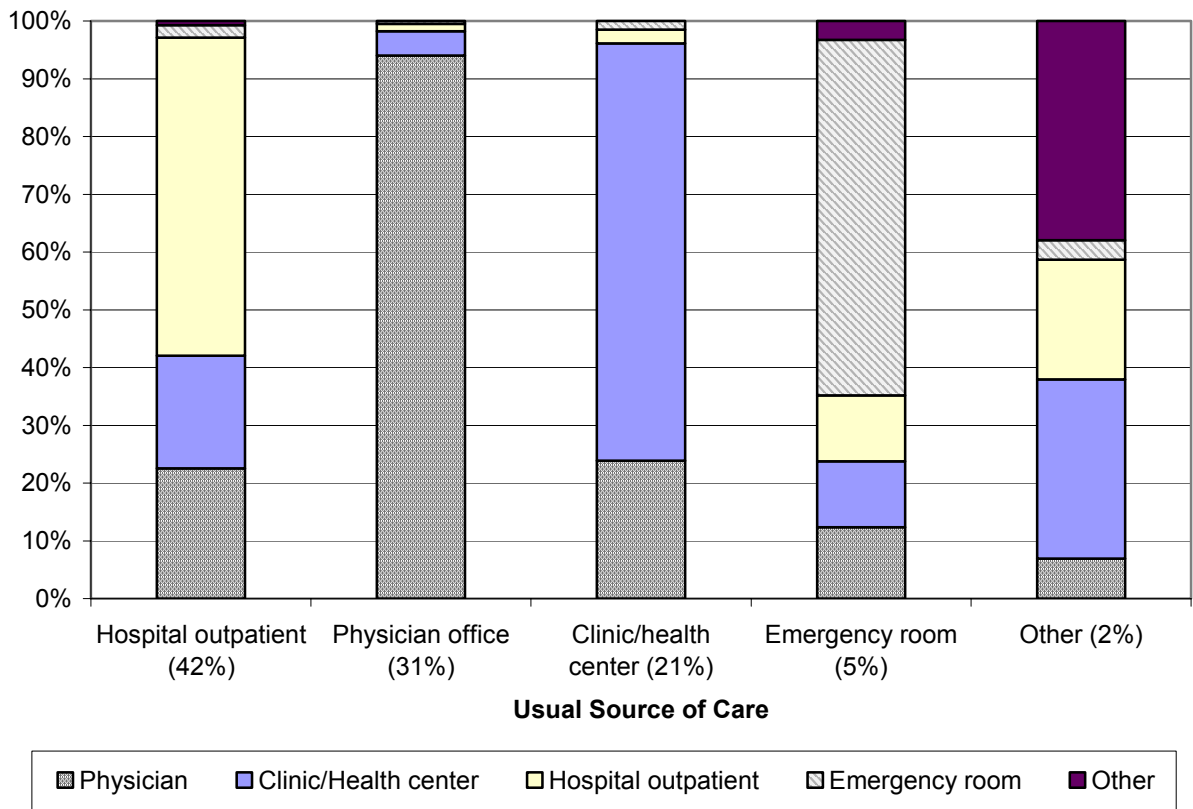
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The American Academy of Pediatrics suggests that to have a medical home, a child's care should be delivered or directed by a well-trained physician who helps to manage and facilitate essentially all aspects of pediatric care. Having a relationship with a single physician is thought to improve health care quality through better provider knowledge about the patient and family and a more trusting relationship. Studies of adults and children show that a good interpersonal relationship between the provider and parent/child improves adherence to medical advice, satisfaction, self-rated access to care, fewer unmet needs, and fewer emergency department visits. Children may receive better care when a practice knows the child well and is accountable for making sure services are authorized, received, and coordinated among providers/programs.

Most children in CCS (85.4%) have not only a usual source of care, but one personal provider. Another 10.5% have more than one. Very few (4.1%) lack a personal provider.

**Exhibit 16** shows that more children whose usual source is a community clinic or outpatient hospital settings have more than one provider, compared to children in physician offices. This is not surprising since not all clinics can guarantee a relationship with a single provider. Similarly, hospital outpatient clinics are often staffed by residents and attending physicians with the patient seeing different people over time. Even among parents who consider the emergency room to be their child's usual source, the majority (72.4%) said the child has a personal provider. For these children, the personal provider may not be in the usual source of care (i.e., the emergency room).

**Exhibit 15**  
**Location of Specialty Care, by Usual Source of Care**

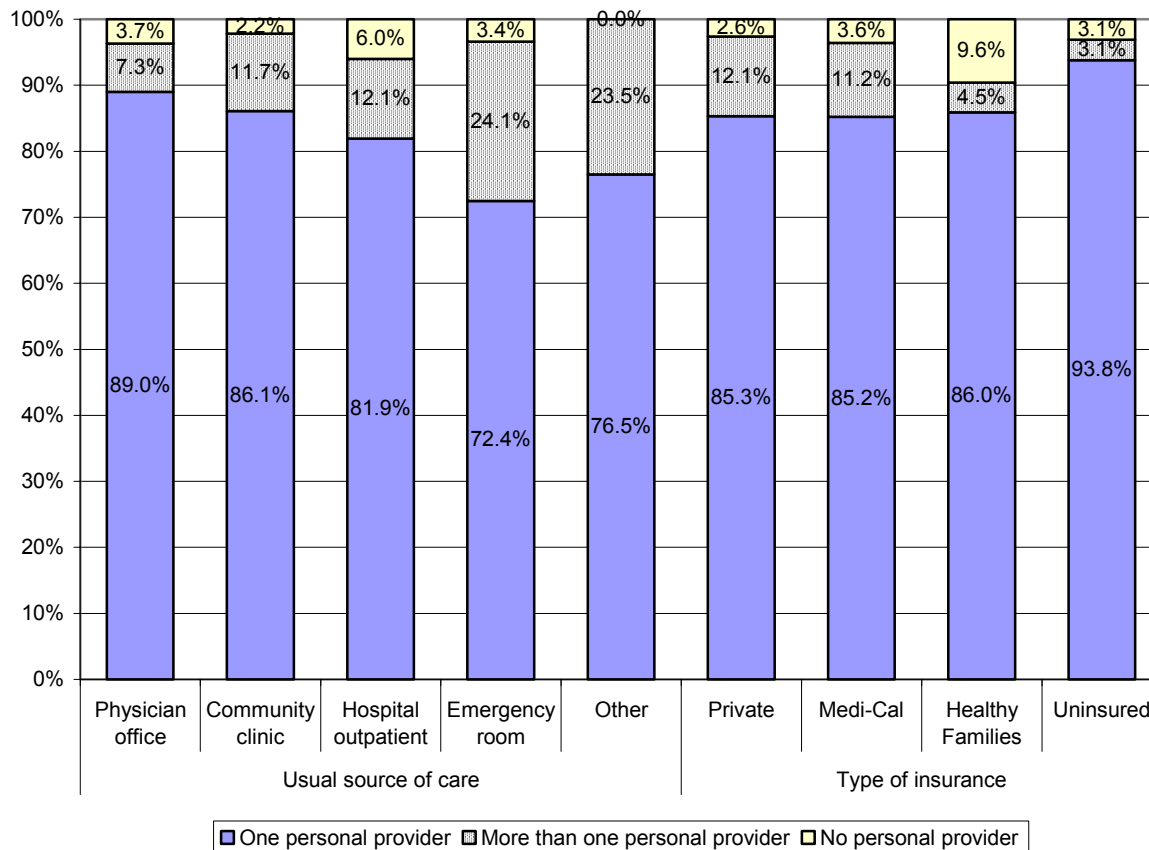


Percentages are among children with a usual place for care when sick or advice needed about the child's health.  
Source: Los Angeles CCS Survey, 2005

Comparison of children with different personal provider arrangements shows the following.

- Having a personal provider is not associated with the severity of the child's condition(s). However, children with more than one provider were more likely to have changing rather than stable needs.
- Lacking a personal provider increases among adolescents and young adults. While only 2.2% of children age 0-12 years lack a provider, about 6.3% of those age 13-17 and 11.4% of those age 18-21 lack a personal provider.
- There were few differences by insurance coverage, with about 85% of private, Medi-Cal, and Healthy Families-insured children having personal providers (**Exhibit 16**). However, more children in Healthy Families lacked a personal provider (9.6%).
- Among children with exclusively Medi-Cal coverage who have personal doctors, slightly more children in managed health plans than in fee-for-service Medi-Cal had one personal provider (92.3% vs. 88.6%).

**Exhibit 16**  
**Having a Personal Physician by Usual Source of Care**



Source: Los Angeles CCS Survey, 2005

Comparison to 2001 data for CSHCN shows that similar proportions of children in CCS and CSHCN have one personal provider, but this varies by insurance type.

- Among children in Medi-Cal, more children in CCS (85.2%) than in the general population of CSHCN (72.2%) have a personal doctor. Similarly, uninsured children in CCS were more likely to have a personal doctor than uninsured CSHCN (93.8% vs. 55.3%).
- In contrast, for privately insured children, fewer children in CCS than among CSHCN generally appear to have one personal doctor (85.3% vs. 91.3%). Because the 2001 NS-CSHCN did not inquire about having more than one personal provider, it is not possible to know if this is partly due to a greater proportion of privately insured children in CCS having more than one personal physician; only 2.6% of these children lack any personal provider.

The 2005 survey shows that while most children in Los Angeles CCS have a personal provider, knowing this about each child is useful because it is associated with important aspects of care.

- Parents were more likely to always receive the information that they need about managing the child’s condition when the child has a personal provider. Rates of receiving adequate information were higher for children with multiple providers (73.7%) or a single provider (64.5%) than for those lacking a provider (47.6%).
- Providers always taking enough time with the child, and treating the parent like a partner in care, are also more common among children with one or more personal providers. Other measures of family-centered care that relate to how physician interact with children and parents—listening carefully to the parent, and respecting family values and customs—showed little relationship with having a personal provider.
- Communication between all of the child’s doctors was rated as “good” to “excellent” for most with one provider (86.2%) or more than one provider (84.8%), with a lower rate for those with no personal provider (73.8%).

## Interpreter Services

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The ability of parents to communicate effectively with their child’s providers is the foundation of family-centered care. Language is particularly important given California’s diversity. About 37.2% of interviews were conducted in Spanish, and nearly all of these parents (91%) reported needing an interpreter in the past year. This comprises 33.1% of all parents in Los Angeles CCS.

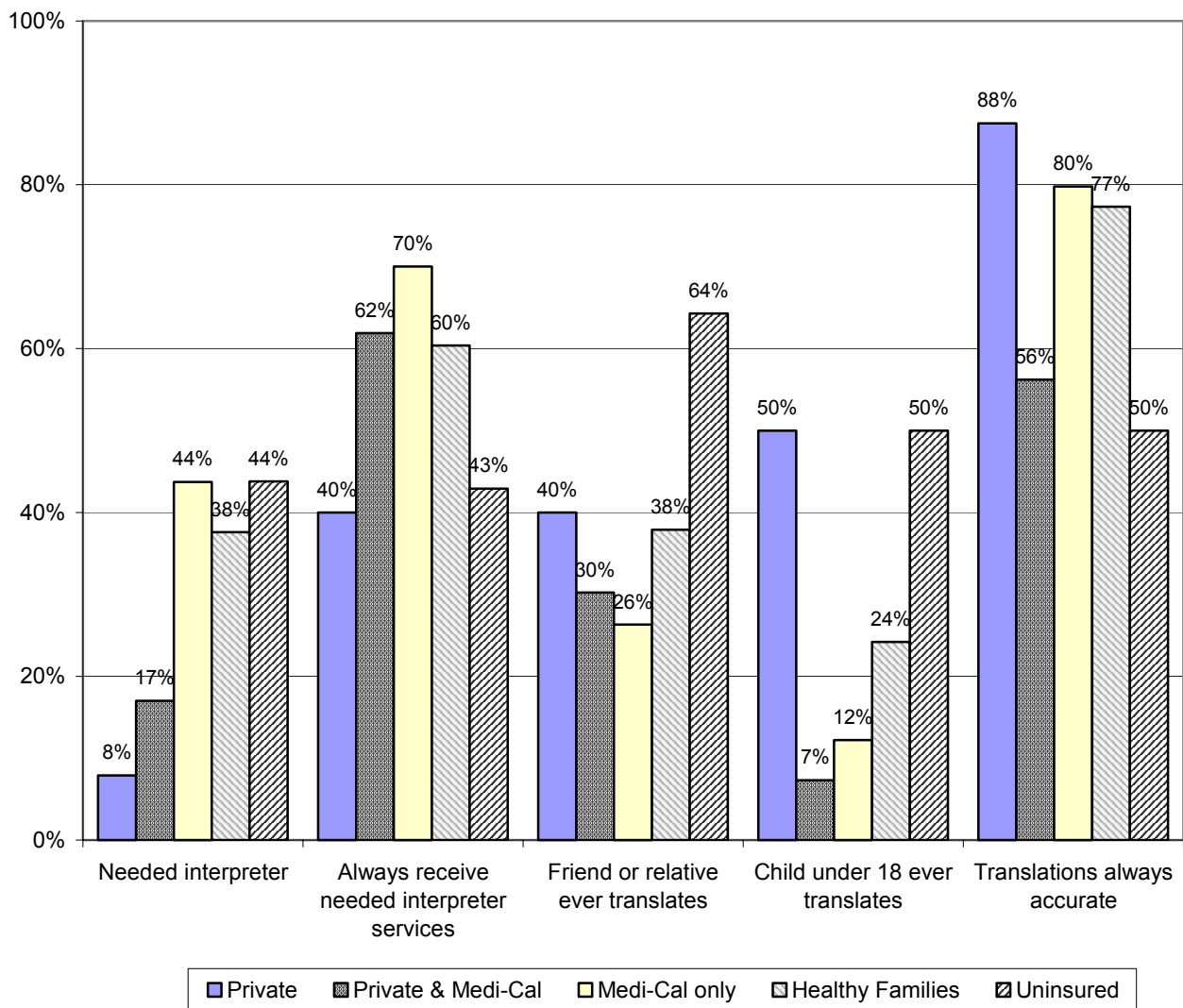
- About three-quarters (75.4%) of parents always received interpreter services when needed.
- Most parents (86%) said that they were always confident that translated information between the parent and the child’s providers (by professional interpreters, relatives, or children) is accurate. Parents are more confident in the accuracy of translation when they have always had an interpreter (87.8%) than when they have not (56.0%).
- About 28.3% of parents interviewed in Spanish ever used a friend or relative to interpret for them and the child’s providers.
- Translation by a child under the age of 18 years was less frequent (13.6%). Parents with less than high school education were more likely to use children to interpret than parents with more education (15.5% compared to 8.7%).
- Although children should not translate medical information for parents, the relatively few parents who always relied on a child to interpret (4.3%) appeared confident in that child’s ability to translate. About 71% believed the translations were always accurate.

Health plans for publicly insured children have guidelines for interpreter services to ensure that information is accurate, improve communication between physicians and patients, and maintain confidentiality within the family. Translation of medical information by children is specifically prohibited.

- **Exhibit 17** shows that need for interpreter services was much higher for children in Medi-Cal (43.7%) and Healthy Families (37.6%) as in exclusively private insurance (7.9%).

- Access to appropriate interpreter services when needed appears best in Medi-Cal.
- Parents of children in Medi-Cal also reported the lowest use of friends/relatives and children under age 18 for translation. About 12.2% of parents in Medi-Cal ever use children to translate compared to 24.2% in Healthy Families, 50.0% in private insurance and 50.0% of uninsured children.
- While parent reports of interpretation accuracy were similar for privately and publicly insured children, parents of uninsured children reported the least confidence in the accuracy of translations.

**Exhibit 17**  
**Access to Interpreter Services**



Source: Los Angeles CCS Survey, 2005

Note: Percentages for needing interpreter are among all parents interviewed. Other percentages are among parents interviewed in Spanish. Estimates of interpreter use are the percentage of parents interviewed in Spanish who say that the interpretation method is ever used.

## **Family Centered Care/Quality of Interpersonal Relationship**

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During the last 20 years, the federal Maternal and Child Health Bureau and state Title V programs have been committed to greater inclusion of parents in the planning and provision of health care to their child with special health care needs. “Family-centered care” is a concept reflecting the importance of ensuring that families are included in all aspects of the child’s care. Family centered care also measures the quality of the interpersonal relationships between providers and parents. Providers who are too rushed, are not sensitive to family customs, or do not provide adequate information to the family are not providing this essential aspect of quality health care. In addition, cultural gaps between provider and parent are important to monitor given national efforts to eliminate racial and ethnic disparities in health. Family centered care is a key component of the federal operationalization of the medical home concept. Family centered care generally refers to the medical care received by children.

About two-thirds of parents (66.5%) said that the child’s health care providers usually or always provided each of the five elements of family-centered care asked about: providing information, listening carefully, sensitivity to family customs and customs, treating the parent like a partner in care, and spending enough time with the child.

**Providing information** About two-thirds of parents (64.9%) reported always receiving the specific information they needed from the child’s providers about topics such as the causes of any health problems, how to care for the child, and what changes to expect in the future. Receiving information was the lowest rated family-centered care measure. Parents of Latino children who completed the survey in English gave the lowest ratings (60.1%) while parents of Latino children surveyed in Spanish gave the highest ratings (70.2%) (**Exhibit 18**).

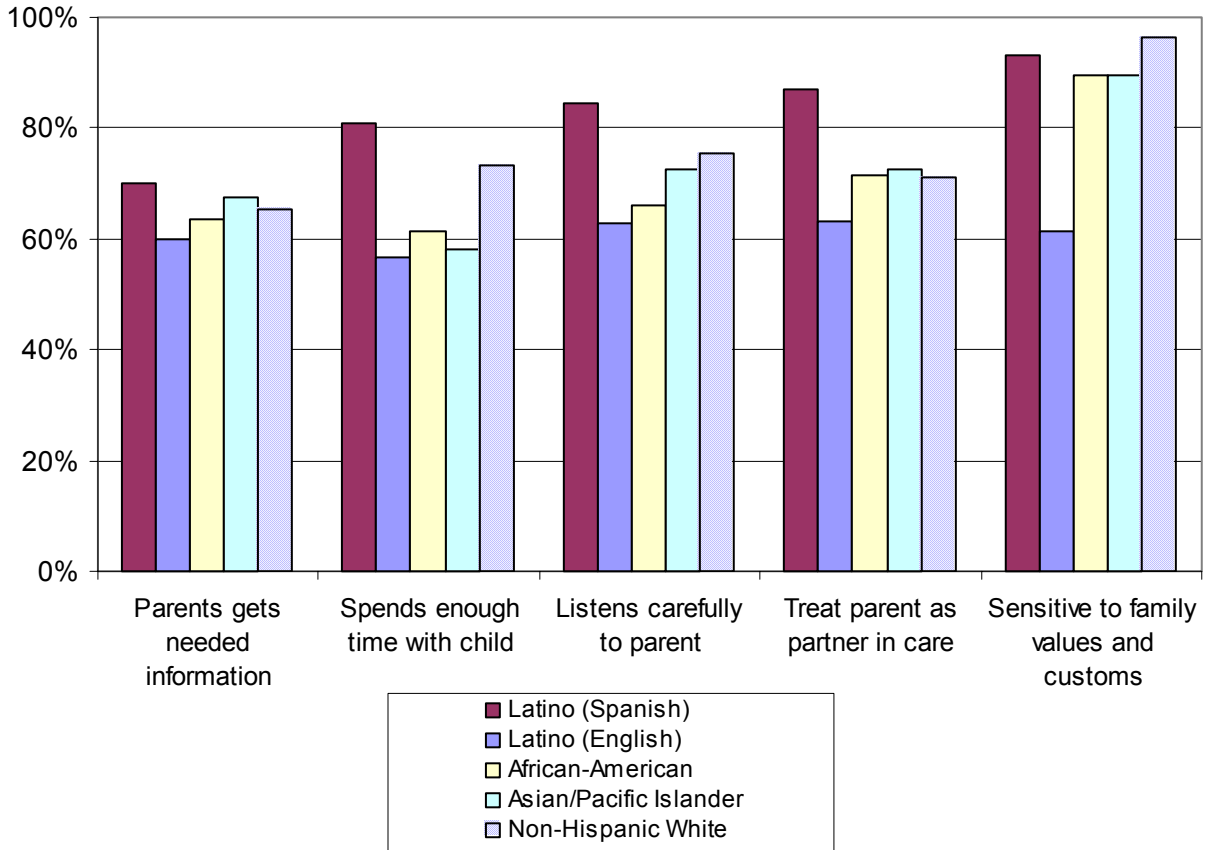
**Listening carefully** Nearly three-quarters of parents (72.5%) reported that their child’s providers always listen carefully to them. The highest ratings were from parents of Latino children surveyed in Spanish (84.6%) and parents of non-Hispanic white children (75.6%).

**Sensitivity to family values and customs** About 74.6% of parents said that doctors and other health care providers are always or usually sensitive to their family’s customs or values. Reports of sensitivity to family customs or values varied little by race/ethnicity with the exception that only 61.3% of parents of Latino children surveyed in English said that providers are always sensitive to their values and customs.

**Making parent feel like a partner** Most parents (about 73.6%) said the child’s doctors help them feel like a partner in the child’s care. Reports of treating the parent as a partner varied little by race/ethnicity with the exception that only 63.0% of parents of Latino children surveyed in English said that providers always made them feel like a partner.

**Spending enough time with child** About two-thirds of parents (about 67.1%) said their child’s doctors and other health care providers spent enough time with the child. Parents of Latino children who completed the survey in English gave the lowest ratings (60.1%) while ratings were higher among parents of non-Hispanic white children (73.3%) and parents of Latino children surveyed in Spanish (81.0%).

**Exhibit 18**  
**Family Centered Care by Child's Race/Ethnicity**



Source: Los Angeles CCS Survey, 2005

Note: Estimates are percentages of parents saying that the child's providers "always" provide the interpersonal aspect of care.

### **Coordination Among Physicians and Programs**

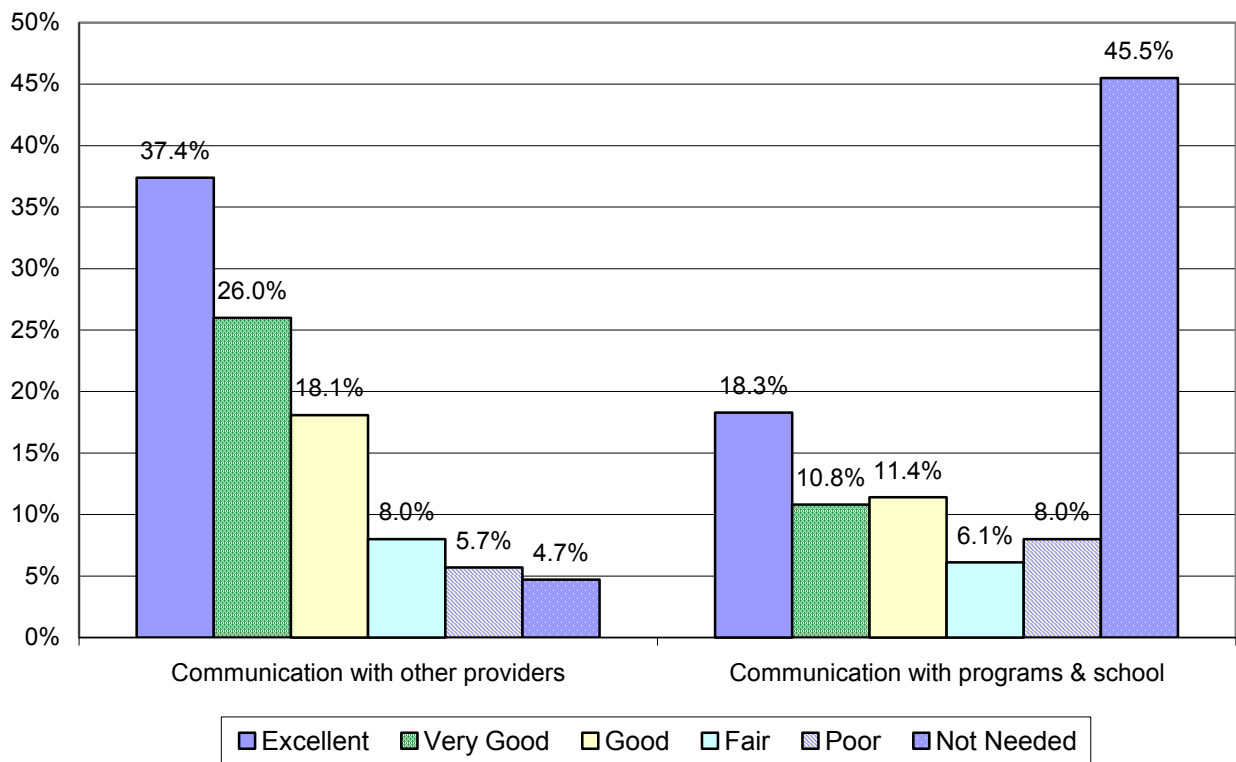
For many children, communication between the child's doctor and other health care providers, such as specialists, is important but not sufficient. Some CSHCN need treatment or special accommodations in their school or child care arrangement. This requires attention and good communication about the child's health needs between the child's doctor and the child's school, early intervention program, or other such providers. Coordination is also important for children in CCS who receive services through early intervention, school-based Medical Therapy Unit (MTU) services, or Regional Centers.

Parents reported the following about coordination by their child's providers.

- More than half of parents (63.4%) said that communication between the child's medical care providers was "excellent" or "very good" (**Exhibit 19**). About 13.7% said that communication was only "fair" or "poor".

- Fewer parents (4.7%) of parents reported that communication between the child’s medical care providers was not needed, compared to needs for communication with programs/school (45.5%).
- Among those indicating a need, communication between physicians and the child’s other programs received lower ratings than communication among medical providers. Of those indicating a need, 63.4% said that communication among physicians was “excellent” or “very good” compared to 53.4% for communication with programs.

**Exhibit 19**  
**Effectiveness of Provider Communication**



Source: Los Angeles CCS Survey, 2005

### **Health Care Transitions and Self-Management for Adolescents and Young Adults**

Recent advances in medical care are improving the survival rate among children with conditions such as cancer or cystic fibrosis. Many more children are surviving into adolescence and adulthood. As a result, many more adolescents now need preparation for disease self-management as adults. Some adolescent CSHCN need preparation for future education or career planning. In addition, given the shortage of physicians who treat adults with congenital problems and who will treat young adults with chronic conditions, most adolescent CSHCN also need a planned transition from pediatric to adult care while they are still receiving support and case management from the CCS program.



## Self-Management of the Condition

About three-quarters (71.8%) of parents of CCS enrollees age 13-21 years said that providers usually or always encouraged the teen/young adult to take responsibility for his or her health care. About 13.9% said that this was never encouraged. These proportions exclude children whose parent reported that self-management by the child was not relevant (reported for 9.7% of children age 13-21 years).

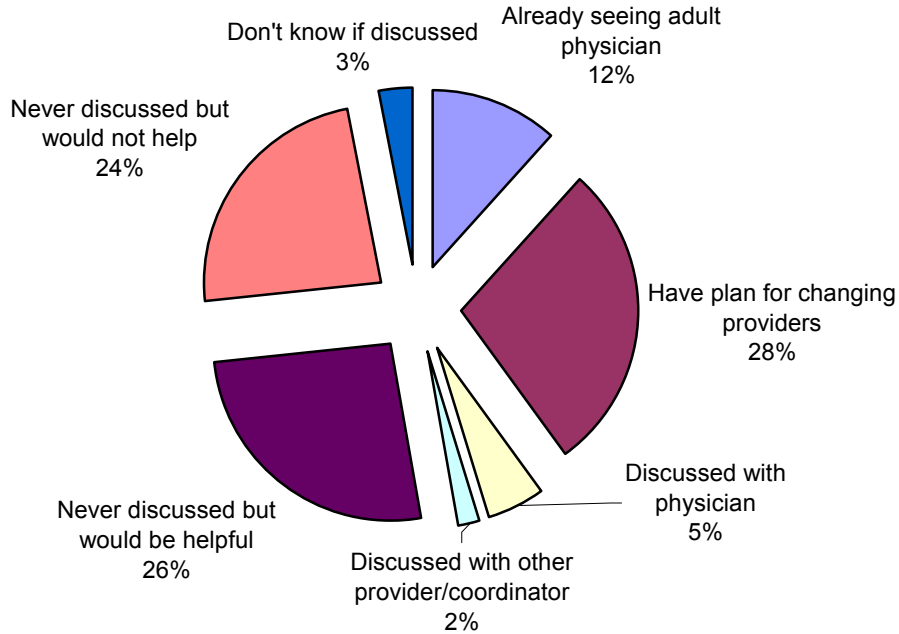
- Among young adults age 18-21, about 69.8% were always encouraged to take responsibility for self-management, which is somewhat higher than the rate for those age 13-17 years (53.5%).
- Most parents (77%) of those 13-18 years who have never been encouraged to take more responsibility said that it would have been helpful.
- The children receiving encouragement for self-management have similar condition impact and severity as those not receiving encouragement.
- These percentages exclude the 12.1% of parents of teens/young adults who said that taking more responsibility for self-managing the condition was not relevant for the child. Possible reasons include the parent's perception of the child's age-related capacity, the type of health condition and care involved, and/or cognitive limitations.

## Transition to Adult Systems of Care

**Exhibit 20** shows the amount of planning and transitions that has already taken place for adolescents and young adults in Los Angeles CCS, as well as parent preferences and reported unmet need among those who have not yet discussed or planned for transition.

- About 12% of those age 13-21 years were already seeing a physician who treats adults.
- Most adolescents and young adults (50.0%) were not yet seeing an adult physician and had not discussed this change. Such a discussion would have been helpful for more than half of this group.
- A small percentage of parents reported that transition had been discussed but that there was no plan in place (5% having discussed with a physician, and 2% having discussed with a care coordinator but not a physician). Overall, including adolescents and young adults with and without transition plans, fewer than one-quarter (22.7%) of parents had discussed changing to physicians who treat adults with their child's physician(s).

**Exhibit 20**  
**Planning for Transition to Adult Providers, Age 13-21 Years**



Source: Los Angeles CCS Survey, 2005

Note: Percentages are mutually exclusive, showing the proportion age 13-21 years who have an adult physician or have a plan for changing to an adult physician (40% of the total), the proportion who have discussed the transition but have no plan (7% of the total), and the proportion who have not yet discussed the transition (50%).

**Summary**

Most children in Los Angeles CCS have a personal physician. Among children in Medi-Cal or lacking insurance, rates of having a personal physician are higher in CCS than among the broader population of CSHCN. Most parents reported receiving family-centered care, but about one-third do not always receive the information they need about how to care for the child, and what changes to expect in the future. Parents of children in Medi-Cal reported the lowest use of friends/relatives and children to translate medical information. They are more likely than parents of children with private insurance or Healthy Families to always receive needed translation.

According to parent report, about half of adolescents age 13-17 years and one-third of young adults age 18-21 years are not always encouraged to take more responsibility for managing their conditions. Most parents of those age 13-21 who are never encouraged in self-management say they would find it helpful. About half of adolescents and young adults are not yet seeing an adult physician and have not discussed future changes in health care with their doctor or any other provider or care coordinator. More than half of their parents say that such discussion would be helpful.

## Part IV

### Care Coordination and Support from CCS

**Care Coordination and Support from CCS** refers to the experiences that parents have with the CCS program and staff. This includes parent ratings of the coordination and the support that they receive through the CCS program, as well as their knowledge of the CCS program.

- ❖ Ease of Service Organization
  - ❖ Care Coordination
- ❖ Support Received from the CCS Program
  - ❖ Preferences for System Improvement

## Ease of Service Organization

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Navigating a system of services can be difficult for parents. CSHCN can have multiple providers in different locations. Many children receive care that is paid for by more than one insurance plan or public program. In addition, CSHCN may receive health-related services through Regional Centers and other programs that have different eligibility, authorization processes, and case managers. To understand how easily parents navigate the service system, parents were asked about (1) the organization of medical care, (2) the organization of any specialized services, and (3) the need to go back and forth between agencies to obtain a needed service for the child.

Most parents (83.2%) said that the child's medical services were always or usually organized in a way that made them easy to use. Many of these parents (comprising 58.1% of all parents) said that medical services were always well organized. About 16.8% said that medical services were never or only sometimes well organized. These perceptions of service organization are considerably higher than those reported by parents of the broader population of CSHCN in 2001.

About half of parents surveyed (41.6%) said that in addition to medical care, their child needed special services such as physical therapy, counseling, or equipment. As with medical care, about half of parents reporting need for special services (61.6%) said these services are always well organized. About 19.2% said that these special services were never or only sometimes organized.

Parents were also asked how often they had needed to go back and forth between agencies to get needed services. About half (42.4%) needed to do this in the past year. About 8.0% reported always having to do this for services.

### Factors Associated with Service Organization

Fewer parents of children with more impairment said that medical services were well-organized (80.2% vs. 85.1%) or that other specialized services were well-organized (77.6% vs. 84.5%). Perceptions of organization were no different for parents with higher or lower education.

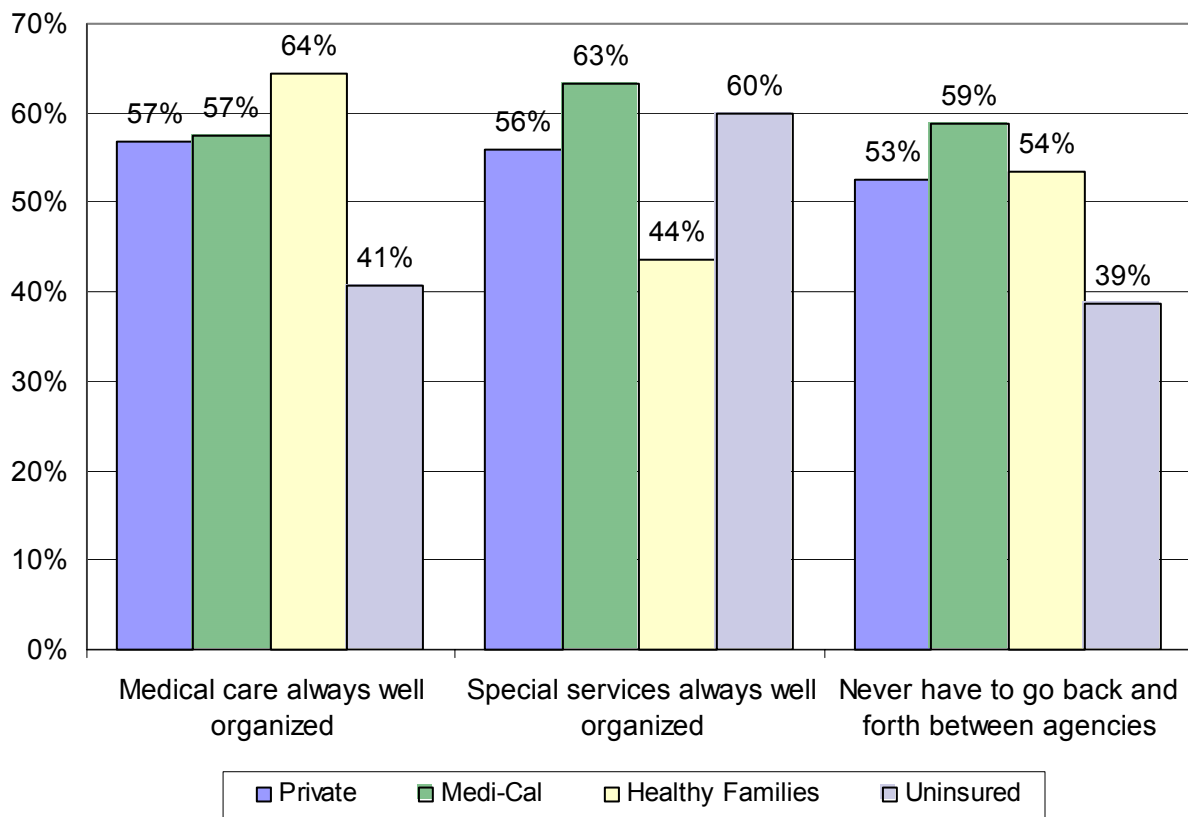
**Exhibit 21** compares parent reports of organization of medical care, organization of special services (for those needing such services), and needing to go back and forth between agencies or programs, by the child's health insurance coverage.

- There was little difference in the organization of medical care between children with private insurance and those with Medi-Cal coverage.
- Specialized services were perceived as less organized for children in Healthy Families than for other insured children.
- Parents of uninsured children were least likely to report well-organized medical services and most likely to report needing to go back and forth between agencies to get needed care.

Parents of children with a personal provider experienced less back and forth between agencies and reported better organization of medical care, but they did not report better organization of specialized services.

- Parents of children with one personal provider more often said that medical services were always well organized, when compared to those without a personal provider (84.0% vs. 62.5%). There was no difference between these groups for the organization of specialized services.
- Fewer children with a personal provider (either one or more than one) than those without usually or always had to go back and forth between agencies (17.8% vs. 26.2%). This problem appeared slightly less frequently for children with one personal provider (18.3%) than for children with more than one personal provider (13.4%).

**Exhibit 21**  
**Organization and Ease of Service Use**



Source: Los Angeles CCS Survey, 2005

Note: Estimates are percentages of parents saying that the services are “always” well organized or that the parent and child “never” have to go back and forth between agencies to obtain needed care.

## Care Coordination

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Having health insurance or receiving financial support for medical care does not guarantee that parents understand how to access services or that children receive needed services. As the ultimate coordinators of their child's care, parents need information about how to take advantage of their child's health insurance plan benefits. Parents may need to know how to negotiate the authorization process in a health plan or with an insurance company. Parents also need information to learn how to navigate the larger system of services. There may be resources available to families that they are unaware of, such as care coordination and transportation, and disease management programs offered by Medi-Cal health plans.

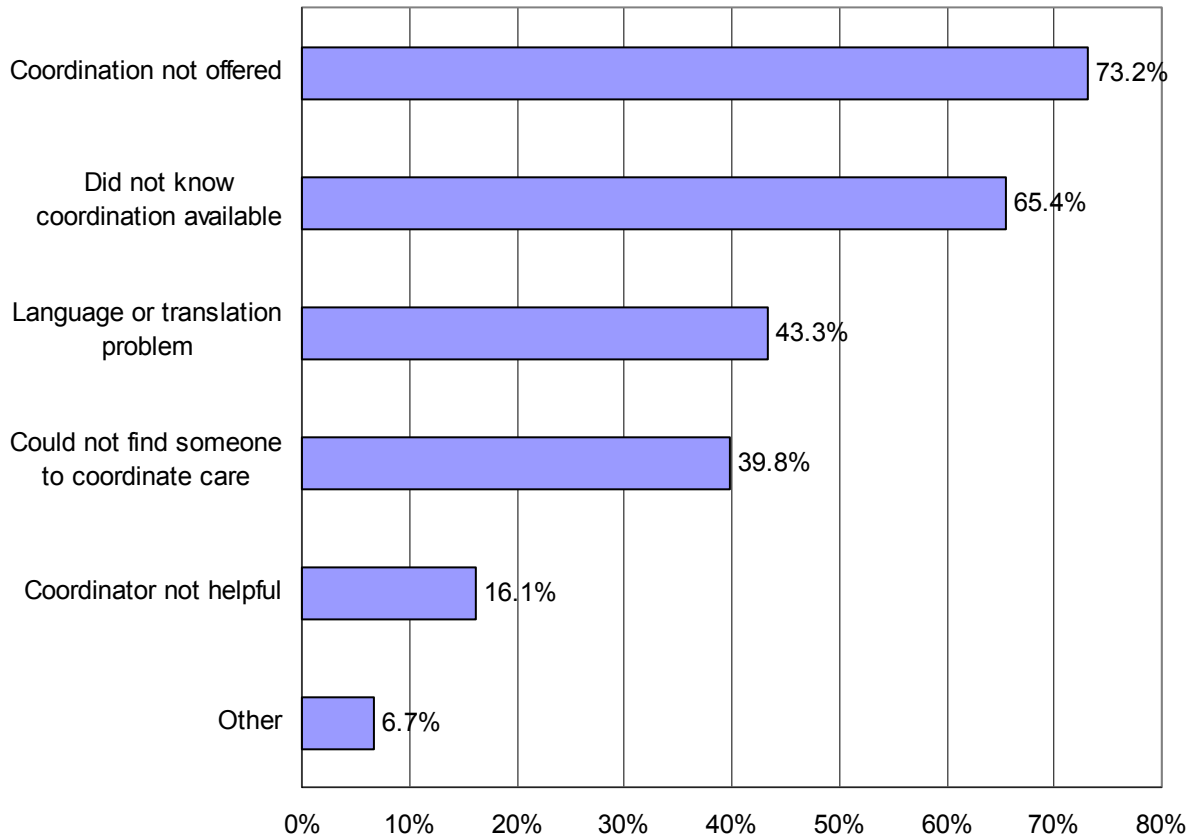
About half of parents (52.4%) said that they received help arranging or coordinating their child's medical care in the past year.

- The most frequently cited source of this coordination was CCS, which was mentioned by 54.6% of parents who recalled receiving coordination.
- A smaller proportion of parents cited a CCS special care center or hospital (23.0%), the child's health insurance plan (11.9%), a specialty care provider (15.9%), a primary care provider (11.4%), and/or a regional center for developmental services (8.7%).
- About 27.2% of all parents who reported that their child received services through a regional center said that the regional center helped them arrange or coordinate care in the past year.

About half of parents said that they had needed help coordinating care over the past year. The majority (73.8%) reported receiving all care coordination needed. Reasons for not receiving all coordination needed among the remaining 25.9% of parents are provided in **Exhibit 22**.

- Most of these parents said that coordination had not been offered to them (73.2%) and/or that they did not know that they could get help in coordinating care (65.4%).
- Nearly half (43.3%) said that a language or translation problem was a barrier to getting help arranging the child's care. About one-third (39.8%) of these parents were unable to find someone who could help them.

**Exhibit 22**  
**Reasons for Not Receiving Needed Care Coordination**



*Source: Los Angeles CCS Survey, 2005*

*Note: Shows reasons among children who did not receive all of the care coordination needed, who comprise about 13% of children in Los Angeles CCS. Parents may cite multiple reasons.*

## Support Received from the CCS Program

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### Knowledge of the CCS Program

In light of multiple publicly-funded medical programs for children, not all parents of children in CCS have been aware of the program and its administrative case management and care coordination capacities. One reason this occurs for children in Medi-Cal is that medically eligible children are not required to apply due to administrative agreement between CCS and Medi-Cal. In the 2001 NS-CSHCN, population estimates of CCS participation were extremely low due to apparent under-reporting of CCS enrollment by surveyed parents, and this is similar to the experience in other states.

Because all children receiving medical services through Los Angeles CCS, or therapy services through the Medical Therapy Program (MTP), have an assigned nurse case manager, it is increasingly important for parents to be aware of CCS program resources. Overall experiences with the CCS program are also important for many reasons. In terms of access to specialty care, awareness of the CCS care coordination capacity, and attempts by CCS staff to identify and address unmet needs of the child, are examples of important enabling factors.

The Los Angeles CCS survey shows that most survey respondents are aware of their child's participation in the program. Fewer than 1% of parents said either that they did not know about CCS or that the child has never participated in CCS. This rate does not generalize to all parents in the program since surveyed parents received a letter about the program and were told that the survey was about the CCS program.

- About 68.7% of parents said that they know the name of the child's nurse case manager at CCS. Parents of about 69.6% of parents whose child is in an MTU said that they know the name of the child's physical therapist.
- Fewer parents of children in Healthy Families (58.4%) or lacking insurance (60.0%) than children with private insurance (67.4%) or Medi-Cal (72.2%) reported knowing the name of the child's nurse case manager at CCS.

While not all parents (76.0%) said that their child was receiving CCS services at the time of the survey, nearly all recalled the last time a service had been authorized by CCS for their child. Dates ranged from late 2003 to the month of the interview, with a median of three months prior to the interview date.

### Experiences with the CCS Program

**Exhibit 23** describes parent experiences with the CCS program, many of which relate to their interactions with nurse case managers who coordinate and authorize services.

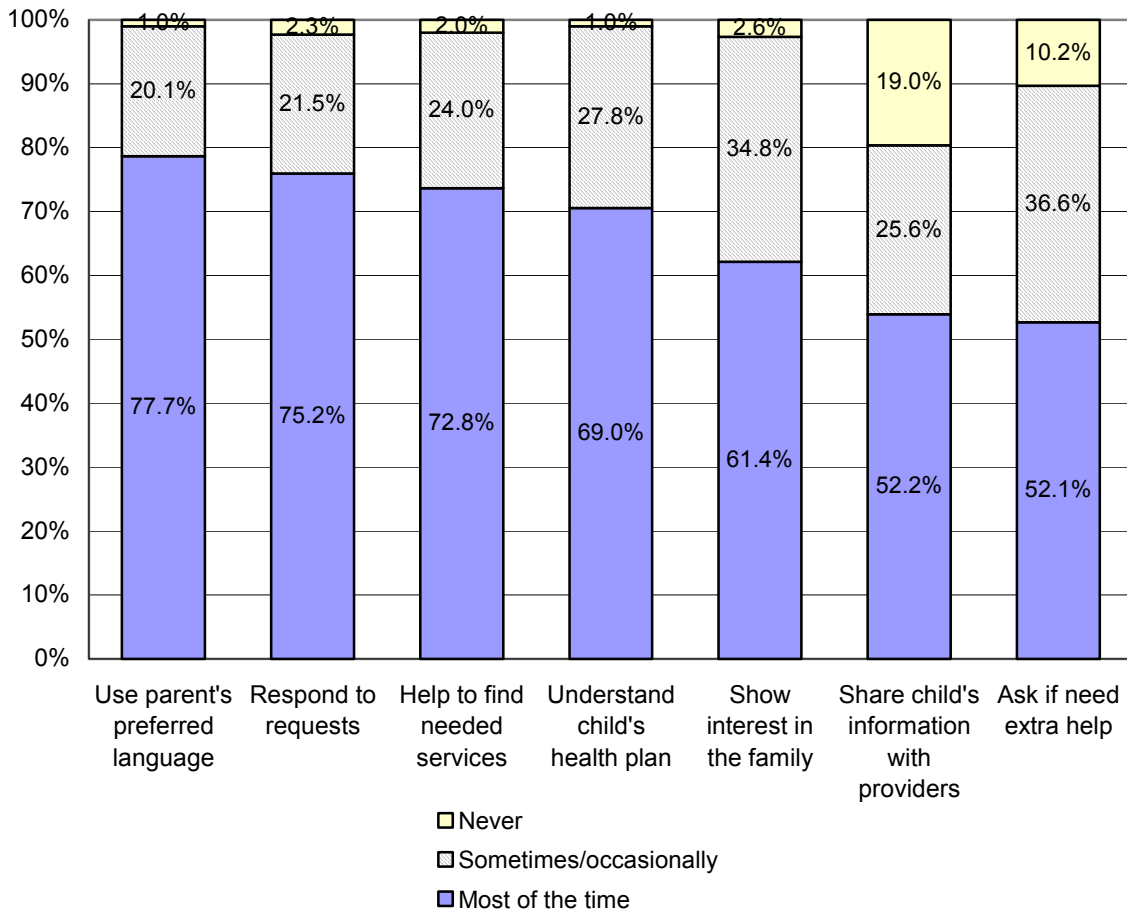
- Parents generally reported positive experiences with the CCS program.
- Nearly three-quarters of parents said that most of the time they can use their preferred language with CCS staff. Because the survey was conducted only in English and Spanish,



this may not reflect the experience of parents whose preferred language is other than English or Spanish.

- Using the parents preferred language, responding to requests, and helping to find needed services received the highest parent ratings. About three-quarters said that the CCS program does this for them most of the time.
- The fewest parents (just over half) said that CCS staff usually ask if they need additional help (52.1%) or share the child’s information with providers (52.2%).
- The least positive experiences with the CCS program were with CCS sharing the child’s information with providers (19.0% saying this “never” happens) and asking if the parent needs extra help (10.2% saying this “never” happens).

**Exhibit 23**  
**Parents’ Experiences with the CCS Program**



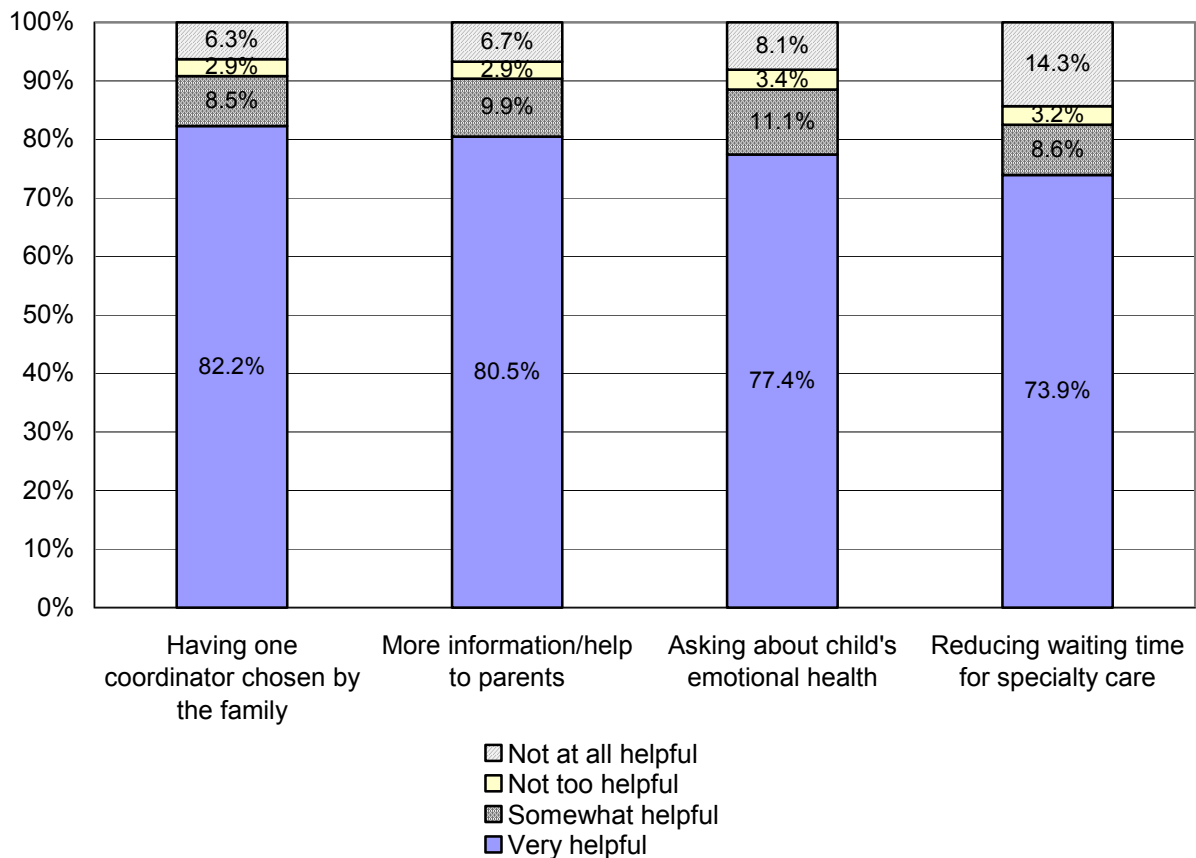
Source: Los Angeles CCS Survey, 2005

Note: Percentages exclude “do not know” responses, ranging from 1 to 3% per question.

## Preferences for System Improvements

**Exhibit 24** shows that parents enthusiastically supported several hypothetical improvements to the system of care for children in CCS. The largest proportion of parents (82.2%) endorsed the idea of having a single care coordinator, chosen by the family, who would help coordinate all of the child’s services across programs and providers. About three-quarters of parents (73.9%) reported that reducing the time between seeking an appointment and visiting the specialist would be very helpful to children and families. In general, fewer than 10% of parents felt that any of the proposed system enhancements—a single principal care coordinator, reduced waiting time, more support for parents, and providers routinely asking about the child’s emotional health—would be unhelpful or not too helpful.

**Exhibit 24**  
**Parent Preferences for System Improvement**



Source: Los Angeles CCS Survey, 2005

## Summary

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About two-thirds of parents report knowing the name of the child's nurse case manager at Los Angeles CCS. Only about half of parents of children in Healthy Families or lacking insurance have this information, with higher rates for children in Medi-Cal and with private insurance.

Most parents who report needing care coordination in the past year say that they received all of the coordination they needed. About 10 percent of parents say that they did not receive all of the coordination they needed because help was not offered to them. About 8 percent say that they did not receive all of the care coordination needed because they did not know that help was available, while 6 percent report a language barrier and 5 percent could not find someone who could provide the coordination needed.

Parents are generally satisfied with their experiences with CCS. Using the parents preferred language, responding to requests, and helping to find needed services receive the highest parent ratings. The fewest parents (just over half) say that CCS staff usually ask if they need additional help (52.1%) or share the child's information with providers (52.2%).

Parents enthusiastically support several hypothetical improvements to the system of care for children in CCS. The largest proportion of parents endorse the ideas of (1) having a single care coordinator, chosen by the family, who would help coordinate all of the child's services across programs and providers, and (2) providing more information and help to parents.

## Conclusion

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This report shows the value of surveying parents of children in CCS about their experiences with obtaining care and with obtaining needed coordination and support. The information provided from this new CCS survey shows how experiences vary with insurance coverage and the health care needs of children in the program. It also provides the first information on how children in CCS may compare with the broader population of CSHCN within the state.

Most children appeared to be obtaining the specialty care that they need, and parents are generally satisfied with their experiences in the CCS program. Among children in Medi-Cal, several aspects of medical care—receiving family-centered care, problems with specialty referral, having a personal doctor, and unmet needs for mental health services—children in CCS appear to fare better than the general population of CSHCN. In several areas, children in Medi-Cal fare better than privately insured children, including better access to interpreter services and less use of children as translators for medical information.

In contrast, children in Medi-Cal lag behind privately insured children in several key areas of specialty access: ease of obtaining referrals or authorization for specialty care, receiving all specialty care needed, receiving all mental health services/counseling needed, and obtaining timely care without health plan problems. Parents of children in Healthy Families generally report more difficulty with authorizations and delays, irrespective of parent educational attainment or the severity/impact of the child's condition.

Given the nature of the survey, it is not clear if the challenges families are facing are related to care for the child's CCS eligible medical condition or care for their other health related needs. The division of responsibility between CCS, health plans, and other public programs makes it difficult to know the specific causes of problems reported by families. Regardless, the survey provides additional evidence to those involved in providing care to these children of the need for a more coordinated system of care with fewer barriers to accessing high quality care in a timely way.

These are challenging concerns in California's health care environment. Adequate specialty provider supply is a continuing challenge for all Californians. California has the lowest Medicaid reimbursement among states, and future budget cuts may further jeopardize the ability of the program to retain its provider network. The following conclusions can be drawn for improvement.

### **Addressing the supply of pediatric subspecialists**

Problems obtaining authorization for services were most frequent in specialty areas of cardiology, neurology, orthopedics, and orthodontia. These specialties also showed the highest rates of unmet need for specialty care. There is role for Children's Medical Services, possibly in partnership with the Medi-Cal Managed Care Division (MMCD) and the Managed Risk Medical Insurance Board (MRMIB) and commercial health plans to better understand the supply of pediatric specialists in California. While parent reports are important, more information is needed to fully assess policy options. Unknowns include the actual time from authorization to appointment (based on objective measures such as time elapsed between authorization and visit)

and the adequacy of this timing using expert judgment. Given the standards in MMCD for time to appointment to primary care and specialty care, establishing expectations or norms for selected specialties used by CCS might enable California to continuously improve access to these providers using incentives and other strategies. The current supply might be improved by more efficient use of existing pediatric subspecialists and by payment rate changes. A comprehensive analysis of this problem is needed given the dynamic and complicated nature of California's health care system and the potential for unintended consequences of new incentives. Legislative relief through improved Medi-Cal/CCS payment rates is an essential strategy.

### **Addressing pressures for cost reduction**

These survey findings show that caution in cost reduction for specialized services and chronically ill populations is warranted. For many with ongoing chronic conditions, childhood and young adulthood are the period of time when disease management skills develop, with important implications for the disease trajectory over the life course. There are significant potential cost implications for California if management of conditions such as diabetes and severe asthma is poor, in terms of workforce participation, productivity, and health expenditures (particularly for Medi-Cal).

### **Improving pathways to mental health/counseling services**

Addressing unmet need for mental health care/counseling is important, given that CSHCN are at risk for depression and given the undersupply of providers in California. The survey showed that accessing mental health services was problematic, and the estimates in this survey likely underestimate need for mental health services/counseling. Knowing where to go prevented about half of these children from obtaining needed care. Currently the MMCD is working on the respective responsibilities and interfaces of public programs providing services for developmental, emotional, and behavioral concerns, which could help address informational barriers faced by providers. A Los Angeles coalition of stakeholders is examining access of mental health care/counseling for children in CCS, especially issues of screening for mental health issues and also referral and payment issues. A statewide question is the extent to which CCS special care centers can improve any elements of the pathways to services through screening, referral, and billing changes. Greater information for parents on available services might also improve demand for this care.

### **Improving communication and information for parents**

Communication between doctors and the child's other providers in the community, such as schools and early intervention programs, needs to be improved. Communication between physicians was not optimal but was less problematic than communication with other services and programs. Since obtaining adequate information is an issue for parents in CCS, greater involvement of family resource centers (FRCs) could improve the flow of information between parents about available resources. Use of parent consultants (a Family Centered Care Committee review materials and other policies/procedures within Los Angeles CCS) is a promising strategy for other counties that do not have as much formal family involvement as Los Angeles, and may continue to improve parent experiences in Los Angeles CCS.

### **Expanded transition support for adolescents and young adults with chronic conditions**

Children’s Medical Services has recently increased its focus on transition support for adolescents and young adults, with counties developing protocols within CCS. Frequently relevant aspects of transition include finding an adult provider who is willing and able to care for the young adult’s needs as well as support in domains of insurance coverage, education and independent living, and self management. Parents in Los Angeles have expressed not only the need to help adolescents and young adults transition into the adult system of care, but also the need for physicians to encourage adolescents and young adults to take more responsibility for managing their health conditions.

There is almost no information within the state about the effectiveness of current transition support and the health status and well-being of young adults who have graduated from CCS. This is an opportune time to evaluate transition support given plans within Medi-Cal Redesign to expand Medi-Cal managed care to the aged, blind, and disabled (ABD) population. If implemented, this organizational change will give health plans an added incentive and opportunity to examine the transition process since young adults with the most substantial health care concerns would be graduating into the health plans when they leave CCS at age 21. This is in contrast to the current transition (of those retaining Medi-Cal) to a fee-for-service system that lacks the infrastructure that health plans could potentially bring to bear (e.g., case management, health education, disease management).

### **Extending access to interpreter services across all insurance groups**

In Los Angeles CCS, children in Medi-Cal appear to have better access to interpreter services and much lower use of children under age 18 for translation. It is not known if this is occurring for services paid by CCS or for medical care generally. The current gap between Medi-Cal and both Healthy Families and private insurance may stem from different standards and expectations for provision of professional translation. Even though the majority of surveyed non-English-speaking parents is in Medi-Cal, this is an important issue for all children in CCS since there are substantial numbers of Spanish-speaking parents of children with private coverage and Healthy Families.

### **Ongoing needs assessment for CSHCN**

Ongoing assessment of needs, and information on any regional differences in parent experiences, would be very useful to the CCS program. The recent incorporation of federal performance measures on CSHCN for California’s Title V program (Children’s Medical Services) is encouraging more routine and comprehensive evaluation of children’s needs. In particular, further exploration is needed of the needs and unmet needs for parents of different educational backgrounds and language. Unmet need can be difficult to measure since parents with less information about what is available may be less likely to say that they needed and did not receive care or supports, both for the child and for family members.

### **Supporting local stakeholder groups focusing on CSHCN**

Several of the health care disparities identified in this survey—such as information needs of parents, problems with specialty care authorization, lack of a personal provider, and communication gaps between physicians and community programs—have been the target of California’s Medical Home Project, created in 2001. While this project is no longer fully funded,

several local coalitions created by the project are continuing to address systems issues for the CCS population. An essential area is working with pediatric practices to be better organized around the needs of CSHCN by providing extra time and the information that parents need, among other practice improvements. Some elements of coordination between physicians and programs such as schools, and the back and forth between community agencies for services, deserve statewide solutions but can be initially tackled at the local level. These coalitions have sought to help parents better navigate the complex system in place for CSCHN.

### **Taking advantage of statewide CMS information systems**

The new statewide Children's Medical Services information system (CMS-Net) created particular opportunities to improve information about the "medical home" for children in CCS. It is important to evaluate how this information system, and the associated changes to authorization procedures, may influence access. As counties begin to more routinely collect information about children's medical home, developing meaningful measures of this concept is vital. There is also an opportunity to more systematically assess parents needs for information and assistance. For example, about half of the surveyed parents of children in Los Angeles CCS say that they are never or only occasionally asked if they need extra help. While CCS likely is not responsible for all of those needs that may be identified, there is an opportunity to better solicit such needs as they may affect children's ability to obtain care in a timely way and affect the ability of the family to help meet the child's needs through care management and coordination.

# Appendix

## Comparison of CSHCN and Children in CCS Age 0-17 Years

**Exhibit 25** presents highlights for children in Los Angeles CCS in 2005 and for the larger population of California CSHCN statewide in 2001, limited to children age 0-17 years. Since children in Medi-Cal comprise more of the total Los Angeles CCS population (56.1%) than the general CSHCN population statewide (15.2%), it is expected that experiences will be similar for Medi-Cal and for the full CCS population, for the Los Angeles CCS program percentages.

<b>Exhibit 25</b>				
<b>Access to Care for Children 0-17 Years, Los Angeles CCS Program and CSHCN in California</b>				
	<b>Los Angeles CCS</b>		<b>CSHCN in California</b>	
	<b>Total (%)</b>	<b>In Medi-Cal only (%)</b>	<b>Total (%)</b>	<b>In Medi-Cal only (%)</b>
<b>Usual Source of Health Care</b>				
Have a usual source of health care	98.6	99.0	91.5	83.6
Doctor's office	42.5	37.2	71.9	49.4
Hospital clinic	24.5	28.0	6.1	11.1
Community health clinic	26.8	28.3	19.4	37.8
<b>Medical Home</b>				
Child has a personal doctor or nurse	86.5	86.6	86.8	72.2
Providers communicate well with school, early intervention, programs, providers	43.0	45.2	52.6	56.1
Providers are sensitive to family values and customs	90.5	92.0	84.5	75.0
Providers spend enough time with child	87.5	90.0	77.8	62.3
Providers give specific information needed	80.4	79.8	72.3	61.1
<b>Specialty Care</b>				
Any problem getting referral to specialist	23.6	21.7	21.1	34.9
Did not get needed specialty care, among children needing it	15.8	10.0	9.4	10.4
Did not get needed mental health services, among children needing it	27.3	30.5	22.3	41.5
Any delayed or foregone care	18.5	17.5	22.3	41.5
<b>Ease of Accessing Services</b>				
Child's services are organized and easy to use	83.0	83.2	66.0	58.0

Sources: Los Angeles CCS Survey (2005) for children age 0-21 years and the National Survey of Children with Special Health Care Needs (2001) for children 0-17 years

Note: Percentages for children in Medi-Cal are those with exclusively Medi-Cal coverage. Children reported to have both private insurance and Medi-Cal coverage are not included in these percentages. Comparisons between CSHCN in Medi-Cal and all other CSHCN are statistically significant for all indicators in the NS-CSHCN.



# Glossary

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**California Children Services (CCS)** – CCS is a statewide program that treats children with certain physical limitations and chronic health conditions or diseases. CCS can authorize and pay for specific medical services and equipment provided by CCS-approved specialists. The California Department of Health Services manages the CCS program. Larger counties operate their own CCS programs, while smaller counties rely on medical consultation of state CCS regional offices in Sacramento, San Francisco, and Los Angeles. The program is funded with state, county, and federal monies, and modest parent application fees.

**Children with Special Health Care Needs (CSHCN)** – The federal Maternal and Child Health Bureau (MCHB) developed a standard definition of CSHCN to describe those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. This definition captures a larger group of children than those with disabilities.

**Family Centered Care** – Family centered care is a concept reflecting the importance of effectively addressing emotional, social, and developmental health care needs and integrating families into all aspects of the child’s health care plan. The family-centered philosophy reflects parent involvement in the child’s care and calls for attention to each child and family’s unique needs. As the primary providers of care, parents have a wealth of unique knowledge and information about their children’s health.

**Federal Poverty Level (FPL)** – The Federal Poverty Guidelines, often referred to as the “Federal Poverty Level,” are issued each year in the Federal Register by the U.S. Department of Health and Human Services. The guidelines, a simplified version of the poverty thresholds used by the Census Bureau for statistical purposes, are used to determine financial eligibility for certain federal and state programs, including Medi-Cal. As of 2003, the Federal Poverty Level is \$8,860 (in annual income) for an individual and \$18,100 for a family of four.

**Healthy Families** – California’s State Children’s Health Insurance Program (SCHIP), Healthy Families, provides health coverage to citizen children in families with incomes between 100 and 250 percent of the FPL who do not qualify for Medi-Cal and do not have private insurance. Services covered are similar to those in the benefits package for California state employees and require payment of a monthly premium.

**Medi-Cal** – California’s Medicaid program provides health care coverage for low-income and disabled individuals who lack health insurance. Jointly funded by the state and federal government, it is the primary source of health and long-term care coverage for 5.1 million Californians. The federal Medicaid program was established in 1965 as Title XIX of the Social Security Act. Federal and state governments share the cost of Medicaid services.

**Medical Home** – The purpose of a medical home is to provide an ongoing source of coordinated health care for children. The American Academy of Pediatrics (AAP) defines the medical

home as medical care that is: 1) accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective; and 2) delivered or directed by a well-trained physician who helps to manage and facilitate essentially all aspects of pediatrics care.

**National Survey of Children with Special Health Care Needs (NS-CSHCN)** - Funded by the federal MCHB and conducted by the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC) in 2000-2001, the NS-CSHCN provides national and state-specific prevalence estimates of children with special health care needs using a standard definition of CSHCN. The NS-CSHCN describes access to the types of services more commonly needed and used by these children. It examines experiences with the current systems of care for CSHCN to identify barriers to accessing care and possible areas of improvement.

**Regional Centers** – The California Department of Developmental Services (DDS) provides case management and funding for services to Californians with developmental disabilities through 21 state-operated nonprofit agencies throughout California, which are called Regional Centers. Regional Centers also provide services to infants and toddlers age 0-3 years who are at risk for or have developmental delay.

**Title V** - In 1935 Congress enacted Title V of the Social Security Act, which authorized the creation of the Maternal and Child Health Services programs, providing a foundation and structure for ensuring the health of mothers and children for more than 60 years. Title V is administered by the federal MCHB as part of the Health Resources and Services Administration, U.S. Department of Health and Human Services. California's Title V program funds California Children Services (CCS).

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