



California's Service System for Children and Youth with Special Health Care Needs

ANALYSIS AND RECOMMENDATIONS
FOR A SERVICE SYSTEM THAT WORKS
FOR CHILDREN AND FAMILIES

DECEMBER, 2009

PREPARED FOR


Lucile Packard
FOUNDATION *for Children's Health*

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TABLE OF CONTENTS

Executive Summary 1

Acknowledgments 13

Introduction 14

Who Are Children and Youth with Special Health Care Needs and Their Families? 14

MCHB Core Performance Measures 16

California’s “System of Care” 17

Publicly Funded Programs for Children: Overview of Major Systems and Their Components in the Public Sector 19

Basic Health Service Programs 19

Federal Medicaid 19

Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program: Vital Comprehensive Benefit for Children 20

Federal Medicaid Waivers 21

California’s Medicaid Program: Medi-Cal 22

Health Services for Immigrants Under Medicaid 26

California’s Health Care Services for Immigrants Under Medi-Cal 27

State Children’s Health Insurance Program (CHIP) 28

California’s CHIP: Healthy Families 29

Other Federally Funded Health Care Programs 30

Medicare 30

TRICARE 30

Indian Health Service 30

Federally Qualified/Migrant and Rural Health Centers (FQHC) 31

Supplemental Security Income (SSI) 32

Social Security Disability Insurance (SSDI) 32

State Funded Health Care Programs 33

Child Health and Disability Prevention Program (CHDP) 33

Access for Infants and Mothers (AIM) 34

County Funded Health Care Programs 34

Children's Health Initiatives 34

Specialized Service Programs 35

California Children's Services (CCS) 35

Genetically Handicapped Persons Program (GHPP) 37

Regional Centers for Persons with Developmental Disabilities 37

Special Education 38

In-Home Supportive Services (IHSS) 39

High Risk Insurance Pool 39

Mental Health Services 40

Private Sector Services: Overview of Major Systems and Their Components in the Private Sector 41

Private Coverage 41

Foundations/Support Organizations 43

Overview of Special Populations Within CYSHCN 44

Adolescents 44

Children and Youth in Foster Care 44

Homeless Families 45

Families Experiencing Other Challenges 46

Overview of Services for Family Support 47

Family Resource Centers (FRC) 48

Family Empowerment Centers (FEC) and The California Association of Family Empowerment Centers (CAFEC) 49

Family Voices of California (FVCA) 49

Parent Training and Information Centers (PTI) and Community Parent Resource Centers (CPRC) 51

United Advocates for Children of California (UACC) Statewide Family Networks (SFN) 51

Is There a System of Care for CYSHCN? Analysis of the Systems, Their Strengths, and Challenges 52

Health Systems	52
Children’s Hospitals	52
CCS Special Care Centers	53
Community Hospitals and Clinics	53
Pediatric Subacute Facilities	54
Home Health Care	54
Developmental and Mental Health Services	55
Regional Centers	55
Mental Health Services	55
Special Education	56
Summary	56

Prior Efforts Addressing CYSHCN 57

Your Voice Counts, Family Voices of California	57
California’s Ailing System of Caring for Children With Special Health Care Needs (Peter Hansel and Cori Reifman, California Senate Office of Research, May, 2000)	59
Medi-Cal Managed Care Division, Task Force on Children with Special Health Care Needs (Linda Rudolph, MD, and Sharon Rothman King, MSW, 2003)	61
California Medical Home Project	64
Title V Children with Special Health Care Needs (CSHCN) Needs Assessment Report: California Children’s Services (CCS) Program Systems Issues and Priority Action Objectives (Family Health Outcomes Project, May 23, 2005)	66
Children’s Medical Services Branch (California Department of Health Services California Statewide Strategic Plan for Children with Special Health Care Needs 2006–2010)	68

Strengths, Challenges, and Gaps in the Service System 70

Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive. **71**

Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home. **72**

Families of CYSHCN have adequate private and/or public insurance to pay for the services they need. **73**

Children are screened early and continuously for special health care needs. **74**

Community-based services for children and youth with special health care needs are organized so families can use them easily. **74**

Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. **75**

Summary and Recommendations 76

Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive. **76**

Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home. **77**

Families of CYSHCN have adequate private and/or public insurance to pay for the services they need. **78**

Children are screened early and continuously for special health care needs. **79**

Community-based services for children and youth with special health care needs are organized so families can use them easily. **80**

Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. **81**

Looking Forward: California at a Crossroads 82

List of Acronyms 87

Key Stakeholders 89

References 93

Appendices 99

Appendix 1: Federal Waiver Options **99**

Appendix 2: Federal Health Care Programs **101**

Appendix 3: Publicly Funded Health Care Services—State Level **110**

Appendix 4: Immigrant Services and Categories **117**

Appendix 5: Health Insurance and Health Services—
Income Guidelines **118**

Appendix 6: List of Children’s Hospitals **119**

Appendix 7: The Family Partners Project: A Survey (“Your Voice Counts”) of Families of Children with Special Health Care Needs (Completed Project) **122**

Appendix 8: California’s Ailing System of Caring for Children with Special Health Care Needs, Prepared by Peter Hansel and Cori Reifman, California Senate Office of Research **123**

Appendix 9: Medi-Cal Managed Care Division: Task Force on Children with Special Health Care Needs: Summary **124**

Appendix 10: Specialty Health Care for Children in the Los Angeles California Children’s Services Program (CCS), a report by Moira Inkelas, PhD, and Kyra Samson, MD, UCLA Center for Healthier Children, Families and Communities, 2005 **163**

Appendix 11: Title V Children with Special Health Care Needs (CSHCN) Needs Assessment Report: California Children’s Services (CCS) Program Systems Issues and Priority Action Objectives, Report Submitted by Family Health Outcomes Project, May 23, 2005 **231**

Appendix 12: Children’s Medical Services Branch, California Department of Health Services California Statewide Strategic Plan for Children with Special Health care Needs, 2006-2010 **330**

EXECUTIVE SUMMARY



The authors believe that proposals that further achievement of the MCHB Core Performance Measures and meet core principles for health care delivery to CYSHCN stand the best chance of building a true system of care for vulnerable children and youth.

The future of children with special health care needs and their families is at a crossroads as a result of a number of pressing factors: ever-increasing numbers of children with special health care needs due to lifesaving interventions and early identification; the push toward full inclusion and optimal independence for individuals with disabilities and chronic conditions; the increasing cost of health care; the public debate to reduce health care costs and lower taxes; the decreasing availability of specialty care providers; the lack of access to comprehensive care coordination; and recent service cuts for vulnerable populations.

Children and youth with special health care needs (CYSHCN) are caught in the throes of this perfect storm; their well being is at risk. The Lucile Packard Foundation for Children’s Health has requested a paper that provides an overview of the current system of care for children with special needs and their families in California as the state contemplates changes in how these services are organized and delivered.

This report begins with an overview of the health and related systems designed to serve children with special health care needs, including publicly and privately funded services, as well as those specific to certain populations. Detailed information about each service system is located in the appendices at the end of the report, and referenced in the text. The next section consists of an analysis of the strengths and gaps within the current service system, and their impact on families. The report ends with a summary and recommendations for addressing some of the primary concerns in the current system of care.

WHO ARE CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES?

Children and youth with special health care needs are defined by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration, U.S. Department of Health and Human Services (US DHHS), as:

“...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

This definition was deliberately designed to be broad and inclusive, to reflect the characteristics held in common by children with a wide range of

diagnoses. However, publicly funded agencies do not base eligibility for services and programs on this broad federal MCHB definition, and instead tend to base their program eligibility on very specific conditions and diagnoses. In many instances, a single child with multiple special needs receives services and case management from a host of public programs for a complex medical condition, a developmental disability, a specific mental illness, and for special educational needs, while at the same time receiving basic health care via public and/or private health insurance.

According to the 2005-06 National Survey of Children with Special Health Care Needs (NS-CSHCN), 13.9% of U.S. children have special health care needs, and 21.8% of households include at least one child with a special health care need. According to the NS-CSHCN, children with special health care needs comprise between 9.9%-14.5% of children in California (US DHHS, 2008; CAHMI), or approximately 964,167 children.

Special populations within the broader group of CYSHCN face greater difficulties accessing health, developmental, behavioral, and educational services. These special populations include children in poverty; children whose parents do not speak English; children in foster care and other out-of-home care; and adolescents, including emancipated and homeless youth.

MCHB CORE PERFORMANCE MEASURES

In 1998, the federal Maternal and Child Health Bureau established a goal for state Title V programs for children with special health care needs to provide and promote family-centered, community-based, coordinated care for CYSHCN and to facilitate the development of community-based systems of services for these children and their families (MCHB, 2008). MCHB identified six core outcomes to promote this system of care mandated for all children with special health care needs under Title V, Healthy People 2010:

- Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive.
- Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home.
- Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.
- Children are screened early and continuously for special health care needs.
- Community-based services for children and youth with special health care needs are organized so families can use them easily.
- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Cultural competence is not a performance measure, but MCHB has included it as a guiding principle, which goes across all performance measures

(Goode, T.D., et al, 2007). This guiding principle and the six outcomes are designed to give the states and MCHB a way to measure progress on achieving the goal of family-centered care. The authors use the core measures as a framework for identifying strengths, gaps, challenges, and recommendations.

CALIFORNIA'S "SYSTEM OF CARE"

Terms like "system of care" are often used to refer to the panoply of services available to CYSHCN in California. In fact there is no "single system" but rather a complex "series of systems" that exist independently of each other, occasionally overlapping and sometimes conflicting. These coexisting, overlapping, and contradictory systems and funding mechanisms result in an extraordinarily complex maze of services, dueling eligibility criteria, and financing approaches that can confuse even the savviest advocate and result in delayed or denied services for children and major financial outlays for families. Ultimately, the success of CYSHCN in accessing services in the "system of care" is dependent on families' ability to negotiate this maze.

At the time of this writing, as a result of the state's desperate financial situation, everything connected with these "systems" is fluid, and there could be major changes in the coming year. We also recognize the potential impact of federal health care reform, which could result in significant redesign of the health system nationally, with repercussions for public and private health care coverage in our state.

PROGRAMS FOR CHILDREN

Publicly funded services for CYSHCN in California can be characterized in two ways: (1) basic health service programs, and (2) specialized service programs.

The report goes into depth on basic health service programs, including federal Medicaid; Early Periodic Screening, Diagnosis, and Treatment (EPSDT); federal Medicaid waivers; California's Medi-Cal; health services for immigrants under Medicaid; state Children's Health Insurance Program (CHIP) and Healthy Families; Medicare; TRICARE; Indian Health Service; Federally Qualified/Migrant and Rural Health Centers (FQHC); Supplemental Security Income (SSI); Social Security Disability Insurance (SSDI); Child Health and Disability Prevention (CHDP); and Access for Infants and Mothers (AIM).

The report also goes into depth on specialized service programs, including California Children's Services (CCS); the Genetically Handicapped Persons Program (GHPP); Regional Centers for Persons with Developmental Disabilities; special education; In-Home Supportive Services (IHSS); the state High Risk Insurance Pool; and mental health services.

Privately funded services for CYSHCN in California include private health insurance and foundations/support organizations and are discussed in detail in the full report.

OVERVIEW OF SERVICES FOR FAMILY SUPPORT

Whether families are in the hospital, at a doctor’s office, or at a community-based agency, they face a confusing maze of services and systems. As their children grow older and become more independent, the youth themselves need to understand the systems that serve them. Although many systems have case managers, families and youth often take the primary responsibility for coordinating their care across systems. In order to do this, families and youth need ongoing information, education, and support. They need to learn the intricacies of the different systems, and how to become partners in making decisions about their own care.

California has a variety of cost-effective, community-based resources that work together to assist families in navigating these complex systems and regulations. These services help families obtain adequate and appropriate care for children and youth with special health care needs. These community-based resources are rooted in a parent-to-parent and empowerment-focused philosophy and include Family Resource Centers (FRC); California Association of Family Empowerment Centers (CAFEC); Family Voices of California (FVCA); Parent Training and Information Centers (PTI) and Community Parent Resource Centers (CPRC); and United Advocates for Children and Families (UACF).

IS THERE A SYSTEM OF CARE FOR CYSHCN? ANALYSIS OF THE SYSTEMS, THEIR STRENGTHS AND CHALLENGES

Services for CYSHCN are provided in a variety of inpatient, outpatient, and community settings, depending on a number of factors including funding source, where the child lives, services needed, the child’s medical condition, and available specialists. These settings include children’s hospitals, CCS special care centers, community hospitals and clinics, pediatric subacute facilities, and home health care. Developmental and mental health services are provided by regional centers and county mental health programs; special education services are provided by individual or county school districts. Every report addressing access to care for CYSHCN in our state has commented on the need for California to address its silos of health, developmental, and mental health programs and to create mechanisms for the delivery of true coordinated, collaborative care.

PRIOR EFFORTS ADDRESSING CYSHCN

A number of reports aimed at assessing or improving California’s system of care for children with special health care needs are highlighted and discussed in this report. The paper builds on and incorporates these findings in its analysis of system gaps and recommendations.

STRENGTHS, CHALLENGES, AND GAPS IN THE SERVICE SYSTEM

California has many important components in place that foster implementation of a system of care for CYSHCN, including:

- A strong network of family organizations and a statewide chapter of Family Voices that bring the perspective of families to the design and operation of a family-centered system of care for CYSHCN.
- A dedicated pediatric provider network of physicians and other health care providers and tertiary and quaternary pediatric hospitals that are the envy of many states.
- Committed advocates for children and youth, including advocates specifically focused on improving access and care for CYSHCN.
- Publicly funded programs such as Medi-Cal that typically exceed the minimum required by federal law, bringing vitally needed services to low-income CYSHCN.
- A number of specialized programs designed specifically for special populations of children such as CCS and regional centers/Early Start.
- Public and private foundations whose interests are focused on CYSHCN.

At the same time, the national and global economic downturn, coupled with the state's own political and budgetary problems, presents major challenges at the macro level to achievement and maintenance of any system of care. These challenges, which affect funding and political support for programs that serve CYSHCN, include the following:

- The impact of the global economic meltdown has had catastrophic effects on California, including double-digit unemployment (11.6% in August, 2009) and a substantial drop in revenue to the state.
- California has a huge economy (8th largest in the world) that typically is slower to move into a recession but also slower to recover from one.
- California has severe structural budget imbalances, e.g., 55% of state revenue comes from personal income tax, as opposed to most other states that typically have a one third division among income tax, property tax, and sales tax. This imbalance leaves the state very vulnerable to a drop in income tax receipts such as the state is experiencing now.
- The economic situation is compounded by huge state budget deficits over the past few years that have resulted in major reductions in overall state spending, amounting to a drop in state spending of almost 20% in the last two years.
- The power of the governor and legislature to address structural imbalances is limited by California's status as the only state to require a super majority for both passage of the budget and any increase in state taxes.

As a result of these factors, California finds itself in the worst fiscal crisis in at least 20 years, with concomitant impact on funding for the services that make up the existing system of care for CYSHCN.

Even before the current fiscal situation and its potential impact, California had major gaps in its service system that leave vulnerable children and families at risk. Major service gaps that we have identified are grouped according to the six federal MCHB Core Performance Measures. The service gaps are organized

by measure because these are national goals our state is expected to meet. These measures define the service system that families and maternal and child health professionals agree must be in place for vulnerable children. Most of the gaps identified below have been culled from existing reports and surveys concerning access to care for California’s CYSHCN that have been produced by major stakeholder processes over the years and reflect the thinking of many professionals and family members.

Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive.

1. Families in California do not have structured and institutionalized opportunities to partner in decision-making at all levels.
2. There are no clear, published standards for family-centered care.
3. There is no formal evaluation or tracking system.
4. Infrastructure does not exist to ensure that families or youth have ongoing access to information, education, and support for leadership.

Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home.

1. California does not have an operational definition of “medical home” for CYSHCN and it does not have clear numbers on how many medical homes really exist or a way to ensure that all CYSHCN have one.
2. There is no infrastructure to support ongoing training of and information for providers who want to implement medical homes.
3. There is no mechanism for Medi-Cal billing or other financial enhancement for care coordination in the medical home context.
4. California has an increasingly fragile provider network and continues to lose pediatric subspecialists to other states.
5. There also are long wait times for other providers serving CYSHCN, e.g., mental health professionals, particularly child/adolescent psychiatrists and physical and occupational therapists.
6. Health, developmental, and mental health services are more likely to be located in urban areas than in rural areas.

Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.

1. Many families and youth with special health care needs do not have insurance or are underinsured.
2. Children may lose eligibility for public or private health insurance throughout the year.
3. Many families may qualify for insurance but because of a lack of information, they do not access it.

4. High out-of-pocket expenses are a barrier to children receiving the comprehensive services they need.
5. “Adequate” insurance can be a nebulous concept, since coverage that may appear adequate at first can lose its effectiveness depending on the changing health needs and program policies related to payment.

Children are screened early and continuously for special health care needs.

1. California does not have a standardized screening tool for identifying special health care needs.
2. Providers are not always knowledgeable about resources for follow-up when screening identifies problems.
3. Appropriate resources for follow-up once screening has taken place often are limited

Community-based services for children and youth with special health care needs are organized so families can use them easily.

1. There is no state inter-departmental coordinating body to work toward better organization of the multiple service systems for CYSHCN.
2. There is a lack of consistency of interpretation of state regulations/laws from county-to-county and across the multiple systems serving CYSHCN.
3. While many entities purportedly provide care coordination, there is a lack of communication among the multiple agencies serving the same child.
4. Most families report that they serve as their children’s care coordinators.

Youth with special health care needs (YSHCN) receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

1. There is no coordinated transition process for youth who are aging out of child-focused programs.
2. There are too few adult-oriented health care and other providers for youth as they age out of pediatric-oriented care.
3. Many youth lose insurance as they age out of eligibility for public insurance or insurance coverage through their parents’ employers.

SUMMARY AND RECOMMENDATIONS

The following recommendations build on findings in previous reports addressing service delivery organization for CYSHCN. The recommendations from earlier findings represent the analysis and experience of many stakeholders whose lives and work focus on vulnerable children and their families.

In keeping with national directives for the care of children with special health care needs, our recommendations are framed in the context of the MCHB Core Performance Measures.

Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive.

1. Families and youth should be represented at all levels of planning and implementation in a formalized structure at the state level to model parent/professional collaboration.
2. There should be a formal evaluation process, including ongoing interviews and surveys, to assess family and youth satisfaction with the services they receive.
3. There should be clear state standards for family-centered care in all systems serving CYSHCN.
4. There should be mechanisms for providing ongoing information, education and support for leadership development among families and youth.
5. Parent health liaison services should be made available for all CYSHCN receiving services from public programs at the local level.
6. The state should set clear criteria for achievement of this core measure and ensure that its performance and progress are measured periodically and reported publicly.

Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home.

1. The state should define and operationalize the concept of a “medical home” for CYSHCN.
2. An infrastructure to support training and education of providers to assist them in serving as medical homes for CYSHCN should be developed.
3. Mechanisms should be established for Medi-Cal billing and other reimbursements for care coordination in the medical home context.
4. The state must address the crisis in the pediatric provider network by taking steps to increase the numbers of primary and specialty care providers serving CYSHCN; appropriate reimbursement is critical.
5. Regionalized services from multiple counties should ensure that children’s care is coordinated with the medical home in order to address the needs of the child regardless of the county of residence.
6. Families must be recognized as the true medical home for their CYSHCN, and their participation in formal medical home approaches or structures should be supported at both the state and local levels.
7. The state should set clear criteria for achievement of this core measure and ensure that its performance and progress are measured periodically and reported publicly.

Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.

1. California should set as an overarching goal the assurance of comprehensive insurance coverage for all CYSHCN.
2. The state should clarify payment policies among its various agencies so that there is a payer of first resort,
3. The EPSDT benefit package and federal medical necessity definition should be established as the medical standard for care for all children in the state.
4. CCS quality standards should be established as the standard for all pediatric care in the state.
5. The state should establish the CCS program as the whole-child program of comprehensive care for CYSHCN and should consider adjustment of CCS program financial eligibility to restore the income limit to \$100,000; deem children enrolled in Healthy Kids programs as financially eligible for CCS; and link CCS financial eligibility to the federal poverty level (FPL) with calibration by family size.
6. The state should strengthen Healthy Kids programs by setting statewide standards for benefits and financial eligibility criteria.
7. The inadequacy of private insurance in addressing CYSHCN should be addressed through such steps as elimination of annual and lifetime caps on insurance coverage and establishment of the right of young adults to age 28 to buy into parents' insurance at group rates.
8. The state should set clear criteria for achievement of this core measure and ensure that its performance and progress are measured periodically and reported publicly.

Children are screened early and continuously for special health care needs.

1. As recommended by a number of reports, the state should establish use of a standardized screening tool or tools for identification of children with health, developmental, behavioral, and mental health concerns.
2. There should be state performance standards for early and continuous screenings (e.g., CHDP Health Assessment Guidelines) for use in both public and private health plans, including HMOs and PPOs.
3. The state should implement an outreach and education plan for health providers that will promote early and continuous screening and surveillance, identification of CYSHCN, and understanding of appropriate resources for follow-up.
4. The state should align the CHDP periodicity schedule with the current American Academy of Pediatrics (AAP) schedule and ensure that children can obtain both periodic and inter-periodic visits as needed.
5. The state should set clear criteria for achievement of this core measure and ensure that its performance and progress are measured periodically and reported publicly.

Community-based services for children and youth with special health care needs are organized so families can use them easily.

1. The state should create a statewide interdepartmental coordinating body with entities such as the departments of health, mental health, social services, developmental services, education, and others as needed; families; advocates; and representatives of county departments.
2. The state should ensure consistency across regions and counties in the interpretation and implementation of state law, regulations, and procedures.
3. Policies on sharing of information among public and private agencies under the Health Insurance Portability and Accountability Act (HIPAA) and other federal and state laws should be clarified and all agencies serving CYSHCN should be required to share information to the extent permitted by confidentiality law in order to ensure identification, access to care, coordination of services, and quality improvement.
4. The state should develop and implement strategies and funding mechanisms that will support activities to improve coordination of services such as:
 - Local agency “roundtables” to coordinate access to services;
 - “Single point of entry” (SPOE) mechanisms for easy access to all children’s programs;
 - Special care center-sponsored multidisciplinary team meetings with community-based services and families;
 - Neonatal intensive care unit (NICU) discharge planning meetings with all agencies;
 - Universal parental consent form to improve referral to and sharing of information among agencies;
 - CCS public health nurse positions (modeled after foster care PHNs to coordinate between CCS and schools);
 - Increased support component within CCS through CCS social workers and/or parent health liaison (PHL) services;
 - Models for a “system navigator” and/or ombudsperson to assist parents to access service across systems.
5. All families should have a hard copy and/or electronic health record for their children and tools to assist them in tracking their medical care, including child health notebooks that can be used across service systems.
6. The state should set clear criteria for achievement of this core measure and ensure that its performance and progress are measured periodically and reported publicly.

Youth with special health care needs (YSHCN) receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

1. An infrastructure to support the implementation of standardized transition plans and coordinate transition among the multiple systems serving YSHCN should be created.

2. The state should commit to ensuring that YSHCN do not transition out of public or private insurance into the ranks of the uninsured and consider strategies such as increasing the number of conditions covered by the GHPP and/or extending CCS coverage beyond age 21 for specific conditions; modifying financial eligibility for Medi-Cal for YSHCN over age 21 to expand their access; and establishing a right to benefits for YSHCN under parental coverage to a specific age such as 24.
3. The state, in concert with pediatric experts and adult-oriented medical groups, should consider ways to support and strengthen the capacity of adult-oriented providers to serve youth and young adults.
4. Provider rates and other incentives should be instituted to fortify the provider network for YSHCN.
5. California must set clear criteria for achievement of this core measure and ensure that its performance and progress are measured periodically and reported publicly.

LOOKING FORWARD: CALIFORNIA AT A CROSSROADS

As noted throughout this report, California's budget situation has resulted in major cuts to a number of programs that serve children and youth, including those with special health care needs. While the situation is fluid and not all details are known, certain budget impacts are clear for health and developmental programs that are fundamental to the care of CYSHCN.

In this climate of severe budget reductions, program rollbacks, and state proposals for major overhaul of long-standing programs, it is especially critical that there are clear standards for the treatment of children and youth with special health care needs, against which proposals for change can be measured. For this reason, the authors strongly recommend two steps:

1. **The state must commit to achieve the federal MCHB Core Performance Measures**, which lay out nationally accepted goals for the care of CYSHCN and the system that serves them. The state should set clear operational criteria for achievement of each measure, and state progress should be evaluated and reported publicly on a regular basis.
2. **The state must commit to basic principles of care for CYSHCN in any major change of the health care system that serves them.** These principles, which have been accepted by several groups of providers and families in California, include the following:
 - Families/youth must have access to ongoing information, education, and support in order to be an informed and effective partner in the care of their children/themselves.
 - All health care delivery to children, particularly children and youth with special health care needs, should be based on and flow from their medical and related needs.
 - Children should have access to medically, developmentally, and behaviorally appropriate care regardless of their geographic region. County-based

systems of care that limit access to pediatric and/or other appropriate providers are not acceptable for CYSHCN. Children should retain access to regionalized pediatric health care systems such as CCS-approved neonatal, pediatric intensive care, and other pediatric care.

- CYSHCN should have clearly identified medical homes including primary care providers, access to pediatric subspecialists, and care coordination. Families should be recognized and supported as central to the organization and coordination of their children's care, and should have the ability to exercise choice in selecting providers that meet pediatric credentialing standards.
- Provider networks should include all pediatric sub-specialties, pediatric hospitals, child-appropriate durable medical equipment (DME) and other supply vendors, and other pediatric-appropriate services. Providers should meet clearly established standards for credentialing that reflect pediatric training and experience.
- The benefits package for children should be broad and representative of children's needs, including appropriate medical, dental, developmental, behavioral, and rehabilitative services; pharmaceuticals; DME and medical supplies; and ancillary services. Care coordination should be a recognized component of service delivery to CYSHCN. The federal EPSDT benefit and medical necessity definition should serve as the model for care of children and youth.
- Financing of health care delivery to CYSHCN should recognize their special needs, and children's access to health care should not be hindered by inadequate reimbursement to providers. Fee-for-service systems should reimburse at rates that reflect actual costs of care, and reimbursement should include the capacity to cover pediatric services beyond typical medical care (e.g., office visits), such as care coordination. Capitated systems should have rates that are risk-adjusted to reflect actual costs of care, and include additional services such as care coordination. Capitated systems should not include risk to providers (thus removing financial disincentives to provision of necessary care) and should avoid full risk to plans through strategies such as reinsurance or risk-sharing with the state (such as the current CCS carve-out).

Drawing on these past experiences, the authors believe that proposals that further achievement of the MCHB Core Performance Measures and meet core principles for health care delivery to CYSHCN stand the best chance of building a true system of quality care for vulnerable children and youth. California is indeed at a crossroads, with difficult decisions ahead, and with the most vulnerable populations at risk. It is clear that in order to address the strategies and recommendations outlined in this report, we must also garner the political will to make this systemic change.

ACKNOWLEDGMENTS



The authors would like to express their appreciation to the following for their assistance in preparing this paper:

- **Steve Barrow**, Project Coordinator/Executive Director, California Premature Infant Health Coalition
- **Marian Dalsey, MD, MPH**, former Chief, Children’s Medical Services Branch, Department of Health Care Services
- **Rocio De Mateo Smith**, Executive Director, State Council on Developmental Disabilities Area Board V
- **Cora Hoover, MD**, family physician and student, University of California, Berkeley School of Public Health
- **Mara McGrath, MPH**, Policy Analyst, Lucile Packard Children's Hospital
- **Suzanne Nelson**, Director, North Region Special Education Local Plan Area, Alameda County
- **Paul Newacheck, DrPH**, Professor of Health Policy and Pediatrics at the Institute for Health Policy Studies and the Department of Pediatrics at University of California, San Francisco
- **Sherri Sager**, Chief Government Relations Officer, Lucile Packard Children's Hospital
- **Paul Wise, MD, MPH**, Richard E. Behrman Professor of Child Health and Society and Core Faculty Member, Center for Health Policy/Center for Primary Care and Outcomes Research, Stanford University.

For their thoughtful commentary and careful review of the report, the authors are grateful to:

- **Lynn Kersey, MA**, Executive Director, and the staff of Maternal and Child Health Access for serving as the inspiration for the program income graph found in Appendix 5.
- **Marianne Ward, MA**, University of Southern California University Center of Excellence in Developmental Disabilities at Children’s Hospital Los Angeles for her assistance with editing and formatting the report.
- **Families and parent-to-parent staff members** across California who contributed their stories to this report.
- **Family Voices of California members** who reviewed the report and provided valuable comments, including **Reva Guimont**, Family Resource Center Program Director, Exceptional Parents Unlimited; **Wendy Longwell**, Parent Liaison, Rowell Family Empowerment of Northern California; and, **Diane Storman**, Health Programs Manager, Exceptional Family Resource Center.

INTRODUCTION



The future of children with special health care needs and their families is at a crossroads as a result of a number of pressing factors: ever-increasing numbers of children with special health care needs due to lifesaving interventions and early identification; the push toward full inclusion and optimal independence for individuals with disabilities and chronic conditions; the increasing cost of health care; the public debate to reduce health care costs and lower taxes; the decreasing availability of specialty care providers; the lack of access to comprehensive care coordination; and recent service cuts for vulnerable populations.

Children and youth with special health care needs (CYSHCN) are caught in the throes of this perfect storm; their well being is at risk. With that in mind, the Lucile Packard Foundation for Children's Health has requested a paper that provides an overview of the current system of care for children with special needs and their families in California, as the state contemplates changes in how these services are organized and delivered.

This report begins with an overview of the health and related systems designed to serve children with special health care needs. This section includes publicly and privately funded services, as well as those specific to certain populations. Detailed information about each service system is located in the appendices at the end of the report, and referenced in the text. The next section of the report consists of an analysis of the strengths and gaps within the current service system, and their impact on families. The report ends with a summary and recommendations for addressing some of the primary concerns in the current system of care.

WHO ARE CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES?

Children and youth with special health care needs are defined by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration, U.S. Department of Health and Human Services (US DHHS), as:

"...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

This definition was deliberately designed to be broad and inclusive, to reflect the characteristics held in common by children with a wide range of

diagnoses. As discussed in the sections to follow, the various publicly funded agencies do not base eligibility for services and programs on this broad federal MCHB definition, and instead tend to base their program eligibility on very specific conditions and diagnoses. In many instances, a single child with multiple special needs receives services and case management from a variety of public programs—for a complex medical condition, a developmental disability, a specific mental illness, and for special educational needs—while at the same time receiving basic health care via public and/or private health insurance.

The National Survey of Children with Special Health Care Needs (NS-CSHCN) provides a consistent source of national and state level data on the size and characteristics of the population of CYSHCN. This survey, sponsored by MCHB and carried out by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics, provides detailed information on the prevalence of CYSHCN in the nation and in each state, the demographic characteristics of these children, the types of health and support services they and their families need, and their access to and satisfaction with the care they receive.

The 2005-06 survey reported that 13.9% of U.S. children have special health care needs, and 21.8% of households include at least one child with a special health care need. According to the NS-CSHCN, children with special health care needs comprise 9.9% of children in California (US DHHS, 2007; The Child and Adolescent Health Measurement Initiative (CAHMI), NS-CSHCN, 2005-06), or approximately 964,200 children. This represents 5.6% of children from birth through age five, 11.7% of children ages 6-11, and 12.4% of children ages 12-17 in California (CAHMI, NS-CSHCN, 2005-06).

Children and youth with special health care needs, like all children in California, represent a diverse population in many ways. Children with special health care needs in the state are ethnically diverse; 47.7% are White (non-Latino), 10.5% are Black (non-Latino), 29.1% are Latino, and 12.7% are multiple or other race/ethnicity (CAHMI, NS-CSHCN, 2005-06). In California, 14.4% of CYSHCN live in families that primarily speak a language other than English at home (CAHMI, NS-CSHCN, 2005-06). Many children with special health care needs live in families with incomes that are at or near poverty, with 18.3% of CYSHCN in California living in families with incomes under 100% of the federal poverty level (FPL), and 39.5% living under 200% FPL (CAHMI, NS-CSHCN, 2005-06). (The FPL in 2006 was \$20,000 for a family of four, according to US DHHS, 2009.)

In California, CYSHCN have better rates of insurance coverage than the general child population. However, according to the NS-CSHCN, 3.1% were uninsured at the time of the survey and 8% were without insurance at some time within the past year (US DHHS, 2008). The predominant form of insurance is private insurance, with 63.6% having private insurance only, 26.2% receiving public insurance only, and 7.1% receiving both public and private insurance (CAHMI, NS-CSHCN, 2005-06).

Special populations within the broader group of CYSHCN face greater difficulties accessing health, developmental, behavioral, and educational services. These populations include children in poverty; children whose parents

do not speak English; children in foster care and other out-of-home care; and adolescents, including emancipated and homeless youth.

MCHB CORE PERFORMANCE MEASURES

In 1998, the federal MCHB established a goal for state Title V programs for children with special health care needs to provide and promote family-centered, community-based, coordinated care for CYSHCN, and to facilitate the development of community-based systems of services for these children and their families (MCHB, 2008). MCHB has identified six core outcomes which promote this system of care, also mandated by Healthy People 2010 (a comprehensive set of disease prevention and health promotion objectives promulgated by DHHS, Office of Disease Prevention and Health Promotion) and the New Freedom Initiative (an Executive Order to remove barriers to community living for people of all ages with disabilities and long-term illnesses).

Cultural competence is not a performance measure, but MCHB has included it as a guiding principle, which goes across all performance measures (Goode, T.D., et al, 2007). This guiding principle and the six outcomes are designed to give the states and MCHB a way to measure progress on achieving their goals. Progress toward achievement of the core outcomes is measured in several ways. The National Survey of Children with Special Health Care Needs (NS-CSHCN), as discussed above, provides information about CYSHCN in all 50 states and the territories by conducting telephone interviews with at least 3,000 families in each state, with in-depth interviews of 750-850 families per state specifically addressing the core outcomes. The survey was conducted in 2001 and 2005-06. In addition, California monitors some of the core outcomes as part of its Title V needs assessment process.

Tracking these core outcomes provides valuable information about a state’s progress in achieving a family-centered system of care. Below is a summary of California’s progress from the 2005-06 NS-CSHCN (US DHHS, 2007).

MCHB Core Outcomes	% CYSHCN Achieving Outcome in California	% CYSHCN Achieving Outcome in U.S.
Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive.	46.6%	57.4%
Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home.*	42.2%	47.1%
Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.	59.6%	62.0%
Children are screened early and continuously for special health care needs.	62.7%	63.8%
Community-based services for children and youth with special health care needs are organized so families can use them easily.	85.3%	89.1%
Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.	37.1%	41.2%

* The American Academy of Pediatrics describes the medical home as a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. Additionally, the American Academy of Family Physicians (AAFP), the American Academy of Pediatrics (AAP), the American College of Physicians (ACP), and the American Osteopathic Association (AOA) have produced Joint Principles of the Patient-Centered Medical Home.

(Note: The MCHB performance measure for early and continuous screening is the rate of parents reporting that their child with special health care needs received routine preventive medical and dental care in the past year. Data from the 2007 National Survey of Children’s Health showed that California children receiving a structured developmental screening in the past year lagged behind the national average more significantly for children ages 10 months to 5 years (14% of young Californians compared to 19.5% nationally) (CAHMI, NSCH, 2007). This rate of screening varied by insurance type; those screened were 15% of children in California with public insurance coverage, 14% of children with private coverage, and 10% of children who are uninsured (CAHMI, NSCH, 2007).

CALIFORNIA’S “SYSTEM OF CARE”

When Henry was born, physicians doubted he would survive the first 24 hours. When he was three, his parents were told he was retarded and would require special education classes the rest of his life. When he was five years old, he had logged hundreds of hours in physical, occupational and speech therapy. He’d received the best care by pediatric subspecialists. At 15 years old, he is enrolled in accelerated courses in a college prep high school program. This year, he will compete in the Junior Olympics with his water polo team. He is a walking, talking testament to early intervention.

Terms like “system of care” are often used to refer to the panoply of services available to CYSHCN in California. In fact there is no “single system” but rather a complex “series of systems” that exist independently of each other, occasionally overlapping and sometimes conflicting. Publicly funded services include basic health services for children, often regardless of any special health care needs but where eligibility typically hinges on family income, such as health coverage via Medi-Cal. As described later in the report, the state also administers specialized services organized by a child’s particular medical or other condition (e.g., California Children’s Services, or CCS, for children with specific medical diagnoses; county-based mental health services for children; regional centers for persons with developmental disabilities; special education; foster care). Some of these programs have financial eligibility criteria while others do not. Also, services are available in the private sector for those with employer-based or privately purchased health insurance coverage.

Many children use both public and private systems, depending on their conditions, needs, and individual programs’ eligibility criteria. These coexisting, overlapping, and contradictory systems and funding mechanisms result in an extraordinarily complex maze of services, dueling eligibility criteria, and financing approaches that can confuse even the savviest advocate, and result in delayed or denied services for children and major financial outlays for families. Ultimately, the success of children and youth with special needs in accessing services in the “system of care” is dependent on families’ abilities to negotiate this maze.

Some examples of the extent of service use by children with special health care needs in California can be seen from the following statistics:

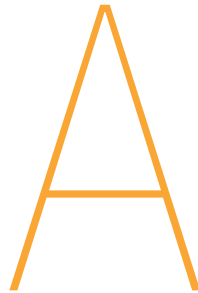
- California provided special education services to 678,105 individuals, newborn up to 22 years of age as of December, 2008 (CDE, 2008).
- As of December, 2007, 80,272 children ages 3 through 17 were clients of regional centers in California, and another 18,383 young adults ages 18-21 were clients of regional centers (DDS, 2007).

- In 2006, 56,000 births, or 10.7% of all California live births, were premature, with a significant number having multiple medical and developmental special needs (March of Dimes Peristats, 2009).
- 64,838 children were in the foster care system in California as of December, 2008 (Needell et al., 2009); children in foster care are regarded as a specific population within CYSHCN because of their high prevalence of physical, developmental, and mental health needs, as documented in a number of studies (Leslie, etc., 2005; Chernoff, Combs-Orme, Risley-Curtiss, and Heisler, 1994).

We note that at the time of this writing, as a result of the state's desperate financial situation, everything connected with these "systems," from eligibility to, in some cases, their existence, is fluid, and there could be major changes in the coming year. We also recognize the potential impact of federal health care reform, which could result in significant redesign of the health care system nationally, with repercussions for public and private health care coverage in our state.

PUBLICLY FUNDED PROGRAMS FOR CHILDREN

OVERVIEW OF MAJOR SYSTEMS AND THEIR COMPONENTS IN THE PUBLIC SECTOR



s discussed above, publicly funded services for CYSHCN in California can be characterized in two ways:

1. **Basic health service programs**, in which individual or family income is the primary eligibility criterion, sometimes in tandem with other criteria such as health status, age, or immigration status. These programs are funded via federal, state, and/or local funds.
2. **Specialized service programs** that serve solely children with special health care needs (and, in some cases, adults as well), in which income may or may not be a criterion for eligibility. These programs typically are organized on the basis of the presence of specific health, mental health, and/or developmental conditions.

BASIC HEALTH SERVICE PROGRAMS

The two major basic health service programs for children that are publicly funded are Medicaid, known as Medi-Cal in California, and the state Children's Health Insurance Program (CHIP), called the Healthy Families program in California. These programs, which are funded through a combination of federal and state funds, are described below. The federal piece is described first, followed by discussion of the state program. Several other health care programs that are funded exclusively by the federal or California state government also are described below.

Federal Medicaid

Medicaid (Title XIX of the Social Security Act) was created in 1965 as the federal program to provide health care coverage for low-income individuals, and is the largest source of funding in the U.S. for medical and health-related services for people with limited income. It is available only to certain low-income individuals and families who meet eligibility criteria that are recognized by federal and state laws.

Medicaid is funded through a combination of federal and state funding and is a state-administered program; each state sets its own guidelines regarding eligibility and services, within guidelines set by the federal government. Federal

guidelines are more prescriptive of the services that must be provided to children than services for adults. For example, federal law requires states to provide Medicaid coverage to all children in families with incomes below poverty. This group of children—the “categorically needy”—is guaranteed Medicaid eligibility and includes children who have poverty-level income, who receive Supplemental Security Income (SSI), or who receive federal foster care or adoption assistance. In addition, states have the option of extending coverage to children at higher income levels through Medicaid and the state Children’s Health Insurance Program. (CHIP is the child health coverage program for low-to-middle income children not eligible for Medicaid; see page 28, for more information.)

Medicaid provides coverage for almost 60 million Americans and finances 16% of national health spending. Medicaid covers over a quarter of all children in the U.S., including nearly one of every five white children and roughly two of every five African American and Latino children. In 2004, 5% of all beneficiaries with the highest health and long term care costs accounted for 57% of total Medicaid spending. For many of those with severely disabling conditions, Medicaid provides access to diverse services and long term care options and assures comprehensive coverage for the complex and extensive health needs of many people with chronic illnesses and severe disabilities. Nearly four in 10 children with special needs are covered by Medicaid (US DHHS, 2005; Kaiser Commission on Medicaid and the Uninsured, 2009; Rowland, 2009).

Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program: Vital Comprehensive Benefit for Children

The EPSDT benefit was added to the federal Medicaid program in 1967. It is required in every state and is designed to improve the health of low-income children by financing appropriate and necessary pediatric services through a comprehensive set of benefits and services specifically for children. Since one in three U.S. children under age six is eligible for Medicaid, EPSDT offers a very important way to ensure that young children receive appropriate health, mental health, and developmental services.

EPSDT was expanded and better defined by the federal Omnibus Budget Reconciliation Act of 1989 (OBRA ‘89), including rewriting the definition of medical necessity to cover services that can “correct or ameliorate” a condition identified on a screening of any Medicaid beneficiary under 21. Under this definition, EPSDT requires that any medically necessary health care service listed in Section 1905(a) of the Act must be provided to an EPSDT recipient even if the service is not available under the state’s Medicaid plan to the rest of its Medicaid population or if frequency or duration of service is limited under the state’s plan. As a result, under EPSDT, eligible children have access to screening services, vision services, preventive and emergency dental services, hearing services, and any other diagnostic service and health treatment that is covered by Medicaid (The Commonwealth Fund, 2005).

The federal EPSDT benefit, coupled with the comprehensive medical necessity definition, makes Medicaid the gold standard of health care services for all children, and particularly for those with special health care needs.

Federal Medicaid Waivers

Under Sections 1915 and 1115 of the Social Security Act, Medicaid waivers are programs that allow the Secretary of Health and Human Services to permit individual states to receive federal matching funds without complying with certain Medicaid rules. Unlike regular Medicaid services, waiver services can be provided to specific targeted populations or to persons in limited parts of a state. (See Appendix 1 for a table describing the current federal waiver options.)

There are two types of federal Medicaid waivers:

1. Program waivers: Sections 1915(b) and (c) of the Social Security Act allow exemptions for managed care or home and community-based care.

- 1915(b) exempts states from the mandate that recipients have a choice of providers. California is one state that uses the waiver to require recipients to enroll in managed care plans. More than two million of California's Medi-Cal recipients are enrolled in programs under the 1915(b) waiver.
- The 1915(c) waiver, the home and community-based services (HCBS) waiver, is the most frequently used waiver for providing services in the community. These waivers are available to Medicaid-eligible individuals who, without the waiver services, would be institutionalized in a hospital or nursing facility. This type of waiver allows the Secretary to waive certain financial eligibility requirements and the Medicaid requirement that services must be "comparable" among beneficiaries and must be provided statewide.

California has six home and community-based service waivers that serve specified subgroups of the Medi-Cal populations. The enrollment cap for these waivers for 2009-10 is 90,000 clients. California is preparing to implement a new palliative care waiver under 1915(c) that will provide an enhanced package of services to children with serious and life-threatening medical conditions.

(Families USA; CA.gov, Department of Health Care Services [a])

2. Research and demonstration waivers: Section 1115 allows for a broader scope of Medicaid law for the purpose of experimentation and testing programs.

- Most states have used 1115 waivers to implement Medicaid managed care. These waivers can be used to waive a broader set of federal Medicaid provisions than 1915 waivers as long as the costs are budget neutral. California has used 1115 waivers for community care for individuals who are eligible for both Medicaid and Medicare (often called dual-eligibles or "Medi-Medis") who otherwise would be institutionalized, and in other special circumstances.
- The In-Home Supportive Services (IHSS) Plus waiver provides an array of self-directed personal care assistance and delivery options that are not available under typical IHSS personal care services to persons who are aged or blind or who have disabilities. This waiver allows recipients to remain in their own home. There is no enrollment cap for this waiver.

The Jones family received inadequate care under the constraints of an HMO for their young son, Max, who has mitochondrial disease. His mother often had to act as the primary care coordinator, spending countless, frustrating hours ensuring that referrals were in place so that his care would not be interrupted. With the help of a Medi-Cal waiver, they were able to change to a PPO that covers the difference in out-of-pocket expenses for Max. Now he is able to receive the care he requires in the facilities that can best meet his needs. For the first time in 14 years, Max is more medically stable than ever, thanks to the physicians that he now has access to. His parents can take him where the experts are, not where the HMO dictated that he go.

More specific information on the federal Medicaid program is displayed in Appendix 2.

California's Medicaid Program: Medi-Cal

The Medi-Cal program was established in California in 1965 as the state version of Medicaid. The program originally was designed for people on welfare, but numerous other aid categories have been added over time. Medi-Cal is the primary funder of health care and related services for low-income families, with specific attention to serving children, mothers, and pregnant women. Federal law requires the program to provide a core of basic services including outpatient care, inpatient hospitalizations, physician services, skilled nursing care, laboratory and X-rays, and family planning. Private and public providers may elect to participate in the program. Mandatory Medicaid services, including EPSDT, are covered by federal funds with a state match. (The federal-state match breakdown for the federal Medicaid and CHIP programs is outlined in a table in Appendix 2.)

California's Federal Medical Assistance Percentage, or FMAP, the rate at which the federal government matches state investment in Medicaid, is 50:50, the lowest match rate in the nation (shared with 13 other states). The American Recovery and Reinvestment Act of 2009 (ARRA) will provide \$87 billion for a temporary increase in the federal share of Medicaid costs through 2010. To be eligible for the enhanced federal financing, states must not make changes to restrict eligibility levels or make it more difficult for people to apply for or renew coverage unless they have explicit federal permission to do so. ARRA has increased California's federal FMAP to 61.6% from October 1, 2008, through December 31, 2010, bringing in an estimated \$11.23 billion in new Medicaid dollars during this period.

As of 2007, the number of Californians enrolled in Medi-Cal was 6,510,009, 17% of the total California population. Medi-Cal enrollment is far higher for children, with 3,607,189 of the state's children ages 0-21 or one third of all children, enrolled in the program (California Department of Health Care Services).

The major Medi-Cal program designed specifically for vulnerable children is EPSDT, the comprehensive federal benefit specifically for children discussed above in the section on federal Medicaid. California has several major categories of eligibility for Medi-Cal available to children, including children with special health care needs:

- 1) Categorically needy:** This category includes children and adults who meet a combination of age and income criteria. Criteria of particular importance to children include:
 - Families meeting state Temporary Aid to Needy Families (TANF) eligibility requirements (in California, TANF is called CalWORKS);
 - Pregnant woman and children under age 6 whose family income is at or below 133% of federal poverty level (FPL);
 - Children ages 6 to 19 with family income up to 100% of FPL;

Mary is two years old. She has cerebral palsy. She was hospitalized and required a tracheotomy. She is ready to go home and needs a suction machine for her care at home. There is a backlog at Medi-Cal for authorizing respiratory supplies. Mary must remain in the hospital for an extra two weeks until the authorization comes through.

- Children receiving federal foster care or adoption assistance; or
- Federal Supplemental Security Income (SSI) recipients (see the discussion of SSI beginning on page 32).

2) Medically Needy: This category includes children and adults who have medical conditions but whose income is too high to be eligible as categorically needy. California’s medically needy program includes pregnant women through a 60-day postpartum period and children under age 18 with such conditions as blindness and other disabilities, and medical conditions that qualify them for the SSI program.

Share-of-Cost Medi-Cal: Share-of-cost (SOC) is a term that refers to the amount of health care expenses that must be paid each month before Medi-Cal eligibility begins and applies to those Medi-Cal recipients whose income exceeds the federal poverty level. The majority of share-of-cost beneficiaries are in two Medi-Cal eligibility categories: the medically needy and the medically indigent. (“Medically indigent” is a state-optional Medicaid aid category that covers pregnant women and children who do not meet financial eligibility criteria for Medicaid as “medically needy”; California has elected to offer this option.)

Once beneficiary health care expenses reach an individual’s determined amount, Medi-Cal will pay for any additional covered benefits for the month. The SOC payment is paid directly to the provider of services, as a deductible is satisfied under private insurance, and not to the state. The amount is determined by the county social services agency and is calculated using a formula based on family size and income and determined by state law under federal guidelines. The higher one’s income, the higher the SOC; SOC is calculated monthly and is adjusted as an individual’s financial situation changes. Beneficiaries on Medi-Cal who receive cash assistance through programs like CalWORKS or SSI (the “categorically needy”) are not required to pay SOC, as it applies to Medi-Cal recipients who choose not to receive cash assistance or whose income and resources are too high to qualify under these programs.

SOC Medi-Cal poses many problems for children and adults who fall in this category. An individual who does not pay or is unable to pay the SOC amount simply is not eligible for Medi-Cal benefits for any month in which the SOC has not been paid, regardless of need for medical care. Individual share-of-cost amounts can be prohibitively high for families, thus preventing them from meeting the payment. The Maintenance Need Level has not been updated since 1989 and is approximately \$600 for an individual; anything earned over \$600 a month becomes part of the beneficiary’s SOC for the month.

In addition, SOC may be based on inaccurate calculations of out-of-pocket costs; as recipient income decreases, SOC payments are not always decreased in a timely manner, forcing the beneficiaries to pay a large part of their income toward health services. As a result, Medi-Cal may function only as catastrophic coverage for recipients with high SOC, impeding their access to routine services when families cannot afford to pay the monthly

share. In 2005, there was an average of 403,984 SOC Medi-Cal beneficiaries each month; of this number, only 20% (73,718) were able to pay their SOC (CalOptima, 2005; CA.gov, Department of Health Care Services [b]; Health Consumer Alliance, 2007).

Other important Medi-Cal-related programs include:

- **Gateway:** In 2003 California created the Gateway as an automated application initiated by Child Health and Disability Prevention (CHDP) program providers that offers up to two months of immediate full-scope Medi-Cal coverage for children while a family completes the full application for continued coverage under either Medi-Cal or Healthy Families. (CHDP is described below in the section beginning on page 33.)
- **Emergency Medi-Cal:** This limited form of Medi-Cal is available to undocumented and recent immigrants who are not otherwise eligible for Medi-Cal. (For details, see the section on health services for immigrants.)

In California, services through Medi-Cal are available through several different delivery mechanisms:

- 1) **Fee-for-Service:** Fee-for-service Medi-Cal is the traditional delivery and payment arrangement for program beneficiaries, under which providers are paid a specified amount for each service rendered. As of January, 2009, there were 1,180,193 children ages 0-21 (32% of Medi-Cal's 0-21 population) enrolled in fee-for-service Medi-Cal (Department of Health Care Services, 2009).

Under fee-for-service Medi-Cal, recipients are free to seek health care from any physicians and other health care providers who participate in the Medi-Cal program. Many children and adults with special health care needs are able to use fee-for-service Medi-Cal and its freedom to choose providers to construct individualized service provider networks that fit their medical and other needs. At the same time, low reimbursement rates and barriers posed by complicated Medi-Cal billing and other requirements have steadily shrunk the Medi-Cal fee-for-service provider network available to children with special health care needs. Medicaid rates are significantly lower than those paid under Medicare, disproportionately affecting children and youth; in addition, adult-oriented procedure codes may be paid at higher rates than pediatric services.

- 2) **Managed Care:** In 1993, the state Department of Health Services (now Department of Health Care Services) began implementation of a plan to transform much of the Medi-Cal program from traditional fee-for-service to managed care. As of January, 2009, there are 2,426,996 children ages 0-21 (68% of Medi-Cal's ages 0-21 population) enrolled in managed care (Department of Health Care Services, 2009). Managed care plans are prospectively paid a capitated payment for each enrollee, for which they are expected to furnish all specified services. The state began managed care implementation in the most populous counties in the state, using three distinct managed care models:

- **Two Plan Model:** In this model, Medi-Cal recipients choose between two plans for their health care services, including perinatal and pediatric care. The two plans include a “local initiative” plan, developed and implemented by a county’s board of supervisors, and a “mainstream” plan, a single HMO selected by the state through a competitive bidding process.

Under the two-plan model, consumers must be offered a choice of primary care providers participating in the plan’s network and must be permitted to change providers if dissatisfied. The local initiative also must ensure a role for “traditional safety net providers” such as public hospitals and clinics.

The 12 counties participating in the two-plan model are Alameda, Contra Costa, Fresno, Kern, Los Angeles, Riverside, San Bernardino, San Francisco, San Joaquin, Santa Clara, Stanislaus, and Tulare. Each county offers a local initiative plan and a commercial plan, except Fresno, which offers two commercial plans. Recipients with full-scope Medi-Cal (typically CalWORKS recipients) are required to join one of the plans; certain groups of recipients such as those on SSI or in foster care are not required to join but may voluntarily enroll in one of the plans.

- **County-Organized Health Systems:** There are five Medi-Cal county-organized managed care plans in the state. Under this model, the plan is created by the county’s board of supervisors to contract with Medi-Cal to administer a countywide capitated health care system that all full-scope Medi-Cal recipients in the county, including SSI recipients and children in foster care, are required to join. Eleven counties currently have or are in the process of joining county-organized health systems: Orange (CalOPTIMA); Merced, Monterey, and Santa Cruz (Central Coast Alliance for Health); San Mateo (Health Plan of San Mateo); Napa, Solano, Sonoma, and Yolo (Partnership HealthPlan of California); and San Luis Obispo and Santa Barbara (CenCal Health).
- **Geographic Managed Care:** Under this model, available in two counties (Sacramento and San Diego), Medi-Cal CalWORKS recipients are required to join one of a group of Medi-Cal managed care plans in the county. As with the two-plan model, full-scope Medi-Cal recipients in CalWORKS are the major target population for mandatory enrollment, although other full-scope populations, such as people on SSI, may join voluntarily.

Medi-Cal plans are contractually obligated to have certain specialists in their networks and have timelines for scheduling visits. The higher reimbursement rates often offered by managed care plans may attract more providers, including pediatricians and pediatric subspecialists. Yet some children with special health care needs and their families report difficulties in finding appropriate providers within managed care plans’ limited networks, and additionally face obstacles to getting to providers outside the plan networks.

More specific information on Medi-Cal is displayed in Appendix 3.

Health Services for Immigrants Under Medicaid

Citizen/Immigration Status	Definition
Naturalized Citizen	A person who was born a noncitizen and was granted U.S. citizenship through the naturalization process.
Lawful Permanent Resident	A noncitizen residing in the U.S. with permission to permanently live and work in the country. May apply for naturalization after five years.
Refugee or Asylee	A noncitizen granted permission to reside in the U.S. due to a well-founded fear of persecution in his or her country of origin. Persons granted such permission while outside of the U.S. are refugees; those granted permission after they enter the U.S. are asylees. Refugees and asylees may apply to adjust their status to Lawful Permanent Resident after one year.
Nonimmigrant	A person granted permission to enter the U.S. for a specific purpose and a limited period of time. This category includes persons granted temporary permission to live and work in the U.S.
Undocumented immigrants	A person who entered the country illegally or who entered through legal channels but then violated the terms of entry by staying past his or her visa expiration date.
Permanent Residence Under Color of Law (PRUCOL)	PRUCOL is not recognized as an immigration status by the U.S. Citizenship and Immigration Services; this category was created by the courts and is a public benefits eligibility category. For a person to be residing under the color of law, the USCIS must know of the person's presence in the U.S. and must provide the person with written assurance that enforcement of deportation is not planned. A person residing under PRUCOL cannot directly apply for U.S. citizenship.

(Source: Usafis.org; IRS.gov)

As shown above, the U.S. noncitizen population falls into several basic groupings for the determination of public assistance entitlements. Prior to 1996, legal immigrants were eligible for Medicaid on the same basis as U.S. citizens. The 1996 Personal Responsibility and Work Opportunity Reconciliation Act terminates federal eligibility for regular Medicaid coverage for most legal immigrants during their first five years in the country, regardless of how poor they are or how serious their medical needs. These provisions also apply to CHIP, which was enacted in 1997. Most of the states that traditionally have high concentrations of immigrants continue to provide substantial coverage for legal immigrant children and pregnant women who otherwise would be disqualified by the five-year bar. Research on immigrant coverage, cost, and utilization indicates that immigrants are not huge and costly users of public services:

- Private insurers pay for more than half of health care expenditures for immigrants; only about one-fourth of health care expenditures for immigrants are reimbursed by government programs (National Immigration Law Center, 2006).
- Two thirds of all immigrants in the U.S. have health insurance coverage and about 78% of these insured immigrants are covered by private plans, whether through employers or as individuals, with the remainder covered by Medicaid or Medicare (Migration Policy Institute, 2004).
- Health cost data demonstrate that immigrants have not been responsible for the overall recent increase in the number of uninsured despite significant declines in their own coverage in the past decade (Kaiser Family Foundation, 2004).

- The claim that immigrants are responsible for high rates of emergency room (ER) usage is contradicted by research; in fact, communities with high rates of emergency room usage tend to have relatively small percentages of noncitizen residents (National Immigration Law Center, 2006).
- Low-income citizen children with citizen parents are more than twice as likely to receive Medicaid or state Children’s Health Insurance Program (CHIP) coverage as are low-income children who are not citizens (Kaiser Family Foundation, 2004).
- Only one in four low-income children who are not citizens have Medicaid coverage, compared to almost two out of every four low-income children who are citizens. Similarly, low-income parents who were born in the U.S. are much more likely to receive Medicaid or CHIP coverage than parents who are noncitizens (National Immigration Law Center, 2006).

Many states view these restrictions based on immigration status as unfair and detrimental to the health and well being of the public. Over half have used their own funds to ensure that immigrant families who were rendered ineligible for federal benefits can secure critical services (Ku, L., 2007; U.S. Senate, Committee on Finance, 2009).

California’s Health Care Services for Immigrants Under Medi-Cal

Half of California’s children—about 4.8 million children ages 0-17—have at least one immigrant parent. Eighty-five percent of children in immigrant families in California were born in the U.S. and 54% of children in immigrant families are low-income (Children Now, 2007).

California has an estimated 180,000 undocumented immigrant children; they are predominantly Latino and live in very-low-income working families, lack access to employer-sponsored health coverage, and typically face the highest barriers to access to health care (Brown, 2002).

As detailed above, after 1996 most legal immigrants become ineligible for federally matched Medicaid coverage during their first five years in the U.S. However, California residents do not need to be U.S. citizens to obtain certain types of Medi-Cal. Most immigrants, including children, are eligible only for emergency Medi-Cal, which covers services that meet the federal definition of emergency care. Full-scope Medi-Cal is available to immigrants with “satisfactory immigration status,” a category that includes lawful permanent residents, people who have Permanent Residence Under Color of Law (PRUCOL), and refugee children, who are eligible for full-scope Medi-Cal for a minimum of eight months.

As of 2008, California covered around 16,000 legal immigrant children in the Healthy Families program (described below), almost 2% of total Healthy Families program enrollment (Harbage Consulting, 2009). Medi-Cal also covers prenatal care, family planning, and some other specific services for immigrants, regardless of immigration status.

The federal Deficit Reduction Act of 2005 requires that all applicants for state Medicaid programs provide documentation of their citizenship status for

federally financed Medicaid services, but states are free to provide services to non-federally eligible populations with state funds (CA.gov. Department of Health Care Services [c]). In addition, it should be noted that the status of California state coverage of health care is fluid now, given the state budget situation, and changes may be made in Medi-Cal coverage of immigrants over the coming year.

More specific information on publicly funded services for documented and undocumented immigrants is displayed in Appendix 4.

State Children's Health Insurance Program (CHIP)

CHIP was established by the federal government to provide matching funds to states for health insurance to families with children. The program is designed to cover uninsured children in families with incomes that are modest but too high to qualify for Medicaid. The statutory authority for CHIP is under Title XXI of the Social Security Act and it is administered by the federal Centers for Medicare and Medicaid Services within the US DHHS.

States are given flexibility in designing their CHIP eligibility requirements and policies within broad federal guidelines. Some states have received authority through waivers of statutory provisions to use CHIP funds to cover the parents of children receiving benefits from both CHIP and Medicaid, pregnant women, and other adults. In some states CHIP is part of the state's Medicaid program, in some states it is separate, and in some states it is a combination of both types of programs. Most states offer this insurance coverage to children in families whose income is at or below 200% of FPL. Children began receiving insurance through CHIP in 1997 and the program helped states expand health care coverage to over five million of the nation's uninsured children. In February, 2009, the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA or Public Law 111-3) was signed into law and formally reauthorized the program.

CHIPRA provides \$33 billion in additional federal funds to extend and expand CHIP for 4.5 years. A cigarette and tobacco tax increase will fund the program's expansion. Under CHIPRA, states will no longer receive full CHIP matching rates for covering children in families with incomes greater than three times the FPL; they can cover these children with federal approval but will receive a lower Medicaid matching rate.

As of January 1, 2010, states will need to apply the Medicaid citizenship documentation requirement to children who apply for CHIP coverage. Under a new provision, states now have the option to use CHIP funding to subsidize health coverage under certain employer-sponsored health plans for low-income children (and, in some cases, their parents) who are eligible for the CHIP program. If the low-income child decides to receive the subsidy, health coverage for the child is provided through the employer-sponsored health plan instead of being provided through the state's CHIP program.

CHIPRA allows states to cover pregnant women through state plan amendments and also eliminates the five year waiting period for legal immigrant

children and pregnant women who are eligible for Medicaid or CHIP. Each state and U.S. territory as well as the District of Columbia has a CHIP program coordinator who is responsible for the administration of the approved CHIP state plan. CHIP is funded through a partnership of the federal and state governments and has a substantial federal match of 65% federal to 35% state, making it a very attractive program for many states, including California (US DHHS, 2005; Kaiser Family Foundation [b]; Families USA, 2009).

More specific information on CHIP is displayed in Appendix 2.

California's CHIP: Healthy Families

The Healthy Families program was established in 1998 as the state version of the federal CHIP. The program, which is administered by the Managed Risk Medical Insurance Board (MRMIB), provides subsidized health coverage, including health, dental, vision, and basic mental health services, to children from birth to age 19 in low-income families who are not eligible for full-scope Medi-Cal and are uninsured. In order to be eligible for Healthy Families, children must meet the following criteria:

- Be citizens
- Live in families with annual incomes between 100% and 250% of the federal poverty level
- Not be eligible for no-cost full-scope Medi-Cal (but children with share-of-cost Medi-Cal are eligible to apply)
- Not have had employer-sponsored health insurance in the last three months

Families of enrolled children pay monthly premiums as well as co-payments for certain services. Healthy Families services are provided through managed care plans. Treatment of complex medical conditions that are eligible for the state's California Children's Services (CCS) program for children with special health care needs are not provided by Healthy Families plans and subscribers are not charged co-payments for the CCS authorized services. (The CCS program is discussed below, beginning on page 35). As of July, 2009, MRMIB reports that about 940,000 children in California were enrolled in Healthy Families.

(Note: The state's budget crisis resulted in a period of frozen enrollment in the Healthy Families program and nearly caused massive disenrollment of currently enrolled children from the program. Program funding has been restored for the current fiscal year by a combination of state First 5 Commission funds (drawn from a tax on tobacco products and dedicated to children ages 0-5), a temporary provider tax on Medi-Cal managed care plans that can draw down federal matching funds, and increased premiums and co-pays for families. This funding solution will sunset in 2010, leaving the program vulnerable again to budget deficits.)

More specific information on Healthy Families is displayed in Appendix 3.

OTHER FEDERALLY FUNDED HEALTH CARE PROGRAMS

The following programs are funded by the federal government (and, in some cases, by other sources, e.g., the payroll taxes that help to support Medicare) without state-required investment.

Medicare

The Centers for Medicare and Medicaid Services administers Medicare, the nation's largest health insurance program, which covers nearly 40 million Americans, most of them seniors and adults with disabilities. Medicare was established in 1965 as the health insurance program for people age 65 or older, some people with disabilities under age 65, and people of all ages with end stage renal disease. Information on the number of children with special health care needs in California who are enrolled in Medicare is not readily available, although it is believed that there are very few and that they are limited to those with end-stage renal disease. (US DHHS, 2009; Kaiser Commission on Medicaid and the Uninsured, 2003)

More specific information on Medicare is displayed in Appendix 2.

TRICARE

TRICARE is the health care program serving active duty service members, National Guard and Reserve members, retirees, their families, survivors, and certain former spouses worldwide. As a major component of the Military Health System, TRICARE brings together the health care resources of the uniformed services and supplements them with networks of civilian health care professionals, institutions, pharmacies, and suppliers to provide access to high-quality health care services while maintaining the capability to support military operations.

TRICARE provides health services to nearly two million children under the age of 18; 23% of these are children who have special health care needs (US DHHS, 2007). Little information is available on the provision of services specifically for CYSHCN under TRICARE (TRICARE, <http://www.tricare.mil/>).

More specific information on TRICARE is displayed in Appendix 2.

Indian Health Service

The Indian Health Service (IHS), an agency within the U.S. Department of Health and Human Services, is responsible for providing federal health services to American Indians and Alaska Natives. The provision of health services to members of federally-recognized tribes grew out of the special government-to-government relationship between the federal government and Indian tribes. This relationship, established in 1787, is based on Article I, Section 8 of the Constitution, and has been given form and substance by numerous treaties, laws, Supreme Court decisions, and Executive Orders. The IHS is the principal federal health care provider and health advocate for Indian people and its goal is to raise their health status to the highest possible level.

The IHS currently provides health services to approximately 1.5 million American Indians and Alaska Natives who belong to more than 557 federally-recognized tribes in 35 states. Health services are provided directly by the IHS, through tribally contracted and operated health programs and through services purchased from private providers. Because of high rates of poverty among Native Americans, Medicaid is an important publicly funded health program and Native Americans who meet Medicaid eligibility standards are entitled to this coverage. Medicaid also assists low-income elderly and disabled Indians who are eligible for Medicare in meeting their premium and cost-sharing obligations. Finally, Medicaid offers coverage for nursing home care and other long-term care services needed by frail elderly and disabled Native Americans.

Although Medicaid is administered and financed in part by the states, Native Americans who meet the Medicaid eligibility requirements of the state in which they reside are, as a matter of law, entitled to Medicaid coverage. Information is not readily available on the number of children with special health care needs in California who are served through the IHS (Kaiser Commission on Medicaid and the Uninsured; Indian Health Service).

More specific information on Indian Health Service is displayed in Appendix 2.

Federally Qualified/Migrant and Rural Health Centers (FQHC)

The FQHC benefit under Medicare and Medicaid statutes was added in 1991 and includes safety net providers such as community health centers, public housing centers, outpatient health programs funded by the Indian Health Service, and programs serving migrants and the homeless. The main purpose of the program is to enhance the provision of primary care services in underserved urban and rural communities.

FQHCs must serve an underserved area or population, offer a sliding fee scale, provide comprehensive services, have an ongoing quality assurance program, and have a governing board of directors of which 50% or more are actual users of clinic services. Section 330 of the Public Health Service Act defines federal grant funding opportunities for organizations to provide care to underserved populations. The types of organizations that may receive Section 330 grants include Community Health Centers, Migrant Health Centers, Health Care for the Homeless Programs, and Public Housing Primary Care Programs. In 2007 there were 110 federally funded Federally Qualified Health Centers in California with 796 service delivery sites that collectively served 2,314,271 patients (California Health Care Foundation, 2009).

Federally Qualified Health Center look-alikes are health centers that have been identified by HRSA and certified by the Centers for Medicare and Medicaid Services as meeting the definition of “health center” under Section 330 of the PHS Act, although they do not receive grant funding under Section 330 (Health Resources and Services Administration; Rural Assistance Center).

More specific information on Federally Qualified/Migrant and Rural Health Centers is displayed in Appendix 2.

Supplemental Security Income (SSI)

Supplemental Security Income (SSI) is a federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help people who are aged or blind or who have disabilities and who have little or no income. The program provides cash to meet their basic needs for food, clothing, and shelter. SSI makes monthly payments to people with low income and limited resources who are age 65 or older or who are blind or have disabilities. Children under age 18 can qualify if they meet Social Security's definition of disability for children, and if their income and resources fall within the eligibility limits. The amount of the SSI payment varies from one state to another because some states add to the SSI payment.

More than 97,775 children in California receive financial assistance from SSI (Social Security Administration, 2007). Many have birth defects and/or a combination of disabilities. Payment rates include both federal and state funds. Payments may be lower depending on the income of the child or the total family income. The SSI law considers the income of the parents as well as the child in determining eligibility and payment amounts. A child under age 18 who lives in his/her parents' household also shares in the family's income and resources.

To receive SSI, the child must have resources (defined as assets such as cash, bank accounts, and land) that do not exceed certain value limits (Social Security Administration, 2009). If a child with a disability resides in an institution, the income and resources of the parents are not usually considered in determining the child's eligibility or payment amount. The SSI payment depends on the type of institution and whether Medi-Cal pays for the cost.

Social Security Disability Insurance (SSDI)

The SSDI program pays benefits to adults who have a disability that began before the age of 22. This SSDI benefit is considered a "child" benefit because it is paid on a parent's Social Security earnings record. For an adult with a disability to become entitled to this "child" benefit, one of his or her parents must be receiving Social Security retirement or disability benefits or have died and worked long enough under Social Security. These benefits also are payable to an adult who received dependent benefits on a parent's Social Security earnings record prior to age 18, if he or she has a disability at age 18. The disability decision is based on disability rules for adults. SSDI disabled adult "child" benefits continue as long as the individual remains disabled (Social Security Online, 2009).

More specific information on SSDI is displayed in Appendix 2.

STATE FUNDED HEALTH CARE PROGRAMS

California has several programs that are state-funded and provide basic health care services for children.

Child Health and Disability Prevention (CHDP) Program

The CHDP program is responsible for early and periodic screening components of the federally mandated Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program for Medi-Cal eligible children and youth. CHDP is a preventive health program that not only delivers periodic health assessments to Medi-Cal beneficiaries under 21 years of age, but also provides these services to low-income children and youth to age 19 living in families with annual incomes at or below 200% of FPL.

CHDP provides care coordination to assist families whose children have received CHDP health assessments with medical appointment scheduling, transportation, and access to diagnostic and treatment services. Health assessments are provided by enrolled private physicians, local health departments, community clinics, managed care plans, and some local school districts. A health assessment consists of a health history, physical examination, developmental assessment, nutritional assessment, dental assessment, vision and hearing tests, a tuberculin test, laboratory tests, immunizations, health education/anticipatory guidance, and referrals for any needed diagnosis and treatment.

CHDP is operated at the local level by counties and the three California cities with their own health departments (Berkeley, Long Beach, and Pasadena). In 2007, 2,016,558 children received screening and health assessments through the CHDP program (Maternal and Child Health Bureau, 2008).

As noted in the Medi-Cal section above, in 2003 the CHDP program began using the “CHDP Gateway,” an automated pre-enrollment process for non-Medi-Cal, uninsured children. The CHDP Gateway serves as the entry point for these children to enroll in ongoing health care coverage through Medi-Cal or the Healthy Families program. The CHDP Gateway is based on federal law found in Titles XIX and XXI of the Social Security Act that allows states to establish presumptive eligibility programs for children/youth.

A 2007 study of the Gateway program found that, although many children received temporary Medi-Cal coverage through Gateway (approximately 600,000 children in one year), only 11% achieved long-term stable enrollment in either Medi-Cal or Healthy Families. In more than 90% of pre-enrollments, families requested a joint application for Medi-Cal and Healthy Families, but fewer than 20% returned them in time to have their children’s temporary eligibility extended. In addition, denial rates for long-term coverage were high, mostly because of a “failure to cooperate” with follow-up requests for information (Teare, Finocchio, & Martin-Young, 2007).

More specific information on CHDP is displayed in Appendix 3.

Access for Infants and Mothers (AIM)

AIM was created in 1992 to provide services to pregnant and postpartum women and their infants up to two years of age in families with incomes between 200% and 300% of FPL who are uninsured and are not eligible for Medi-Cal, or who have insurance that either does not cover perinatal care or has a high deductible. AIM is a private health insurance model; it is not an entitlement program.

The state contracts with private insurance plans to provide perinatal health services to pregnant women and women up to 60 days post-delivery; pediatric health services for their infants up to age two are provided under the Healthy Families program, for which these infants are automatically eligible, as long as the AIM-enrolled mother applies for that coverage. These infants are eligible for Healthy Families until age two with family incomes up to 300% of FPL, as opposed to the standard Healthy Families eligibility ceiling of 250%. AIM has a share-of-cost, with enrollees charged 1.5% of annual adjusted family income. As of June, 2009, 7,025 women were enrolled in AIM (Access for Infants and Mothers, 2002; Harbage Consulting, 2009).

(Note: The status of California state coverage of health care is fluid, given the state budget situation, and changes may be made in funding for the AIM program that will affect access to it.)

More specific information on AIM is displayed in Appendix 3.

COUNTY FUNDED HEALTH CARE PROGRAMS

Children's Health Initiatives

Many California counties across the state have implemented children's health initiatives (CHI). In 2000, Santa Clara County was the first county to implement a CHI, and over the past five years several other counties have followed suit by establishing Healthy Kids programs modeled after Healthy Families.

These initiatives vary by county, but they generally combine several funding sources including state and county First 5 Commission funds (for children ages 0-5 years), public funds, and philanthropic donations raised by their CHI coalitions, including support from The California Endowment and the David and Lucile Packard Foundation. Their aim is to provide health care coverage to children from low- and moderate-income families who are ineligible for Medi-Cal and Healthy Families, and to aid with enrollment in Medi-Cal and Healthy Families for those children who are eligible (Institute for Health Policy Solutions). In addition, some counties have applied to draw down federal matching dollars through CHIP funding to match local funding to provide Healthy Kids insurance to children living in families with incomes between 251% and 300% of the federal poverty level (CA.gov, Managed Risk Medical Insurance Board).

About 25 counties established age and income eligibility criteria, ranging from 300% FPL (in Los Angeles and several other counties) to 400% FPL (in San Mateo County, for example). While the intent was to cover uninsured children who are ineligible for Medi-Cal or Healthy Families, because Medi-Cal and Healthy Families cover citizen children in families with incomes up to 250% FPL, the largest group of children insured through CHI efforts is undocumented children. Continued support of these county programs is threatened by uncertainty about the future funding of the Healthy Families program.

A number of evaluations conducted over the past five years suggests that CHI efforts produced coverage that expanded access to care (Trenholm, Howell, Hill, & Hughes, 2007). For example, the Los Angeles Healthy Kids program evaluation found that 30% of families enrolling their young children in Healthy Kids perceived financial difficulties associated with obtaining needed care for their children compared to a pre-enrollment period rate of 51% (Hill et al., 2008). Because CYSHCN are a small proportion of newly covered children, relatively few outcomes associated with CYSHCN have been assessed in CHI program evaluations.

SPECIALIZED SERVICE PROGRAMS

California Children's Services (CCS)

California Children's Services (CCS), within Children's Medical Services (CMS), was established in 1927 to cover medical care for low-income children with serious medical conditions. It is now the state's Title V Program for Children with Special Health Care Needs. The goal of the federal Title V program is to "support development and implementation of comprehensive, culturally competent, coordinated systems of care for the estimated 18 million U.S. children who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally" (Maternal Child and Health Bureau).

California's Title V program is based on medical diagnoses, reflecting its founding in the era of polio epidemics, and is the most important program in the state for health care delivery to children with complex medical conditions. Children are covered from birth to age 21. CCS-eligible diagnoses include:

- Heart conditions
- Neoplasms
- Blood disorders (hemophilia, sickle cell anemia)
- Respiratory system disorders (cystic fibrosis, chronic lung disease)
- Endocrine, nutritional, and metabolic disorders (PKU, thyroid problems, or diabetes)
- Genito-urinary system disorders (serious kidney problems)
- Gastrointestinal system disorders (biliary atresia)

For the first year of her life, my husband and I stayed home and worked with Alison and her professionals full time. In her busiest week, Alison had 22 appointments with various therapists and doctors. After she turned one, I went back to work. I worked nights so that I could attend meetings and appointments during the day when necessary. The regional center providing respite care was a life-saver for us. As she got older we received equipment through CCS that included a helmet, walker, ankle foot orthoses, and an orthopedic stroller.

- Serious birth defects (cleft lip/palate, spina bifida)
- Sense organ disorders (hearing loss, loss of vision due to glaucoma or cataracts)
- Nervous system disorders (cerebral palsy, uncontrolled epilepsy)
- Musculoskeletal and connective tissue disorders (muscular dystrophy, juvenile rheumatoid arthritis)
- Severe disorders of the immune system (HIV)
- Disabling injuries and poisonings requiring intensive care or rehabilitation (severe brain injuries, spinal cord injuries, and burns)
- Complications of premature birth requiring an intensive level of care

The CCS program has developed quality standards for pediatric specialty care and maintains a pediatric provider network through credentialing of individual pediatric providers and approval of facilities and programs. The program's services include case finding and eligibility determination, coverage of diagnostic services, treatment planning and medical case management, authorization of all services related to the CCS-eligible condition, and program monitoring and oversight. A system of CCS-approved special care centers provides quality specialty and subspecialty care at local and regional locations.

The CCS program also includes a direct services component, the Medical Therapy Program, which provides physical and occupational therapy and other services for medically eligible children regardless of their family income. The majority of these children receive special education services, including physical and occupational therapy and other services included in their Individualized Education Plans (IEP).

CCS is primarily a program for low-income children (i.e., children living in families with annual family income under \$40,000), and the vast majority of children in the program are enrolled in Medi-Cal or Healthy Families or are uninsured. There are two exceptions to the \$40,000 income ceiling:

- 1) CCS covers specialty care for medically eligible children in higher-income families when the costs of their child's care reach 20% or more of annual family income.
- 2) Children with CCS-eligible conditions who are enrolled in Healthy Families are deemed financially eligible for CCS even if their family income exceeds \$40,000. This is an artifact of the mismatch between CCS income eligibility, a flat income ceiling, and Healthy Families income eligibility, based on percentage of the federal poverty level which is calibrated by family size.

Administration of the CCS program is shared between the state and California counties:

- The state develops quality standards; provides panels providers, facilities, and programs; sets policy and procedures for and oversees implementation of the program statewide; and conducts quality assurance activities.

My son, Pablo, is 21 years old and because of extreme prematurity (26 weeks), he has cerebral palsy, developmental disability, and autism. He cannot eat solid foods and does not speak, but he enjoys a happy life with an adoring and supporting family. A client of the regional center, Pablo receives respite care, diapers, academic consultation, and adult transition services. Respite allows us some time away from worrying about our son's care, helping us to strengthen our family. For us, diapers would be an ongoing expense that most families do not have. Academic consultation has guided us through the IEP process, which ensured that Pablo was getting the right academic content and support services.

- The 31 more populated counties fully administer their own CCS programs, including eligibility determination and case management.
- The 27 less populated counties share their administrative and case management activities with the state via several regional offices.

Many of the more populated counties also have significant managed care enrollment of Medi-Cal and Healthy Families recipients. In most of these counties, CCS services are “carved out” of Medi-Cal managed care plans. Under this carve-out arrangement, Medi-Cal managed care plans are responsible for primary care and other services not related to CCS-eligible conditions, while all services related to CCS-eligible conditions are authorized and managed by the CCS program.

Five counties predate the legislation establishing the CCS carve-out from Medi-Cal managed care: Napa, Solano, Yolo, Santa Barbara, and San Mateo. In these counties, all with county organized health systems, the managed care plans bear risk for CCS services and the CCS programs remain responsible for eligibility determination, case management, and service authorizations. CCS services are carved out of all Healthy Families managed care plans, and Healthy Families enrollees are not responsible for co-pays for their CCS-authorized services.

The CCS caseload in July, 2009, was about 175,000. Approximately 75% of these children are enrolled in Medi-Cal; 15% are Healthy Families subscribers and 10% are enrolled in state-only CCS (also known as “straight CCS”). Approximately 26,000 children receive services through the CCS Medical Therapy Program (Personal Communication, Marian Dalsey, Children’s Medical Services).

More specific information on CCS is displayed in Appendix 3.

Genetically Handicapped Persons Program (GHPP)

The Genetically Handicapped Persons Program provides health coverage for adults and financially non-CCS-eligible children who have specific genetic diseases (cystic fibrosis, hemophilia, sickle cell, and certain neurological and metabolic conditions). Unlike most public programs, GHPP has no income ceiling; families with incomes over 200% of FPL pay fees based on a sliding scale. In 2008 there were approximately 1,600 enrollees in the program (Maternal and Child Health Services, 2008).

More specific information on GHPP is displayed in Appendix 3.

Regional Centers for Persons with Developmental Disabilities

Under contract with the state Department of Developmental Services, 21 private nonprofit centers located around the state provide services for children and adults with developmental disabilities, including mental retardation, cerebral palsy, epilepsy, and autism, as well as young children ages 0-3 who have developmental delays, under the Early Start program. Services provided include case management; early intervention services for children ages 0-3 who

have developmental delay; family support; respite; crisis intervention; special living arrangements; community integration; interpreter/translator services; advocacy; transportation vouchers; assessment; rehabilitation and training; vocational placements; and speech/language, vision, and audiology services. Services may be provided from birth throughout the full life course.

(Note: Regional center programs have sustained major service reductions in the wake of the state’s financial crisis, including significant changes in Early Start eligibility and services. These changes include elimination of eligibility for certain populations of at-risk children from birth to three years of age and creation of a new non-entitlement “prevention program” with a capped budget. While details are still being finalized, these changes will have major impact on access to services, particularly for children from birth to age three who have or are at risk for developmental delays.)

More specific information on regional centers is displayed in Appendix 3.

Special Education

Special education is a system of specially designed instruction and related services provided by school districts to meet the unique needs of a pupil with a disability. A “pupil with a disability” is defined as a child or youth from birth through 21 years of age (i.e., to age 22) who meets eligibility criteria as defined in the Education Code and as determined by assessments. A child may be found eligible if one or more of these handicapping conditions exist: hearing impairment (including deafness), visual impairment (including blindness), concomitant hearing and visual impairments, language or speech disorder, severe orthopedic impairment, acute health problems, autism, mental retardation, emotional disturbance, specific learning disability, and traumatic brain injury. The presence of one or more of these conditions also must significantly impact a child’s ability to learn. A child with a “solely low incidence” impairment (i.e., deaf, blind, deaf and blind, or severe orthopedic impairment) may begin receiving services from a school district at birth, but eligibility for children meeting other special education criteria begins at age three. Children and youth receiving special education services also may be eligible for regional center and/or public mental health services.

Special education services are based on a student’s unique needs, are provided through school districts, and may include assistive devices/services, audiology services, family training, counseling, home visits (Early Start-eligible children only), some health services, diagnostic services, nursing assessments, occupational and speech therapy, psychological services, respite (Early Start-eligible children only), special instruction, speech/language services, vision services, and transportation. Through a California interagency agreement known as AB3632, both mental health services and California Children’s Services can be offered through the county to address specific areas for children eligible for special education. There are no income requirements for special education services.

More specific information on special education is displayed in Appendix 3.

I stopped working after the birth of my first child, Simon (now 13) because of his medical problems and physical needs. Now with a second child with special needs, I use In-Home Supportive Services to provide them with 24/7 care. I have not been able to work outside the home because I could not put either of my children in a regular daycare with all of their needs. My husband works to provide health insurance. Just recently, due to the economy, my caseworker told me that my husband makes too much money for my kids to receive IHSS, which devastated us. How am I supposed to go back to work and plug them into a daycare? Instead, I have to go through a long application process to keep my IHSS (to replace county dollars with federal dollars), but I will only be able to claim the hours when my husband is at work. My children are non-ambulatory and sometimes need me all through the night. I am frustrated because these programs are not dedicated to helping children with disabilities and their families. We are struggling because my kids are not getting SSI or Medi-Cal because of my husband's income.

In-Home Supportive Services (IHSS)

IHSS is intended to enable recipients to remain in their own homes and to avoid long-term care facilities. IHSS can cover a variety of services, including housecleaning, meal preparation, laundry, grocery shopping, personal care services (such as bowel and bladder care, bathing, grooming, and paramedical services), accompaniment to medical appointments, and protective supervision for people with mental impairments. IHSS services are available for income-eligible children or adults who are blind or have other disabilities as well as some seniors who require such assistance.

Eligibility criteria include receipt of or income eligibility for Supplemental Security Income (SSI); there also is a share-of-cost option for people who meet the criteria for SSI but exceed the income level. Individuals eligible for IHSS as a result of disability also are eligible for full-scope Medi-Cal, and personal care services are a Medi-Cal benefit. As of May, 2009, there were 446,849 authorized IHSS cases in California (State of California, 2009).

(Note: The status of California state coverage of health care is fluid, given the state budget situation. Major reductions have been made in funding for IHSS and major changes in eligibility and services are anticipated, although final details are not yet available.)

More specific information on IHSS is displayed in Appendix 3.

High Risk Insurance Pool

The state agency, Major Risk Medical Insurance Program (MRMIP), provides health insurance for those unable to obtain coverage in the individual health insurance market (e.g., due to a pre-existing condition). Children and youth who are not eligible for other publicly funded programs and are unable to obtain insurance in the private market may apply for coverage through MRMIP. The cost of premiums is shared between MRMIP and the enrollee and varies by plan and other factors. The program has a set annual deductible (\$450 per household in 2008), an out-of-pocket maximum of \$2,500 per individual and \$4,000 per household, an annual cap on covered service costs (\$75,000), and a lifetime cap on covered costs (\$750,000). Tobacco tax funds currently subsidize the MRMIP.

Program applicants must be California residents. They cannot be eligible for both Part A and Part B of Medicare unless eligibility is based solely on end-stage renal disease. Nor can they be eligible to purchase any health insurance for continuation of benefits under COBRA or CalCOBRA. Finally, they must be unable to secure adequate coverage in the private market. Because of funding limitations, MRMIP may have a wait list; as of August, 2009, there were approximately 230 applicants on the wait list.

More specific information on MRMIP and its insurance program is displayed in Appendix 3.

Mental Health Services

Publicly funded mental health programs serve children and youth with full scope Medi-Cal (ages 0-21 years); children and youth enrolled in the Healthy Families program (ages 0-18 years); and children and youth ages 0-22 who receive special education referrals from schools. Provision of these services can be complex:

- Mental health services for children on full-scope Medi-Cal are provided through county-based mental health managed care plans, with certain exceptions such as psychotropic and other medications that are provided through the child's health services delivery system, whether Medi-Cal fee-for-service or managed care plan.
- Basic mental health services for children enrolled in Healthy Families are provided through the child's Healthy Families managed care plan, but children needing specialized mental health services for a serious emotional disturbance (SED) condition may receive care from their local county department of mental health as part of a carve-out arrangement.

There are no income limits for children referred for mental health services by the school system.

Data from the 2007 National Survey of Children's Health and analyzed by the Kaiser Family Foundation indicated that 54% of children in California who were identified with emotional, developmental, or behavioral problems received mental health care, as opposed to 60% of children in the nation as a whole (Kaiser Family Foundation [c]).

More specific information on mental health services is displayed in Appendix 3. A graphic display of income eligibility for publicly funded programs for children may be found in the Health Insurance Chart in Appendix 5.

PRIVATE SECTOR SERVICES

OVERVIEW OF MAJOR SYSTEMS AND THEIR COMPONENTS IN THE PRIVATE SECTOR



PRIVATE COVERAGE

The majority of CYSHCN in California have private insurance only (63.6%), and another 7.1% have both private and public insurance (CAHMI, NS-CSHCN, 2005-06). Thus, private insurance is the predominant payer for health services for children with special health care needs in the state.

Privately funded health insurance comprises two main categories: employer sponsored insurance and individual insurance. The majority of children and youth with special health care needs in California are served by employer-sponsored insurance, usually through their parent's employer. Employer-sponsored insurance is offered to employees and their dependents; however, employees usually have to bear a greater financial burden in order to add dependents to their policies. With employer-sponsored insurance, all employees and dependents are included in a risk pool so no one is held financially responsible for their individual health care costs.

Individual insurance is purchased directly from an insurance plan (or through an insurance broker) and the individual must undergo underwriting where health conditions are enumerated and premium amounts determined accordingly. Thus, for children with special health care needs, the premiums would be considerably higher and likely unaffordable for most families in an individual plan.

The specific plan offered by employers or purchased by individuals can take on many forms. Most individuals are enrolled in some form of managed care; very few have indemnity insurance where providers are reimbursed at "usual and customary" rates for services provided. The majority of children with special health care needs are enrolled in a health plan with a managed care arrangement. A common characteristic of managed care includes utilization review where the health plans monitor services provided and authorized by health providers. Some also provide case management or disease management, although aside from asthma, disease management programs usually focus on adult-onset diseases such as Type II diabetes.

The three major types of managed care are health maintenance organizations (HMO), preferred provider organization (PPO) plans, and point-of-service

Dr. Thomas had to drop his Blue Cross contract because the reimbursement rates were too low to keep his pediatric specialty care practice solvent. At the same hospital, two other pediatric specialists followed his example for the same reason. Now the patients have to choose to: (1) pay cash and keep those services, (2) take their children to specialists unfamiliar with children's diseases, or (3) not get those services at all.

The Smith family is raising three daughters with mitochondrial disease. Each child is followed by six pediatric subspecialists, plus a pediatrician. On April 15, 2009, the family reported spending \$25,642 on out-of-pocket medical expenses during that year (after taxes, making actual cost substantially higher). Despite the fact that there is a \$1,000 deductible and \$8,000 “stop loss” on their plan, there were clauses in the policy that allowed the company to avoid payment. Since the girls have a chronic life threatening illness, and both parents are self-employed, they have no opportunity to change insurance carriers.

(POS) plans. These three general categories represent a diversity of plans, and within each type there is large variability with regard to referral requirements, reimbursement, co-payments, and a variety of other factors.

In a health maintenance organization, the health plan only pays for services provided within a contracted network of providers. Most HMOs require that members select a primary care provider who, in some cases, acts as a gatekeeper to more specialized medical services.

In a preferred provider organization, individuals seek care within a network of preferred providers who accept reimbursement at a discounted rate; however, the individual may seek care outside of the network and pay more. Unlike a HMO, PPOs do not require a referral to access specialist care.

A point-of-service plan is a hybrid in which patients may decide whether to receive care inside or outside the network at the point of service, but they will pay much larger fees for services outside the network and for services for which they do not have a referral.

Private insurance presents a fluid and changing set of benefits as, unlike public insurance programs, there is no defined set of benefits, other than those mandated by the legislature (e.g., maternity stays of at least 48 hours, contraceptives, and cancer screenings). In addition, one insurer may offer various plans from which employers may choose to offer their employees, with differing benefits in each.

Often, parents struggle to effectively navigate the system because of multiple layers of administration, resulting in uncertainty for families in understanding whom to talk to about services—the doctor’s office, the medical group, the independent practice association (an organization of physicians that negotiates on their behalf with managed care plans), or the health plan itself. Conflicting and confusing information, as well as varied coverage levels, can leave children with special health care needs without adequate coverage. Parents of children with special health care needs often report inadequate insurance coverage even when they are insured. Among CYSHCN with private insurance, 31.8% of parents reported that the insurance was inadequate, compared to 45% of children with public insurance and 23.3% of children with both public and private insurance (CAHMI, NS-CSHCN, 2005-06).

Similarly, in California, parents of children with private insurance pay more out of pocket for health services than those with public insurance, at least partly because public insurance programs have a more generous benefit package and lower cost-sharing requirements than private insurance plans. Nearly one quarter (23%) of parents of children with private insurance pay more than \$1,000 out of pocket. There is indication that a lower percentage of those with public insurance paid more than \$1,000 out of pocket; however these estimates do not meet standards for reliability or precision (4.5% of children with public insurance, 18.7% of children with both private and public insurance, and 21.3% of children who are uninsured) (CAHMI, NS-CSHCN, 2005-06).

FOUNDATIONS/SUPPORT ORGANIZATIONS

Some foundations and support organizations may help to pay for certain services that children with special health care needs and their families need. For example, some may pay for specialized equipment, such as van or home modifications that insurance does not cover, specialized summer camps with medical supports in place, or nonemergency medical transportation for appointments.

Two larger such organizations help families access services for their children when they are either uninsured or underinsured. First, the Kaiser Cares for Kids Health Plan is an insurance plan for children under age 19 who are uninsured and ineligible for Medi-Cal or CHIP. Cost for the program varies by county and children must live in families with incomes between 250% and 300% of the federal poverty level. There are caps on enrollment; for example, enrollment is currently closed in Los Angeles County (Children's Health Access and Medical Program).

Second, the United Health Care Foundation helps children who are either uninsured or underinsured by providing funding for needed medical services (United Healthcare) that are not covered by commercial insurance plans.

These services fill some of the gaps in services not provided by insurers or that uninsured children do not have access to. However they are not comprehensive and in no way cover all care required by children generally and children with special health care needs specifically.

OVERVIEW OF SPECIAL POPULATIONS WITHIN CYSHCN



DOLESCENTS

California is home to 1.73 million teens ages 12-14 and 1.78 million teens ages 15-17, as well as 3.7 million youth ages 18-24 (CHIS, 2007). This is an ethnically diverse population, with 29.3% of adolescents 12-18 years identified as Latino, 36.5% White, 7.5% African American, 9.8% Asian, 0.7% Native American, and 16.3% Other/Multiracial (CHIS, 2007).

Of the teen population, 12.4% have a special health care need (CAHMI, NS-CSHCN, 2005-06). Youth with special health care needs (YSHCN) face numerous challenges, especially as they begin the transition to adulthood. These challenges include identifying resources to assist in transition planning, obtaining adequate health insurance, locating adult-focused practitioners able to provide ongoing primary and specialty care, preparation for employment and/or post secondary education, and learning self care skills associated with the special health care need. While many service systems provide limited assistance in the transition to adult living, a lack of a comprehensive planning structure, an inadequate supply of appropriate health care providers, lack of independent living skills, and potential loss of health insurance combine to make this a challenging developmental period. Additionally, YSHCN are challenged by loss of program eligibility that is variable—at age 21 for CCS, age 19 for some types of Medi-Cal, and up to age 22 for special education services.

CHILDREN AND YOUTH IN FOSTER CARE

As stated earlier, there are 64,838 children in foster care in California. Many children in foster care have special health care needs, displaying higher rates of chronic medical, mental health, and developmental problems than other children from similar socioeconomic backgrounds, and have greater utilization of physical and mental health and developmental services (AAP, 1994). For example, several studies of children entering foster care have found that almost 90% of these children had physical, developmental, or mental health needs, with more than half displaying two or more problems; almost 10% had one or more mental health conditions; and almost a quarter demonstrated concerns on developmental screening (Leslie, et al., 2005; Chernoff, Combs-Orme, Risley-Curtiss, & Heisler, 1994). Their poor health reflects their

exposure to poverty, poor prenatal care, prenatal infection, prenatal maternal, substance abuse, family and neighborhood violence, and parental mental illness prior to their removal from their parents (Simms, Dubowitz, & Szilagyi, 2000).

The special health care needs of these children are complicated by the instability of their home life. Children come into out-of-home placement because of abuse, neglect, or abandonment, and then often undergo multiple placement changes while under the care of child protective services. These changes in placement may necessitate disruptions in usual health care and other provider relationships, loss of medical records, and gaps or duplications in care. Foster parents may be unaware of the type of care needed for a particular condition, or may not know where to seek services. This instability can result in lack of health care continuity and poor health outcomes (Chisolm, Scribano, Purnell, & Kelleher, 2009).

Despite the availability of health care through Medicaid and other funding sources, as well as laws and policies that mandate appropriate care, numerous systemic and direct service barriers prevent many children in state protective custody from receiving adequate health care (GAO, 1995). California's children in foster care have health coverage through Medi-Cal, but it can be challenging for foster parents to find willing primary and specialist providers who accept Medi-Cal and will provide services to the child. Many children in foster care are also clients of other programs, such as CCS, regional centers, and special education. Transition is a particularly perilous stage for many children in foster care: in addition to transitions they must make out of other service programs, they age out of the foster care system itself at age 18.

HOMELESS FAMILIES

The term "homeless children and youth" means individuals who lack a fixed, regular, and adequate night-time residence. This definition also includes children and youth who are sharing the housing of other persons due to loss of housing, economic hardship, or a similar reason; children who may be living in motels, hotels, trailer parks, shelters, or awaiting foster care placement; children and youth who have a primary night-time residence that is a public or private place not designed for or ordinarily used as a regular sleeping accommodation for human beings; children and youth who are living in cars, parks, public spaces, abandoned buildings, substandard housing, bus or train stations, or similar settings; or migratory children who qualify as homeless because they are children who are living in similar circumstances listed above (California Department of Education, 2009). During the 2005-06 school year, there were 292,624 homeless children in California, the 10th largest population in the nation (Hubert, 2009).

Homeless children face numerous health problems and parents more often rate their health as fair or poor. Hospitalization is more common and homeless children are more likely to be seen in the emergency department. Health problems seen more frequently among homeless children include infectious diseases, injuries, elevated blood lead levels, mental health and behavioral

problems, developmental lags, obesity and malnutrition, anemia, dental caries, immunization delays, asthma, vision problems, and child abuse (National Health Care for the Homeless Council, 2009). Homeless children and youth access services from special education, regional centers, California Children's Services, and other programs serving children with special health care needs. Service eligibility can be difficult since they do not have a permanent residence, and communication with them can be difficult as mail is often undeliverable or providers cannot reach them.

FAMILIES EXPERIENCING OTHER CHALLENGES

In addition to the challenge of caring for a child with special needs, families face a variety of barriers in navigating the various systems which require communication and advocacy skills to access services. In California, 3.8% of CYSHCN are immigrants and 39.7% have parents who are immigrants¹ (Centers for Disease Control and Prevention, National Center for Health Statistics). Additionally, more than 14% of families of children with special health care needs speak a language other than English at home (CAHMI, NS-CSHCN, 2005-06). In California, only 38.7% of families who needed interpreter services usually or always received these services, making communication with medical and other service providers challenging (CAHMI, NS-CSHCN, 2005-06).

Further, cultural norms or past experiences often dictate how families interact with systems. Some families may have emigrated from countries where "negotiating" with government officials is not accepted, and, in fact, dangerous, and therefore may not feel comfortable advocating for themselves or their children. Even many English-speaking families are not comfortable with or know how to advocate on behalf of themselves and their children. Some may have had previous negative experiences with government or other agencies, such as having their children taken away from them, and may perceive that they have been treated disrespectfully, and have given up negotiating with these agencies.

Families living at or near poverty have many competing demands, chiefly finding and/or maintaining employment, and they do not have the time or money to negotiate the systems of care. Many children in California live near or in poverty; 39.6% of all children and 37.3% of children with special health care needs live in families with incomes under 200% of the federal poverty level (\$22,050 for a family of four) (CAHMI, NS-CSHCN, 2005-06). Further, 17.9% of families with a child with special health care needs report spending \$1,000 or more in out-of-pocket expenses for medical care for their child and 15.5% report having financial problems related to expenses for their child's care. Thus families living with minimal financial resources bear a heavy financial burden in caring for their children with special needs (CAHMI, NS-CSHCN, 2005-06).

¹Estimates are weighted to account for population characteristics including probability of being selected, telephone lines, and other demographic variables. The wide confidence intervals reflect a small weighted sample.

OVERVIEW OF SERVICES FOR FAMILY SUPPORT



Misconceptions and stereotypes about disability continue to negatively impact people with disabilities. Children, youth, and adults with developmental challenges and special health care needs are often misunderstood by the public due to their special need, especially if they have an “invisible disability” (e.g., mental illness). Children may be chided and bullied by peers, and it continues to be an accepted social practice to exclude children, youth, and adults with disabilities from everyday activities. Segregating those with disabilities in specialized programs, or excluding children and youth from educational and recreational activities premised on the idea that the staff does not have expertise in dealing with them, interferes with the full integration of these children and youth in community-based services.

Owing to these misconceptions, children and youth with special health care needs frequently face social isolation, poor self-esteem, and failure in school. When compared with their peers without special needs, CYSHCN do not fare well across many indicators. For example, they are more likely to have had an emergency room visit. According to the 2003 National Survey of Children’s Health, 31.8% of children with special health care needs had at least one emergency room visit within the last year, compared to only 13.9% of children without special needs (CAHMI, NSCH, 2003). They are at significantly higher risk for involvement with the juvenile justice system. Children with special needs are more likely to struggle in school; among children ages 6-17 in California, 20.9% of those with a special health care need had repeated a grade compared to 7.8% of those who did not have a special health care need (CAHMI, NSCH, 2007). Further, children with chronic medical conditions are more likely to need mental health services; are more likely to be victims of abuse and neglect; and are more likely to be unemployed or have lower earnings if they are employed as adults (van Campen & Cardol, 2009).

The system of services for children, youth, and their families poses many obstacles to families; without adequate coordination to provide seamless care, families are confused by a variety of regulations, eligibility requirements, and other details. Difficulties in obtaining vital information and accessing needed services are compounded for families who live in poverty; speak a language other than English; have cultural norms that are in contradiction with assertive advocacy; or have had previous negative experiences with government services.

Whether families find out in the hospital, at a doctor's office, at a regional center or another community-based agency that their child has special health care needs, they face a confusing maze of services and systems. As children grow older and become more independent, they need to understand the systems that serve them. Although many systems have case managers, families and youth often take the primary responsibility for coordinating their care across systems, and need ongoing information, education, and support. They need to learn the intricacies of the different systems and how to become partners in making decisions about their own care

A variety of cost-effective community-based resources works together to assist families in navigating these complex systems and regulations in order to obtain adequate and appropriate care for children and youth with special health care needs. Many of these community-based resources are rooted in parent-to-parent and empowerment-focused philosophies. Families of CYSHCN require many different kinds of supports to cope and survive. The following community-based resources help families to navigate the complicated service system; provide families with leadership training to most effectively advocate on behalf of their children; provide families with personal and peer support; provide care coordination; assist with service transitions; collaborate with service systems to more effectively serve families; provide families with resources and information; help families solve problems or issues arising with service systems; and fill gaps arising from the existing service system for children and youth with special health care needs.

Jimmy has three pediatric specialists, an IEP, and receives services from the regional center; his mom is overwhelmed with paperwork. Staff from the local family resource center helps her to organize her extensive paperwork. She now has a binder with tabbed sections for medical, IEP, and regional center papers. The binder includes a medical history, plastic pockets for business cards, and blank sheets to record notes from phone calls and appointments. His mom feels more confident about her ability to help manage her son's care and feels a greater sense of control in a situation that is mostly beyond her control.

FAMILY RESOURCE CENTERS (FRC)

FRCs were formally established in 1997 when the California legislature authorized a statewide system of 52 parent-run family resource centers in recognition that family-oriented and parent-to-parent support services are key components of an early intervention (i.e., birth to age three) system for children with disabilities. California's 52 Early Start Family Resource Centers and networks are staffed by parents who have children with special needs. They provide information and parent-to-parent support to families of children from birth to 36 months. Each FRC is unique; some operate as independent sites and others are based in regional centers for persons with developmental disabilities, local education agencies, public health facilities, hospitals, or homes. As part of their contracts with the California Department of Developmental Services, FRCs are required to actively collaborate with other agencies serving families of children with disabilities and help families access early intervention services. FRC services may include:

- Parent-to-parent and family support
- Peer counseling and home visits
- Information and referral
- Public awareness
- Parent education

- Support services in many languages
- Transition assistance
- Support services in urban and rural communities
- Newsletters
- Resource libraries
- Websites
- Parent and/or sibling support groups
- Telephone advice and support lines

FAMILY EMPOWERMENT CENTERS (FEC) AND THE CALIFORNIA ASSOCIATION OF FAMILY EMPOWERMENT CENTERS (CAFEC)

CAFEC is comprised of 14 FECs across the state. CAFEC provides information, resources, technical assistance, and systems change advocacy for a state-wide network of local family empowerment centers. FECs provide family education, empowerment, and parent-professional collaborative activities for families of children with disabilities ages 3-22 years old. California FECs receive funding through the California Department of Education, and must meet specific criteria, centered mainly on the provision of education. Several California FECs also receive funding from the California Department of Developmental Services in addition to the money received by the Department of Education, and as such, these organizations are classified as both FECs and FRCs. Some include:

- Training and information that meet the needs of the parents and guardians of children and young adults with disabilities
- Peer counseling and home visits
- Working with community-based organizations
- Training and support to parents and guardians of children and young adults with disabilities
- Participation in decision-making processes and the development of individualized education programs
- Promoting positive parent and professional collaboration with local education agencies, special education local plan areas, and other community agencies
- Participation and support of surrogate parent training

FAMILY VOICES OF CALIFORNIA (FVCA)

FVCA, a family-to-family health information center (a support center staffed by knowledgeable parents with primary funding from MCHB) was established through the linkage of two different groups, Family Voices National and Family Resource Center Network of California. Family Voices National is part of a national grassroots network of families and friends speaking on behalf of children with special health care needs. It was established in 1992 to ensure

that the health of children with special health care needs was addressed during the national health care reform initiative. Family Voices exists in all 50 states and consists of more than 40,000 families and friends.

FVCA is a collaborative of nine family resource centers across the state of California, representing urban, suburban, and rural areas. Family Voices of California receives private and public funding, and is funded in part through the Maternal and Child Health Bureau. FVCA holds a vision for the provision of parent health liaison (PHL) services across California, including information, education, and support to families and partnerships with medical institutions, CCS and other groups to address family-centered care, access to community-based services, and linkages from hospital to home. It has set standards of services for PHLs through a Parent Health Liaison Training Manual, ongoing trainings, meetings, and conferences specifically to build the capacity of PHLs, and provides ongoing support and technical assistance to existing PHLs.

There are currently three models of the PHL delivery system in California: county CCS programs, hospitals, and/or other health entities that contract with local Family Resource Centers to provide PHL services; county CCS programs, hospitals and/or other health entities that hire PHLs within their system; and Family Resource Centers that provide PHL services through other funding.

When provided by a family resource center, the scope of PHL services goes beyond any one institution helping families and youth integrate services across a variety of systems. The following benefits come from this cross-systems approach:

- PHL services include partnering with families, youth, and the professionals who serve them.
- PHL services provide linkages to community-based resources.
- PHL services provide ongoing information, education, and support.
- PHL services can assist in problem-solving with families and the professionals who serve them.
- PHL services include leadership building for families and youth so they can take an active role in their services.
- Families are more satisfied with the care they receive.
- The state demonstrates its valuing of family-centered care by providing resources to support families.

FVCA was also responsible for creating the widely used “Hospital Discharge Questions for Families of Children with Special Health Care Needs” (in English, Spanish, and Chinese). This tool includes questions designed by families of children with special needs, and families are encouraged to utilize the questions as a guide to ensure that they understand vital information before they leave the hospital (e.g., medical care, medications, equipment and supplies, insurance, respite, and transportation). By providing leadership opportunities for families

and youth, such as the Annual Health Summit in Sacramento, FVCA helps to keep families informed on local, statewide, and national policies affecting children and youth with special health care needs.

Family Voices seeks to improve the lives of CYSHCN through the following means:

- Improving policies and systems of care for children with special health care needs
- Providing information and education to families and professionals regarding health care for children with special health care needs
- Promoting family-centered, culturally competent, community-based coordination, and quality care for children with special health care needs
- Developing family and professional partnerships

PARENT TRAINING AND INFORMATION CENTERS (PTI) AND COMMUNITY PARENT RESOURCE CENTERS (CPRC)

PTIs and CPRCs serve families of children and young adults from birth to age 26 with all disabilities. They are funded by the U.S. Department of Education under the Individuals with Disabilities Education Act (IDEA). Each state has at least one parent center; California has nine PTIs and three CPRCs. The scope of work of PTIs and CPRCs includes:

- Training and informing parents and professionals about issues concerning children and youth with disabilities and the services available to assist them.
- Helping families obtain appropriate education and services for their children with disabilities.
- Working to improve education results for all children.
- Resolving problems between families and schools or other agencies.
- Connecting children with disabilities to community resources that address their needs.

UNITED ADVOCATES FOR CHILDREN AND FAMILIES (UACF) STATEWIDE FAMILY NETWORKS (SFN)

The UACF mission is to promote the emotional, behavioral, and social well being of children, youth, and families through transformational leadership. UACF currently operates three programs to meet its mission, a direct service program in two California counties, a statewide advocacy and training program, and a national training and technical assistance center. With the passing of the Mental Health Services Act, UACF's primary goal in California is to assist independent family organizations at the county level to identify their missions, incorporate, and build intentional and effective strategies to transform California mental health service delivery system for children.

IS THERE A SYSTEM OF CARE FOR CYSHCN IN CALIFORNIA?

ANALYSIS OF THE SYSTEMS, THEIR STRENGTHS, AND CHALLENGES



Health Services

Services for children and youth with special health care needs are provided in a variety of inpatient, outpatient, and community settings, depending on a number of factors, including the funding source, where the child lives, services needed, and the child's medical condition and available specialists.

Children's Hospitals

While there is no formal regional system of care for CYSHCN, there are eight children's hospitals in California that provide primary, specialty, tertiary, and quaternary care. Children's hospitals provide graduate medical training for nearly 700 full time residents, 300 of whom are pediatric subspecialists, and provide almost 40% of all inpatient care for children in California.

Up to 75% of the children treated in children's hospitals are enrolled in Medi-Cal and more than half of the 698 CCS special care centers are located in children's hospitals. The eight children's hospitals provide 72% of inpatient care for children who need heart surgery, 60% of surgery for children who need organ transplants, and more than 55% of the inpatient care for children with cancer; 55-60% of their inpatients are children with serious illnesses. Children's hospitals provide over 1.5 million outpatient visits each year and over 55% of pediatric intensive care beds are located in children's hospitals. The case-mix is more than 25% higher than that of other hospitals that treat children. Managed care plans as well as PPOs and indemnity plans utilize these facilities (CA Children's Hospital Association, 2009). Appendix 6 provides a listing of these facilities.

In addition to children's hospitals, California has a number of tertiary care centers and specialized care units located within university medical centers or other hospitals within the community that have been approved as CCS tertiary hospitals.

Despite world-class facilities available to care for children with special needs in California, families experience long waits, especially for specialist care. This is the result of a shortage of pediatric subspecialists, as well as reluctance on the part of many providers to accept patients with Medi-Cal, Healthy Families, and CCS, due to low reimbursement rates and burdensome administrative

requirements. In addition, pediatric beds are in short supply, resulting in children being turned away when requests for transfers are made between community hospitals and children's hospitals. Further, there has been an overall decrease in pediatric bed supply over the last 10 years. According to an analysis of Office of Statewide Health Planning and Development (OSHPD) data, more than 800 in-patient pediatric beds were eliminated between 1998 and 2007, a 19% decrease (UPI.com, 2009). The hardest hit are rural, non-teaching hospitals, which reported an 80% loss of pediatric beds between 1992 and 2004, according to an unpublished study of the American Academy of Pediatrics (Yoshino, January 25, 2009). In addition to waits for pediatric in-patient and specialty care, families often have to travel great distances to receive this care, adding to their burden.

CCS Special Care Centers

CCS special care centers (SCC) are located throughout the state and provide comprehensive, coordinated health care to children with complex, handicapping medical conditions. There are 698 SCC in the state (Morrow, 2009). Staffed by interdisciplinary teams of experts including pediatric subspecialists, nurses, social workers, and others, the centers are organized around a specific medical condition or system. SCC are charged with evaluating each child's medical condition and developing a family-centered health care plan that will facilitate the provision of timely, coordinated treatment appropriate to each child. Although SCC provide care for a large number of diagnoses, there are CCS-eligible conditions for which there is no designated SCC, leaving some children without the comprehensive and coordinated care offered through these centers.

Community Hospitals and Clinics

While most children with serious chronic or life threatening conditions are cared for in children's hospitals, academic medical centers, or related institutions, some receive care from community hospitals, due to geographic availability, the urgent nature of the condition, or limitations imposed by their health plans. While many community hospitals are able to care for children with common pediatric conditions, they cannot typically care for the most seriously ill children, or those with illnesses complicated by a chronic condition or other special health care need. At times, they are forced to care for children with significant care needs, as beds in children's hospitals may not be available to accept transfers.

Outpatient services are often provided in community clinics or by individual providers in the community. There are 6,157 board certified pediatricians in California, with a pediatrician:child ratio of 65.6 pediatricians per 100,000 children (American Board of Pediatrics, 2008). There are 8,015 family practice physicians in California many of whom serve children as well (American Board of Family Medicine, 2008). Nurse practitioners and physicians' assistants also provide care in outpatient settings. For some children, care is provided by general practitioners, who typically have not had any training specifically in

Keith, a young man living with a complicated health condition, was diagnosed with pneumonia at his pediatrician's office and sent home with an inadequate treatment plan. When his family contacted his pediatric pulmonary specialist, they moved heaven and earth to have him come in the following day to have a complete workup and additional medications added to his plan. Owing to the quick response of the pediatric pulmonary care team, the pneumonia was treated at home, avoiding a costly hospitalization.

the care of children. For those living in rural and underserved areas, the federally qualified health centers, rural health care centers, and other safety net providers are critical to the provision of children's health care.

Pediatric Subacute Facilities

Pediatric subacute facilities provide care to children who require more medical and nursing care than can safely be provided at home. These facilities provide very intensive, licensed, skilled nursing care in acute care hospitals or in free-standing nursing facilities to patients who have fragile medical conditions.

To qualify for the pediatric subacute program, the patient must be under 21 years of age and need one of the following: tracheostomy care with dependence on mechanical ventilation for a minimum of six hours each day; tracheostomy care requiring suctioning at least every six hours, room air mist or oxygen as needed, and dependence on one of four treatment procedures (intermittent suctioning, continuous intravenous therapy or intermittent intravenous medication administration, peritoneal dialysis, tube feedings, and other medical technologies); total parenteral nutrition or other intravenous nutritional support and one of the five treatment procedures; and skilled nursing care in the administration of any three of the five treatment procedures (Medi-Cal, 2000). They may provide short or intermediate term care, while arrangements are made to return the child to the home, or they may provide long-term care. Because of their limited capacity there may be long waits, with children remaining in hospitals longer than necessary, before an adequate and available facility is located.

Home Health Care

Home health care is provided by registered nurses, licensed vocational nurses, and home health aids, most often through home health or nursing agencies. This can be short-term care, for instance to aid in recovery from an acute problem; intermediate term, checking-in on and guiding a family who is learning to care for a chronically ill child; or long-term, to assist families who need ongoing services to care for their child in the home. Included in this are children who need hospice care. Providers and families often encounter difficulties in locating home health care for children, due to poor reimbursement rates and lack of providers qualified to care for children.

In accordance with AB1745, CMS Branch and the Medi-Cal program collaborated to submit a waiver application to the federal Centers for Medicare and Medicaid Services/CMS for a 1915(c) Home and Community-Based Services waiver to allow seriously ill children to receive a range of supportive palliative care services while simultaneously receiving treatment services for their CCS-eligible medical condition. The waiver was scheduled for implementation in October, 2009, in Alameda, Monterey, San Diego, Santa Clara, and Santa Cruz counties.

Developmental and Mental Health Services

Regional Centers

The Department of Developmental Services, through contracts with 21 regional centers throughout the state, provides services to individuals who have qualifying developmental disabilities from birth until death. In addition, the Department of Developmental Services is responsible for Early Start, California's IDEA early intervention program.

Regional centers, like other publicly funded programs, are the payers of last resort. Families are expected to use other public and private resources (Medi-Cal, CCS, special education, commercial insurance) before regional center services are utilized. At times, families are caught in the middle as agencies attempt to shift responsibility for care away from themselves and to another payer. For example, parents often report tension between regional centers and school districts regarding the provision of some services such as behavioral therapies. Families also may have difficulty obtaining the denials of benefits from private insurers that are necessary to trigger access to regional center services.

Each regional center has its own community-based board of directors, responsible for overseeing the operation of its regional center. While regional centers are to provide a basic set of services—for instance, service coordination and respite care—there can be tremendous variability among regional centers in terms of program eligibility and service delivery. This can cause great frustration for families as they move from one area to another, or are aware of different benefits provided by individual regional centers elsewhere.

Mental Health Services

Publicly funded mental health services are provided to children and youth through county mental health programs, typically carved out of Medi-Cal and, in the case of serious mental illnesses, from the Healthy Families program. There may be little coordination between the plan with primary responsibility for health care and the mental health service system, resulting in barriers to access for children who need mental health care. For example, MRMIB reports very low utilization of mental health services by Healthy Families-enrolled children: between 2004 and 2007, only 3% of Healthy Families enrollees received mental health services provided through their plans and only 1% of all enrollees received treatment for serious emotional disturbance (SED) through counties (MRMIB, 2009). As is the case with regional centers, there can be tremendous variability in eligibility and service provision within and between counties. In addition, there can be considerable waits for services, at times up to several months long, shortages of qualified providers, particularly child psychiatrists, and a lack of available pediatric inpatient psychiatric beds, especially for those who have Medi-Cal.

Of particular concern is the conflict that can arise regarding service delivery between regional centers and mental health programs for children and

youth with both developmental disabilities and mental illness. Parents and providers report that regional centers do not have the capacity to serve individuals with mental health needs in addition to their developmental disabilities, and mental health programs often lack experience in dealing with patients who have a developmental disability in addition to their mental health condition.

Special Education

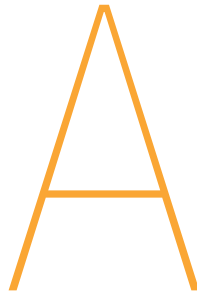
Each child served in special education has an individualized education plan (IEP) that maps out individual educational and related goals and identifies the services to be provided by the school district. For children with special needs, these services can include health care, therapies such as occupational and speech therapy, accommodations for the special need, and specialized approaches to education.

As mentioned above, through a California interagency agreement known as AB3632, both mental health services and California Children’s Services can be offered through the county to address specific areas for children eligible for special education. Families whose children benefit from these services can be stymied to address issues that are caused by conflicting regulations and legal mandates of these agencies. In addition, because of tremendous budget pressures, tensions exist between general education and special education, between school districts and other providers of services such as regional centers and CCS, and between parents and districts, as parents seek services needed to maximize their child’s education and districts are driven to limiting services due to ever tightening budget constraints.

Summary

While California has many services in place that are extremely valuable for children with special health care needs, the state does not have a true system of care for these children. Instead, the services available are a patchwork of programs located in different state departments or in the private sector, often with little formal communication or coordination among them. In addition, their disparate funding sources can put them in direct conflict with each other, as individual “systems” may seek to control their enrollment and expenditures. In one example, cost savings realized in one system as a result of innovations in another system will not be credited to the innovator, thus reducing the incentives for programs to collaborate or to make changes in the ways they organize or deliver services. Every report addressing access to care for CYSHCN in our state has commented on the need for California to address its “siloed” health, developmental, and mental health programs and to create mechanisms for the delivery of true coordinated, collaborative care.

PRIOR EFFORTS ADDRESSING CYSHCN



number of efforts aimed at assessing or improving California's system of care for children with special health care needs have been carried out in recent years. These efforts have served both as incremental steps toward improvement of the system, as well as highlighting challenges that continue. Below is a summary of those efforts.

Your Voice Counts, Family Voices of California

In 1998, Family Voices of California was actively involved with Family Voices National and Abt and Associates, Inc. in a survey of 954 parents of children with special health care needs in California. This survey identified parent concerns and the obstacles they face in obtaining health care services for their children. The main research questions were related to understanding these families' experiences with the health care system, including access to care, utilization, coordination of care, parental satisfaction, and the impact on families of having a child with special health care needs. The entire report is available in Appendix 7.

Most of the children whose parents participated in the study had multiple conditions and disabilities that were moderate to severe. The most common condition was cerebral palsy, and 14% of the children were technology dependent. Findings from the study were as follows:

- **Health insurance coverage:** Most were enrolled in Medi-Cal and CCS and 82% were in managed care, with 10% without health care coverage at some point during the previous 12 months.
- **Utilization of providers and hospitals:** Almost all children had seen a primary care provider and a specialist at least once and 28% had seen a specialist six or more times in the last 12 months. Half had been hospitalized at least once, 10% had been hospitalized three or more times, half had been treated in an emergency department (ED) and 15% had been treated in an ED three or more times. As expected, utilization was higher among those with more severe levels of disability or more unstable health care needs.
- **Need for specialty services and problems with access in the prior 12 months:** Over 80% needed a specialist, two-thirds needed therapies, and half needed durable medical equipment. Forty percent of parents reported

having difficulty getting mental health services, 39% had difficulty getting home health services, and 35% had difficulty getting therapy services for their child. Children with health care needs that change often were twice as likely to have difficulty obtaining medication, and those with behavior problems were more likely to have difficulty accessing mental health services.

- **Coordination of benefits and care.** Parents reported they were unaware of any formal coordination of benefits between their insurers, including CCS; only half identified a case manager for their child, typically from regional center (35%) or CCS (28%); and case management services varied greatly. Many parents reported that they find information themselves or from other parents.
- **Satisfaction with primary health plan.** Two-thirds were satisfied with their child's plan in terms of capacity and overall benefits package, but less were happy with the family centeredness of the plan. Parents were more likely to be dissatisfied with their plan if their child was more severely disabled and less stable. Satisfaction was low among parents whose children were in private managed care compared to Medi-Cal managed care plans, and lower among those in Medi-Cal managed care compared to fee-for-service Medi-Cal.
- **Satisfaction with the physician care.** Most parents were highly satisfied with their child's physician, but less so in terms of availability and coordination of care. Parents of those in Medi-Cal managed care were less satisfied with provider communication with other providers and agencies compared to those in fee-for-service Medi-Cal; those in commercial managed care were least satisfied.
- **Family impact.** Having a child with special needs has a significant impact on families, affecting finances, jobs, and time spent providing care at home. Approximately half of parents reported spending over \$1,000 out of pocket for services for their children while 10% reported spending \$5,000 or more. Nearly two-thirds of parents reported either reducing work hours or stopping work due to their children's health care needs. Over half of mothers reported spending time providing health care (e.g., physical therapy, dressing changes, etc.) for their children at home, with 20% reporting spending at least 20 hours a week providing health care services.

The report recommends a comprehensive benefits package whether the child is in the Medi-Cal program or commercially insured, flexibility in health care plans, in particular related to choice of providers, care coordination, clear information from the health plan about plan benefits, improved access to mental health, home health, and durable medical equipment providers, and more information and help in order to ensure that the health care system works for their children. While there have been no specific initiatives to address the identified issues, the information has been used to inform other processes.

California's Ailing System of Caring for Children With Special Health Care Needs (Peter Hansel and Cori Reifman, California Senate Office of Research, May, 2000)

In June, 1998, the Senate Office of Research (SOR) was asked by the then-chair of the Senate Health and Human Services Committee to study the California Children's Services (CCS) program to determine the extent to which the program was providing timely access to services for children eligible for the program. SOR interviewed numerous organizations and individuals involved with the CCS program, including medical providers, state and county program administrators, and family representatives. In total, SOR interviewed or received comments from over 50 stakeholder representatives and policy experts. This report often is mentioned in state-level discussions of potential strategies to strengthen the CCS program, but no specific commitment to implementing its recommendations has been made by the state. See Appendix 8 for the Executive Summary of the report.

Despite the success of the CCS program in helping children with special health care needs gain access to medical treatment and therapy necessary to restore and improve their functioning and long-term prognosis, SOR concluded that a number of problems limited the ability of the program to provide timely and seamless services to eligible children. In some cases, this produced very lengthy delays in children receiving services. These problems included:

Ten year old Sue is hearing impaired and needs to see an audiologist. The first available appointment is in three months for this pediatric specialist.

- **The adequacy of provider participation:** The report found that low reimbursement rates for CCS and Medi-Cal services caused many physicians and other providers to cease seeing CCS/Medi-Cal patients or limit the number they treated. As a result, waiting times of three to six months or longer for services were not uncommon, depending on the subspecialty. Lengthy delays in claims reimbursement and claims editing procedures only served to further reduce the effective rate of payment to providers. The report outlined options to increase rates, speed up payment, and better track provider participation in the CCS and Medi-Cal programs.
- **Inadequate case management staffing:** According to material reviewed by SOR, staffing standards at the time permitted staff-to-client ratios in excess of 500-to-1 in larger counties and in excess of 1,000-to-1 in the state regional offices serving smaller counties, far too high to permit timely eligibility determinations, treatment authorizations, and claims payment in many counties. Providers and families reported having to wait months for treatment approval in some cases, while the child's condition went untreated. The report recommended that CCS staffing standards be updated and made more consistent with those used in other programs serving children and adolescents.
- **Need for better state oversight and enforcement of program standards:** Lack of resources for state oversight of the CCS program and delays in implementation of a state-county linked management-information system resulted in a lack of compliance in many counties with basic program standards, including timeliness standards. The report outlined a number of options for addressing this, including increasing the frequency of county and

provider site reviews and expediting implementation to all California counties of CMS Net, the state database and management information system for the CCS program. There has been continued improvement in this area with the nearly complete statewide implementation of CMS Net.

- **Inadequate attention to family-centered care as a program goal:** The report found that lack of focus on family-centered approaches to care resulted in the CCS program being frequently confusing for families, making it difficult for them to participate. The report identified a number of options for addressing these problems, including increased training for CCS staff and providers, greater efforts to make CCS documents and materials more understandable, establishment of a family ombudsperson and 800 telephone number, and clarification of standards regarding access to medical transportation services. A network of parent health liaisons developed, in part, as a result of these findings.
- **Inconsistent county application of program standards.** The report found that county funding pressures may have led to an inconsistent application of program standards. This resulted in children with similar conditions receiving publicly financed health services in some counties and not in others or receiving different types of care. Differences in application of standards also resulted in different financial obligations for similarly situated families. The report outlined options that include providing greater CCS staff training on program standards, conducting more frequent county site reviews, making it easier for families to access CCS services while their Medi-Cal applications are pending, and returning the county share-of-cost for CCS to the 25% level that existed prior to the 1991 program realignment.

The Children's Regional Integrated Service System (CRISS) project, a collaborative of family support organizations, pediatric provider organizations, and hospitals, and county CCS programs in 25 Northern California counties, was cited in the report as an example of a successful strategy for reducing inter-county variability. For example, CRISS has reduced inter-county differences in medical eligibility determination and benefits in its region, and developed guidelines for inter-county case transfers for CCS-enrolled children who move among CRISS member counties. The inter-county transfer guidelines, which preserve children's access to authorized services during family moves to other counties, were subsequently established as statewide CCS policy.

- **Fragmented service delivery as a result of managed care carve-out.** Because CCS services are provided separately from other services children receive when they are enrolled in Medi-Cal managed care plans (referred to as being "carved out" of the plan contracts), delays and disruptions in continuity of care frequently resulted. The report detailed options in this area, including implementing a "medical home" concept for CCS-eligible children, in which responsibility for primary care and care coordination would be assigned to a primary care provider or specialist, depending on the nature of the condition. In addition, DHS could be required to contract for a study of medical outcomes, family satisfaction, and health status of CCS-eligible children enrolled in managed care plans.

- **Outdated income eligibility standards.** Over 27 years ago, in 1982, the financial ceiling for eligibility for the CCS program was reduced from \$100,000 in annual gross household income to \$40,000. Over time, the effect of this change has been to reduce the number of children eligible for the program, as well as those who remain eligible for the program once in it. At least 22,000 and perhaps as many as 130,000 additional children would be eligible for the program if the income standard was returned to \$100,000. The report put forward options to increase or index the financial eligibility limit to a standard that more realistically reflected the financial burdens CCS conditions could impose on families.
- **Need to develop more flexible medical eligibility standards.** A number of stakeholder representatives expressed a desire to see medical eligibility for the CCS program eventually based on general criteria, including a child's functional status, level of condition, or need for services, rather than on defined medical conditions, which they believed acted to exclude some children who could benefit from the services provided by the program. The report suggested requiring DHS to study the feasibility of developing alternative medical eligibility criteria.

Medi-Cal Managed Care Division, Task Force on Children with Special Health Care Needs (Linda Rudolph, MD, and Sharon Rothman King, MSW, 2003)

In February, 2002, the Medi-Cal Managed Care Division (MMCD) of the California Department of Health Care Services convened a task force on Children with Special Health Care Needs to provide input on improving the quality of care for CYSHCN enrolled in Medi-Cal managed care plans and implementing the federal requirements of the Balanced Budget Act of 1997. (The Act was federal legislation that required states to meet specific requirements for individuals with special health care needs enrolled in Medicaid managed care plans; these requirements included plan identification and assessment of these individuals, attention to their access to specialists, and measurement of the quality of care they receive from plans.)

MMCD's longer term goals were to ensure that: (1) children with special health care needs who are enrolled in Medi-Cal managed care plans have adequate access to high quality, coordinated services which meet the needs of the children and their families; (2) MMCD implements quality measures to facilitate monitoring and improvement of care for CYSHCN; and (3) MMCD, contracted plans, and other agencies build a culture of collaboration to foster quality care for CYSHCN. The task force comprised a wide variety of stakeholders from many groups serving children with special health care needs including representatives from state and local agencies (e.g., health, mental health, regional centers); managed health care plans; advocates; and pediatricians and children's hospitals.

For over a year, the task force met monthly to examine the definition and identification of children with special health care needs, access to specialists and special services, care coordination, confidentiality, quality measures and

monitoring, and quality improvement. In addition, the task force examined the coordination of care for specific population groups receiving services from Medi-Cal managed care and other service systems, including children with developmental disabilities, children in foster care, children who need mental health and special education services, children with drug and alcohol problems, and children who are clients of CCS. A full copy of the report can be found in Appendix 9.

A number of recommendations were made by the task force, and are grouped by key areas. Overarching recommendations include the following:

- Mandate all agencies serving CYSHCN to develop a matrix that clarifies agency roles and responsibilities with respect to identification, screening, referrals, assessment, treatment, and care coordination.
- Require that all agencies serving CYSHCN and plans at the state and local levels meet regularly and share information (as allowed by confidentiality laws) to ensure identification, access to care, coordination of services, and quality improvement.
- Clarify the way in which federal and state laws allow sharing of information among providers of care for CYSHCN for purposes of improving care coordination and quality of care.
- Convene an ongoing workgroup with representation from parents, agencies, providers, and plans to specify and review the implementation of the task force recommendations.
- Require inclusion of families at the agency, plan, and provider levels.
- Address diverse cultural and linguistic needs of CYSHCN and their families.

Identification

Identification is a necessary first step to ensure the quality of care for CYSHCN; without awareness that a child has special needs, providers and plans cannot take steps to assess how well those needs are being addressed, or to arrange for or provide needed services. Task force recommendations on identification of children with special health care needs include the following:

- Develop and implement a process to supplement and verify identification based on administrative data, through use of a parent-reported CYSHCN screener.
- Use state-held eligibility and administrative (encounter and claims payment) data to pre-identify some CYSHCN to health plans.

Coordination

Many children require services from multiple providers in separate care delivery systems. Coordination of care among providers and systems is perhaps the most critical element in ensuring that CYSHCN have access to the quality care they need. Care coordination also increases family satisfaction and helps prevent costly medical errors and duplication of services. Task force recommendations on identification of, and coordination of care for, children with special health care needs include the following:

- Educate agencies and providers about legal information sharing, consistent with federal and state laws.
- Develop a standardized informed consent for information sharing.
- Implement and promote a standardized parent/caretaker held tool (i.e., a “health passport” or parent notebook) to facilitate information sharing and encourage the use of a written care plan with input from the family and all of a child’s providers.
- Clarify policies and increase consistency of policy administration and processes across counties for program eligibility determination, referrals, information sharing, authorization, and payment.
- Require that plans ensure the designation of CYSHCN care coordinators who are available to participate in the coordination of care so that the needs of all CYSHCN are appropriately met.
- Support and encourage development of “medical homes” for all CYSHCN.

Quality of Care

Measuring the quality of care is fundamental to health care accountability and improvement. Two core dimensions of quality should be assessed: (1) the health care needs of consumers, and (2) components of quality such as effectiveness, safety, and timeliness. Selecting quality measures requires decisions about what and whom to measure, and what indicators to use. Task force recommendations related to quality of care include the following:

- Implement a core CYSHCN measure set, including the Consumer Assessment of Healthcare Providers and Systems (CAHPS) CYSHCN survey and other CYSHCN-relevant Healthcare Effectiveness Data and Information Set (HEDIS) measures, to annually assess access, care coordination, and parent and child experience of care in Medi-Cal managed care plans.
- Report on quality measures in ways that maximize value for plans, providers, and state agencies.
- Implement a cross-agency program to train and support providers on CYSHCN screening, primary care treatment, and referral for mental health, developmental, and substance abuse problems.
- Implement payment strategies to ensure fair, timely, and appropriate reimbursement of plans and providers for time and resources required for quality care and care coordination for CYSHCN, based on the prevalence and burden of service needs of their population (e.g., streamline payment, increase reimbursement, risk adjustment, reimbursement for assessments).
- Offer financial and other incentives to plans and providers for quality improvement.
- Initiate collaborative quality improvement efforts to improve the care of CYSHCN.

Virtually none of the recommendations of the MMCD have been implemented on a systematic, statewide basis, although there are local efforts aimed

at some of the recommendations. For instance, interagency groups meet locally to discuss efforts aimed at improving care for CYSHCN, including the CRISS group in the north, a CCS Workgroup in the south, and a group in San Diego County.

Prior to devastating budget cuts, many of the county CCS programs included families as advisors either by employing family support staff or contracting with local family resource centers. Both the CCS Workgroup and the CRISS group include family representatives, and Family Voices of California is actively involved in advocating on behalf of CYSHCN. These activities are not well integrated into agency operations. Legislation exists to address cultural and linguistic needs of CYSHCN and their families. This is likely the only recommendation that appears to be implemented statewide through Medi-Cal requirements for linguistic services by Medi-Cal managed care plans.

CYSHCN are not routinely identified by health plans, although some, such as HealthNet, do make an effort to identify these children and coordinate care based on this identification. Family Voices of California, many family resource centers, CCS special care centers, the CRISS group, and the CCS Workgroup promote and facilitate the use of parent notebooks to promote information sharing and encourage the use of a written care plan, but this effort represents a small number of children with special needs. One of the primary goals of the CRISS group, as a multi-county organization, is to clarify policies and increase consistency of policy administration and processes across counties for program eligibility determination, referrals, information sharing, authorization, and payment. Finally, state CMS had begun an initiative to support and encourage development of “medical homes” for all CYSHCN, but this has been curtailed due to budget cuts.

California Medical Home Project

In 2001, the California HealthCare Foundation funded the California Medical Home Project, aimed at spreading the medical home model by increasing the quantity and quality of medical homes, as well as the number of children who have a medical home, particularly those served by the CCS program. The project used three strategies to address policy, community, and practice level barriers, including a statewide coalition to address state policy and administrative barriers, seven local coalitions, each receiving 18 months of funding to plan and implement improvements, and a program office to provide technical assistance to the local coalitions and convene them periodically to exchange knowledge. The local coalitions and their lead agencies included:

- Alameda County: Alameda County Committee on Children with Special Needs
- Contra Costa County: Contra Costa County Health Services
- Los Angeles County: Los Angeles Partnership for Special Needs Children
- Santa Clara County: Parents Helping Parents, Inc.
- San Benito County: San Benito Public Health Services

My son’s medical care has been orchestrated by a special needs pediatrician who coordinates his health needs: immunizations, check-ups, therapies, orthopedic surgeon, ophthalmologist, neurologist, and podiatrist, to name just a few.

- Shasta County: Far Northern Regional Center
- Solano, Napa, and Yolo counties: Partnership Health Plan of CA

Each coalition was charged with developing strategies and carrying out activities to address the project aim, based on local needs and resources. Activities included parent and provider trainings, outreach activities, recruitment of providers, and development and implementation of practice improvement tools and strategies.

An evaluation of the project was conducted by the UCLA Center for Healthier Children, Families, and Communities. A copy of the final evaluation can be found in Appendix 10. The evaluation identified the following:

- **Improvements in care**, including identifying primary care providers in the two rural counties, helping families to organize medical records for improved communication with providers, especially in underserved areas, increasing the number of children with an identified medical home, practice level change, improved relationships with community-based providers, and increased expertise regarding the medical home model.
- **Successful strategies**, including using a structured approach to physician education and practice change, providing practical tools and coaching to physicians, using physician time wisely, providing ongoing support to physicians from an expert team, targeting practices willing to make change, having action oriented agendas for coalition meetings, focusing on practical steps, and focusing on the consumer perspective.
- **Barriers and environmental factors**, including an unstable financial environment limiting implementation of some strategies and attention to the project goals by some agency stakeholders, and limited impact on state-level planning due to barriers such as difficulty obtaining and sharing information about clients, difficulties in engaging key agencies, and lack of progress on systemic issues such as physician reimbursement and risk adjustment.
- **Opportunities for sustainability and replicability**, including professional development among physicians, improving policies and procedures of organizations and agencies, such as identification of CYSHCN by health plans and providers, sustaining planning efforts to continue improvements, and expansion of project activities into other geographic regions.

To date, some activities have been carried out to continue to move the medical home efforts for CYSHCN forward, although as with other efforts, some have been halted or limited due to budget constraints. In 2008, Children’s Medical Services (CMS) began a Medical Home Initiative to include identification of medical homes for children in the CCS program, linking individual children to a medical home, providing resources to county CCS programs and to providers regarding medical home activities, and early discussion regarding funding of care coordination efforts carried out within medical homes. This initiative was developed with the assistance of the Los Angeles CCS Workgroup/ Los Angeles Partnership for Special Needs Children (LAPSNC), Family Voices of California, and the Children’s Regional Integrated Service System (CRISS) and

drew on these organizations' experiences with organizing medical homes for CYSHCN. Unfortunately, this process was stalled in the fall of 2008 due to California's budget crisis.

Nationally, as well as within California, there is increasing interest about the medical home model as part of health reform. Much of the work done in the California Medical Home Project and by CMS can be used to inform and operationalize efforts in this area.

Title V Children with Special Health Care Needs (CSHCN) Needs Assessment Report: California Children's Services (CCS) Program Systems Issues and Priority Action Objectives (Family Health Outcomes Project, May 23, 2005)

As per federal statute, California's Title V CSHCN program, California Children's Services, must complete an assessment of the health problems and needs of its target population every five years; the last assessment was completed in 2005. The Children's Medical Services Branch, the administrator of the CCS program, recognized that a critical aspect of the assessment process was to encourage and facilitate participation by stakeholders throughout the state to assist in identifying health systems' problems/needs, prioritizing among the identified issues, developing strategies to intervene in prioritized issue areas, and evaluating the effectiveness of intervention strategies. Accordingly, CMS established a CCS Needs Assessment Stakeholders Group and contracted with the Family Health Outcomes Project (FHOP) to: (1) identify and analyze data for the purpose of targeting the most important and potentially effective areas in which CCS could improve services for CCS-eligible children, and (2) facilitate the stakeholder process for providing input into problem/issue identification and determining the action priorities that would be addressed during FY 2005-10.

Based on this requirement, it was decided that the workgroup would identify three priority needs to be addressed in the five-year plan and for which action strategies and performance measures would be included. As part of the broader planning process and the identification of the three priority CYSHCN action areas, CMS conducted an assessment of the needs and systems issues related to delivering services to children and families eligible for the CCS program. A complete copy of this report can be found in Appendix 11.

Fifteen major systems issues were identified through examination of the data, stakeholder interviews/questionnaires, breakout workgroups, and by CCS staff. Two overarching principles were identified: (1) CCS will address disparities in impact and outcomes by gender, age, geographic location, and race/ethnicity issues when developing strategies and tracking priority objective outcomes, and (2) the CCS program will ensure that children participating in CCS have access to and receive services from appropriately trained pediatric providers and develop and apply standards of care intended to lower morbidity and mortality rates among eligible children.

The resulting priority objectives were ranked as follows:

1. Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists.
2. Coordinate to develop and implement a system of timely referral between mental health, developmental services, social services, special education services, and CCS.
3. Increase the number of family-centered medical homes for CYSHCN and the number/percentage of CCS children who have a designated medical home.
4. Increase access of CCS children to preventive health care services (e.g., primary care providers, well child care, immunizations, screening) as recommended by the American Academy of Pediatrics (AAP).
5. Increase family access to educational information and information about accessing CCS services, including availability of and access to services offered by health plans.
6. Increase access to services for CCS youth, 17-21 years of age.
7. Decrease the time between referral to CCS and receipt of CCS services.

As with many of the other efforts identified, there has been progress in some, but not all, of the objectives, often limited by severe budgetary constraints. Per the 2007 Specialty Care Coalition survey cited in the Gaps section (see page 73), the number of qualified providers continues to drop as inflation and costs rise and reimbursement remains flat or decreases. While individual nurse case managers and social workers in various service systems (CCS, regional centers, schools, health plans, special care centers) coordinate care and provide referrals to related services, there is no systematic effort to assure that this occurs for all children with special health care needs, nor are there standards in place for care coordination.

While efforts to increase the number of medical homes for CYSHCN have begun, as described above, greater attention needs to be paid to this, and funding for provider training and compensation will be required to achieve this objective statewide. Although there were efforts to address parent information and education through delivery of parent health liaison services, those services have been cut dramatically. Family access to information and support varies, and responsibility often rests with the family to seek this out. CMS has developed information for county CCS programs and providers related to transition services for youth; some individual counties—for instance, Los Angeles County—have initiated their own transition efforts. A lack of adult providers willing to care for these youth and lack of clear standards regarding transition services continue to hinder achievement of this objective.

(Note: State Children's Medical Services recently began convening stakeholders for a new Title V Needs Assessment process for the new five-year period beginning in 2010.)

Children’s Medical Services Branch (California Department of Health Services California Statewide Strategic Plan for Children with Special Health Care Needs 2006–2010)

In August 2005, the State Children’s Medical Services (CMS) Branch of the California Department of Health Care Services convened a nine-month strategic planning process on behalf of children with special health care needs. The planning effort was funded by the federal Champions for Progress, a Maternal and Child Health Bureau (MCHB) initiative to support state efforts to develop a statewide strategic plan to meet the needs of CYSHCN. California’s state plan was intended to assist the state in reaching the national MCHB core performance measures for CYSHCN. This plan focused on those children eligible for the state CCS program, while recognizing the importance of improving communication and coordination among systems serving all CYSHCN and their families.

The state strategic plan for CYSHCN was part of a three-pronged effort by the CMS Branch to achieve a statewide system of care for these children:

1. State CMS Branch Needs Assessment

The Champions planning process was built on a needs assessment for CYSHCN conducted in 2005 by the Family Health Outcomes Project (FHOP) at UCSF for the CMS Branch as part of the state’s Title V Block Grant application. The needs assessment employed a broadly representative stakeholder group to identify the top priority issues for the Branch.

2. Champions for Progress State Strategic Plan

The Champions project convened the stakeholders group from the needs assessment project in order to develop the strategic plan. The stakeholder group adopted the following vision statement, developed by an earlier Task Force on Children with Special Health Care Needs.

Vision for Children with Special Health Care Needs: All children with special health care needs will be identified and will have access to quality health care that is:

- Family-centered and supportive
- Community-based
- Coordinated and seamless
- Effective, appropriate, and efficient
- Culturally and linguistically effective

(Task Force on Children with Special Health Care Needs, August, 2003)

The Champions stakeholder group considered strategies that would assist the state to achieve the six MCHB core performance measures and to meet the priorities identified by the state in its needs assessment process. The core performance measures served as the goals for the plan, with specific and measurable objectives and action steps, and assignments of responsibility for implementing the objectives.

Each stakeholder was charged with assisting in developing strategies for action, circulating draft documents within member organizations for feedback and support, and reaching consensus within the group on a final plan. The Champions planning process was convened by Dr. Marian Dalsey, then chief of the Children’s Medical Services Branch; facilitated by Carolyn Verheyen of Moore Iacofano Goltsman; and staffed by Juno Duenas, Family Voices of California; Kathryn Smith, Los Angeles Partnership for Special Needs Children; and Laurie A. Soman, Children’s Regional Integrated Service System (CRISS) Project.

See Appendix 12 for the Strategic Plan.

3. Federal MCHB Grant: “Implementing Integrated Systems of Care for CSHCN”

This federally funded project, conducted by Juno Duenas of Family Voices of California, Kathryn Smith, and Laurie A. Soman under the auspices of the USC University Center of Excellence in Developmental Disabilities at Children’s Hospital Los Angeles, in collaboration with Children’s Medical Services, promoted implementation of the state plan strategies both statewide and regionally. The Champions stakeholder group served as the advisory group to the MCHB grant and met on a quarterly basis to review and comment on implementation progress through June, 2008.

The MCHB, in awarding the Integrated Systems Grant, intended that the money be used to begin the process of addressing the core measures, with the state Title V program assuming responsibility for resourcing the continuation of the efforts. Initial efforts began to address the medical home and transition core measures, but due to severe budgetary constraints, efforts have not continued. The state is currently engaged in discussions aimed at developing a waiver to incorporate medical homes into the CCS program and this will require renewed attention to the concept, including education, and the development of implementation and training strategies.

Progress was made on a number of steps during the grant period that subsequently were sidetracked by state budget reductions (e.g., planning for a state CCS Medical Home Initiative; plans for a major statewide transition planning process through county CCS programs; and plans to establish a state inter-departmental group on CYSHCN). Other activities, such as the promotion of family-centered care by Family Voices, meetings of a statewide youth advisory council established under the grant, and the activities of established local coalitions such as the Los Angeles CCS Workgroup and CRISS, and emerging coalitions in Riverside-San Bernardino and San Diego continue today.

STRENGTHS, CHALLENGES, AND GAPS IN THE SERVICE SYSTEM



With the recent cuts in IHSS, Rosie's benefits have been cut in half. She is blind and without this in-home support, her father will now have to quit his job to care for Rosie full time.

California has many important components in place that foster implementation of a system of care for CYSHCN:

- A strong network of family organizations and a statewide chapter of Family Voices that bring community-based information, education, and support to families as well as bring the perspective of families to the design and operation of a family-centered system of care for CYSHCN.
- A dedicated pediatric provider network of physicians and other health care providers and tertiary and quaternary pediatric hospitals that are the envy of many states.
- Committed advocates for children and youth, including advocates specifically focused on improving access and care for CYSHCN.
- Publicly funded programs such as Medi-Cal that typically have exceeded the minimum required by federal law, bringing vitally needed services to low-income CYSHCN.
- Specialized programs designed specifically for special populations of children such as CCS and regional centers/Early Start.
- Child health policy and clinical researchers who are nationally known and respected to assist in design and implementation of an appropriate system of care for vulnerable children.
- Public and private foundations whose interest is focused on children with special health care needs.

At the same time, the national and global economic downturn coupled with the state's own political and budgetary problems present major challenges at the macro level to achievement and maintenance of any system of care. These challenges, which affect funding and political support for programs that serve CYSHCN, include the following:

- The impact of the global economic meltdown has had catastrophic effects on California, including double-digit unemployment (11.6% in August, 2009; *San Francisco Chronicle*, 8/8/09) and a substantial drop in revenue to the state.
- California has a huge economy (eighth largest in the world) that typically is slower to move into a recession but also slower to recover from one.
- California has severe structural budget imbalances; e.g., 55% of state revenue comes from personal income tax, as opposed to most other states that

typically have a one-third division among income tax, property tax, and sales tax. This imbalance leaves the state very vulnerable to a drop in income tax receipts such as the state is experiencing now.

- The economic situation is compounded by huge state budget deficits over the past few years that have resulted in major reductions in overall state spending, amounting to a drop in state spending of almost 20% in the last two years (California Department of Finance).
- The power of the governor and legislature to address structural imbalances is limited by California's status as the only state to require a super majority for both passage of the budget and any increase in state taxes.

As a result of these factors, California finds itself in the worst fiscal crisis in at least 20 years, with concomitant impact on funding for the services that make up the existing system of care for CYSHCN. As noted throughout this report, the recently finalized current state budget includes major reductions in many of the programs that support care for children. Details on these reductions and their impact are not yet available at the time of this report but they are expected to be profound.

Even before the current fiscal situation and its potential impact, California had major gaps in its service system that leave vulnerable children and families at risk. Major service gaps that we have identified are grouped according to the six federal MCHB core performance measures discussed earlier in this report. The service gaps are organized by measure because these measures are national goals for CYSHCN that every state is expected to meet and they help to define the service system that families and maternal and child health professionals agree must be in place for vulnerable children.

The authors wish to stress that the gaps reviewed below are not newly identified; they have been culled from existing reports and surveys concerning access to care for California's CYSHCN that have been produced by major stakeholder processes over the years and reflect the thinking of many professionals and family members. See the earlier section on "Prior Efforts Addressing CYSHCN" for a review of some of these reports indicating how thoroughly the gaps and barriers in California's system of care have been analyzed over the past decade.

Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive.

1. Families in California do not have structured and institutionalized opportunities to partner in decision-making at all levels. Although there are "moments" of partnership, at this time there is no formal infrastructure for ensuring family participation at the state or local level. For example, until recently the state and a number of county CCS programs were supporting the work of parent health liaisons. Because of state and county budget cuts, these positions have been decimated, with six counties having cancelled their contracts, and one reducing the hours of the PHL (personal communi-

My daughter, Marci, was born with a left clubbed foot. Shriners Hospital helped with surgery when she was a few weeks old. Then several weeks later, we learned her neck was not strong enough. As she grew, we found out that her arms and legs were not strong enough to do the usual things babies her age do. I realized I needed to be strong. Through her doctor we found out about a program that sends someone to our house to give her therapy and exercises. Then Marcia started having seizures. We have taken her to many doctors' appointments but no one seems to be able to really stop the seizures. She has tried many different medicines and none really seem to stop the seizures. Right now she is on two different kinds of medicine and it seems to be helping more than before, but it's still not right. I hope someone will help me help my child.

cation, T. Robinson, 10/21/09). State CMS, the Department of Developmental Services, and other state agencies often send family-oriented materials to family organizations for review, but the timeline typically has been short and the impact uncertain.

2. There are no clear, published standards for family-centered care in the multiple systems serving CYSHCN.
3. There is no formal evaluation or tracking system to see whether families are satisfied with the services they receive.
4. Infrastructure does not exist to ensure that families or youth have ongoing access to information, education, and support for leadership that would promote their active participation in decision-making about services. Access to information is critical no matter what happens in terms of restructuring California's systems. Families will need to be informed and educated to understand their child's special health care needs, partner with professionals, navigate systems, and understand eligibility and regulations in order to secure appropriate health care services for their children.

Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home.

1. California does not have an operational definition of "medical home" for CYSHCN and it does not have clear numbers on how many medical homes really exist or a way to ensure that all CYSHCN have one. At the same time, we do know from family surveys that many families of children with disabilities do not even have a primary care provider, the first step in achievement of a medical home. In California, 42.2% of children have a medical home (CAHMI, NS-CSHCN, 2005-06).
2. There is no infrastructure to support ongoing training of and information for providers who want to implement medical homes. Several years ago state CMS embarked on development of a Medical Home Initiative for CCS children with complex medical conditions with the goal of achieving true medical homes at the local level through education of primary care providers serving CCS children, enhanced coordination between community-based providers and county CCS programs, CCS reimbursement for care coordination, and a certification process for medical homes for CYSHCN. Implementation of the initiative's first phase was derailed by budget cuts at the state and county levels and planning on the initiative has ceased.
3. There currently is no mechanism for Medi-Cal billing or other financial enhancement for care coordination in the medical home context. Particularly given the current financial climate, most pediatric providers will be unable to establish or expand care coordination activities without clear mechanisms for additional reimbursement.
4. California has an increasingly fragile provider network and continues to lose pediatric subspecialists to other states and to retirement. In addition, specialists are dropping out of participation in the Medi-Cal and CCS programs. California has been losing pediatric subspecialists steadily over the years and

the state's physician-patient ratio for pediatric subspecialists is below the national average. Many believe that this shortage is a result of low Medi-Cal (and even some private insurance plan) reimbursement rates coupled with the state's high cost of living.

Most CCS claims are handled electronically through (Electronic Data Systems (EDS), the state's fiscal intermediary for the Medi-Cal program. Many providers complain about delays in and denials of CCS claims submitted via EDS, a factor that may contribute to provider dissatisfaction with the CCS program. In addition, CCS electronic billing via EDS requires that physicians and other providers obtain Medi-Cal provider numbers through a process that can be confusing and onerous. Because one third of the state's children are enrolled in Medi-Cal, low rates and other barriers in that program can have a profound impact on the overall health of the entire pediatric subspecialty network for all children in the state (California Health-Care Foundation, 2007).

A 2007 survey of pediatric specialty care access indicated that in some areas of the state children wait months for a non-urgent new patient appointment; three months or more to see a pediatric neurologist and in one region, nine months; four to six months to see a pediatric endocrinologist; and four months to see a pediatric plastic surgeon for cleft lip and palate. The same survey also reported that in many areas of the state, pediatric medical groups have a difficult time filling open pediatric subspecialty positions, with some medical groups recruiting for open positions for one to two years. The length of time spent in recruiting was one year or more for open positions in endocrinology, behavioral/developmental pediatrics, gastroenterology, genetics, neurology, rheumatology, surgery, plastic surgery, and pulmonary medicine (Children's Specialty Care Coalition, 2007, personal communication).

5. There are long wait times for other providers serving CYSHCN, e.g., mental health professionals, particularly child/adolescent psychiatrists, and physical and occupational therapists, both among private providers and in the CCS Medical Therapy Program.
6. Health, developmental, and mental health services are more likely to be located in urban areas than in rural areas, resulting in access barriers to services based on geographic location of families and increased need for support for transportation and lodging for families who must travel to obtain comprehensive services.

Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.

1. Many families of children and youth with special health care needs do not have insurance or are underinsured.
2. Children may lose eligibility for publicly or privately funded insurance throughout the year, due to changes in income or parent employment, or family inability to meet periodic paperwork requirements for eligibility

redetermination, resulting in periods of uninsurance and lack of access to health care.

3. Many families may qualify for insurance but because of a lack of information (on their part and that of providers), they do not access it.
4. High out-of-pocket expenses are a barrier to children receiving the comprehensive services they need. According to the Your Voice Counts survey, almost half of parents reported spending between \$500 and \$3,000 on the special health care needs of their child in the past year. One-tenth reported that they spent \$3,000 or more in that year.
5. “Adequate” insurance can be a slippery concept, since coverage that may appear adequate at first can lose its effectiveness as a result of such barriers as the payer of last resort issue (e.g., some public and private insurers require that families obtain formal denials of coverage from other insurers before paying for needed services) and long waits for access to appropriate pediatric providers.

Children are screened early and continuously for special health care needs.

1. California does not have a standardized screening tool for identifying special health care needs, nor is there an institutionalized funding/billing mechanism for administration of developmental, behavioral, and/or mental health screenings. The State Medi-Cal Managed Care Task Force on Children with Special Needs report cited earlier in this paper included a recommendation that the state develop and implement a process to identify CYSHCN using a parent-reported screener, but this recommendation has not been implemented.
2. Providers are not always knowledgeable about resources for follow-up when screening identifies problems and/or they do not refer children and families to appropriate resources.
3. Appropriate resources for follow-up once screening has taken place often are limited, particularly for children needing mental health services and for families that are non-English-speaking. The lack of services available to CYSHCN in fact may compromise providers’ willingness to screen children for special needs.

Community-based services for children and youth with special health care needs are organized so families can use them easily.

1. There is no state inter-departmental coordinating body to work toward better organization of the multiple service systems for CYSHCN ages three and up, nor are there local bodies throughout California to assist in coordinating local agencies and making community-based services easier to access.
2. There is a lack of consistency of interpretation of state regulations/laws from county-to-county and across the multiple systems serving CYSHCN that confounds families who move from one region to another and contributes to services being available in one county or region but not in another.

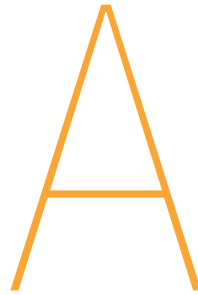
Born prematurely, Stuart was enrolled in California Early Start, an extraordinary early stimulation program at home that allowed him to start walking at age four, communicate better, accept new foods (other than water and formula), and increasingly tolerate a wider range of sensory input—all this while Early Start also supported the family. Now that Stuart is an adult, the regional center is helping him transition into an adult program, where he will spend most of his life learning new skills and hopefully become a productive member of society.

3. While many entities purportedly provide care coordination, there is a lack of communication among the multiple agencies serving the same child that can make care coordination difficult and shift responsibility for most care coordination to families. Oftentimes the care coordination involves a gate-keeper role for the organization's services, rather than a true coordination of all available services across agencies and providers. This lack of communication is exacerbated by confidentiality concerns that may preclude agencies from sharing important information on mutual clients.
4. Most families report that they serve as their children's care coordinators. In a recent Family Voice survey, almost all families reported that they spent time each week arranging and coordinating their children's care, and 41% spent five or more hours per week on care coordination activities.

Youth with special health care needs (YSHCN) receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

1. There is no coordinated transition process for youth who are aging out of child-focused programs, and progress toward improving the transition process in several service systems has been derailed by recent budget cuts. For example, in early 2009, the state CCS program was in the process of issuing a policy letter mandating standardized scheduled transition activities but opted instead for an information notice with suggestions for transition activities because county programs had lost too many of the staff who would have been expected to implement the transition plans.
2. There is no standardized and coordinated transition process among the multiple systems serving youth. Youth often do not receive the education and training they need to be prepared for transition, and this is particularly problematic when they are receiving services from systems with different "graduation" ages; e.g., CCS coverage ends at age 21, while special education services end when the youth turns 22, foster care ends at age 18, and health insurance may end at varying times, depending on the coverage source.
3. There are too few adult-oriented health care and other providers for youth as they age out of pediatric-oriented care.
4. Many youth transition into no insurance at all; they no longer are eligible for Medi-Cal or CCS or they age off their families' private insurance coverage. In California, 9.1% of youth ages 12-17 with special health care needs were without insurance at some point within the past year according to the National Survey of Children with Special Health Care Needs, and among those with insurance, 38.9% reported that the insurance was inadequate (CAHMI, NS-CSHCN, 2005-06). Among all youth ages 18-24 in California, 19.4% are uninsured (CHIS, 2007), many of whom are youth with special needs.
5. An emerging issue is that the success of new treatments with certain conditions seen in CYSHCN (e.g., cystic fibrosis, certain heart conditions) is enabling these youth to survive into adulthood in far greater numbers than in earlier years, resulting in a lack of adult-oriented providers familiar with the care of these conditions.

SUMMARY AND RECOMMENDATIONS



As with the discussion of system gaps above, the following recommendations were culled from earlier papers addressing service delivery organization for CYSHCN. The recommendations cited from those earlier papers represent the analysis and experience of many stakeholders whose lives and work focus on vulnerable children and their families. As the authors note in the above section on gaps in the service system, the reports cited earlier in this paper demonstrate that there has been substantial work already in California to analyze gaps and barriers and recommend strategies to address those problems and create a true system of care for CYSHCN. In fact, to a great degree the recommendations from the different reports are in agreement.

The authors present the following recommendations as the latest in a long series of attempts to move California toward a comprehensive system of care for its children and youth with special health care needs and their families. In keeping with national directives for the care of CYSHCN, the recommendations are framed in the context of the MCHB Core Performance Measures.

Each core performance measure includes a recommendation that the state set clear criteria for state achievement of that measure and that state progress be measured and reported publicly. This recommendation is made in order to ensure that the state has clear and measurable goals for the achievement of each measure and that its performance is evaluated and reported.

Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive.

1. Families and youth should be represented at all levels of planning and implementation of the service system, including a formalized structure at the state level to model parent/professional collaboration. This could be accomplished via an ongoing state-level workgroup with representation from family groups, agencies, providers, and others involved in care for CYSHCN that is charged with improving quality, family-centeredness, and coordination of care.
2. There should be a formal evaluation process, including ongoing interviews and surveys, to assess family and youth satisfaction with the services they receive. At minimum, state programs essential to this population of children

and youth should participate, such as regional centers, CCS, special education, and mental health, with periodic public reporting of results.

3. There should be clear state standards for family-centered care in all systems serving CYSHCN. For example, standards for local public programs, special care centers, and other services for CYSHCN should address the provision of family centered care.
4. There should be mechanisms for providing ongoing information, education and support for leadership development among families and youth to improve their capacity to represent their interests and participate fully in decision-making at the state and local levels.
5. Parent health liaison services should be made available for all CYSHCN receiving services from public programs at the local level to assist families in navigating the different systems children require; PHLs also can assist local programs in assessing the degree to which families are satisfied with the services received. Ideally, implementation of PHL services would be provided by funded contracts with family resource centers in order to build on a system that already exists and build on families' knowledge of and experience with the services for CYSHCN. Such contracts also would contribute to leadership development and capacity-building with families and youth.
6. The state should ensure that California sets clear criteria for achievement of this core measure and that the state's performance and progress are measured periodically and reported publicly.

Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home.

1. The state should define and operationalize the concept of a “medical home” for CYSHCN, ensuring that mechanisms are in place to assist in linking families to a medical home. All publicly funded programs should ensure that CYSHCN have an identified medical home and if not, should assist families in identifying an appropriate one. As a first step, the state should ensure that all children have an identified primary health care provider, the designated health care provider who will hold responsibility for coordinating health care for the child. This provider may be a pediatric subspecialist or other provider rather than a primary care physician, depending on the needs of the child.
2. An infrastructure to support training and education of providers to assist them in serving as medical homes for CYSHCN should be developed. Preliminary work on the state CCS Medical Home Initiative could assist planners in this task; in addition, there are several interesting models in other states that can provide guidance (e.g., Illinois, Washington, and Texas).
3. Mechanisms should be established for Medi-Cal billing and other reimbursements for care coordination within the medical home. Preliminary work was done on potential Medi-Cal billing options in the state CCS Medical Home Initiative; other states also offer possible options for structuring and financing of care coordination reimbursement.

4. The state must address the crisis in the pediatric provider network by taking steps to increase the numbers of primary, specialty care, and other providers serving CYSHCN. Appropriate reimbursement is critical to maintaining the adequacy of the provider network. Reducing CCS and Medi-Cal claims problems with EDS and reducing administrative burdens in the Medi-Cal system in general also would support provider participation in CCS and Medi-Cal.
5. Regionalized services such as hospitals and other providers serving CYSHCN from multiple counties should ensure that children's care is coordinated with the medical home in order to address the needs of the child regardless of the county of residence.
6. Families must be recognized as the true medical home for many CYSHCN and their participation in formal medical home approaches and structures should be supported at both the state and local levels.
7. The state should ensure that California sets clear criteria for achievement of this core measure and that the state's performance and progress are measured periodically and reported publicly.

Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.

1. California should set as an overarching goal the assurance of comprehensive insurance coverage for all CYSHCN, regardless of income, and should consider strategies to achieve this goal, including implementation of the Family Opportunity Act (federal legislation that permits states to create a Medicaid buy-in option for individuals who have SSI-eligible disabilities and have incomes below 300% of FPL, but whose income is above regular Medicaid income eligibility) as a potential source of insurance for families of CYSHCN who currently are not Medi-Cal-eligible; review of existing Medicaid waivers and consideration of opportunities for expansion to include Medi-Cal determination of eligibility for additional CYSHCN and elimination of a waiting list for access to home- and community-based waivers; and elimination of exclusions based on preexisting conditions.
2. The state should clarify payment policy among its various agencies so that there is a payer of first resort, rather than families and providers having to sort out payment among multiple "payers of last resort." "Pay and chase" and other strategies could be explored to solve the payment dilemma.
3. The EPSDT benefit package and federal medical necessity definition should be established as the medical standard for care for all children in the state. As discussed earlier in this paper, EPSDT and the medical necessity definition together constitute the gold standard for care of children, particularly for CYSHCN.
4. CCS state quality standards should be established as the standard for all pediatric care in the state. These standards set the bar for pediatric subspe-

cialty care for CCS certification and in the process create standards of excellence for pediatric services for all children. Implementation of this recommendation would require amendment of the state Insurance Code to require private health maintenance organizations (HMO) and preferred provider organizations (PPO) to meet CCS pediatric standards of care.

5. The state should establish the CCS program as the whole-child program of comprehensive care for CYSHCN and should consider adjustment of CCS program financial eligibility to restore the income limit to \$100,000; deem children enrolled in Healthy Kids programs as financially eligible for CCS; and link CCS financial eligibility to the federal poverty level (FPL) with calibration by family size.
6. The state should strengthen Healthy Kids programs by setting statewide standards for benefits and financial eligibility criteria.
7. The inadequacy of private insurance in addressing CYSHCN should be addressed through such steps as elimination of annual and lifetime caps on insurance coverage and establishment of the right of young adults to age 28 to buy into their parents' insurance at group rates.
8. The state should ensure that it sets clear criteria for achievement of this core measure and that the state's performance and progress are measured periodically and reported publicly.

Children are screened early and continuously for special health care needs.

1. As recommended by a number of reports, the state should establish use of a standardized screening tool or tools for identification of children with health, developmental, behavioral, and mental health concerns. Clear and workable funding and billing mechanisms should be established for administration of the screening tool(s).
2. There should be state performance standards for early and continuous screenings (e.g., CHDP Health Assessment Guidelines) implemented in both public and private health plans. The standards should include the use of accepted health, developmental, and mental health screening tools.
3. The state should implement an outreach and education plan for health providers that will promote early and continuous screening and surveillance, identification of CYSHCN, partnering with families, and understanding of appropriate resources for follow-up.
4. The state should align the CHDP periodicity schedule with the current American Academy of Pediatrics (AAP) schedule and ensure that children can obtain both periodic and inter-periodic visits as needed. The state could consider developing a risk-adjusted screening periodicity schedule for CYSHCN with a number of visits beyond the current American Academy of Pediatrics (AAP) periodicity schedule.

5. The state should ensure that California sets clear criteria for achievement of this core measure and that the state's performance and progress are measured periodically and reported publicly.

Community-based services for children and youth with special health care needs are organized so families can use them easily.

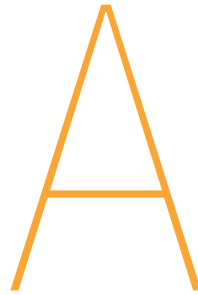
1. There should be a statewide interdepartmental coordinating body created, with entities such as the departments of health, mental health, social services, developmental services, education, and others as needed; families; advocates; and representatives of county departments, in order to address how the multiple services for CYSHCN can be better organized and coordinated for easier use by families. This recommendation is a common theme in many statewide reports addressing organization of care for CYSHCN and is essential to think through and address strategies recommended under other core performance measures.
2. The state should ensure consistency across regions and counties in the interpretation and implementation of state law, regulations and procedures regarding program and benefits eligibility for children's programs, including regional centers, CCS, and mental health.
3. Policies on sharing of information among public and private agencies under the Health Insurance Portability and Accountability Act (HIPAA) and other federal and state laws should be clarified. All agencies serving CYSHCN should be required to share information to the extent permitted by confidentiality law in order to ensure identification, access to care, coordination of services, and quality improvement. This recommendation has consistently been identified as critical in existing state reports on CYSHCN.
4. The state should develop and implement strategies and funding mechanisms that will support activities to improve coordination of services such as:
 - Local agency "roundtables" to coordinate access to services;
 - "Single point of entry" (SPOE) mechanisms for easy access to all children's programs;
 - Special care center-sponsored multidisciplinary team meetings with community-based services and families;
 - Neonatal intensive care unit (NICU) discharge planning meetings with all agencies;
 - Universal parental consent form to improve referral to and sharing of information among agencies;
 - CCS public health nurse (PHN) positions (modeled after foster care PHNs to coordinate between CCS and schools);
 - Increased support component within CCS through CCS social workers and/or parent health liaison (PHL) services;
 - Models for a "system navigator" and/or ombudsperson to assist parents to access service across systems.

5. All families should have a hard copy and/or electronic health record for their children and tools to assist them in tracking their medical care, including child health notebooks that can be used across service systems. Several models of hard-copy child health notebooks already in use in the state among CYSHCN could be distributed to families; in addition, several models of family-friendly electronic medical records currently are being tested for wider use.
6. The state should ensure that California sets clear criteria for achievement of this core measure and that the state's performance and progress are measured periodically and reported publicly.

Kathy, who just turned 18, has developmental disabilities and special medical needs. Her parents were just provided with some basic information on conservatorship, special needs trusts, adult day programs, supported living, and other transitional programs. Her parents are frantic and feel pressed for time. They wish one of the professionals in their daughter's life had exposed them to these issues when she was 16 instead of now, when she is 18.

Youth with special health care needs (YSHCN) receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

1. An infrastructure to support the implementation of standardized transition plans and coordinate transition among the multiple systems serving YSHCN should be created. Creation of the infrastructure and implementation process could be taken on by the statewide interdepartmental body recommended above.
2. The state should commit to ensuring that YSHCN do not transition out of public or private insurance into the ranks of the uninsured. To that end, the state should consider strategies to assure that youth retain current coverage or achieve new comprehensive coverage through means such as increasing the number of conditions covered by the Genetically Handicapped Persons Program and/or extending CCS coverage beyond age 21 for specific conditions; modifying financial eligibility for Medi-Cal for YSHCN over age 21 to expand their access; and establishing a right to benefits for YSHCN under parental coverage to a specific age such as 24. (See also strategies to address private insurance issues discussed earlier.)
3. The state, in concert with pediatric experts and adult-oriented medical groups, should consider ways to support and strengthen the capacity of adult-oriented providers to serve youth and young adults with special health care needs, including adults with pediatric-oriented conditions that are more commonly being seen now among adults.
4. Provider rates and other incentives should be instituted to fortify the provider network for YSHCN, e.g., by applying the increased CCS specialty rate to Genetically Handicapped Persons Program (GHPP) specialists and to other non-physician CCS providers such as durable medical equipment (DME) vendors.
5. California must set clear criteria for achievement of this core measure and the state's performance and progress measured periodically and reported publicly.



As noted throughout this report, California's budget situation has resulted in major cuts to a number of programs that serve children and youth, including those with special health care needs. While the situation is fluid and not all details are known, certain budget impacts are clear for health and developmental programs that are fundamental to the care of CYSHCN.

Healthy Families Program

State budget cuts resulted in a \$195 million shortfall in this program. On August 13, 2009, the First 5 California Commission voted to commit \$81.4 million to support premiums and other costs for children from birth through age five enrolled in the program. At the same time, MRMIB agreed that, in addition to the enrollment freeze implemented in July, 2009, it would begin disenrolling children from Healthy Families in order to address the remaining budget shortfall, effective October 1, 2009. MRMIB agreed to some protections for particularly vulnerable children in the program, determining that those children who are enrolled in both Healthy Families and CCS and whose families have incomes over \$40,000 per year (i.e., those children who are deemed financially eligible for CCS because they are enrolled in Healthy Families) would not be disenrolled from the Healthy Families program. This decision is important for CYSHCN; without this exemption and if these children lose their Healthy Families coverage, they also lose their CCS coverage.

As noted earlier in this report, funding was restored for the current fiscal year through the combination of state First 5 funds, a temporary provider tax on Medi-Cal managed care plans (and the federal matching funds it will draw), and increased premiums and co-pays for families. However, this funding solution will sunset in 2010, leaving the program vulnerable once more to the state's budget deficits.

Regional Centers/Early Start Program

There have been three separate major cuts to services affecting children with developmental concerns, particularly children from birth to age three:

- A 3% reduction in overall regional center spending, followed by a \$100 million reduction, to be implemented through approaches developed via a statewide stakeholder process (finalized in budget agreement, February 20, 2009);

- A \$234 million reduction in DDS spending, including but not limited to regional centers; once again, a statewide stakeholder process including community forums and solicited comments was charged with recommending areas for program cuts to meet the funding reductions (finalized in budget agreement, July 24, 2009); and
- The Governor’s veto of an additional \$50 million, specific to the Early Start program for children from birth to age three with or at risk for developmental delays or disabilities (finalized in Governor’s veto message, July 28, 2009).

These cuts follow several years of budget reductions to regional center operations and to vendor rates and are expected to have a profound impact on access to care, particularly for young children at risk for or with developmental delay. Major budget-driven changes include:

- Early Start eligibility for toddlers age 24 months or older who were “at risk” of a developmental delay has been eliminated. Toddlers who are “developmentally delayed” and age 24 months or older will be eligible for entry to the Early Start program only if they have a 50% or greater delay in one domain or 33% or greater delay in two domains, a change from the current threshold of 33% in one domain regardless of age. These changes in eligibility will mean a loss of early intervention services for children who do not meet the new eligibility test.
- Elimination of eligibility for Early Start services for all “at-risk” infants and toddlers, including babies who were premature or with low birth weight, was proposed by Governor Schwarzenegger’s administration. In its place, a new prevention program has been authorized to provide specific services to these infants and toddlers as well as to several other categories of young children who also lost eligibility for Early Start. This new “prevention program,” which began October 1, 2009, includes “intake and assessment, case management, and referral to appropriate generic resources,” but other details are not yet available. This new program has a capped budget and so will not be an entitlement for infants and toddlers. The reduction in Early Start eligibility coupled with a new prevention program with limited funding may mean the loss of access to early intervention services for thousands of young children in the state.
- The Governor’s veto message included an additional reduction of \$50 million in funding for the Early Start program and urged that these funds be provided by the First 5 Commission. There is no indication yet whether and to what extent First 5 might replace this reduction and what specific steps will be taken to meet the additional reduction in the event that all or part of the reduction is enforced. This additional reduction in the Early Start budget could have profound impact on the program’s ability to serve even those children eligible under the new program criteria.

Medi-Cal Program

The budget agreement cuts overall state funding for Medi-Cal by \$1.3 billion in unspecified reductions. (The budget assumes receipt of an additional \$1 billion in federal funds; if received, this would reduce Medi-Cal cuts to \$323 million.) While still unknown, cuts could resurrect past proposals such as requiring quarterly Medi-Cal certification for children and adults and implementation of premiums and co-pays. The Administration is also seeking major administrative changes to Medi-Cal that include mandatory enrollment in Medi-Cal managed care plans of adults and children in Medi-Cal disability aid codes; a move that would affect approximately 50,000 children and youth with disabilities.

In-Home Supportive Services

The budget agreement included a major reduction of domestic services for IHSS enrollees based on their “functional level,” limiting services to only those recipients with very severe disabilities. The Governor further reduced funding for IHSS, resulting in even more restrictive eligibility criteria for domestic and related services. It is not yet known how many or which children and youth will be affected by these reductions.

California Children’s Services

The state and county CCS programs have absorbed major budget reductions over the past year. At the local level this has resulted in the loss of CCS case management staff, social workers, and parent health liaison contracts; increased time for eligibility determinations and service authorizations; and reduction of many family-centered care activities such as standardized transition planning. In addition, the Department of Health Care Services has launched a project to analyze and make recommendations for potentially major changes in the CCS program; a significant redesign of the program would be built into planning for a federal waiver due for submission in 2010.

In this climate of severe budget reductions, program rollbacks, and state proposals for major overhaul of long-standing programs, it is especially critical that there are clear standards for the treatment of children and youth with special health care needs, against which proposals for change can be measured. For this reason, the authors strongly recommend two steps:

1. The state must commit to achieving the federal MCHB Core Performance Measures, which lay out nationally accepted goals for the care of CYSHCN and the system that serves them. The state should set clear operational criteria for achievement of each measure, and state progress should be evaluated and reported publicly on a regular basis. In this way there are measurable criteria for state performance that can be compared over time as well as compared with progress other states have made toward achieving core performance measures. The authors believe that commitment to and achievement of these measures would result in design of a better organized

and more usable system for children and families and ultimately could reduce the contradictions, gaps, and overlaps that bedevil families and providers and often result in additional costs to the system as a whole.

2. The state must commit to basic principles of care for CYSHCN in any major change of the health care system that serves them. These principles, which have been accepted by several groups of providers and families in California, include the following:
 - Families and youth must have access to ongoing information, education, and support in order to be an informed and effective partner in the care of their children and themselves.
 - All health care delivery to children, particularly children and youth with special health care needs, should be based on and flow from their medical and related needs. The medical necessity definition and standards-of-care for all children, including CYSHCN, should reflect sound pediatric principles and address children’s health, developmental, social, and behavioral needs.
 - Children should have access to medically, developmentally, and behaviorally appropriate care regardless of their geographic region. County-based systems of care that limit access to pediatric and/or other appropriate providers are not acceptable for CYSHCN. Children should retain access to regionalized pediatric health care systems such as CCS-approved neonatal, pediatric intensive care, and other pediatric care.
 - CYSHCN should have clearly identified medical homes, including primary care providers, access to pediatric subspecialists, and care coordination. Families should be recognized and supported as central to the organization and coordination of their children’s care, and should have the ability to exercise choice in selecting providers that meet pediatric credentialing standards.
 - Provider networks should include all pediatric subspecialties, pediatric hospitals, child-appropriate durable medical equipment (DME) and other supply vendors, and other pediatric-appropriate services. Providers should meet clearly established standards for credentialing that reflect pediatric training and experience.
 - The benefits package for children should be broad and representative of children’s needs, including appropriate medical, dental, developmental, behavioral, and rehabilitative services; pharmaceuticals; DME and medical supplies; and ancillary services. Care coordination should be a recognized component of service delivery to CYSHCN. The federal EPSDT benefit and medical necessity definition should serve as the model for care of children and youth.
 - Financing of health care delivery to CYSHCN should recognize their special needs, and children’s access to health care should not be hindered by inadequate reimbursement to providers. Fee-for-service systems

should reimburse at rates that reflect actual costs of care, and reimbursement should include the capacity to cover pediatric services beyond typical medical care (e.g., office visits), such as care coordination. Capitated systems should have rates that are risk-adjusted to reflect actual costs of care, and include additional services such as care coordination. Capitated systems should not include risk to providers (thus removing financial disincentives to provision of necessary care) and should avoid full risk to plans through strategies such as reinsurance or risk-sharing with the state (such as the current CCS carve-out).

Drawing on these past experiences, the authors believe that proposals that further achievement of the MCHB Core Performance Measures and meet core principles for health care delivery to CYSHCN stand the best chance of building a true system of quality care for vulnerable children and youth. California is indeed at a crossroads, with difficult decisions ahead and perhaps a “perfect storm,” putting our most vulnerable population at risk. It is clear that to address what past reports have recommended and to address the strategies outlined in this report, we must also garner the political will to make this systemic change.

LIST OF ACRONYMS

AAP	American Academy of Pediatrics
AIM	Access for Infants and Mothers Program
ARRA	American Recovery and Reinvestment Act of 2009
CAFEC	California Association of Family Empowerment Centers
CalWORKS	California’s Temporary Aid to Needy Families (TANF) program
CAHMI	Child and Adolescent Health Measurement Initiative
CCS	California Children’s Services
CDE	California Department of Education
CHDP	Child Health and Disability Prevention Program
CHI	Children’s Health Insurance Program
CHIPRA	Children’s Health Insurance Program Reauthorization Act of 2009
CMS	Children’s Medical Services
COHS	County-Organized Health System
CPRC	Community Parent Resource Center
CRISS	Children’s Regional Integrated Service System
CSHCN	Children with Special Health Care Needs
CYSHCN	Children and Youth with Special Health Care Needs
DDS	Department of Developmental Services
DHCS	Department of Health Care Services
DHHS	Department of Health and Human Services
DMH	Department of Mental Health
DSS	Department of Social Services
EDS	Electronic Data Systems
EI	Early Intervention
EPSDT	Early Periodic Screening, Diagnosis, and Treatment
FEC	Family Empowerment Center
FFS	Fee-for-Service
FHOP	Family Health Outcomes Project
FMAP	Federal Medical Assistance Percentage
FPL	Federal Poverty Level
FQHC	Federally Qualified/Migrant and Rural Health Centers
FRC	Family Resource Center
FVCA	Family Voices of California
GHPP	Genetically Handicapped Persons Program
HCBS	Home and Community-Based Services

HHS	Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HMO	Health Maintenance Organization
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Plan
IFSP	Individualized Family Service Plan
IHS	Indian Health Service
IHSS	In-Home Supportive Services
IPP	Individualized Program Plan
LAPSNC	Los Angeles Partnership for Special Needs Children
MCHB	Maternal and Child Health Bureau
MMCD	Medi-Cal Managed Care Division
MRMIB	Managed Risk Medical Insurance Board
MRMIP	Major Risk Medical Insurance Program
NSCN	National Survey of Children's Health
NS-CSHCN	National Survey of Children with Special Health Care Needs
OSHPD	Office of Statewide Health Planning Department
PCP	Primary Care Provider
PHL	Parent Health Liaison
POS	Point-of-Service
PPO	Preferred Provider Organization
PRUCOL	Permanent Residence Under Color of Law
PTI	Parent Training and Information Center
RC	Regional Center
SAMHSA	Substance Abuse and Mental Health Services Administration
SFN	Statewide Family Networks
SOC	Share-of-Cost
SOR	Senate Office of Research
SSA	Social Security Administration
SSI	Supplemental Security Income
SSDI	Supplemental Security Disability Income
TANF	Temporary Aid to Needy Families
UACF	United Advocates for Children and Families
YSHCN	Youth with Special Health Care Needs

KEY STAKEHOLDERS¹

INDIVIDUALS

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Debra Lotstein, MD, MPH, David Geffen School of Medicine

ORGANIZATIONS

Association of Regional Center Agencies

ARCA) represents 21 regional centers in California that provide services to more than 200,000 Californians with developmental disabilities. Regional centers are nonprofit organizations that contract with the state Department of Developmental Services. This public-private nonprofit partnership results in the expenditure and monitoring of more than two billion state and federal dollars for people with developmental disabilities and their families.

Robert Baldo, Executive Director ■ <http://www.arcenet.org/>

American Academy of Pediatrics (AAP)

The AAP is a professional membership organization aimed at attaining optimal physical, mental, and social health and well being for all infants, children, adolescents, and young adults. In California, there are four AAP Chapters, comprising District 9. There are over 5000 board certified pediatrician members of all 4 California regional chapters. The organization focuses on advocacy on behalf of children and education of its members.

Kris Calvin, Executive Director ■ <http://www.aap-ca.org/>

California Budget Project

The California Budget Project engages in independent fiscal and policy analysis and public education with the goal of improving public policies affecting the economic and social well being of low- and middle-income Californians.

<http://www.cbp.org/>

¹ These are individuals and organizations that have been consistently involved in CYSHCN issues over several years.

California Children's Hospital Association

The Association works with state and national leaders in government and private industry to address issues impacting the hospitals' ability to provide the best care possible to the children of California, especially those with special and complex medical conditions. The eight private, not-for-profit regional children's hospitals are regular members of the association and the chief executive of each of these hospitals is a member of the association's board of directors. The five University of California children's hospitals and the Children's Center at Sutter Sacramento are associate members of the Association.

Diana S. Dooley, President & CEO ■ ddooley@ccha.org

California Premature Infant Health Coalition

The coalition exists to create a strong unified voice in California to help reduce the rate of premature births and improve outcomes for children born prematurely and their families. The coalition provides a sustainable setting to network, share best practices and other information, address policy, resource and systems change, and help keep decision-makers and the general public educated and knowledgeable about prematurity.

<http://capihc.blogspot.com/2009/03/organizational-structure.html>

Children's Regional Integrated Service System (CRISS) Project

Since 1996 CRISS has worked to create a regional seamless system of care for CCS children in Northern California. The current CRISS region encompasses 25 counties. CRISS membership includes the region's county CCS programs, major pediatric provider organizations and pediatric institutions, California's statewide family support organization, and the local family support organizations in the region.

CRISS activities focus on:

- Promoting seamless access to care for children in the region through regional planning and collaboration;
- Building a stronger, more consistent regionwide program by reducing intercounty variation in medical decision-making and other arenas;
- Promoting family-centered care through conferences and workshops and support for medical homes, parent health liaisons, transition planning, and other strategies;
- Supporting the provider network through reducing barriers to authorizations and timely payment; and
- Identifying and addressing critical policy areas for the CCS program and the children and families it serves.

Laurie Soman, Project Director ■ Lsoman6708@aol.com ■ <http://criss-ca.org/>

Children's Hospice and Palliative Care Coalition

The Children's Hospice and Palliative Care Coalition is a social movement led by children's hospitals, hospices, home health and grassroots agencies, and individuals to improve care for children with life-threatening conditions and their families.

Lori Butterworth, Executive Director ■ <http://www.childrenshospice.org/>

Children's Specialty Care Coalition (CSCC)

CSCC is a nonprofit organization representing more than 1,000 pediatric specialists in California, dedicated to educating and advocating for access to quality health care for California's children with special health care needs. The organization's objectives include educating the public and decision-makers about the importance of ensuring appropriate, high quality health care for children with special health care needs, providing and exchanging information on new developments and pending legislation in the area of financing and the provision of pediatric care programs for children with special health care needs, and increasing awareness.

Erin Aaberg Givens, Executive Director ■ <http://www.childrens-coalition.org>

Disability Rights California

Formerly Protection and Advocacy, Inc., Disability Rights California exists to advance the rights of Californians with disabilities.

Catherine Blakemore, Executive Director ■ <http://www.disabilityrightsca.org/>

Family Voices of California

Family Voices of California (FVCA) is a statewide grassroots clearinghouse for information and education about ways to assure and improve health care for children with disabilities and chronic conditions. FVCA was established through the linkage of Family Voices National and the Family Resource Centers Network of California.

<http://www.familyvoicesofca.org/>

Family Resource Centers Network of California

In California, Early Start Family Resource Centers are part of the Early Start Program. Staffed by families of children with special needs, family resource centers offer parent-to-parent support and help parents, families, and children locate and use needed services. They offer support services and resources in many languages, which may include newsletters, resource libraries, Websites, parent-to-parent groups, sibling support groups, warmlines, and information and referral for parents and professionals.

Linda Joy Landry, Chair ■ LindaJoyLA@aol.com ■ <http://www.frcnca.org/>

Los Angeles Partnership for Special Needs Children/CCS Workgroup

The mission of LAPSNC is to improve the health and well being of children with special needs in Los Angeles County by improving the systems of care for these children, advocating for clients served by LA County CCS, assisting with the provision of high quality services, advocating for improved systems of care at the county, state and federal levels, serving as a resource for other public and private entities serving CYSHCN, and assisting in educating providers and consumers regarding systems of care. Members of LAPSNC include major pediatric hospitals, health plans, LA County Department of Health Services, the local chapter of the American Academy of Pediatrics (AAP), and advocates. LAPSNC provides oversight and funding for the CCS Workgroup, and LAPSNC activities are carried out by Workgroup members.

Kathryn Smith, Chair ■ Kasmith@chla.usc.edu

March of Dimes

The March of Dimes is an organization dedicated to improving the health of mothers and babies by preventing birth defects, premature birth and infant mortality through advocacy, research, community services, and education.

California: (415) 788-2202 ■ <http://www.marchofdimes.com/home.asp>

National Health Law Program (NHeLP)

The National Health Law Program is a national public interest law firm that seeks to improve health care for America's working and unemployed poor, minorities, the elderly and people with disabilities. NHeLP serves legal services programs, community-based organizations, the private bar, providers, and individuals who work to preserve a health care safety net for the millions of uninsured or underinsured low-income people.

<http://www.healthlaw.org/>

State Council on Developmental Disabilities (SCDD) and Area Boards

The SCDD is an independent state agency to ensure that people with developmental disabilities and their families receive the services and supports they need. SCDD is composed of individuals with disabilities and their family members, and representatives of state agencies that provide services to individuals with developmental disabilities. SCDD includes 13 area boards that serve the consumer population of California. The mission of the area boards is to protect and advocate for the civil, legal and service rights of persons with developmental disabilities and to ensure that the services and supports they use are of the highest quality.

<http://www.scdd.ca.gov/>

State Interagency Coordinating Council (ICC) on Early Intervention

The ICC, appointed by the Governor, is comprised of parents of children with disabilities, early intervention service providers, health care professionals, state agency representatives, and others interested in early intervention. The ICC provides advice and assistance to the Department of Developmental Services regarding the statewide system of early intervention to achieve the full participation, cooperation, and coordination of appropriate public agencies in the state. It also offers a forum for public input.

<http://www.dds.ca.gov/EarlyStart/ICCOverview.cfm>

Western Center on Law and Poverty

Western Center advances and enforces the rights of low-income Californians to the basic necessities of life by working statewide for systemic change. Through legislative and administrative advocacy and impact litigation, we improve the lives of our clients. And by working closely with and supporting legal and social services organizations, we ensure that our work is responsive to the most critical human needs, while enhancing the capacity of community-based organizations to work in their neighborhoods.

<http://www.wclp.org/>

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APPENDIX 1: FEDERAL WAIVER OPTIONS

Federal Waiver Options

Waivers	1915 (b) Freedom of Choice Waivers	1915(c) Home and Community Based Services Waivers	115 Research and Demonstration Waivers
Federal Requirements Waived	Statewide. Compatibility of services. Choice of providers.	Statewide. Compatibility of services. Income and resource standards.	Broad scope of Medicaid rules.
Approval Process	From federal Centers for Medicare and Medicaid Services (CMS) with strict review timeline.	From federal Centers for Medicare and Medicaid Services (CMS) with strict review timeline.	From US DHHS with no specific review timeline.
Time Period	Two years for initial waiver. Two-year extensions.	Three years for initial waiver. Five-year extensions.	Five years for initial waiver. Three-year extensions for statewide programs. One-year extensions for other programs.
Examples of Use	Managed care.	Alternatives to institutional care for elderly and disabled.	Expansion of eligibility cap. Managed care.

Current California 1115 Demonstration Project Waivers

Title	Description	Waiver Capacity by Waiver Year	Waiver Term	Expiration Date	Waiver Currently Operating Under an Extension?
Family Planning, Access, Care, and Treatment Program (Family PACT)	Allows federal reimbursement for reproductive health services for medically indigent females and males.	No cap	12/1/99-11/30/04	Currently on month-to-month approved CMS extension	Yes
In-Home Supportive Services Plus (IHSS Plus)	Provides aged, blind, and disabled individuals an array of self-directed personal care assistance and delivery options that are not available under the Personal Care Services Programs. This Independence Plus waiver enables recipients to remain in their own home or family home.	No cap	8/1/04-7/31/09	7/31/09	No

Current California 1915(b) Freedom of Choice Waivers

Title	Description	Waiver Capacity by Waiver Year	Waiver Term	Expiration Date	Waiver Currently Operating Under an Extension?
California Children Services/ Dental Managed Care (CCS/Dental)	Combines the prior Two Plan Model and Geographic Managed Care waivers to provide medical managed care services to children who meet the eligibility requirements of the CCS program or, for all adults and children that are eligible for enrollment in a Dental Managed Care plan. Enrollment is mandatory for TANF linked Medi-Cal beneficiaries, unless medically exempt.	No cap	10/1/07-9/30/09	9/30/09	No
County Organized Health Systems Health Insuring Organizations of California	Authorizes county operated managed health care programs in Orange, Santa Cruz, Monterey, Solano, Napa, and Yolo Counties. This waiver includes CalOPTIMA, CCAH, and Partnership Health Plan of California Enrollment is mandatory for all covered aid codes.	No cap	7/1/07-6/30/09	7/31/09	No

Current California 1915(c) Home and Community Based Services Waivers (HCBS)

Title	Description	Waiver Capacity by Waiver Year	Waiver Term	Expiration Date	Waiver Currently Operating Under an Extension?
Home and Community-Based Services Waiver for the Developmentally Disabled	Provides home and community-based services to Regional Center consumers with disabilities, enabling them to live in the community rather than in an intermediate care facility.	85,000-WY 08/09 90,000-WY 09/10 95,000-WY 10/11	10/1/06-9/30/11	9/30/11	No

Source: <http://www.dhcs.ca.gov/services/medi-cal/Documents/MediCalWaivers.pdf>

APPENDIX 2: FEDERAL HEALTH CARE PROGRAMS

Medicaid

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>Medicaid (Title XIX) was created in 1965 as the federal program to provide health care coverage for low-income individuals. Medicaid is a state administered program. Each state sets its own guidelines regarding eligibility and services.</p>	<p>Funded with federal and state funds. States have different federal matching rates to fund the services provided under their Medicaid programs.</p> <p>The American Recovery and Reinvestment Act provides \$87 billion for a temporary increase in the federal share of Medicaid costs through 2010. To be eligible for the enhanced federal financing, states must not make changes to restrict eligibility levels or make it more difficult for people to apply for or renew coverage.</p>	<p>Under EPSDT benefit, children in Medicaid are entitled to a comprehensive range of service and supports</p> <p>See Federal Medicaid Eligibility Criteria and Benefits chart below.</p>	<p>See Federal Medicaid Eligibility Criteria and Benefits chart below.</p>	<p>Does not provide health care services for all poor persons, unless they are in one of the designated eligibility groups.</p> <p>Nearly 9 million children remain uninsured; most of these children are eligible for Medicaid.</p> <p>Systemwide shortages of pediatric specialists and dentists result in limited access to these services. Low provider participation and payment rates compound these problems.</p>	<p>Covers almost 60 million Americans.</p> <p>Finances 16% of national health spending.</p> <p>Medicaid covers over a quarter of all children in the U.S. including nearly 1 of every 5 white children and roughly 2 of every 5 African American and Hispanic children.</p> <p>Nearly 4 in 10 children with special needs are covered by Medicaid.</p>	<p>Federal/state program.</p> <p>Federal government establishes general guidelines and Medicaid program requirements established by each state.</p> <p>Administered by the Centers for Medicare and Medicaid Services, US DHHS.</p>

Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>EPSDT is the child health component of Medicaid. It is required in every state for all categorically needy individuals under age 21 enrolled in Medicaid.</p>	<p>Funded with federal and state funds.</p>	<p>EPSDT is a required benefit for all “categorically needy” children under 21 who have poverty-level income, receive Supplemental Security Income, or receive federal foster care or adoption assistance.</p>	<p>Federal law defines EPSDT to cover certain screening, diagnostic, and treatment services at periodic intervals and as needed.</p> <p>Services include:</p> <ul style="list-style-type: none"> • Screening; • Vision services; • Preventive and emergency dental; • Hearing; and • Any other health care diagnostic services and treatment. 	<p>Under the Deficit Reduction Act of 2005 states have the option to modify the approach to delivery of services to children enrolled in Medicaid. States can also restructure their benefits under Medicaid without a federal waiver and may enroll certain groups in benchmark or benchmark equivalent benefit packages and wrap-around benefits consisting of EPSDT benefits for any child under age 19 covered under a state plan.</p> <p>The DRA includes a more specific definition of case management and places limits on use of targeted case management and administrative case management.</p> <p>Restricted level of services when transitioning into adult Medicaid.</p>	<p>One in three U.S. children under age 6 is eligible for EPSDT.</p>	<p>US DHHS.</p>

Children’s Health Insurance Program (CHIP)

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>State CHIP is administered by US DHHS to provide matching funds to states for health insurance to families with children. The program was designed with the intent to cover uninsured children in families with incomes that are modest but too high to qualify for Medicaid.</p>	<p>Financed with federal and state funds. CHIP provides a capped amount of funds to states on a matching basis. Each state determines the design of its program, eligibility, benefits, payment levels for coverage, and administrative and operating procedures.</p> <p>CHIPRA provides \$33 billion in additional federal funds to extend and expand CHIP for 4.5 years.</p> <p>A cigarette and tobacco tax increase will fund the program’s expansion.</p>	<p>CHIP statute defines low-income children as those at or below 200% of poverty. Under CHIPRA, states will no longer receive full CHIP matching rates for covering children in families with incomes greater than 300% FPL. They can cover these children with federal approval but will receive a lower Medicaid matching rate.</p> <p>Starting January 1, 2010, states must apply the Medicaid citizenship documentation requirement to children who apply for CHIP coverage. States now have the option to use CHIP funding to subsidize qualified job-based coverage for children who are eligible for CHIP.</p> <p>CHIPRA allows states to cover pregnant women through state plan amendments. It eliminates the five year waiting period for legal immigrant children and pregnant women who are eligible for Medicaid or CHIP.</p>	<p>Title XXI allows states to expand coverage for children primarily through one of three ways:</p> <ul style="list-style-type: none"> • Separate child health insurance program; • Medicaid program; and • Through a combination of these programs. <p>States choosing to expand their Medicaid program must follow Medicaid requirements regarding benefit structure. Section 1115 waivers will allow States to modify the Medicaid requirements within expansion programs. Under CHIPRA, states are required to include dental coverage in their CHIP benefit packages as well as guarantees mental health parity.</p>	<p>CHIP enrollment is a complicated process which is separate from other social services.</p> <p>To address the issue of knowledge gaps and access, CHIPRA includes \$100 million in funding that will be used to promote CHIP and Medicaid outreach and enrollment for eligible children in areas with high percentages of uninsured children.</p>	<p>7.4 million children were enrolled in CHIP at some point during 2008.</p> <p>During 2008, there were 334,616 adults covered with CHIP funds.</p> <p>CHIPRA provides \$33 billion in additional federal funds to extend and expand CHIP for 4.5 years to enable states to reach an additional 4.1 million children who would otherwise be uninsured, with no waiting period for the first time.</p>	<p>The statutory authority for CHIP is under title XXI of the Social Security Act. States are given flexibility in designing their CHIP eligibility requirements and policies within broad federal guidelines.</p> <p>Administered by the Centers for Medicare and Medicaid Services, US DHHS.</p>

Medicare

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>Medicare was established in 1965 as the health insurance program for people aged 65 or older, some people with disabilities under age 65, and people of all ages with end-stage renal disease.</p>	<p>Funding comes partially from payroll taxes, known as FICA taxes. FICA comprises Social Security tax and Medicare tax. High-income Social Security beneficiaries also pay income tax on their Social Security income, some of which goes toward Medicare. This money goes into a trust fund used to pay doctors, hospitals, and private insurance companies when Medicare patients use these services.</p>	<p>Individuals are eligible for Medicare if they are:</p> <ul style="list-style-type: none"> • U.S. citizens or have been a permanent legal residents for five continuous years; • 65 years or older • Under 65, disabled and have been receiving either Social Security benefits or the Railroad; and • Retirement Board disability benefits for at least 24 months from date of entitlement (first disability payment), or they get continuing dialysis for end stage renal disease or need a kidney transplant, or they are eligible for Social Security Disability Insurance and ALS-Lou Gehrig's disease. <p>Many beneficiaries are dual-eligible and qualify for both Medicare and Medicaid. In some states for those making below a certain income, Medicaid will pay the beneficiaries' Part B premium and drugs not covered by Part D.</p>	<p>The different parts of Medicare help cover specific services if certain conditions are met.</p> <p>Part A helps cover inpatient care in hospitals, skilled nursing facilities, hospice, and home health care.</p> <p>Part B helps cover doctors' services and outpatient care and some preventive services to maintain good health and keep certain illness from getting worse.</p> <p>Part C is a health coverage choice run by private companies approved by Medicare. It includes Part A, Part B, and usually other coverage, including prescription drugs</p> <p>Part D helps cover the cost of prescription drugs and may lower prescription drug costs and protect against higher costs in the future.</p>	<p>Medicare is not available to all people with severe disabilities. Benefits package is inadequate for most people with disabilities.</p> <p>The program provides coverage for primary care and hospital services, but Medicare benefits package is notably lacking coverage for prescription drugs and long term care services and supports.</p> <p>The program also has limited coverage for medical equipment that limits access to home health services for persons who are homebound.</p> <p>Many individuals with disabilities need Medicaid as a wraparound for the additional benefits.</p>	<p>Total 2008 Medicare beneficiaries:</p> <ul style="list-style-type: none"> • 44,831,390 (15% of U.S. total population) <p>Distribution of 2006 beneficiaries by eligibility:</p> <ul style="list-style-type: none"> • Aged: 83.7% • Disabled: 16% <p>Distribution of 2005 dual eligible enrollment:</p> <ul style="list-style-type: none"> • Partial: 1,708,992 • Full: 7,098,168 • Total: 8,807,160 	<p>Centers for Medicare and Medicaid Services, US DHHS.</p>

TRICARE

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>TRICARE is the health care program serving active duty service members, National Guard and Reserve members, retirees, their families, survivors, and certain former spouses worldwide. As a major component of the Military Health System, TRICARE brings together the health care resources of the uniformed services and supplements them with networks of civilian health care professionals, institutions, pharmacies, and suppliers to provide access to high-quality health care services while maintaining the capability to support military operations.</p>	<p>The ultimate responsible organization for administration of TRICARE is the U.S. Department of Defense Military Health System, which organized the TRICARE Management Activity (TMA). TMA contracts with several large health insurance corporations to provide claims processing, customer service, and other administrative functions to the TRICARE program.</p>	<p>Active duty service members and retirees of the seven uniformed services, members of the National Guard, their family members, and survivors.</p> <p>Unmarried biological and adopted children up to age 21, up to age 23 if enrolled in college full-time.</p> <p>A child may be covered beyond the normal limits if he or she is severely disabled and the condition existed prior to the child's 21st birthday.</p> <p>When an active duty service member dies while serving more than 30 days, his or her biological and adopted children will remain eligible for TRICARE as "transitional survivors" until they reach the eligibility age limit.</p>	<p>Beneficiaries can use any civilian health care provider that is payable under TRICARE regulations. The beneficiary is responsible for payment of an annual deductible and coinsurance, and may be responsible for certain other out-of-pocket expenses.</p> <p>US Family Health Plan is a TRICARE prime option that offers benefits to active duty family members and all military retirees and their eligible family members, including those 65 years of age and over, regardless of whether or not they participate in Medicare Part B.</p>		<p>Eligible beneficiaries: 9.4 million</p> <p>Military facilities worldwide:</p> <ul style="list-style-type: none"> • 63 military hospitals • 413 medical clinics • 413 dental clinics 	<p>The ultimate responsible organization for administration of TRICARE is the U.S. Department of Defense Military Health System, which organized the TRICARE Management Activity.</p>

Indian Health Service (IHS)

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>Indian Health Service (IHS), an agency within US DHHS, is responsible for providing federal health services to American Indians and Alaska Natives. This relationship, established in 1787, is based on Article I, Section 8 of the Constitution, and has been given form and substance by numerous treaties, laws, Supreme Court decisions, and Executive Orders.</p>	<p>With the passage of the Indian Health Care Improvement Act in 1976, IHS was authorized to bill for services provided to American Indians and Alaska Natives who are beneficiaries of CMS programs. IHS receives in excess of \$650 million annually in revenue from CMS for services provided to Medicaid, Medicare, and CHIP eligible patients. Enrollment in these programs also provides payments for referral services previously paid for by IHS Contract Health Services.</p> <p>The Medicaid program acts as:</p> <ul style="list-style-type: none"> • An insurance program covering physician, hospital, and other basic health care services for eligible Native Americans, especially families with children; • A source of revenue for IHS and tribal-operated clinics and hospitals; • A purchaser of managed care products; • A source of financial assistance for low-income elderly and disabled Native Americans to meet Medicare premium and cost-sharing obligations; and • A source of coverage for nursing home care and other long-term care services for frail elderly and disabled Native Americans. The structure of the Medicaid program provides financial incentives for states to encourage beneficiaries to use tribal health facilities. The federal government's share of these costs ranges from 50% in wealthier states to nearly 80% in the poorest states. On average, the federal government pays 57% of a state's Medicaid costs. 	<p>Eligible if not otherwise excluded by provision of law, and is:</p> <ul style="list-style-type: none"> • Of Indian and/or Alaska Native descent; • An Indian of Canadian or Mexican origin recognized by any Indian tribe or group as a member of an Indian community served by the Indian health program; • A non-Indian woman pregnant with an eligible Indian's child for the duration of her pregnancy through postpartum; or • A non-Indian member of an eligible Indian's household and the medical officer in charge determines that services are necessary to control a public health hazard. <p>Although Medicaid is administered and financed in part by the states, Native Americans who meet the Medicaid eligibility requirements of the state in which they reside are, as a matter of law, entitled to Medicaid coverage. This is true whether a Native American lives on or near a reservation or in an urban area, and whether or not a Native American is eligible for IHS services</p>	<p>Health services are provided directly by IHS, through tribally contracted and operated health programs, and through services purchased from private providers. Because of high rates of poverty among Native Americans, Medicaid is an important publicly funded health program for Native Americans. Medicaid also assists low-income elderly and disabled Indians who are eligible for Medicare in meeting their premium and cost-sharing obligations.</p>	<p>Most urban Indians who are members of federally recognized tribes do not have access to services through IHS facilities because the hospitals and clinics run by IHS or tribes under contract with IHS are located primarily on reservations in rural areas.</p> <p>Many urban Indians are not enrolled members of federally recognized tribes and IHS generally does not consider these individuals as eligible for services provided by its hospitals and clinics.</p> <p>The American Indian and Alaska Native population is increasing at a greater pace than the capacity of the Indian health system to provide services. IHS is a discretionary service subject to annual appropriation amounts. The combination of an increasing population and extended life expectancy, changes in community disease patterns from acute to chronic diseases, limited resources for purchasing medical services at the local level, increasing costs, and limited resources result in denial of health services.</p>	<p>Currently provides health services to approximately 1.5 million American Indians and Alaska Natives who belong to more than 557 federally recognized tribes in 35 states.</p> <p>Federal system consists of 31 hospitals, 63 health centers, and 30 health stations. In addition, 34 urban Indian health projects provide a variety of health and referral services.</p> <p>There are an estimated 2.3 million Native Americans (American Indians and Alaska Natives) in the U.S. About half of the Native American population lives on or near reservations; the other half resides in other rural areas and in urban areas.</p> <p>The Native American population includes 554 tribes recognized by the federal government as well as other tribes, largely in California, that do not have federal recognition.</p>	<p>The IHS is the principal federal health care provider.</p>

Federally Qualified Health Centers (FQHC)

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>The FQHC benefit under Medicare was added in 1991 and includes safety net providers such as community health centers, public housing centers, outpatient's health programs funded by Indian Health Service, and programs serving migrants and the homeless. The main purpose of the program is to enhance the provision of primary care services in underserved urban and rural communities.</p>	<p>FQHCs must use a sliding fee scale with discounts based on patient family size and income in accordance with federal poverty guidelines. The beneficiary is responsible for paying the coinsurance, which is 20%, except for mental health treatment services, which are subject to the 62.5% outpatient mental health treatment limitation.</p> <p>FQHCs must be open to all, regardless of ability to pay.</p> <p>FQHCs also receive Enhanced Medicare and Medicaid reimbursement, Medical malpractice coverage.</p> <p>Eligible for various other federal grants and programs. Medicare pays FQHCs an all-inclusive per visit payment amount based on reasonable costs.</p>	<p>FQHCs must provide primary care services for all age groups. FQHCs must provide preventive health services on site or by arrangement with another provider.</p>	<p>Services include:</p> <ul style="list-style-type: none"> • Dental; • Mental health and substance abuse; • Transportation services necessary for adequate patient care; • Hospital and specialty care. • Physician services and supplies, physician assistant, certified midwife, clinical psychologist, clinical social worker, and visiting nurse services to the homebound; • Drugs furnished by and incident to services of a provider; • Outpatient diabetes self management training; • Nutrition therapy; • Health education; • Eye and ear examinations; • Well child care and periodic screenings; • Immunizations; • Family planning; • Blood pressure, hearing, cholesterol, and TB testing; • Prenatal and post-partum care; and • Breast exams. 	<p>Services not covered include eyeglasses, hearing aids, dental services, certain lab services, durable medical equipment, ambulance services, x-rays and other diagnostic tests, technical components of preventative services, prosthetic devices, and artificial limbs/braces.</p>	<p>In 2007:</p> <ul style="list-style-type: none"> • Total FQHCs: 1,067 • Total patients served: 16,050,835 • Total encounters or visits: 63,036,475 	

Supplemental Security Income (SSI)

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>Supplemental Security Income (SSI) is a federal income supplement program. It is designed to help aged, blind, and disabled people who have little or no income and provides cash to meet basic needs for food, clothing, and shelter. SSI makes monthly payments to people with low income and limited resources who are age 65 or older or who are blind or disabled. Children under age 18 can qualify if they meet Social Security's definition of disability for children.</p>	<p>Federal income supplement program funded by general tax revenues (not Social Security taxes).</p>	<p>Social Security provides benefits to children with disabilities. A child who is eligible for federal SSI cash benefits is also eligible, depending on the state, for state supplemental payments, Medicaid, food stamps, and other social services. Child must meet two sets of eligibility criteria: financial criteria and medical criteria.</p> <p>To meet SSI definition of disability, a child's impairment must result from anatomical, physiological, or psychological abnormalities that are demonstrable by medically acceptable clinical and laboratory diagnostic techniques.</p>	<p>A child who is eligible for federal SSI cash benefits is also eligible, depending on the state, for state supplemental payments, Medicaid, food stamps, and other social services. However, not all SSI beneficiaries automatically qualify for Medicaid.</p>	<p>Not all physical and mental impairments meet the standard of disability. People with several disability conditions only meet the criteria once the condition is in an advanced stage, which is problematic since treatment is often more effective if it is received early in the course of disease or condition.</p>	<p>All beneficiaries receiving SSI in 2009: 4,953,000.</p> <p>Number of disabled under age 65 receiving SSI in 2009: 4,070,000.</p> <p>Number of children under 18 receiving SSI in 2009: 1,174,000.</p>	<p>Administered by the U.S. Social Security Administration.</p>

Federal Medicaid Eligibility Criteria and Benefits

Eligibility Groups	Eligibility Criteria	Benefits
Categorically Needy	<ul style="list-style-type: none"> • Families who meet states' Aid to Families with Dependent Children eligibility requirements; • Pregnant women and children under age 6 whose family income is at or below 133% of federal poverty level. • Children ages 6 to 19 with family income up to 100% of FPL. • Caretakers. • SSI recipients or in certain states, aged, blind, and disabled people who meet requirements that are more restrictive than those of the SSI program. • Individuals and couples who are living in medical institutions and who have monthly income up to 300% of the SSI income standard. 	<p>Entitled to following services unless waived under section 1115 of Medicaid law:</p> <ul style="list-style-type: none"> • Inpatient hospital (excluding institutions for mental disease); • Outpatient hospital including FQHCs, rural health clinic, and other ambulatory services; • Other laboratory and x-ray; • Certified pediatric and family nurse practitioners; • Nursing facility services for age 21 and older; • Early and periodic screening diagnosis and treatment for children under age 21; • Family planning services and supplies; • Physicians' services; • Medical and surgical services of a dentist; • Home health services for beneficiaries who are entitled to nursing facility services under the states' Medicaid plan; • Nurse mid-wife services; • Pregnancy related services and service for other conditions that might complicate pregnancy; and • 60 days postpartum pregnancy related services.
Medically Needy	<p>The family's income is too high to be eligible as categorically needy. If a state has a medically needy program, it must include pregnant women through a 60 day postpartum period, children under age 18, certain newborns for one year, and certain protected blind persons.</p>	<p>States must provide at least the following services when the medically needy are included under the Medicaid plans:</p> <ul style="list-style-type: none"> • Prenatal and delivery services; • Postpartum pregnancy related services for beneficiaries under age 18 and who are entitled to institutional and ambulatory services defined in a state's plan; and • Home health services. <p>States may include any other service described under Medicaid law subject to any limits based on comparability of services. States may provide different services to different groups of medically needy.</p>
Special Groups	<ul style="list-style-type: none"> • Medicare beneficiaries. • Qualified working disabled individuals. • States may also improve access to employment, training, and placement of people with disabilities who want to work through expanded Medicaid eligibility. • Time limited eligibility group for women who have breast or cervical cancer and people with TB who are uninsured. • Long term care. 	<p>There are two eligibility groups related to specific medical conditions that states may include under their Medicaid plans. One is a time limited eligibility group for women who have breast or cervical cancer, the other is for people with TB who are uninsured. Women with breast or cervical cancer receive all plan services; TB patients receive only services related to the treatment of TB.</p> <p>All states provide community long term care services for individuals who are Medicaid eligible and qualify for institutional care. Most states use eligibility requirements for such individuals that are more liberal than those normally used in the community.</p>
Other	<p>States may also, under state's option, provide Medicaid to:</p> <ul style="list-style-type: none"> • Children under ages 21, 20, 19 or under age 9 who are full time students; • Caretaker relatives or legal guardians who live with and take care of children; • Aged persons age 65 and older; • Blind persons; • Disabled persons; and • Person who would be eligible if not enrolled in a HMO. 	

APPENDIX 3: PUBLICLY FUNDED HEALTH CARE SERVICES – STATE LEVEL

Medi-Cal

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>Medi-Cal was established in 1965 as the state version of Medicaid, originally for people on welfare. Additional aid categories were added over time.</p> <p>EPSDT (Early Periodic Screening, Diagnosis, and Treatment) created in 1965 and expanded by Congress in 1989 under OBRA '89 as Medicaid's comprehensive benefit for children.</p> <p>Gateway created in 2003 as automated application initiated by CHDP provider that provides up to two months of immediate Medi-Cal eligibility while family completes full application for continued coverage.</p> <p>Emergency Medi-Cal available to undocumented and recent immigrants who are not otherwise eligible for Medi-Cal.</p>	<p>Federal Title XIX funds. State fund match.</p> <p>See Medi-Cal and Healthy Families Funding Sources chart below.</p>	<p>Infants to age 1 with income up to 200% of FPL.</p> <p>Children ages 1 to 6 with income up to 133% of FPL.</p> <p>Children ages 6 to 19 with income up to 100% of FPL.</p> <p>See Medicaid and Medi-Cal Eligibility chart below.</p>	<p>Comprehensive health and mental health services for children through EPSDT benefit.</p> <p>Children with full-scope Medi-Cal are legally entitled to any Medicaid-coverable service that is considered medically necessary.</p>	<p>California's Federal Medical Assistance Percentage, or FMAP, the rate at which the federal government matches state investment in Medicaid, is 50:50, the lowest match rate in the nation (without temporary increase under ARRA).</p> <p>Children and families report difficulties in finding appropriate providers within managed care plans' limited networks and obstacles to getting to providers outside the plan networks.</p> <p>Low reimbursement rates and barriers posed by complicated Medi-Cal billing and other requirements have steadily shrunk the Medi-Cal fee-for-service provider network available to children with special health care needs.</p>	<p>Total 2007 California population: 37,771,431.</p> <p>Average 2007 Medi-Cal population: 6,510,009.</p> <p>% in Medi-Cal, 2007: 17.24%.</p> <p>Total number of children in Medi-Cal: 3,607,189; approx 33% of all California children.</p>	<p>Federal/state program.</p> <p>State sets policy in accordance with federal standards.</p> <p>Counties responsible for (re)determination of eligibility.</p> <p>Administered by state Department of Health Care Services.</p>

Healthy Families Program

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>Established in 1998 as the state version of CHIP.</p> <p>Provides subsidized health coverage to children from birth to age 19 in low-income families not eligible for Medi-Cal.</p>	<p>Federal Title XIX funds.</p> <p>State fund match.</p> <p>See Medi-Cal and Healthy Families Funding Sources chart below.</p>	<p>Children from birth to age 19.</p> <p>Family incomes up to 250% of FPL .</p> <p>Children who do not qualify for full-scope Medi-Cal.</p> <p>Children who do not have private insurance.</p> <p>See Healthy Families Program Eligibility chart below.</p>	<p>Subsidized health coverage, including health, dental, vision and basic mental health services.</p>	<p>The current state budget crisis has resulted in major changes to the Healthy Families program. As of August 1, 2009, it is estimated that 585,000 current enrollees could lose their coverage and another 335,000 eligible children will be wait-listed over the course of the current fiscal year.</p> <p>Offers good primary care/ preventive services for children but its benefit package is not comprehensive enough for CSHCN; these children depend on the CCS carve-out for access to comprehensive subspecialty care.</p>	<p>940,000 children in California are enrolled in Healthy Families.</p> <p>Enrollment FY 07-08 (average monthly) 851,000 children.</p> <p>Total spending FY 07-08: \$1,077 million.</p> <p>State spending FY 07-08: \$398 million.</p>	<p>Administered at state level by MRMIB (Managed Risk Medical Insurance Board).</p> <p>Services delivered through managed care plans.</p>

Access for Infants and Mothers (AIM)

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>Established in 1992 to provide health coverage to pregnant women and their newborns/ infants.</p>	<p>Not an entitlement; level of state funding determines number of enrollees.</p> <p>Enrollees are charged 1.5% of annual adjusted family income.</p> <p>Funding sources include tobacco tax (Proposition 99), enrollee fees, federal CHIP funds (Title XXI), and state match.</p>	<p>Pregnant women and infants with family incomes between 200% and 300% of FPL.</p> <p>Women with no maternity insurance or maternity-only coverage with high deductible/co-payment (i.e., <\$500).</p> <p>Not eligible for full-scope Medi-Cal.</p> <p>California resident (intends to stay).</p>	<p>Prenatal visits, hospital delivery, and 60-day post-partum care for women.</p> <p>Full health services for children provided through Healthy Families from child's birth to 2nd birthday.</p>	<p>Very short-term care for pregnant and postpartum women.</p> <p>Infant/toddler care depends on access to Healthy Families (although infants are eligible for Healthy Families up to age 2 with incomes up to 300% of FPL).</p>	<p>As of June 2009, 7,025 women were enrolled in AIM.</p>	<p>Administered at state level by MRMIB (Managed Risk Medical Insurance Board).</p> <p>Services delivered through managed care plans.</p>

Child Health and Disability Prevention Program (CHDP)

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>CHDP is a preventive health program that delivers periodic health assessments and services to low income children and youth up to age 19.</p> <p>The CHDP program also oversees the screening and follow-up components of the federally mandated Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program for Medi-Cal eligible children and youth.</p>	<p>State funding through tobacco tax funds.</p>	<p>Families with annual incomes up to 200% of FPL.</p> <p>Covers children and youth from birth to age 19.</p>	<p>CHDP provides care coordination to assist families with medical appointment scheduling, transportation, and access to diagnostic and treatment services. Health assessments are provided by enrolled private physicians, local health departments, community clinics, managed care plans, and some local school districts.</p>	<p>Treatment services may be very limited at local level.</p>	<p>In 2007, 2,016,558 children received screening and health assessments through the CHDP program.</p>	<p>Administered by state CCS office in Children's Medical Services Branch, Department of Health Care Services.</p> <p>Counties responsible for delivery of services.</p>

California Children's Services (CCS)

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>California Children's Services was established in 1927 to cover medical care for low-income children with serious medical conditions.</p>	<p>Federal funding via Title V/MCH Block Grant and in federal match for CCS enrollees on Medi-Cal or Healthy Families.</p> <p>State funding for diagnosis and treatment costs and for county administration of program.</p> <p>County funding for local share of staffing costs, treatment costs for Medi-Cal and Healthy Families enrollees, and "straight CCS" (i.e., children not eligible for Medi-Cal or Healthy Families).</p> <p>See CCS Funding Sources chart below.</p>	<p>For diagnostics and Medical Therapy Program PT & OT: no income requirements.</p> <p>For coverage of CCS condition, income less than \$40,000 or enrolled in Healthy Families (if income above \$40,000).</p> <p>If medical expenses greater than 20% family income.</p>	<p>Diagnosis, comprehensive pediatric subspecialty inpatient and outpatient care, medical case management related to CCS-eligible conditions.</p> <p>Physical/occupational therapy and other services through Medical Therapy Program.</p>	<p>CCS services are available only to children with covered conditions or those requiring diagnosis of a suspected CCS-eligible condition; medical eligibility criteria do not cover many children with other conditions or disabilities.</p> <p>Division of care for CCS children enrolled in traditional managed care plans can be confusing.</p> <p>Low reimbursement rates have reduced paneled provider network in state.</p>	<p>Estimated caseload for CCS in 2009:175,000.</p> <p>Approximately 80% of these children were enrolled in Medi-Cal, 10% in Healthy Families, and 10% in state-only CCS (also known as "straight CCS").</p> <p>Approximately 26,000 of the children were enrolled in CCS Medical Therapy Program.</p>	<p>Federal/state/county program.</p> <p>CCS is California's Title V Program for Children with Special Health Care Needs (per federal MCHB, HRSA, DHHS).</p> <p>State sets policy and procedures for program.</p> <p>Counties responsible for determination of medical, financial, and residential eligibility; case management; and management of Medical Therapy Program.</p> <p>Administered by state CCS office in Children's Medical Services Branch, Department of Health Care Services.</p>

Genetically Handicapped Persons Program (GHPP)

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
GHPP provides health coverage for adults and non-CCS-eligible children who have specific genetic diseases.		Covers eligible children and adults from birth through adulthood with specific diseases (cystic fibrosis, hemophilia, sickle cell, certain neurological and meta-bolic conditions). No income ceiling. Families with incomes over 200% of FPL pay fees on a sliding scale.		Very narrow eligibility criteria. Enrollment is very low, which may be result of low awareness of program.	In 2008 there were approximately 1,600 enrollees in the program.	Administered by state GHPP office in Children's Medical Services Branch, Department of Health Care Services.

Regional Centers

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
21 private nonprofit centers located around the state provide services for children and adults with developmental disabilities. Early Intervention (EI) services for children ages 0-3 who are at risk for or display developmental delay.	Federal and state funding.	Life Span Services for persons of all ages with developmental disabilities including retardation, cerebral palsy, epilepsy, autism. Early Start Program for children ages 0-3 who are: <ul style="list-style-type: none"> • At risk for developmental disabilities • Developmentally delayed • Diagnosed physical or mental condition that has a high probability of resulting in a developmental delay (also known as "established developmental delay") • Solely low incidence in hearing, visual, and/or orthopedic impairments. 	<ul style="list-style-type: none"> • Early intervention services through Early Start • Nonmedical services, mostly case management • Family support • Respite • Crisis intervention • Special living arrangements • Community integration • Interpreter/translator • Advocacy • Transportation vouchers • Assessment • Rehabilitation and training • Treatment • Therapy • Prevention • Special equipment (usually as a payer of last resort) • Vocational placements 	Regional Center programs have sustained major budget reductions in the wake of the state's financial crisis. Details of reductions in regional center services, including potentially major changes in Early Start eligibility and services, are still being finalized, but the proposed changes would have major impact on access to services, particularly for children from birth to age 3 who have or are at risk for developmental delays.	130,285 children and youth to age 22 served by DDS, 12/07 (DDS Fact Book, October 2008).	Administered by state Department of Developmental Services.

Special Education

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>In 1975, Congress passed a law—renamed the Individuals with Disabilities Education Act (IDEA)—that required states to provide special services to children with exceptional needs.</p> <p>Children and youth eligible for regional center and/or mental health services.</p> <p>Children with other health or sensory impairments, and/or learning disabilities</p> <p>Early Start eligible (see Regional Centers).</p>	Federal, state, and local funding.	No income limits.	<ul style="list-style-type: none"> • Assistive devices/ services • Audiology services • Family training, counseling, home visits (Early Start only) • Some health services • Diagnostic services • Nursing assessments • OT & PT • Psychological services • Respite (Early Start only) • Special instruction • Speech/language services • Transportation • Vision services • Others as needed 	<p>No true system of care for children; services available are patchwork of programs located in different state departments or in the private sector, with little formal communication or coordination among them.</p> <p>Disparate funding sources may be in direct conflict with each other.</p>	<p>About 11% of California students qualify for special education services because of physical, emotional, or educational disabilities.</p> <p>Almost half of those enrolled have a specific learning disability, and more than a quarter have a speech or language impairment.</p> <p>Altogether, there are 13 categories of disabilities.</p>	Administered at state level by Department of Education and at local level by Special Education Local Plan Areas (collaborations of school districts and county offices of education).

In-Home Supportive Services (IHSS)

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>IHSS helps pay for domestic services, such as cleaning, meal preparation, laundry, and shopping for children and adults who are blind or have other disabilities and for senior adults.</p> <p>Intended to enable recipients to remain in their own homes and avoid long-term care facilities.</p> <p>Automatically eligible for full-scope Medi-Cal.</p>	Federal (Title XIX), state, and county funded.	<p>SSI-linked Medi-Cal.</p> <p>Disability FPL-linked Medi-Cal.</p> <p>Medically needy Medi-Cal.</p>	Personal care (e.g., feeding, bathing, bladder and bowel care, help with medications) and domestic services (e.g., cleaning, meal preparation).	IHSS has sustained major budget cuts that will have significant impact on eligibility and services; details are not yet available.	In May 2009, there were 446,849 authorized IHSS cases in California.	<p>Administered at state level by Department of Health Care Services.</p> <p>County assessments and oversight by county Medi-Cal offices.</p>

High-Risk Insurance Pool (MRMIP/MRMIB)

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
MRMIP (Major Risk Medical Insurance Program) provides health insurance for those unable to obtain coverage in individual health insurance market (e.g., due to pre-existing condition).	Premium costs shared between MRMIP and participant. State supplements premiums to cover the cost of care in MRMIP. Tobacco tax funds currently subsidize MRMIP.	Must be California resident; not eligible for both Part A and Part B of Medicare, unless eligible solely because of end-stage renal disease; not eligible to purchase any health insurance for continuation of benefits under Cobra or CalCobra; and unable to secure adequate coverage in the private market.	MRMIB administers three health care programs: <ul style="list-style-type: none"> • Access for Infants and Mothers; • Healthy Families; and • MRMIP. 	Because of funding limitations, MRMIP may have a wait list; as of August 2009 there were approximately 230 applicants on the wait list. Benefit package is function of individual health insurance plan.	As of June 2008, 7,300 people enrolled in MRMIP; not known how many are children/youth.	Administered at state level by MRMIB (Managed Risk Medical Insurance Board)

Mental Health

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
Publicly funded mental health programs serve children and youth with full scope Medi-Cal (ages 0-21 years); children and youth enrolled in the Healthy Families (ages 0-18 years); and children and youth ages 0-22 who receive special education referrals from schools.	Federal (Title XIX), state, and county funding.	Medi-Cal or Healthy Families income limits. No income limits if referred by school system.	Children and youth with full scope Medi-Cal (ages 0-21 years). Children and youth in Healthy Families (ages 0-18 years). Special education referrals from schools (ages 0-22 years).	Data from 2007 indicated that 54% of children in California identified with emotional, developmental, or behavioral problems received mental health care in 2007, as opposed to 60% of children in the nation as a whole. County-based Medi-Cal managed care plans for mental health limit opportunities for children to reach child psychiatrists and other providers not located in county of residence.	Data not readily available on number of children/youth receiving publicly funded mental health services.	Federal/state/county program. Administered by Department of Mental Health at state level. County-based mental health managed care plans; some counties contract with private behavioral health plans.

Current Eligibility for Medi-Cal and Healthy Families

The following charts outline income and age eligibility criteria for Medicaid/Medi-Cal and for CHIP/Healthy Families. The Medicaid/Medi-Cal chart outlines the federally mandated income/age eligibility for children; the coverage that states may elect to offer with federal matching funds; and the coverage provided in California. (State funds fill in for those categories where California exceeds the federal mandate or the federally supported optional coverage.)

Medicaid and Medi-Cal Eligibility

Mandated Coverage	Optional Coverage	California Coverage
Infants to age 1 with income up to 133% of FPL	Infants to age 1 with income up to 200% of FPL	Infants to age 1 with income up to 200% of FPL
Children ages 1 to 6 with income up to 133% of FPL	Children ages 1 to 6 with income up to 185% of FPL	Children ages 1 to 6 with income up to 133% of FPL
Children ages 6 to 19 with income up to 100% of FPL	Children ages 6 to 19 with income up to 133% or 185% of FPL	Children ages 6 to 19 with income up to 100% of FPL

Healthy Families Program Eligibility

Age/Income Criteria	Other Criteria
Infants to age 1 with income 200 to 250% of FPL	Not eligible for full-scope Medi-Cal Children may be eligible for share-of-cost Medi-Cal
Children ages 1 to 6 with income 133 to 250% of FPL	Not eligible for full-scope Medi-Cal Children may be eligible for share-of-cost Medi-Cal
Children ages 6 to 19 with income 100 to 250% of FPL	Not eligible for full-scope Medi-Cal Children may be eligible for share-of-cost Medi-Cal

Medi-Cal and Healthy Families Funding Sources

Program	Federal Funding %	State Funding %
Medi-Cal	50%*	50%*
Healthy Families	65%	35%

* California's FMAP percentage has been increased temporarily to 61.6% as a result of federal stimulus funding. The FMAP increase is due to sunset December 31, 2010.

Soman/Burke; 8/09

California Children's Services (CCS) Funding Sources

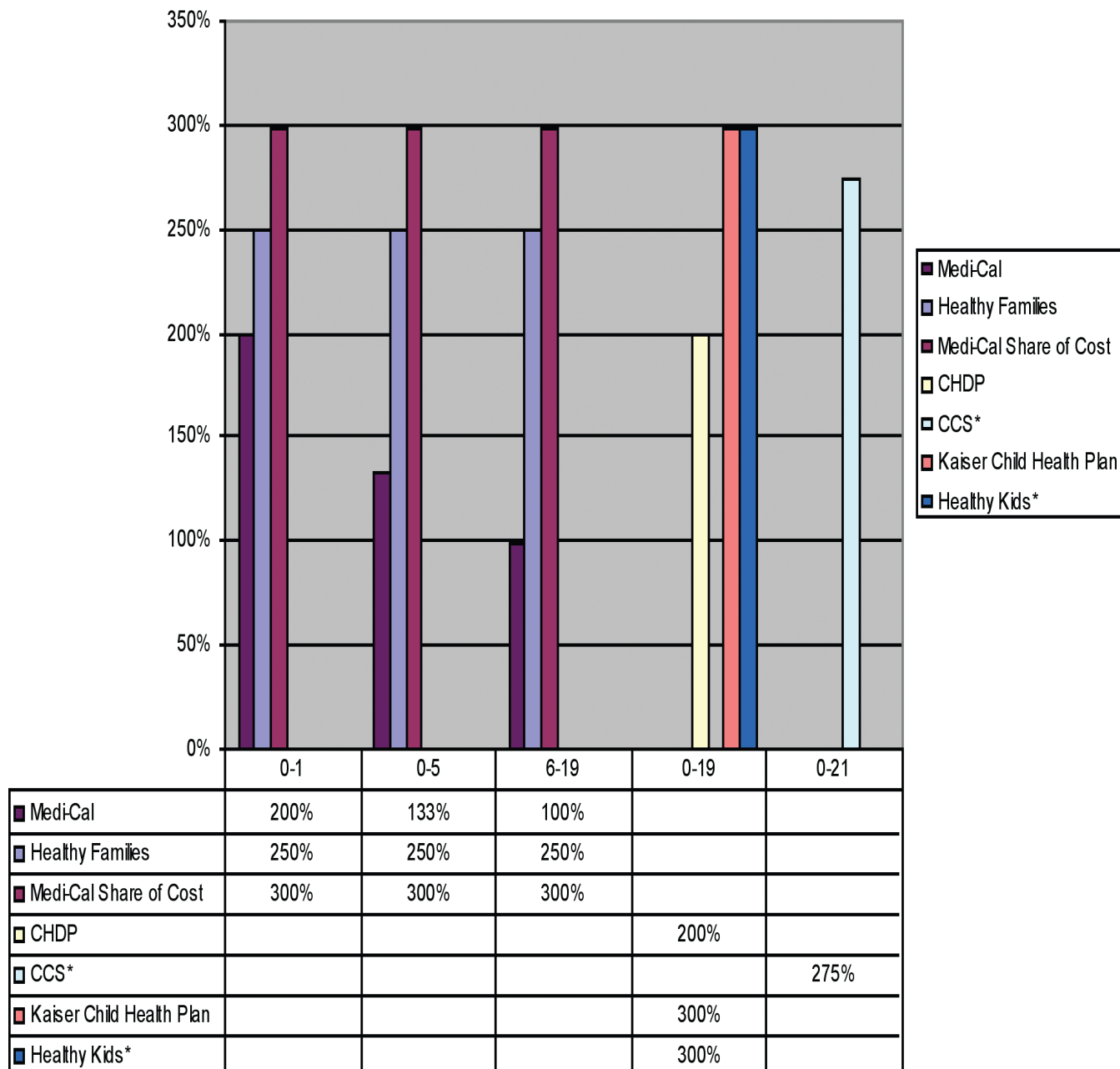
Eligible Child's Primary Health Source	Federal Funding %	State Funding %	County Funding %
Medi-Cal	50%	50%	0%
Healthy Families	65%	17.5%	17.5%
Private Insurance/ Eligible under 20% Rule	0%	50%	50%
Uninsured/Not Eligible for Medi-Cal or Healthy Families	0%	50%	50%

APPENDIX 4: IMMIGRANT SERVICES AND CATEGORIES

Immigrant Services

Description	Funding	Eligibility	Benefits	Limitations/Gaps	Enrollment Numbers	Administration
<p>The U.S. noncitizen population falls into several basic groupings for the determination of public assistance entitlements.</p> <p>See table on page 26 of report for categories of citizenship.</p>	<p>The federal government shares the cost of emergency care for undocumented immigrants with states through Medicaid. Health and other benefits for undocumented immigrants vary state by state.</p>	<p>Alien entitlement depends on two sets of criteria: immigration status and the specific program. People in the PRUCOL category generally have been held to be eligible for the majority of federal public benefit programs. A child may be eligible for coverage if he or she is a U.S. citizen or a lawfully admitted immigrant, even if the parent is not. Eligibility for children is based on the child's status, not the parent's. Many immigrant families have a mixed status and include both citizen and noncitizen members. Many parents in immigrant families are noncitizen but more than 70% of noncitizens' children are citizens.</p> <p>Most documented immigrants cannot receive federal Medicaid or SSI during their first five years or longer in the U.S., regardless of how much they have worked or paid in taxes. There are exceptions for some immigrants, such as refugees and asylees, who can continue to get insurance during their first seven years in the United States. (U.S.-born children of immigrants, who constitute the great majority of children in immigrant-headed families, are citizens and remain eligible for Medicaid and CHIP.)</p>	<p>Those who are otherwise barred from Medicaid due to their immigration status are eligible for Medicaid coverage for emergency medical care, which includes childbirth but not prenatal care. The federal government defines an emergency as "an acute condition that, without immediate care, would seriously jeopardize a patient's health or impair bodily functions, parts or organs."</p> <p>To allow legal immigrant children to receive doctor's visits, medicines and care, CHIP Reauthorization Act of 2009 gives states the option to enroll legal immigrant children and legal immigrant pregnant women who have been in the U.S. fewer than five years.</p>	<p>Health insurance coverage can help immigrant children and pregnant immigrant women access cost-effective preventive and parental care and avoid expensive emergency room care.</p> <p>Research has shown that immigrant children are less likely to have a medical home, see a physician, receive dental care, or be fully immunized than children from citizen families; and tend to rely on safety net health care providers and clinics.</p> <p>The lack of health insurance coverage is not the only barrier to health care for immigrant children. Language barriers create difficulties for immigrants trying to enroll in insurance coverage and, even if immigrants are insured, can create further problems when they try to locate health care providers or communicate with them.</p> <p>Many states have developed effective strategies to help those with limited English proficiency enroll in Medicaid and CHIP because confusing eligibility rules deter immigrant children from participating even if they are eligible.</p>	<p>In 2005, among children living in immigrant families, about 4.7 million have undocumented immigrant parents, although there was an estimated 1.6 million undocumented children.</p> <p>The percentage of low-income immigrant children who lack health coverage has climbed since 1996, when federal legislation restricted the eligibility of legal immigrants for Medicaid and CHIP during their first five years in the U.S. The disparities in health insurance coverage between citizen and immigrant children have grown significantly larger. Today, almost half of low-income immigrant children are uninsured. In California, undocumented immigrants account for 1,350 of 61,000 people receiving state-funded dialysis, and the group's portion cost the state \$51 million. Opponents of the policies are against using taxpayer funds to pay for services to undocumented immigrants and some states are concerned that covering the life saving procedures would draw more undocumented immigrants to their jurisdictions. The average immigrant utilizes less than half the dollar amount of health care services as the average native-born citizen; U.S. born persons receive about \$2,546 per capita in health care, compared to only \$1,139 for immigrants.</p>	<p>Federal and state Medicare and Medicaid programs.</p>

APPENDIX 5: HEALTH INSURANCE AND HEALTH SERVICES – INCOME GUIDELINES



***Medi-Cal Share of Cost:** Income eligibility for Share of Cost Medi-Cal varies depending on family income.

***CCS:** \$40,000 limit or 20% of income spent on condition.

***Healthy Kids:** Income eligibility for Healthy Kids programs varies by county.

***AIM Program (not pictured):** AIM provides services only to pregnant and post-partum women and their infants up to two years of age who are not eligible for Medi-Cal and with incomes between 200%-300% of FPL .

APPENDIX 6: LIST OF CHILDREN’S HOSPITALS

California Children’s Hospital Association Members and Associate Members

Children’s Hospital	Special Care Centers	Affiliated Medical School
Children’s Hospital Central California http://www.childrenscentralcal.org	Cardiac Center, Communication Disorder Center, Craniofacial Center, Cystic Fibrosis and Pulmonary Disease Center, Endocrine Center, Gastrointestinal Center, Hematology/Oncology Center, Hemophilia Center, High Risk Infant Follow-up (Regional), Metabolic, Musculoskeletal/Neuromusculoskeletal, Rheumatology Disease, Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Rehabilitation Center, Renal Dialysis and Transplant Centers, Sickle Cell Disease Center, Spina Bifida Center	University of California, Merced (in development)
Childrens Hospital Los Angeles http://www.childrenshospitalla.org	Bone Marrow Transplant Center, Cardiac Center, Cochlear Implant Center, Communication Disorder Center, Craniofacial Center, Cystic Fibrosis and Pulmonary Disease Center, Cystic Fibrosis and Pulmonary Disease Center, Extracorporeal Membrane Oxygenator (ECMO) Center, Gastrointestinal Center, Heart and Lung Transplant Center, Heart Transplant Center, Hematology/Oncology Center, Hematology/Oncology Center (Bone and Extremity Tumor Program), Hematology/Oncology Center (Neuro-Oncology Program), Hemophilia Center, High Risk Infant Follow-up (Community), High Risk Infant Follow-up (Regional), Immunology/Infectious Disease Center, Liver Transplant Center, Metabolic and Endocrine Center (Metabolic Only), Metabolic and Endocrine Center (Endocrine Only), Miscellaneous Center (Rheumatology Disease), Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Rehabilitation Center, Renal Dialysis and Transplant Center, Selective Posterior Center, Sickle Cell Disease Center, Spina Bifida Center	University of Southern California, Keck School of Medicine
Children’s Hospital of Orange County www.choc.com	Bone Marrow Transplant Center, Cardiac Center, Craniofacial Center, Cystic Fibrosis and Pulmonary Disease Center, Endocrine Center, Extracorporeal Membrane Oxygenator (ECMO) Center, Gastrointestinal Center, Hematology/Oncology Center, Hemophilia Center, High Risk Infant Follow-up (Regional), Immunology/Infectious Disease Center, Metabolic Center, Miscellaneous Center (Rheumatology Disease), Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Renal Dialysis and Transplant Center, Sickle Cell Disease Center, Spina Bifida Center	University of California, Irvine, School of Medicine
Children’s Hospital and Research Center at Oakland http://www.childrenshospitaloakland.org	Bone Marrow Transplant Center, Cardiac Center, Communication Disorder Center, Cochlear Implant Center, Craniofacial Center, Cystic Fibrosis and Pulmonary Disease Center, Extracorporeal Membrane Oxygenator (ECMO) Center, Gastrointestinal Center, Hematology/Oncology Center, Hemophilia Center, High Risk Infant Follow-up (Regional), Immunology/Infectious Disease Center, Metabolic and Endocrine Center, Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Rehabilitation Center, Sickle Cell Disease Center, Spina Bifida Center	
Loma Linda University Children’s Hospital	Cardiac Center, Communication Disorder Center, Craniofacial Center, Cystic Fibrosis and Pulmonary Disease Center, Extracorporeal Membrane Oxygenator (ECMO) Center, Gastrointestinal Center, Heart Transplant Center, Hematology/Oncology Center, Hemophilia Center, High Risk Infant Follow-up (Regional), Immunology/Infectious Disease, Metabolic and Endocrine Center (Endocrine Only), Rheumatology Disease, Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Rehabilitation, Renal Dialysis and Transplant Center, Sickle Cell Disease Center, Spina Bifida Center	Loma Linda University School of Medicine

Children's Hospital	Special Care Centers	Affiliated Medical School
Lucile Packard Children's Hospital at Stanford www.lpch.org	Bone Marrow Transplant Center, Cardiac Center, Communication Disorder Center, Craniofacial Center, Cystic Fibrosis and Pulmonary Disease Center, Extracorporeal Membrane Oxygenator (ECMO) Center, Gastrointestinal Center, Heart and Lung Transplant Center, Heart Transplant Center, Hematology/Oncology Center, Hemophilia Center, High Risk Infant Follow-up (Regional), Immunology/Infectious Disease Center, Liver Transplant Center, Metabolic and Endocrine Center (Endocrine Only), Metabolic and Endocrine Center (Metabolic Only), Rheumatology Disease, Neonatal Intensive Care Unit (Intermediate), Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Renal Dialysis and Transplant Center, Sickle Cell Disease Center	Stanford University School of Medicine
Mattel Children's Hospital at UCLA http://www.uclahealth.org/homepage_mattel.cfm	Bone Marrow Transplant Center, Cardiac Center, Cochlear Implant Center, Craniofacial Center, Gastrointestinal Center, Heart Transplant Center, Hematology/Oncology Center, High Risk Infant Follow-up (Regional), Immunology/Infectious Disease Center, Liver Transplant Center, Metabolic Center (Endocrine Only), Metabolic Center (Metabolic Only), Rheumatology Disease, Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Renal Dialysis and Transplant Center, Selective Posterior Center, Sickle Cell Disease Center, Specified Inherited Neurological Diseases Center	University of California, Los Angeles, Geffen School of Medicine
Miller Children's Hospital http://www.memorialcare.org/miller	Cardiac Center, Craniofacial Center, Cystic Fibrosis and Pulmonary Disease Center, Gastrointestinal Center, Hematology/Oncology Center, Immunology/Infectious Disease Center, Metabolic and Endocrine Center (Endocrine Only), Miscellaneous Center (Rheumatology Disease), Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Rehabilitation Center, Renal Dialysis and Transplant Center, Sickle Cell Disease Center, Spina Bifida Center	University of California, Irvine School of Medicine
Rady Children's Hospital – San Diego http://www.chsd.org	Amputee Center, Bone Marrow Transplant Center, Cardiac Center, Communication Disorder Center, Cochlear Implant Center, Craniofacial Center, Cystic Fibrosis and Pulmonary Disease Center, Extracorporeal Membrane Oxygenator (ECMO) Center, Endocrine Center, Gastrointestinal Center, Hematology/Oncology Center, Hemophilia Center, High Risk Infant Follow-up (Regional), Immunology/Infectious Disease Center, Metabolic Center, Rheumatology Disease, Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Rehabilitation Center, Renal Dialysis and Transplant Center, Sickle Cell Disease Center, Specified Inherited Neurological Diseases Center, Spina Bifida Center	University of California, San Diego, Department of Pediatrics
University Children's Hospital at University of California Irvine http://www.healthcare.uci.edu/peds.asp	Cardiac Center, Cochlear Implant Center, Communication Disorder Center, Cystic Fibrosis and Pulmonary Disease Center, Gastrointestinal Center, Hematology/Oncology Center, Hemophilia Center, High Risk Infant Follow-up (Regional), Metabolic and Endocrine Center (Metabolic Only), Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit (PICU), Rehabilitation Center, Renal Dialysis and Transplant Center, Selective Posterior Center, Sickle Cell Disease Center, Spina Bifida Center	University of California, Irvine, School of Medicine
University of California, Davis Children's Hospital http://www.ucdmc.ucdavis.edu/children/	Amputee Center, Cardiac Center, Cochlear Implant Center, Communication Disorder Center, Craniofacial Center, Cystic Fibrosis and Pulmonary Disease Center, Gastrointestinal Center, Hematology/Oncology Center, Hemophilia Center, High Risk Infant Follow-up (Regional), Immunology/Infectious Disease Center, Metabolic and Endocrine Center, Musculoskeletal/Neuromusculoskeletal, Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Rehabilitation Center, Renal Dialysis and Transplant Center, Sickle Cell Disease Center, Specified Inherited Neurological Diseases Center, Spina Bifida Center	University of California, Davis School of Medicine
University of California, San Diego Children's Hospital http://www-pediatrics.ucsd.edu	Heart Transplant Center, Heart and Lung Transplant Center, Hemophilia Center, High Risk Infant Follow-up (Regional), Neonatal Intensive Care Unit (Regional), Specified Inherited Neurological Diseases Center	University of California, San Diego School of Medicine

Children's Hospital	Special Care Centers	Affiliated Medical School
University of California, San Francisco Children's Hospital http://www.ucsfhealth.org/childrens	Cardiac Center, Communication Disorder Center, Craniofacial Center, Cystic Fibrosis and Pulmonary Disease Center, Extracorporeal Membrane Oxygenator (ECMO) Center, Gastrointestinal Center, Hematology/Oncology Center, Hemophilia Center, High Risk Infant Follow-up (Regional), Immunology/Infectious Disease Center, Liver Transplant Center, Metabolic and Endocrine Center (Endocrine Only), Metabolic and Endocrine Center (Metabolic Only), Rheumatology Disease, Neonatal Intensive Care Unit (Regional), Prosthetics/Orthotics Center, Pediatric Intensive Care Unit, Rehabilitation Center, Renal Dialysis and Transplant Center, Selective Posterior Center, Sickle Cell Disease Center, Spina Bifida Center	University of California, San Francisco School of Medicine
Children's Center at Sutter Medical Center, Sacramento http://checksutterfirst.org/children	Cardiac Center, Craniofacial Center, Cystic Fibrosis and Pulmonary Disease Center, Extracorporeal Membrane Oxygenator (ECMO) Center, Gastrointestinal Center, Hematology/Oncology Center, High Risk Infant Follow-up (Regional), Metabolic and Endocrine Center (Endocrine Only), Metabolic and Endocrine Center (Metabolic Only), Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Sickle Cell Disease Center	

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Children's Hospital	Special Care Centers	Affiliated Medical School
Cedar's Sinai Medical Center http://www.cedars-sinai.edu/	Cardiac Center, Cystic Fibrosis and Pulmonary Disease Center, Endocrine Center, Hematology/Oncology Center, High Risk Infant Follow-up (Regional), Immunology/Infectious Disease Center, Metabolic Center, Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit, Renal Dialysis and Transplant Center, Sickle Cell Disease Center	University of California, Los Angeles, Geffen School of Medicine
Childrens Hospital Los Angeles County University of Southern California Medical Center http://www.lacusc.org/childrenshospitala.org	Cleft Palate, Communication Disorder Center, Craniofacial, High Risk Infant Follow-up (Regional), Immunology/Infectious Disease Center, Metabolic and Endocrine Center (Metabolic Only), Neonatal Intensive Care Unit (Regional), Pediatric Intensive Care Unit (PICU), Sickle Cell Disease Center, Spina Bifida Center	University of Southern California, Keck School of Medicine
Shriner's Hospital, Los Angeles http://www.shrinershq.org/hospitals/los_angeles	CCS paneled—provides pediatric specialty care, and orthopedics	University of California, Los Angeles, Geffen School of Medicine University of Southern California, Keck School of Medicine
Shriner's Hospital for Children, Sacramento http://www.shrinershq.org/Hospitals/Northern_California/	CCS paneled—provides pediatric specialty care, orthopedics, and care for burns and spinal cord injury	

APPENDIX 7: THE FAMILY PARTNERS PROJECT

A SURVEY (“YOUR VOICE COUNTS”) OF FAMILIES OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS (COMPLETED PROJECT)

<http://www.familyvoices.org/projects/yourvoicecounts.php#top>

APPENDIX 8: CALIFORNIA'S AILING SYSTEM OF CARING FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

PREPARED BY PETER HANSEL AND CORI REIFMAN, CALIFORNIA SENATE OFFICE OF RESEARCH, MAY, 2000

<http://www.kaiserpapers.org/news/ca/childlrenspecial.html>

APPENDIX 9: MEDI-CAL MANAGED CARE DIVISION
TASK FORCE ON CHILDREN WITH SPECIAL HEALTH CARE NEEDS:
SUMMARY

MEDI-CAL MANAGED CARE DIVISION
TASK FORCE ON CHILDREN WITH SPECIAL
HEALTH CARE NEEDS

SUMMARY

Children with special health care needs are 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.

U.S. Maternal and Child Health Bureau

August, 2003

This summary was prepared by Linda Rudolph, M.D. and Sharon Rothman King, M.S.W.

We thank Debra Read and Christina Bethell of The Foundation for Accountability (FACCT) for their expert consultation and technical assistance, and also thank the many Task Force participants who provided comments on earlier versions of the report. The Task Force was partially supported by a grant from the California Health Care Foundation.

We are especially grateful to all of those who graciously gave of their time and expertise to participate in the Medi-Cal managed Care Task Force on Children with Special Health Care Needs.

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TABLE OF CONTENTS

Executive Summary	6
Introduction	10
Identification	13
Access	15
Care Coordination	17
Mental Health	20
Developmental Disabilities	22
Alcohol and Drug Problems	23
California Children’s Services	23
Children in Foster Care	25
Schools	26
Confidentiality	27
Care Coordination Summary	29
Quality Measurement	30
Quality Improvement	31
Balanced Budget Act	32
Conclusion	33
Table One: Care Model	34
Notes	35
Medicaid Managed Care Rules	37

EXECUTIVE SUMMARY

Children with special health care needs (CSHCN) are children with an array of different physical, developmental, or emotional conditions, with a broad spectrum of needs. It is estimated that about one quarter of children in Medi-Cal have special needs. These children are some of the most vulnerable in our society. The Federal government incorporated specific requirements pertinent to individuals with special health care needs enrolled in the Medicaid managed care program, in its implementation of the Balanced Budget Act of 1997. The Medi-Cal Managed Care Division convened a Task Force on Children with Special Health Care Needs to provide input to the Division on improving the quality of care for CSHCN enrolled in Medi-Cal managed care plans and implementing the new federal requirements.

The Task Force, comprised of representatives of State agencies serving CSHCN, providers, managed care plans, and consumer and family advocates, met eleven times over the course of more than a year. Discussions included definition and identification of CSHCN, care coordination, confidentiality, and quality measurement and improvement. Participants in the Task Force did not agree on basic issues such as whether children with special health care needs should be enrolled in managed care plans at all, or whether the relationship between managed care and other agencies is workable as currently structured. But all agreed that there is much room for improvement in the quality of care for CSHCN, and that a committed and concerted effort toward improvement should be made within the current context of Medi-Cal managed care.

This report summarizes the Task Force discussions and its recommendations for improvement. While the Task Force focused on children with special needs, many of the discussions and recommendations are highly relevant to all Medi-Cal Managed Care enrollees with chronic illness or special needs.

Overarching Issues

Task Force discussions returned repeatedly to several over-arching issues that must be addressed if the care of CSHCN is to be improved. CSHCN receive care from multiple systems of care, each of which is complex. Families, providers, Plans, and agencies themselves are often confused about the roles and responsibilities of the various parties. There are frequently differences in policies and processes among county-based agencies and Plans, which exacerbate this confusion. There are many examples of excellent collaboration, but too many agencies maintain a silo mentality. Building and maintaining avenues for good communication, in the context of clearly defined roles, is key to the creation of a culture of collaboration.

The critical role of parents in caring for CSHCN, and in designing programs and systems that work for CSHCN, is often overlooked. Inclusion of families at all levels is an important mechanism to assure that service delivery systems and care are patient-

centered. The cultural and linguistic diversity of CSHCN and their families must be consistently addressed.

Several challenges must be overcome to implement the Task Force recommendations on these issues. Not all agencies are currently required to coordinate with each other. It is unclear which agency should take the lead to convene an on-going inter-agency and stakeholder work group or initiate a process to clarify roles. Also, many agencies are operating with a “scarcity mindset”, although building a culture of collaboration may be more important than ever in an era of limited resources.

Task Force Overarching Recommendations

- ***Mandate all agencies serving CSHCN to develop a matrix which clarifies agency roles and responsibilities with respect to identification, screening, referrals, assessment, treatment, and care coordination.***
- ***Require that all agencies serving CSHCN and plans – at the state and local levels - meet regularly and share information (as allowed by confidentiality laws) to ensure identification, access to care, coordination of services, and quality improvement.***
- ***Clarify the way in which federal and State laws allow sharing of information among providers of care for CSHCN for purposes of improving care coordination and quality of care.***
- ***Convene an on-going workgroup with representation from parents, agencies, providers, and Plans to specify and review the implementation of the Task Force recommendations.***
- ***Require inclusion of families at the agency, plan, and provider levels.***
- ***Address diverse cultural and linguistic needs of CSHCN and their families.***

Identification

Identification is a necessary first step to ensure the quality of care for CSHCN; without an awareness that a child has special needs, providers and Plans cannot take steps to assess how well those needs are being addressed, nor to arrange for or provide needed services. Early identification allows early intervention; because childrens’ conditions and needs change over time, identification should ideally occur at multiple points of contact.

There are several different approaches to the identification of CSHCN, each with its pros and cons. Administrative encounter and claims payment data are often unable to identify many CSHCN, especially those with developmental disabilities and mental health problems. Many experts now recommend the use of a consequences-based survey screening tool; the parent-reported CSHCN screener has been validated and is in widespread use.

Administration of the screener requires considerable resources. The use of state-held administrative data to pre-identify some CSHCN could help reduce the burden of survey administration. Implementation issues include determination of exact specifications for administrative identification, and assignment of the responsibility to administer the screener at various possible points of contact (e.g. at the time of eligibility determination, Plan enrollment, Initial Health Assessment, or during well child visits).

Task Force Recommendations on Identification

- ***Develop and implement a process to supplement and verify identification based on administrative data, through use of the parent-reported CSHCN screener.***
- ***Use state-held eligibility and administrative (encounter and claims payment) data to pre-identify some CSHCN to health plans.***

Care Coordination

Many children require services from multiple providers in separate care delivery systems. Coordination of care among providers and systems is perhaps the most critical element in ensuring that CSHCN have access to the quality care they need. Care coordination also increases family satisfaction, and helps prevent costly medical errors and duplication of services.

Care coordination is a proactive, family-centered, collaborative, outcomes-focused process of teamwork with families and providers designed to: assess child and family needs; facilitate timely access to needed services and resources; promote bridges between families and health, education, and social services; provide referrals, information and education for families and across systems; and maximize effective and efficient use of available resources.

Families need a “yes”-driven system in which each family has access to an individual who can provide needed care coordination, and communication and coordination across providers and agencies allow streamlined access to needed services. But the challenges to care coordination are legion. Care for CSHCN in California is extremely fragmented and complex, involving many agencies, inadequate reimbursement for the time and resources required, confusing and variable policies and processes, and diverse cultural and linguistic needs. Some families have many assigned case managers, but none coordinating across agencies. Delays in access may occur as “payors of last resort” sort out which agency is responsible for care. Concern and confusion about state and federal confidentiality laws inhibit sharing of information, even when it is legally allowed.

Task Force Recommendations on Care Coordination

- ***Educate agencies and providers about legal information sharing, consistent with federal and state law.***
- ***Develop a standardized informed consent for information sharing.***
- ***Implement and promote a standardized parent/caretaker held tool (i.e. a “health passport” or parent notebook) to facilitate information sharing and encourage the use of a written care plan with input from the family and all of a child’s providers.***
- ***Clarify policies and increase consistency of policy administration and processes across counties for program eligibility determination, referrals, information sharing, authorization, and payment.***
- ***Require that plans ensure the designation of CSHCN care coordinators who are available to participate in the coordination of care so that the needs of all CSHCN are appropriately met.***
- ***Support and encourage development of “medical homes” for all CSHCN.***

Quality Measurement and Quality Improvement

Measuring the quality of care is fundamental to health care accountability and improvement. Two core dimensions of quality should be assessed: the health care needs of consumers, and components of quality such as effectiveness, safety, and timeliness. Selecting quality measures requires decisions about what and who to measure, and what indicators to use. Quality measurement uses many sources of data, each with strengths and weaknesses; the CAHPS CSHCN module is in increasingly widespread use to assess the family and patient experience with care.

Challenges in the measurement of quality of care for CSHCN include the small numbers of children with any one condition, and lack of evidence-based guidelines for many conditions. The fragmented delivery system also makes it especially difficult to assess the quality of care, because it is more difficult to ascertain which services have been received. Also, when many providers and agencies all share responsibility for the quality

of care, it is important that each be held accountable only for the care for which they are responsible.

Quality improvement requires systematic efforts to enhance efficiency and consistency, eliminate defects, and achieve higher levels of performance. Improvement requires attention at all levels – the patient/family, the provider, the health care organization and system, and the policy environment. Key challenges for providers and Plans in implementing quality improvement programs include lack of time, money, and resources, non-recognition of the need for improvement, and the lack of incentives (financial and non-financial) for improvement. The fragmented nature of service delivery for CSHCN may also complicate the implementation of quality improvement and incentives for quality. Collaborative projects provide support for organizations engaged in quality improvement efforts.

***Task Force Recommendations on
Quality Measurement and Quality Improvement***

- ***Implement a core CSHCN measure set, including the CAHPS CSHCN survey and other CSHCN-relevant HEDIS measures, to annually assess access, care coordination, and parent and child experience of care in Medi-Cal managed care plans.***
- ***Report on quality measures in ways that maximize value for plans, providers, and state agencies.***
- ***Implement a cross-agency program to train and support providers on CSHCN screening, primary care treatment, and referral for mental health, developmental, and substance abuse problems.***
- ***Implement payment strategies to ensure fair, timely, and appropriate reimbursement of plans and providers for time and resources required for quality care and care coordination for CSHCN, based on the prevalence and burden of service needs of their population (e.g. streamline payment, increase reimbursement, risk adjustment, reimbursement for assessments).***
- ***Offer financial and other incentives to plans and providers for quality improvement.***
- ***Initiate collaborative quality improvement efforts to improve the care of CSHCN.***

Improving the quality of care for CSHCN will require leadership, commitment, and resources. But the payoff is potentially great – in increased family, child, and provider satisfaction, in more effective and efficient use of limited resources, and in improved health, education, and social outcomes for children with special health care needs.

INTRODUCTION

Children with special health care needs (CSHCN) are children with an array of different physical, developmental, or emotional conditions that, if not properly managed, may affect their ability to function, with a broad spectrum of needs. These children are some of the most vulnerable in our society. Not only are they in need of the routine care afforded all children, but also they and their families must learn to negotiate many complex systems to assemble services and health care that meet their changing needs on a daily basis. Providing comprehensive, coordinated, family-centered care to children with special needs can be very challenging, particularly when systems of care are fragmented as in California.

In 1994 the U.S. Maternal and Child Health Bureau (MCHB) established a work group to recommend a definition of children with special health care needs. The definition adopted represents a consequence-based definition that captures children with any chronic condition requiring more health care than the average user. The definition considers the existence of a condition and its expected duration, in addition to how much health care the child is expected to need.ⁱ The California Task Force agreed to use the Federal definition, while recognizing that the “at-risk” component may be difficult to operationalize. Using this definition, it is estimated that 13 - 18% of all children in this country have special health care needsⁱⁱ; about one-quarter of the Medicaid child population has special health care needs.ⁱⁱⁱ

Definition

Children with special health care needs are 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.

U.S. Maternal and Child Health

Children with special health care needs merit special attention because their needs are both different than other children and different than adults with special needs. Children with special health care needs utilize substantially more service dollars and a larger variety of services than other children. They may need multiple visits to a primary care physician, and access to pediatric subspecialists and any or all of the following services: mental health care, habilitative services, special education, durable medical equipment, emergency services, hospital care, durable medical equipment, speech therapy, prescription medications, substance abuse treatment, child welfare services, legal services, or many others.

Children’s needs change as they grow, and the nature of their condition changes as well. Children are dependent upon adults for their care and their health is influenced by their family’s health and socioeconomic status. Children with special health care needs experience many rare conditions of low incidence as opposed to adults, more of whom experience more common conditions.^{iv}

Managed care could potentially benefit children and their families by improving access and coordination of services. However, there have been concerns that managed care could also create incentives to limit utilization or access to specialists, and that safeguards are needed to ensure that CSHCN enrolled in managed care plans receive needed services.^v Therefore, the Federal government incorporated specific requirements pertinent to individuals with special health care needs enrolled in the Medicaid managed care program, in its implementation of the Balanced Budget Act of 1997. The final rules for Medicaid Managed Care include requirements for identification, assessment, access to specialists, and measurement of quality of care for enrollees with special health care needs.^{vi}

In February, 2002 the Medi-Cal Managed Care Division (MMCD) of the California Department of Health Services convened a Task Force on Children With Special Health Care Needs to discuss approaches to improving the quality of care for children with special health care needs who are enrolled in Medi-Cal managed care. Through the Task Force deliberations, MMCD sought public input that could inform MMCD’s implementation of the new Federal requirements, and its development of an all-plan policy letter on children with special health care needs.

Task Force Vision

All children with special health care needs will be identified and will have access to quality health care that is:

- *family-centered and supportive*
- *community-based*
- *coordinated and seamless*
- *effective, appropriate, and efficient*
- *culturally and linguistically effective.*

MMCD’s longer term goals are to ensure that:

- (1) children with special health care needs who are enrolled in Medi-Cal managed care plans have adequate access to high quality, coordinated services which meet the needs of the children and their families;
- (2) MMCD implements quality measures to facilitate monitoring and improvement of care for CSHCN; and
- (3) MMCD, contracted plans, and other agencies build a culture of collaboration to foster quality care for CSHCN.

The Task Force comprised a wide variety of stakeholders from many groups serving children with special health care needs including representatives from State and local

agencies (e.g. health, mental health, regional centers); managed health care plans; advocates; and pediatricians and children's hospitals.

For over a year, the Task Force met monthly to examine the definition and identification of children with special health care needs, access to specialists and special services, care coordination, confidentiality, quality measures and monitoring, and quality improvement. In addition, the Task Force examined the coordination of care for specific population groups receiving services from Medi-Cal Managed Care and other service systems including children with developmental disabilities, children in foster care, children who need mental health and special education services, children with drug and alcohol problems, and children who are clients of California Children's Services.

The Task Force discussions were often highly spirited and contentious. Task Force members maintain very different perspectives on the basic question of whether managed care is a viable approach to improving care for CSHCN. Some participants believe the current carve-out structure should be terminated and the role of managed care expanded; others think that CSHCN should never be mandatorily enrolled in managed care. Some participants wanted to focus only on the responsibilities of managed care plans, while others urged more focus on the issues related to inter-agency and plan-agency coordination.

However, every Task Force member genuinely cares about children with special health care needs. The focus of the Task Force was to find areas of common ground for improving their care ***within the context of the current Medi-Cal managed care structure***. This document summarizes the discussions of the Task Force, and identifies specific recommendations around which the group was able to reach agreement.

MMCD Task Force on CSHCN Topics

- *Overview of CSHCN*
- *Definition and Identification of CSHCN*
- *Access to Specialists and Special Services*
- *Care Coordination for CSHCN*
- *Confidentiality Concerns*
- *Care Coordination for Children with Mental Health Care Needs*
- *Care Coordination for Children with Developmental Disabilities*
- *Care Coordination for Children with Drug and Alcohol Problems*
- *Care Coordination for Children in the California Children's Services Program*
- *Care Coordination for Children in Foster Care*
- *Coordination with Schools*
- *Measuring Quality of Care for CSHCN*
- *Quality Improvement for CSHCN*
- *Balanced Budget Act Medicaid Managed Care Final Rules*

IDENTIFICATION

The Federal government requires that individuals with special health care needs in Medicaid managed care are identified by or for managed care organizations. Identification is necessary in order to ensure that CSHCN receive adequate assessment of their needs, appropriate access and referrals to care, and care coordination. Without identification, the quality of care for CSHCN cannot be measured and monitored, and managed care plans (Plans) cannot implement quality improvement efforts. Risk adjustment of payments to reflect CSHCN enrollment and increased utilization of services also requires identification.^{vii}

The earlier that CSHCN are identified, the sooner their needs can be appropriately addressed. Early identification allows early intervention, with improved medical and functional outcomes. Because CSHCN have changing needs over time, and because children may develop special needs at any time, it is important that identification efforts be continuous. Children with special health care needs may be screened at multiple points of contact with the family: at eligibility, at plan enrollment, and periodically at the primary care physician level.

The use of standardized methods to identify CSHCN provides consistency in estimating the population of CSHCN, and in measuring quality across Plans. However, there is no perfect tool for identification; any one approach to identifying CSHCN will be imperfect and each has its strengths and weaknesses. Some children may still fall through the cracks, while some children who do not have special needs may spark unnecessary or redundant further assessment and attention. The goal is to use a simple, quick, feasible method that finds most of the children who have special needs, and does not identify large numbers of children who do not have such needs. Identification of large numbers of children could dilute attention to the children most in need. There are many approaches to the identification of CSHCN, using either administrative (e.g. claims or encounter) or survey data.

Approaches to Identification

- *Categorical (aid code) : requires eligibility in specific programs (e.g. SSI, Title V)*
- *Diagnostic: requires specific diagnoses in patient record or condition checklist*
- *Services: based on utilization of service, e.g. hospitalization, therapies, drug use*
- *Cost: based on total cost of medical services*
- *Consequences-based: based on health consequences and need for services*

Advantages and Disadvantages of Identification Methods

Administrative Data

- (+) *Readily available*
- (+) *Relatively inexpensive*
- (-) *Misses uncoded educational, behavioral, developmental disorders*
- (-) *Misses CSHCN using services outside benefit structure*
- (-) *Misses children in transition (e.g. foster children)*

Survey Data

- (+) *Captures experience of family and child*
- (+) *More accurate and timely*
- (-) *Resource intensive*
- (-) *Relatively expensive*
- (-) *Difficult to reach enrollees for good*

Many experts now favor a parent-reported consequences-based approach.^{viii} This approach is amenable to uniform data collection through parent survey. It increases the probability of identifying children without recorded diagnoses in patient records, or whose diagnosis is not recalled by parents; at the same time, it reduces the likelihood of identifying children who have a condition, but who have no or few functional or service use needs consequences. Unfortunately, one-question screens have been demonstrated to be ineffective for the identification of CSHCN, both identifying children without special needs, and missing children with special needs.

Several survey tools have been validated, including the CSHCN Screener^{ix}, and the original and shorter revised version of the Questionnaire for Identifying Children with Chronic Conditions (QuICCC and QuICC-R). The CSHCN Screen is currently being used in the National Survey of Children with Special Health Care Needs, the National Medical Expenditure Panel Survey (MEPS), and has been incorporated as an optional module in the Consumer Assessment of Health Plans Survey.^x

Children with Special Health Care Needs Screener

The CSHCN Screener, developed by the Child and Adolescent Health Measurement Initiative coordinated by FACCT, was designed to reflect the MCHB definition of children with special health care needs.

The Screener first ascertains whether a child experiences any of five health consequences:

- 1) Use or need of prescription medication*
- 2) Above average use or need of medical, mental health, or educational services*
- 3) Functional limitations compared with others of same age*
- 4) Use or need of specialized therapies (e.g. OT, PT, speech)*
- 5) Treatment or counseling for emotional or developmental problems.*

To qualify as having special health needs, a child must meet these three conditions:

- a) the child currently experiences one of the above consequences.*
- b) the consequence is due to a medical or health condition*
- c) the duration or expected duration of the condition is 12 months or longer.*

Using a combination of administrative and survey approaches to identification addresses some of the flaws in each separate approach. In the Medi-Cal population, survey responses have been low, in part due to frequently inaccurate contact information. Supplementing surveys with administrative data (aid code, diagnosis, services) may allow identification of some children for whom additional outreach or coordination efforts are warranted.

Task Force Recommendations on Identification

- ***Use state-held administrative data to pre-identify some CSHCN to health plans. (encounter and claims payment).***
- ***Develop and implement a process to supplement and verify identification based on administrative data, through use of the parent-reported CSHCN screener.***
- ***Convene a Work Group to define specifications for the use of encounter and claims data, including diagnosis, aid code, and paid services from other agencies, and to consider data confidentiality issues.***

ACCESS TO CARE

Access to care can be a major challenge for children with special health care needs. Of particular concern are the problems that families report in accessing pediatric subspecialty care, and in access to a “medical home”. About 22% of parents of CSHCN in Medi-Cal report that they can not see the providers their child needs. While nearly all children eventually get the specialty care they need, about 1/3 of CSHCN in Medi-Cal - twice as many as in private insurance) - report problems getting referrals to specialists. And, many CSHCN parents report that they do not have a personal doctor (24%), don’t have enough time with their child’s provider (33%), and don’t receive information they need about caring for their child (15%).^{xi} In one published study, all private patients but only 2% of Medi-Cal patients were offered pediatric orthopedic appointments within one week.^{xii}

These problems persist despite Medi-Cal managed care requirements to assign every enrollee to a primary care provider, to maintain adequate networks of specialists, and to allow direct access to specialists for children with chronic illness through standing referrals, use of specialists as primary care providers, or other mechanisms. In fact, for most CSHCN in most Medi-Cal Plans, specialist care and specialty services are “carved out” (excluded) from the Plan’s responsibilities. Thus, most CSHCN specialty care is

delivered through programs such as California Children’s Services (CCS), or the local mental health agencies.

There are complex reasons for access problems. There do appear to be absolute shortages of pediatric sub-specialists in California.^{xiii} Anecdotally, these shortages are most notable in the areas of mental health, developmental pediatrics, orthopedics, dermatology, and neurology. More important, however, is that many physicians are unwilling to participate in Medi-Cal. A recent survey of California physicians found that only 25% of specialists have Medi-Cal managed care patients in their practice, and that less than ½ of all physicians are accepting any new Medi-Cal patients. Medi-Cal patients are perceived by physicians as having complex medical and psychosocial problems that require extra time.^{xiv} For pediatricians, major reasons for limiting participation in Medicaid are low reimbursement (68% of California pediatricians), paperwork concerns, and unpredictable payments.^{xv} Some specialists also perceive that time-pressured primary care providers may “over-refer” children, creating additional backlogs for specialist care. Medi-Cal managed care plans have attempted to alleviate access problems through higher specialist reimbursements or subsidization of specialty clinics, with some success.

The complexity of California’s child health system is another major factor which impedes access to care for CSHCN enrolled in Medi-Cal managed care plans. Multiple public care delivery systems maintain responsibility for the delivery of particular segments of services to which children are entitled. Each has its own eligibility rules, referral procedures, provider networks, reimbursement structures, and case management processes. This complexity has led to what Task Force Participant Juno Duenas describes as “a system driven by ‘no’”. It leads to significant delays in access to needed services and in provider reimbursement. In some cases children “slip through the cracks” and forego needed services altogether. This issue is addressed in further detail in the next section.

Task Force Recommendations on Improving Access

- ***Provide resources and train providers on referral processes and appropriateness***
- ***Provide additional training for some primary care pediatricians in key areas (e.g. mental health, developmental issues, orthopedics), and on referral processes and available services.***
- ***Reimburse providers for care coordination***
- ***Streamline reimbursement by addressing administrative inefficiencies, and improve reimbursement levels for providers and plans***
- ***Conduct QI activities to improve referrals and access.***

CARE COORDINATION

Children with special health care needs may require services over time from a broad range of providers and agencies, including medical, mental health, social, developmental, and educational services and supports. Only through the integration of these services can children be assured a high quality program of care for the child and family.^{xvi} Experts believe that care coordination can realize substantial benefits, including less stress and more satisfaction for families and providers, higher school attendance, improved self-sufficiency, improved clinical outcomes, and cost savings realized from fewer and shorter hospital stays.^{xvii}

California's Medi-Cal provides a rich benefit package to enrolled children, including full Early Periodic Screening, Diagnosis, and Treatment (EPSDT) supplemental services. The Medi-Cal benefit is thus intended to provide access to regular primary care and timely access to specialist providers and special services. However, California's health system for children is extraordinarily complex and fragmented. Often, the maintenance of separate and distinct funding streams is not aligned with the needs of children.

Navigating through multiple different systems can be extremely challenging for both families and providers. Coordination of care among these systems is perhaps the most critical element in ensuring that CSHCN have access to the quality care they need, and it requires the commitment and cooperation of all of the agencies and individuals involved in caring for CSHCN.

California Agencies Serving CSHCN

- *Medi-Cal – Plans and FFS*
- *County Mental Health Agencies*
- *Regional Centers*
- *California Children's Services*
- *CHDP*
- *Local Education Agencies*
- *Special Education Local Programs*
- *Social Services – Foster Care*
- *Alcohol and Drug Programs*
- *Juvenile Justice*
- *GHPP (Genetically Handicapped)*

Care coordination is a proactive, family-centered, collaborative, outcomes-focused process of teamwork with families and providers designed to assess child and family needs; facilitate timely access to needed services and resources; promote bridges between families and health, education, and social services; provide referrals, information and education for families and across systems; and maximize effective and efficient use of available resources.^{xviii}

Care coordination and traditional case management are not the same. Case management is based on a traditional medical model, focused on medical costs and services within an organization. Care coordination uses a social services model, and focuses on facilitating access to services through patient advocacy, problem-solving, family involvement, and collaboration across providers and organizations to meet the ever-changing needs of children and their families.^{xix} The goals of care coordination are to improve and sustain

family and child quality of life; assure access to optimal care; and improve the system of care.^{xx}

Key Elements in Family-Centered Care Coordination for CSHCN

- *Locus: family focused with on-going family involvement and cultural sensitivity*
- *Assessment: written care plan identifies needs, clarifies roles and responsibilities of all care providers to meet needs*
- *Access to health, developmental, and behavioral services: to variety of providers in different systems, with means to ensure timeliness and payment; access to care coordinator 24/7*
- *Access to non-health services: address home, social, educational needs; transportation, respite care, etc.*
- *Assures linkages: to community services and among agencies; sensitivity to confidentiality;*
- *Facilitates access to benefits: find and refer; advocate for receipt of benefits*
- *Monitors satisfaction and quality*

(Matrix from Susan Epstein, MSW, of New England Serve, with integration of Task Force priorities)

Families, providers, plans, and agencies all have important roles in care coordination. Families are, in fact, at the center of care coordination. They assess a child's status on a daily basis, determine the need to seek care, provide information to care providers, and directly experience the impacts of care on a child. Ensuring family participation in the child's care is thus a critical component of care coordination, and good care coordination empowers families to better fulfill their role, through respect, support, provision of information and training, cultural sensitivity, and involvement in systems design.^{xxi}

Medical Home

“A Medical Home is the provision of care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent. Providing a medical home means addressing the medical and non-medical needs of the child and family.”

The American Academy of Pediatrics encourages primary care physicians to provide a “medical home” for all CSHCN. Providing a medical home means creating a partnership with the child's family to develop a long-range health care plan for the child which address the medical and non-medical needs of the child and family.^{xxii}

Comprehensive assessment and development of a written care plan are important components of good care coordination. Once identified as being a child with special

needs, careful and regular assessment is required to determine the full scope of needs, and to monitor whether the care plan as implemented is addressing needs and fostering improvement in a child's health and well-being. The initial assessment should also identify services currently being received, to facilitate coordination among all care providers.

While care coordination is an essential element of health care for children with special needs, providers are often constrained in their ability to provide it. Good care coordination requires time, resources, information, skills, and support. Providers generally receive no additional reimbursement for care coordination, and often have no training in this area.

Medi-Cal managed care plans and other agencies (CCS, RC) are already required to case manage and coordinate care for CSHCN. Plans are specifically required to enter into Memoranda of Understanding with their local public health department's California Children's Services (CCS) and Child Health and Disability Prevention (CHDP) programs, and with the local County Mental Health agency. However, operational challenges in implementing the MOUs remain; plans and primary care providers are often unaware that children are receiving services from other agencies, or the nature of those services. Lack of communication and coordination still cause some families to confront delays or impediments in accessing care, and to inefficient care delivery. Families complain that they are "punted" from one agency to another, while each agency waits to see if another will assume responsibility for the child. Ironically, some families have many case managers from different agencies, but none who really fulfill the families' care coordination needs because of role limitations and turf issues.

Challenges to Improved Care Coordination

- *Complexity of system and programs*
- *Organizational culture of silos, lack of trust*
- *Inadequate (or no) reimbursement for care coordination*
- *Provider lack of time and staff*
- *Lack of information about resources*
- *Concerns about confidentiality*
- *Shortages of specialists*
- *Variation in local and Plan processes*
- *Delays in determining payment responsibility*
- *Diversity of cultural – linguistic needs*

There are significant challenges in improving care coordination for CSHCN enrolled in Medi-Cal managed care plans. Foremost amongst these is the complexity of California's child health system. Multiple programs, each with complex eligibility and operational requirements, operate in their own silos, with legal, financial, and organizational constraints on their ability to weave a whole system of care for CSHCN. In some cases,

several case managers (e.g. from Plans, CCS, Regional Centers, foster care public health nursing), may all attempt to coordinate care at once. Variations in processes (e.g. for determining eligibility or handling referrals) among locally-controlled agencies and among Plans lend to further confusion. Also, because several agencies are “payors of last resort”, multiple written denials may be required before responsibility for payment can be determined, leading to delays in accessing services.

The sections below provide an overview of the key agencies with responsibilities for providing health care services to children with special health care needs, and a brief summary of some of the special issues confronting sub-groups of CSHCN.

CARE COORDINATION FOR CHILDREN WITH MENTAL HEALTH NEEDS

It is estimated that more than a million California children experience emotional, behavioral, or mental health problems each year.^{xxiii} With a few exceptions, mental health services in Medi-Cal are “carved out” of Plan contracts under the Specialty Mental Health Services Consolidation program. Plans are responsible for provision of “primary care mental health services”.

Specialty mental health services are provided by locally controlled county mental health agencies on a fee-for-service basis. Children with serious emotional disturbances (SED) receive care through a comprehensive mental health services system – Children’s System of Care – which was designed to facilitate collaboration among all systems providing care for children with SED. Some mental health services may also be provided through special education, juvenile justice, child welfare, or CCS.

The Department of Mental Health determines eligibility for specialty mental health services on the basis of stringent “medical necessity” criteria. The child must have a qualifying diagnosis, significant impairment as a result of the mental disorder, and the expectation that the proposed intervention will be helpful.^{xxiv}

Every child should regularly receive screening for emotional or behavioral problems; if a mental health disorder is suspected, the child should be evaluated and treated, if necessary, by a mental health professional. Many children who need mental health services may not receive them because their needs are not identified; the use of standardized tools considerably increases identification rates.^{xxv} Some providers are not familiar with universal screening recommendations; others are reluctant to identify mental health needs, because of difficulties in accessing consultations and services.

Challenges in Mental Health Coordination

- *Shortage of child mental health providers*
- *Poor access to mental health consultation and services*
- *Lack of universal screening to identify children with mental health needs*
- *Confusion about agency/Plan responsibilities*
- *Confidentiality concerns*
- *Stringent mental health eligibility criteria*

There is significant confusion on the part of providers, Plans, and even county agencies regarding access to and responsibility for mental health evaluations, and for care of children with mental and behavioral health problems who are not eligible for carved out specialty mental health services.

However, there is general agreement that there is a severe shortage of child mental health professionals in the state; this shortage is exacerbated in Medi-Cal, in part due to low reimbursement rates. Because of the shortage, there are long waiting lists to access mental health evaluation and treatment services in many areas. Children who need mental health services but are ineligible for county services under consolidation may find access especially difficult.

There is a special sensitivity, and specific regulations, about the confidentiality of mental health services, due to concerns about the still-present stigma of mental illness. However, it is also particularly important that there be coordination of physical and mental health care. Providers must be aware of all of the medications a patient is prescribed in order to prevent adverse drug interactions. Mental health problems may also impact patient compliance. Better mechanisms for appropriate exchange of information between mental and physical health providers must be implemented.

Task Force Recommendations on Mental Health

- ***Clarify agency and plan responsibilities for mental health services.***
- ***Educate providers about use of screening tools, mental health referrals, and available resources.***
- ***Increase training for PCPs on child mental health.***
- ***Improve information sharing (among physical/mental health); clarify that sharing of mental health information for care coordination and quality improvement is allowed..***
- ***Increase provider reimbursement.***
- ***Decrease variation in local policies/procedures.***

CARE COORDINATION FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

The Federal Individuals with Disabilities Education Act (IDEA) and the California Early Intervention Services Act and Lanterman Act mandate provision of a broad array of services and supports, including assessment and case management, for children with or at risk for developmental disabilities. Early Start provides services for children ages zero to three with or at risk of developmental disabilities (DD), and their families.^{xxvi} The State Department of Developmental Services contracts with a network of twenty-one independent, not-for-profit, locally controlled Regional Centers for services provided to about 170,000 persons with developmental disabilities.

Medi-Cal Managed Care Plans are required to coordinate closely with Regional Centers in providing screening, assessment, development of treatment and service plans, and case management services.^{xxvii} Regional Centers do their own assessments and provide case management; determinations of eligibility may lead to lifetime services.

As in mental health, confidentiality concerns often hinder information sharing or identification of patients receiving Regional Center services. The Welfare & Institutions Code specifies that Regional Centers are the payors of last resort. Poor coordination may result in duplication of services. Lack of clarity regarding payment responsibility, inadequate primary care screening for developmental delay, and shortages of developmental pediatricians may lead to delays in services, particularly for developmental assessments, neuropsychological testing, and therapies.

Challenges in Coordination with Regional Centers

- *Shortage of developmental pediatricians*
- *Lack of universal screening to identify children with developmental delay*
- *Confusion about agency/Plan responsibilities for assessments, services, and payments*
- *Cumbersome process for determination of payment*

Task Force Recommendations on Developmental Disabilities

- ***Improve information sharing among Regional Centers and Plans; clarify that sharing of information for care coordination and quality improvement is allowed..***
- ***Clarify and streamline payment determinations.***
- ***Decrease variation in local policies/procedures.***
- ***Train providers on use of developmental screening tools.***
- ***Cross-train Regional Center and Plan staff on role/responsibilities of each.***

CARE COORDINATION FOR CHILDREN WITH ALCOHOL AND DRUG PROBLEMS

Early identification and treatment of substance abusing youths results in better outcomes. The 1998 Adolescent Alcohol and Drug Treatment and Recovery Program Act provided \$5 million annually to about half of California counties to support substance abuse treatment for youth. However, there remains a severe shortage of youth drug treatment facilities; while between 252,000 and 315,000 California adolescents need some level of drug or alcohol treatment respectively, only 21,000 received publicly funded treatment in 2001. No residential drug treatment programs are currently available for youth in the Drug Medi-Cal program.^{xxviii}

Mental health systems may also provide drug treatment, including through the federally funded EPSDT program. However, many providers erroneously believe that these services can only be provided to children with a dual diagnosis of mental illness, exacerbating the difficulties in accessing substance abuse treatment for youth. Finally, providers lack training in screening for substance abuse problems, and may be reluctant to screen if resources for referral are inadequate.

Task Force Recommendations on Alcohol and Drug Problems

- ***Educate providers about screening and referrals for substance abuse.***
- ***Clarify availability of substance abuse treatment through mental health services and other sources.***
- ***Provide information about substance abuse services to Plans and providers.***
- ***Increase availability of substance abuse services for children.***

CARE COORDINATION WITH CALIFORNIA CHILDREN'S SERVICES

The California Children's Services Program (CCS), supported by Federal Title V Maternal and Child Health Program funds, assures that children with certain physically handicapping conditions receive necessary and appropriate health care to treat their eligible conditions at the appropriate time and place. The CCS program provides diagnosis, treatment, and medical therapy services for children with certain acute and chronic diseases, many of which are rarely observed in the usual pediatric practice. CCS empanels health care providers who have expertise in caring for pediatric conditions and approves facilities with a higher level of pediatric staffing for the provision of those services. Specific conditions are followed in Special Care Centers with multidisciplinary staffing and supervision. About 80,000 children receiving CCS services are enrolled in Medi-Cal managed care.

For most Medi-Cal managed care plans, CCS services are "carved out"; children with CCS conditions receive their primary and preventive care through the Plan, and care for

the CCS condition through the local CCS program. The carve-out is intended to assure care by sub-specialists and teams experienced in the care of rare or complex conditions, allow continuity of providers irrespective of payment source, and remove any fiscal incentives for limitation of services.

Plans are required to implement MOUs with local CCS programs, develop procedures to identify, refer, and track enrollees, and coordinate care with CCS. CCS provides listings of approved facilities and paneled providers, and plans are expected to identify CCS paneled providers within their organizations to maintain continuity of care.^{xxix}

Challenges in Coordination with CCS

- *Shortages of pediatric specialists*
- *Low provider reimbursements*
- *Unclear roles in diagnostic work-up*
- *Lack of PCP training about CCS*
- *Variability in plan and CCS processes*
- *CCS staff shortages*
- *Emergency coverage confusion*
- *Inadequate transition out of CCS*
- *Uneven communication between CCS and primary care provider*

Differences among plans and local CCS programs, and lack of provider education about Medi-Cal and CCS policies, create confusion for providers which can result in referral, eligibility, authorization, payment, and service delays. State billing and payment procedures add to provider frustration. State approved rates for sub-specialists may be lower than plan rates, in spite of an additional modification to state rates when the services are approved by the CCS program. Urgent or emergent care by non-paneled providers or facilities becomes problematic because of timely referral or payment issues. For a variety of reasons, primary care providers may be unaware of a child's participation in CCS.

Task Force Recommendations on Coordination with California Children's Services

- ***Increase provider education on CCS referral and authorization policies and requirements.***
- ***Increase provider reimbursements and simplify CCS paneling process***
- ***Institutionalize multiple mechanisms for CCS/Plan communication and info-sharing.***
- ***Clarify coverage for emergency services and transition services***
- ***Clarify provider/plan/CCS roles in diagnosis, case management, and care coordination.***
- ***Develop mechanisms to ensure PCP awareness of patients' CCS services.***
- ***Decrease variation in local policies/procedures regarding eligibility, authorization, payment.***
- ***Streamline claims payment process and consider mechanisms to take provider out of middle of funding disputes.***

CARE COORDINATION FOR CHILDREN IN FOSTER CARE

There are over 96,000 children in foster care in California, with about 35,000 new cases each year. These are children who have been removed from their homes due to substantiated abuse or neglect. Children in foster care have a higher prevalence of physical, developmental, dental, substance abuse, and behavioral health problems than any other group of children. 60-80% of children in foster care require ongoing medical treatment and have mental health problems.^{xxx}

Children in the foster care or adoption assistance programs can voluntarily enroll in Medi-Cal managed care plans, but are exempt from mandatory enrollment, except in those counties with County Organized Health Systems. The California Departments of Social Services (CDSS) and Health Services (DHS) have recently implemented several programs which have significantly improved health care for children in foster care. The Health Care Program for Children in Foster Care employs 211 Public Health Nurses in addition to nurses employed by county child welfare agencies – who work collaboratively with social services and probation staff to coordinate the delivery of health services to children in foster care. The CDSS Child Welfare Services Case Management System (CWS/CMS) is a database which stores information on each child in the child welfare program throughout the 58 counties in California.

Health Care Challenges for Children in Foster Care

- *High prevalence of health and mental health problems*
- *Multiple systems involved (health, child welfare, juvenile justice, mental health)*
- *Many transitions in living and health arrangements*
- *Eligibility system doesn't address transitions quickly*
- *Coordination and continuity (of care and medications) among counties difficult when children move*

However, due to the transient nature of this population, major challenges persist in providing comprehensive coordinated health care and continuity of care in the Medi-Cal managed care model. Placement out of the county of origin often results in delays and access problems for children in foster care; anecdotally, this may be especially difficult for children in County Organized Health Systems counties. Access and coordination of care continue to be problematic at times of transition, which children in foster care experience with frequency. Coordination among different Plans, CCS offices, and county mental health offices is especially difficult with between-county moves, including barriers to continuing access to psychiatric medications. Transition at the time of emancipation requires special attention. A Health and Education Passport (HEP), part of the CSW/CMS, facilitates sharing of information as the child and foster parent interacts with multiple systems, such as social services, probation, juvenile justice, education and public health.^{xxxi} While the HEP provides a mechanism for improved continuity of care, it requires considerable resources to keep updated.

Task Force Recommendations on Care Coordination for Children in Foster Care

- ***Implement eligibility system changes to address delays associated with changes in residency, including more rapid processing of expedited disenrollment with out of county placement.***
- ***Designate plan foster care liaison to coordinate with Foster Care Public Health Nurses.***
- ***Expand public health nursing programs in child welfare agencies.***

CARE COORDINATION WITH SCHOOLS

School health services include screening (vision, hearing, scoliosis, TB) and assessment, nursing services, and specialized physical health care services for children with medical needs. Schools also provide mental health and special education services, including development of Individual Education Plans. Schools are particularly well situated for early detection of some problems, such as developmental delays, substance abuse, hearing, speech, and vision problems, and behavioral or emotional problems. However, much of the health care provided in schools is provided by unlicensed assistive personnel with limited training. Only about ½ of schools statewide have on-site staff with health training; still fewer schools have school-based clinics, most of which are located in high schools.

Coordination with schools can be challenging due to limited resources and the wide array of services provided. Plans may need to coordinate with a large number of school districts and special education programs, each of which has its own forms, policies, and procedures.

There are a variety of opportunities for Medi-Cal managed care plans to coordinate with local education agencies and schools. Plans can contract with school districts to reimburse for EPSDT and other preventive and primary care services. School districts can use medical consultants to facilitate coordination of care among schools and providers, and can include informed consent forms in school registration packets.

Task Force Recommendations for Coordination with Schools

- ***Develop tools for information exchange among schools, plans, and providers, and encourage plan-school communication .***
- ***Encourage plans to contract with school based clinics.***

A compelling conceptual framework for care coordination for CSHCN has been developed by The National Initiative for Child Health Quality (NICHQ[®]) and the Center for Medical Home Improvement. The Care Model for Child Health in a Medical Home integrates Dr. Ed Wagner's Chronic Care Model with the concept of the Medical Home.^{xxxii} (see Table One)

In this model, community resources partner with the health care system to create community systems of support for CSHCN and their families. The health system adopts effective performance improvement models, fosters family participation, and provides incentives and supports for primary care providers in their care of CSHCN. CHSCN and families play an active and central role in managing care needs. The delivery system provides streamlined access to preventive and special services, and offers a CSHCN care coordinator for continuous, culturally-sensitive, comprehensive care coordination. Information is shared, with sensitivity to confidentiality and parental consent, among care providers. Providers are supported and encouraged in their use of evidence-based care. Clinical information systems are available to maintain a registry of CSHCN, monitor the quality of care, and provide feedback to family and providers for quality improvement efforts.

CONFIDENTIALITY

Comprehensive care coordination requires sharing of information among the multiple agencies and health care professionals that are providing services for a child. Appropriate sharing of information: allows streamlined coordination of benefits, prevents duplication of services, protects against medical errors and adverse drug interactions, relieves families of the responsibility of repeatedly providing full medical histories, facilitates the provision of a medical home, and hastens provider reimbursement.

Yet patients and families are legitimately concerned that people who do not need medical information will access it, or that the information will be used in ways that are deleterious to a child's well-being (e.g. labeling a child in school, mental health stigma). Balancing the need for sharing information with concerns about confidentiality emerged as a major theme in Task Force discussions of care coordination for CSHCN.

A confusing multiplicity of Federal and State laws govern the exchange of confidential health and medical information, including: the Confidentiality of Medical Information Act, the Lanterman-Petris-Short Act (public mental health system), the Lanterman Developmental Disabilities Services Act (Regional Center clients), federal Confidentiality of Alcohol and Drug Abuse Patient Records provisions, federal regulations on mental health information, California Education Code sections on school and school counseling records, provisions related to juvenile court records, and special protections for adolescent sensitive services.^{xxxiii}

These laws have been implemented in order to protect medical privacy, and to maintain a healthcare environment in which patients feel free to share sensitive information with

their providers without fear that it will be used in ways they do not want. Informed consent is always the best framework for sharing information. Many patients and families do not clearly understand how information will be used, whom it will be shared with, or why information exchange may benefit a child.

Currently, federal and state laws protecting confidentiality do allow for the sharing of information for the purpose of facilitating and coordinating the provision of care and administering State-funded benefits. Increased education of patients/families, providers, and agency staff about confidentiality and the use of standardized consent forms could facilitate information exchange. Implementation of a standardized CSHCN “health passport” or “parent notebook” would also help. But legislative clarification is also needed, to more explicitly allow for information sharing among providers and agencies caring for the same individual, consistent with HIPAA requirements.

Task Force Recommendations on Information Exchange for Improved Care Coordination

- ***Clarify that State laws allow sharing of information among providers of care for CSHCN for purposes of improving care coordination and quality of care.***
- ***Develop a standardized informed consent.***
- ***Implement a parent-held standardized tool for information sharing: a “health passport” or parent notebook***
- ***Educate patients and families about the reasons and mechanisms for sharing information.***
- ***Educate providers and agencies about the importance of information sharing as allowed under state and federal laws.***

Nurturing a culture of collaboration among all who provide care for CSHCN must be a top priority if the barriers to coordinated high quality care are to be eased and California is to move toward the Care Model for Child Health in a Medical Home. While the Task Force heard many inspiring stories about agencies that are genuinely working together to improve care, there remains a pervasive distrust that hinders true collaboration. Mutual respect may be the foundation for improved trust, recognizing each of the many agencies that care for CSHCN brings its own special expertise to the table. Developing an appreciation for each other’s expertise requires continued education and communication. Although laws cannot force people to trust or respect one another, requiring the development of inter-organizational structures within which communication can flower may be an important step in improving care coordination. At the State level, a thoughtful effort to carefully clarify the roles and responsibilities of each agency in each area of confusion or overlap (e.g. screening, consultation, care coordination) is much needed. The critical role of families in providing care for CSHCN must be recognized and integrated into each of the systems of care that provide CHSCN services, and in the care coordination model.

Summary of Task Force Recommendations on Coordination of Care

- *Clarify agency roles and responsibilities with respect to identification, screening, referrals, assessment, treatment, and care coordination.*
- *Require that all agencies serving CSHCN and plans – at the state and local levels - meet regularly and share information (as allowed by confidentiality laws) to ensure identification, access to care, coordination of services, and quality improvement.*
- *Clarify policies and increase consistency of policy administration and processes across counties for program eligibility determination, referrals, information sharing, authorization, and payment.*
- *Improve State agency mechanisms for sharing data, and Plan-agency data sharing, within confidentiality laws.*
- *Clarify that State laws allow sharing of information among providers of care and services for CHSCN for purposes of improving care coordination and the quality of care.*
- *Develop a standardized consent form.*
- *Implement and promote a standardized parent/caretaker held tool(a “health passport” or parent notebook) to facilitate information sharing and encourage the use of a written care plan with input from the family and all of a child’s providers.*
- *Develop reimbursement mechanisms that do not delay payment and that don’t put families in the middle.*
- *Educate parents and providers about the importance of sharing information with all providers.*
- *Provide information and training on care coordination to families, providers, plans, and agencies.*
- *Require that plans designate CSHCN care coordinators who are available to participate in the coordination of care so that the needs of all CSHCN are appropriately met.*
- *Require inclusion and partnering with families in all aspects of the child’s health care plan at the agency, Plan, and provider levels.*
- *Implement a cross-agency program to train and support providers on CSHCN screening, primary care treatment, and referral for mental health, developmental, and substance abuse problems.*
- *Implement payment strategies (e.g. pay for care coordination activities, risk adjustment) which allow fair reimbursement for time and resources devoted to care coordination for CSHCN.*
- *Develop pilot projects for integrated care coordination, e.g., lead care coordinator who can work across systems of care, or blended funding streams for CSHCN.*

MEASURING THE QUALITY OF CARE for CSHCN

The Institute of Medicine defines quality as “*the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.*”^{xxxiv} Numerous studies have documented serious quality issues in U.S. health care, including: underuse, overuse, and misuse; variable and unpredictable performance; poor compliance with best practices; poor chronic disease care; medical errors; and severe inequities in access.^{xxxv}

Measuring the quality of care is fundamental to health care accountability and improvement. Quality information helps consumers make informed choices, allows purchasers and taxpayers to evaluate whether the huge resources invested in health care are well-spent, helps policymakers monitor health system performance, and both encourages and helps providers and Plans improve the quality of care.

The health care needs of CSHCN differ from those of other children. CSHCN generally have increased exposure to the health care system; 80% of health care costs for children are for CSHCN. Yet little is known about the quality of care for CSHCN.^{xxxvi} Measuring the quality of health care for CSHCN is especially challenging because there are often small numbers of children with any one condition, and there may not be evidence-based guidelines available. Operationalizing important concepts – such as “medical home” and continuity of care is also difficult. The fragmented delivery system, in which CSHCN may receive care in multiple systems, also makes it especially difficult to assess the quality of care, because it is more difficult to ascertain which services have been received. Also, when many providers and agencies are involved in care, each must be held accountable only for that care for which they are responsible.

<i>Dimensions of Quality</i>	
<u><i>Components of Quality</i></u>	<u><i>Needs of Consumers</i></u>
<i>Safety</i>	<i>Staying Healthy</i>
<i>Effectiveness</i>	<i>Getting Better</i>
<i>Patient Centeredness</i>	<i>Living with Illness</i>
<i>Timeliness</i>	<i>Coping with End of Life</i>
<i>Equity</i>	
<i>Efficiency</i>	

Selecting quality measures requires decisions about what and who to measure, and what indicators to use. Ideally, measures are meaningful to users, measure things that are worth measuring, and are feasible, valid and reliable, and able to discriminate among different levels of performance. The National Health Care Quality Report Framework for quality measurement defines two dimensions of quality: quality components, and health care needs of consumers.^{xxxvii}

Quality measurement uses many sources of data, each with strengths and weaknesses. Administrative (claims/encounter) data is relatively easy to obtain, but may be

incomplete or inaccurate. Medical records review provides a lot of detail, but is time consuming and expensive; for CSHCN, it is hard to track down multiple records from different providers and systems of care. Patient or family surveys are uniquely able to provide information on the patient perspective, and on function and outcomes; however, surveys are also expensive, and getting adequate response rates is difficult.

There are many individual aspects of quality which would be important to measure for CSHCN, including but not limited to: access to specialists, durable medical equipment, drugs; occurrence of screening for special needs, developmental disabilities, mental health; family involvement and satisfaction; access to a medical home and family support services; availability of a written care plan; provision of routine preventive services and well child care; adherence to evidence-based guidelines (e.g. asthma, diabetes); general and school-related functioning; services utilization; cultural/linguistic services and effectiveness; and satisfaction of caregivers with coordination of care.

The Child and Adolescent Health Measurement Initiative (CAHMI) developed a supplemental module for the Consumer Assessment of Health Plans Survey (CAHPS[®]), a standardized, validated tool which has been incorporated by the National Committee for Quality Assurance into its Health Plan Employer Data and Information Set (HEDIS[®]). HEDIS[®] is a set of quality measures used in accreditation of managed care plans, and by many purchasers, including Medi-Cal, to assess plan quality.^{xxxviii}

The CAHPS survey is administered to families by mail and/or by phone. Nine children with special needs measures can be constructed from data collected using the CSHCN module.^{xxxix} Additionally, the Child CAHPS with the CSHCN module can also be used to construct a measure of Medical Home, to assess the extent to which CSHCN have accessible, family-centered, comprehensive, coordinated, compassionate, and culturally effective care.^{xl}

CAHPS[®] Child Health Survey with CSHCN Module

- *Doctors Who Communicate*
- *Getting Care Quickly*
- *Getting Needed Care*
- *Courteous and Helpful Office Staff*
- *Customer Service and Information*
- *Access to Specialized Services*
- *Access to Prescription Drugs*
- *Family Centered Care*
- *Coordination of Care*

Task Force Recommendations on Measuring Quality of Care

- ***Implement a core CSHCN measure set, including the CAHPS CSHCN survey and other CSHCN-relevant HEDIS measures, to annually assess access, care coordination, and parent and child experience of care in Medi-Cal managed care plans***
- ***Report on quality measures in ways that maximize value for plans, providers, and state agencies.***

QUALITY IMPROVEMENT

Quality improvement is a systematic program to better the level of system performance through enhancing efficiency and consistency, eliminating defects, and achieving new levels of performance. The specific aims of health care are to be safe, effective, efficient, timely, family centered, and equitable. Improving the quality of health care requires attention at all levels – the patient/family, the provider, the health care organization and system, and the policy environment. Sometimes even very simple changes (e.g. in office systems) can have big impacts on quality. Quality improvement also requires awareness of the need for improvement, leadership and organizational commitment to improvement, ideas for improvement, and support for change. Key challenges for providers and Plans in implementing quality improvement programs include lack of time, money, and resources, non-recognition of the need for improvement, and the lack of incentives (financial and non-financial) for improvement.

One example of an idea for improvement is the model for child health care presented earlier. The Plan-Do-Study-Act Cycle for learning and improvement is a model for quality improvement that has been demonstrated to be effective in improving child health care and care for CSHCN.^{xli}

Task Force Recommendations on Quality Improvement for CSHCN

- ***Implement payment strategies to ensure fair, timely, and appropriate reimbursement of plans and providers for time and resources required for quality care and care coordination for CSHCN, based on the prevalence and burden of service needs of their population (e.g. streamline payment, increase reimbursement, risk adjustment, pay for assessments and coordination).***
- ***Offer incentives (financial and non-financial) to plans and providers for quality improvement.***
- ***Provide resources for QI through adequate reimbursement for CSHCN care.***
- ***Implement Quality Improvement collaboratives to improve the care of CSHCN***

BALANCED BUDGET ACT - MEDICAID MANAGED CARE FINAL RULES

The final Medicaid Managed Care Rules implementing the Balanced Budget Act of 1997 were published on June 14, 2002, replacing previously published rules and an earlier State Medicaid Director Letter on CSHCN. The final rules permit a greater degree of state flexibility in many areas. The rules require that State Medicaid agencies: define individuals with special needs, assess the quality of care for those individuals, identify enrollees with special needs, provide for coordination and continuity of care and direct access to specialists, and set actuarially sound capitation rates.^{xliii}

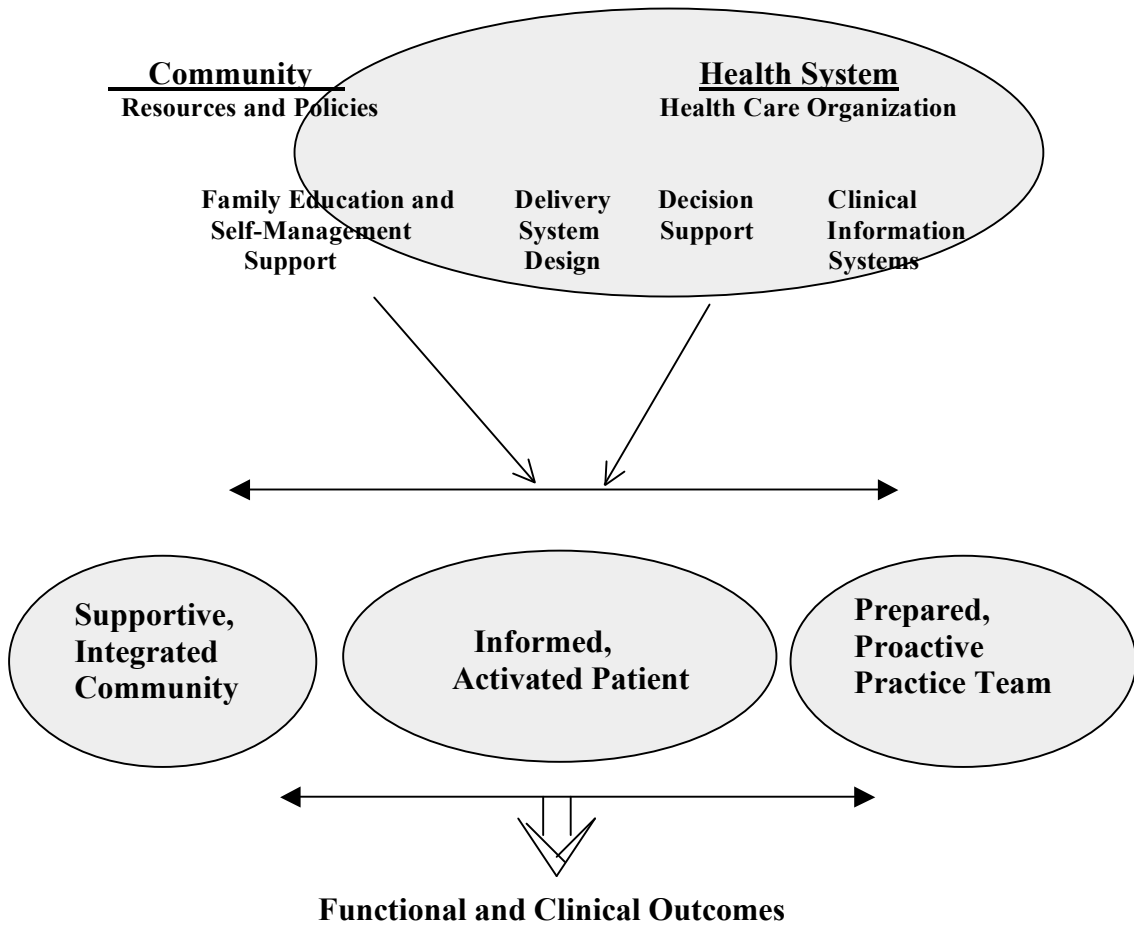
CONCLUSION

CSHCN are one of the most vulnerable groups in our society. Providing them with the comprehensive, coordinated, family-centered care they need is a high priority. The Medi-Cal Managed Care Task Force on Children with Special Health Care Needs, comprised of representatives from managed care plans, providers, families, advocacy organizations, and agencies that provide services for CSHCN, met over the past year to discuss challenges and opportunities for improving the care of CSHCN.

Despite philosophical differences in individual perspectives about current and proposed child health care service systems, the Task Force agreed on a variety of key steps that must be taken to improve care for CSHCN within the context of the current structure of Medi-Cal Managed Care. It is incumbent on the Medi-Cal Managed Care Division, Plans, other State agencies, and provider and advocacy organizations to continue working together to implement these recommendations.

Table One

Care Model for Child Health in a Medical Home



CMHI/NICHO®

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FEDERAL LEGISLATION AND REGULATORY CITATIONS

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Social Security Act

1915(c)(8) The State agency administering the plan under this Title may, whenever appropriate, enter into cooperative arrangements with the State agency responsible for administering the program for children with special health care needs under Title V in order to assure improved access to coordinated services to meet the needs of such children.

42 Code of Federal Regulations

438.204 Elements of State quality strategies

At a minimum, State strategies must include the following:

...

(b) Procedures that--

(1) Assess the quality and appropriateness of care and services furnished to all Medicaid enrollees under the MCO and PIHP contracts, and to individuals with special health care needs.

438.208 Coordination and continuity of care.

(a) Basic requirement--(1) General rule. Except as specified in paragraphs (a)(2) and (a)(3) of this section, the State must ensure through its contracts, that each MCO, PIHP, and PAHP complies with the requirements of this section.

...

(b) Primary care and coordination of health care services for all MCO, PIHP, and PAHP enrollees. Each MCO, PIHP, and PAHP must implement procedures to deliver primary care to and coordinate health care service for all MCO, PIHP, and PAHP enrollees. These procedures must meet State requirements and must do the following:

(1) Ensure that each enrollee has an ongoing source of primary care appropriate to his or her needs and a person or entity formally designated as primarily responsible for coordinating the health care services furnished to the enrollee.

(2) Coordinate the services the MCO, PIHP, or PAHP furnishes to the enrollee with the services the enrollee receives from any other MCO, PIHP, or PAHP.

(3) Share with other MCOs, PIHPs, and PAHPs serving the enrollee with special health care needs the results of its identification and assessment of that enrollee's needs to prevent duplication of those activities.

(4) Ensure that in the process of coordinating care, each enrollee's privacy is protected in accordance with the privacy requirements in 45 CFR parts 160 and 164 subparts A and E, to the extent that they are applicable.

(c) Additional services for enrollees with special health care needs.

(1) Identification. The State must implement mechanisms to identify persons with special health care needs to MCOs, PIHPs and PAHPs, as those persons are defined by the State. These identification mechanisms--

(i) Must be specified in the State's quality improvement strategy in Sec. 438.202; and

(ii) May use State staff, the State's enrollment broker, or the State's MCOs, PIHPs and PAHPs.

(2) Assessment. Each MCO, PIHP, and PAHP must implement mechanisms to assess each Medicaid enrollee identified by the State (through the mechanism specified in paragraph (c)(1) of this section) and identified to the MCO, PIHP, and PAHP by the State as having special health care needs in order to identify any ongoing special conditions of the enrollee that require a course of treatment or regular care monitoring. The assessment mechanisms must use appropriate health care professionals.

(3) Treatment plans. If the State requires MCOs, PIHPs, and PAHPs to produce a treatment plan for enrollees with special health care needs who are determined through assessment to need a course of treatment or regular care monitoring, the treatment plan must be--

(i) Developed by the enrollee's primary care provider with enrollee participation, and in consultation with any specialists caring for the enrollee;

(ii) Approved by the MCO, PIHP, or PAHP in a timely manner, if this approval is required by the MCO, PIHP, or PAHP; and

(iii) In accord with any applicable State quality assurance and utilization review standards.

(4) Direct access to specialists. For enrollees with special health care needs determined through an assessment by appropriate health care professionals (consistent with Sec. 438.208(c)(2)) to need a course of treatment or regular care monitoring, each MCO, PIHP, and PAHP must have a mechanism in place to allow enrollees to directly access a specialist (for example, through a standing referral or an approved number of visits) as appropriate for the enrollee's condition and identified needs.

438.240 Quality assessment and performance improvement program

...

(b) Basic elements of MCO and PIHP quality assessment and performance improvement programs. At a minimum, the State must require

that each MCO and PIHP comply with the following requirements:

(1) Conduct performance improvement projects as described in paragraph (d) of this section. These projects must be designed to achieve, through ongoing measurements and intervention, significant improvement, sustained over time, in clinical care and nonclinical care areas that are expected to have a favorable effect on health outcomes and enrollee satisfaction.

(2) Submit performance measurement data as described in paragraph (c) of this section.

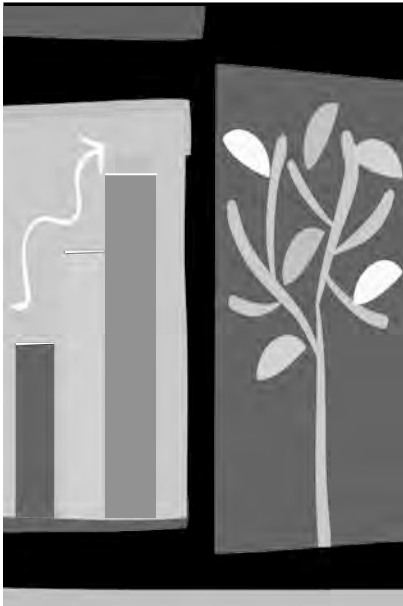
(3) Have in effect mechanisms to detect both underutilization and overutilization of services.

(4) Have in effect mechanisms to assess the quality and appropriateness of care furnished to enrollees with special health care needs.

**APPENDIX 10: SPECIALTY HEALTH CARE FOR
CHILDREN IN THE LOS ANGELES CALIFORNIA
CHILDREN'S SERVICES PROGRAM (CCS)**

**A REPORT BY MOIRA INKELAS, PHD, AND KYRA SAMSON, MD, UCLA
CENTER FOR HEALTHIER CHILDREN, FAMILIES AND COMMUNITIES,
2005**

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

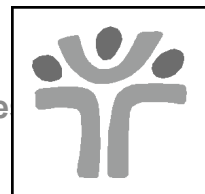


R E P O R T

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2005

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Acknowledgements

This report was made possible through the support of the California HealthCare Foundation.

The authors are grateful to Paul Newacheck of the Institute for Health Policy Studies at the University of California San Francisco and Lucy Streett and Chris Perrone of the California HealthCare Foundation. The Los Angeles CCS Survey would not have been possible without the contributions of Lisa Schoyer from the Los Angeles County Department of Health Services, Children's Medical Services program, and thanks are extended to Cheri Todoroff, Ed Bloch, and Jonathan Fielding of the Los Angeles County Department of Health Services. The author also gratefully acknowledges the contributions of Nicole Garro in the UCLA School of Public Health, Kathryn Smith at the USC University Center for Excellence in Developmental Disabilities, Childrens Hospital Los Angeles, the Family Centered Care Committee in Los Angeles CCS, and the parents who graciously volunteered their time to participate in this survey. Report content is the sole responsibility of the authors.

Table of Contents

List of Exhibits		
Executive Summary		i
Introduction		1
Methodology		3
Findings		
Part I: Characteristics of Children in CCS		6
Sociodemographic Characteristics of Children in CCS		7
Condition Severity and Impact		9
Types of Conditions		10
Part II Specialty Care		13
Specialty Care		14
Delayed and Foregone Care		19
Mental Health Services		24
Part III Medical Home		28
The Medical Home Concept		29
Setting of Health Care		30
Having a Personal Health Care Provider		30
Interpreter Services		33
Family Centered Care/Quality of Interpersonal Relationship		35
Coordination Among Physicians and Programs		36
Health Care Transitions and Self-Management for Adolescents and Young Adults		37
Part IV Care Coordination and Support from CCS		40
Ease of Service Organization		41
Care Coordination		43
Support Received from the CCS Program		45
Preferences for System Improvement		47
Conclusion		49
Appendix		53
Glossary		54
Bibliography		56

List of Exhibits

Introduction

1. Indicators of Health Care Access in Los Angeles CCS Survey

Part I: Characteristics of Children in CCS

2. Sociodemographic Characteristics of Children in Los Angeles CCS and CSHCN in California
3. Characteristics of Children in Los Angeles CCS, by Insurance Type
4. Parent Rating of Severity of Condition
5. Medical Conditions of Children in CCS
6. Frequencies of Conditions, by Insurance Type

Part II: Specialty Care

7. Problems with Specialty Care Authorization and Unmet Need, by Insurance Type
8. Reasons for Not Receiving Needed Specialty Care
9. Causes of Delayed or Foregone Care, Children in CCS and CSHCN in California
10. Having Delay/Forgone Care by Child Characteristics
11. Having Delay/Forgone Care by Child Characteristics, Within Insurance Type
12. Access to Mental Health Services
13. Counseling/Mental Health Needs and Unmet Need for Child and Family

Part III: Medical Home

14. Having a Usual Source of Care by Insurance, Los Angeles CCS and CSHCN in California
15. Location of Specialty Care, by Usual Source of Care
16. Having a Personal Physician by Usual Source of Care
17. Access to Interpreter Services
18. Family Centered Care by Child's Race/Ethnicity
19. Effectiveness of Provider Communication
20. Planning for Transition to Adult Providers, Age 13-21 Years

Part IV: Care Coordination and Support from CCS

21. Organization and Ease of Service Use
22. Reasons for Not Receiving Needed Care Coordination
23. Parents' Experiences with the CCS Program
24. Parent Preferences for System Improvement

Appendix

25. Access to Care for Children 0-17 Years, Los Angeles CCS and CSHCN in California

Executive Summary

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

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**.

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

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.

Part I

Characteristics of Children in CCS

Characteristics 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.

Exhibit 2		
Sociodemographic Characteristics of Children in Los Angeles CCS and CSHCN in California		
	Los Angeles CCS (2005)	Statewide CSHCN (2001)*
	%	%
<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.

Exhibit 3					
Characteristics of Children in Los Angeles CCS, by Insurance Type					
	Private (n=190)	Medi-Cal & private (n=482)	Medi-Cal only (n=1,099)	Healthy Families (n=157)	Uninsured (n=32)
	%	%	%	%	%
Parent education					
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
Child race/ethnicity					
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
Activities affected often/always					
Severity (mean, 0-10)	25.8	**38.5	***47.9	23.6	15.6
	6.1	5.7	*6.6	***7.2	5.8
Child age					
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

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

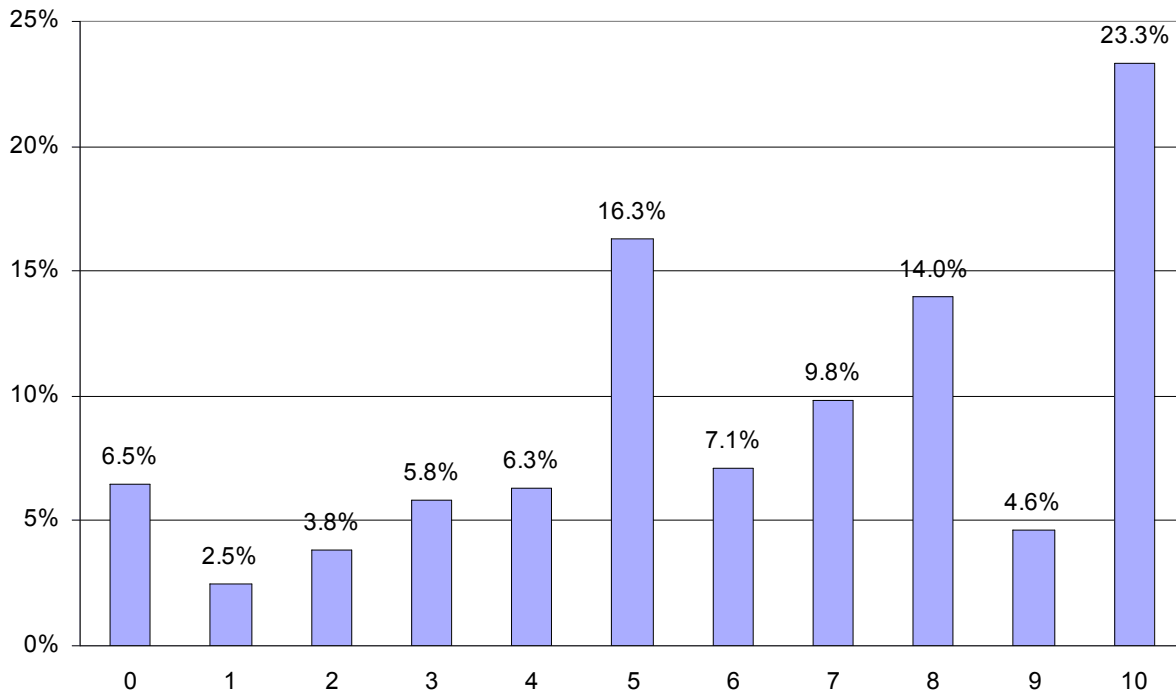
Not all CSHCN are affected in the same way by their health condition(s). Some chronic conditions, such as sickle cell anemia and asthma, are episodic and do not always affect the child in the same way each day. Other chronic conditions such as cerebral palsy tend to have the same impact on the child 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



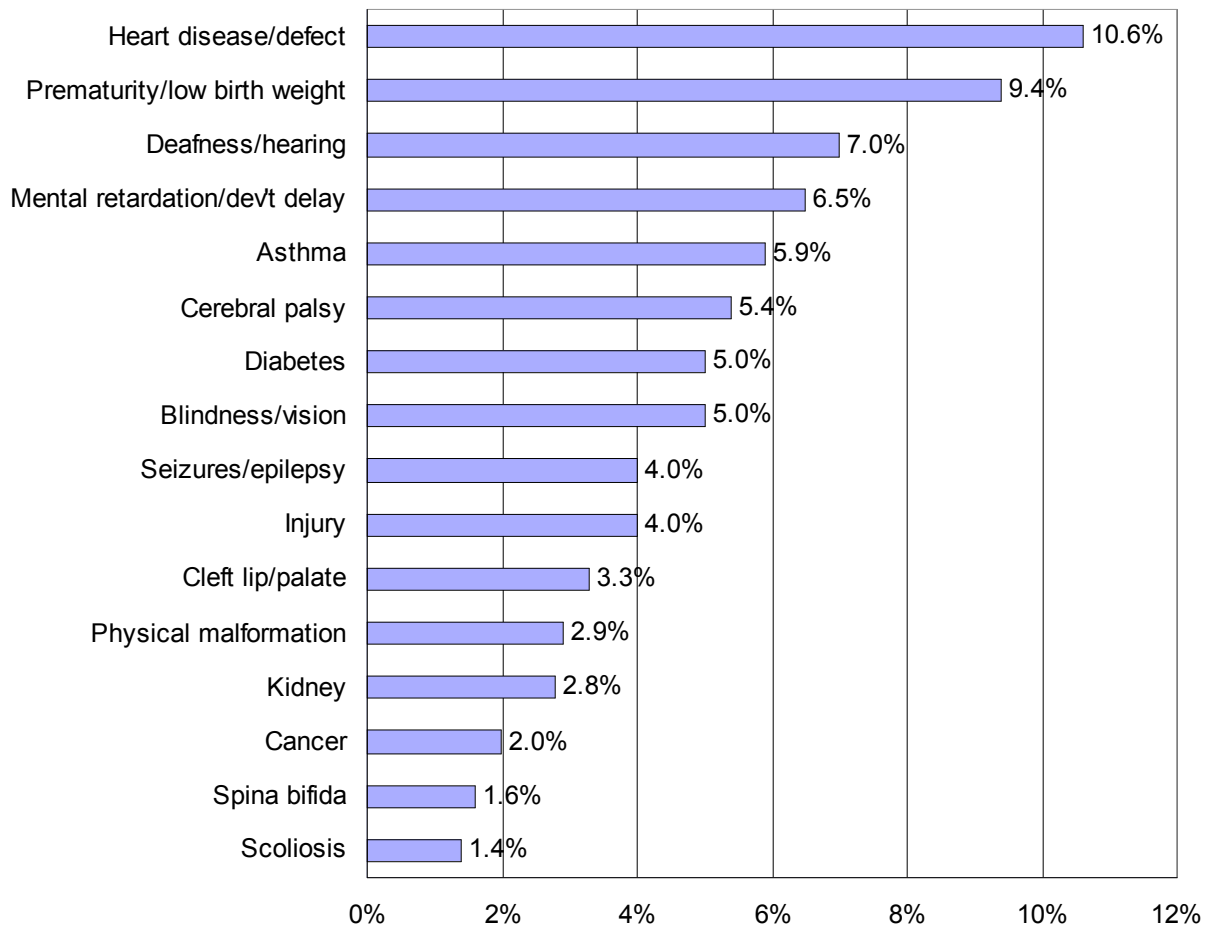
*Note: Parents rated severity of the child's condition(s) using a scale of 0-10, with 10 indicating greatest severity.
Source: Los Angeles CCS Survey, 2005*

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.

Exhibit 6				
Frequencies of Conditions, by Insurance Type				
	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

Specialty 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

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%).

Exhibit 7						
Problems with Specialty Care Authorization and Unmet Need, by Insurance Type						
	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.

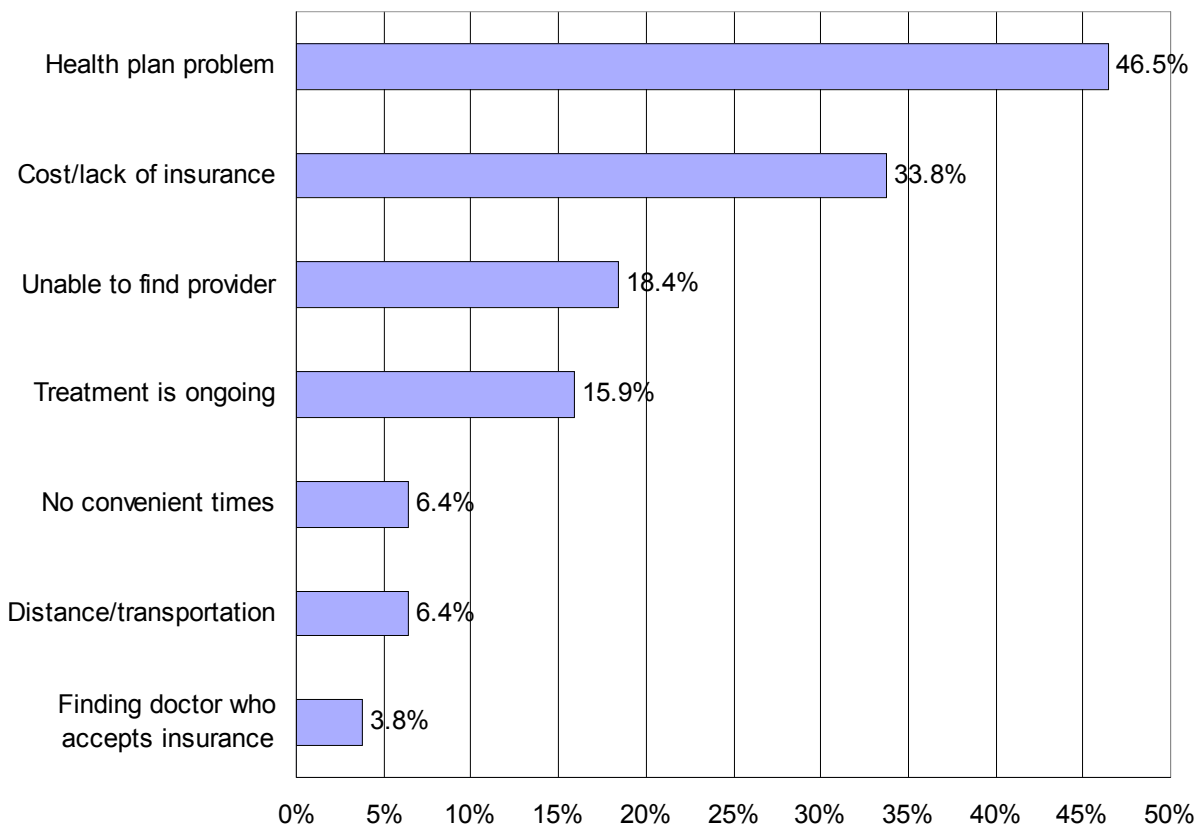
- Parents with lower educational attainment (less than high school, and high school only) reported at least twice the rate of specialty authorization problems when their child is in Healthy Families. For example, among parents with less than high school, 34.0% with a child in Healthy Families and only 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%).

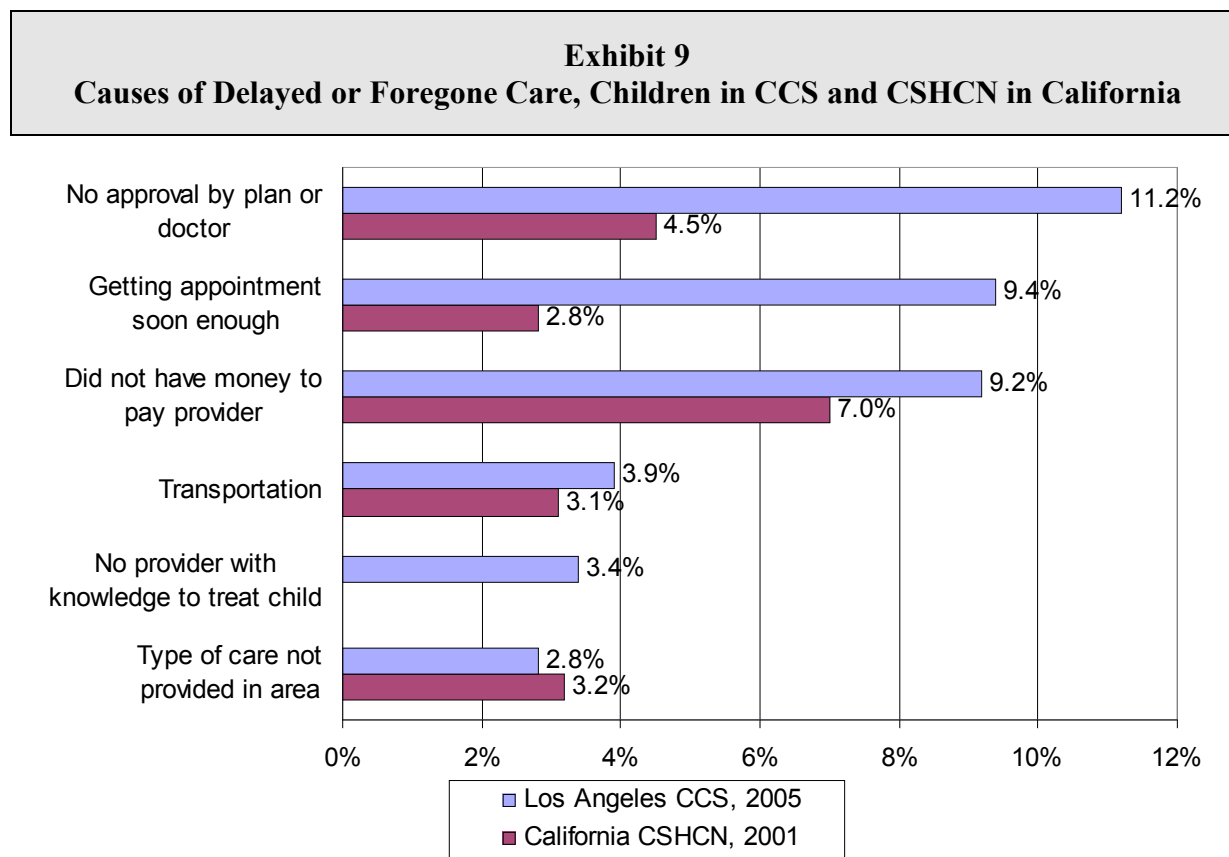
Factors other than the child's insurance coverage could influence these apparent differences. For example, parent educational attainment varies with the child's health insurance coverage and might itself influence perception of need and care-seeking, and therefore influence perceptions of needed care 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%).

Exhibit 10				
Having Delay/Foregone Care by Child Characteristics				
	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.

Exhibit 11				
Having Delay/Foregone Care by Child Characteristics, Within Insurance Type				
	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

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%).

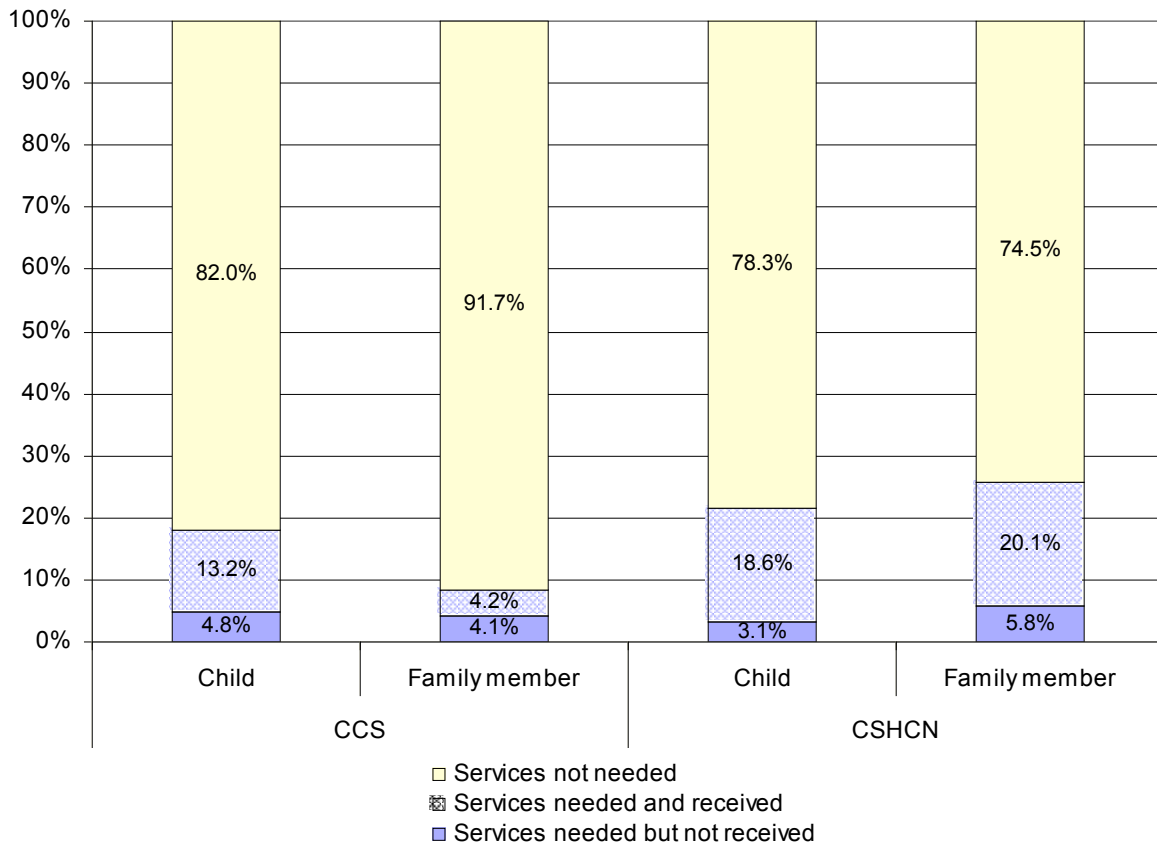
- Finding a provider was more frequently a problem for children age 0-5 years (72.2%) than for older children age 6-21 years (40.5%).
- Finding a provider or knowing where to go was much more common among children in Medi-Cal (57.4%) than among children with private coverage (17.4%).

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

Exhibit 13
Counseling/Mental Health Needs and Unmet Need, for Child and Family

	Child		Family	
	Need	Unmet need	Need	Unmet need
	%	%	%	%
Activities affected by condition				
Always/usually	***25.9	***8.0	***12.8	***6.8
Sometimes/never	13.0	3.1	5.4	2.3
Parent education				
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
Child race/ethnicity				
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
Child age				
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
Health insurance				
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

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

Medical 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.

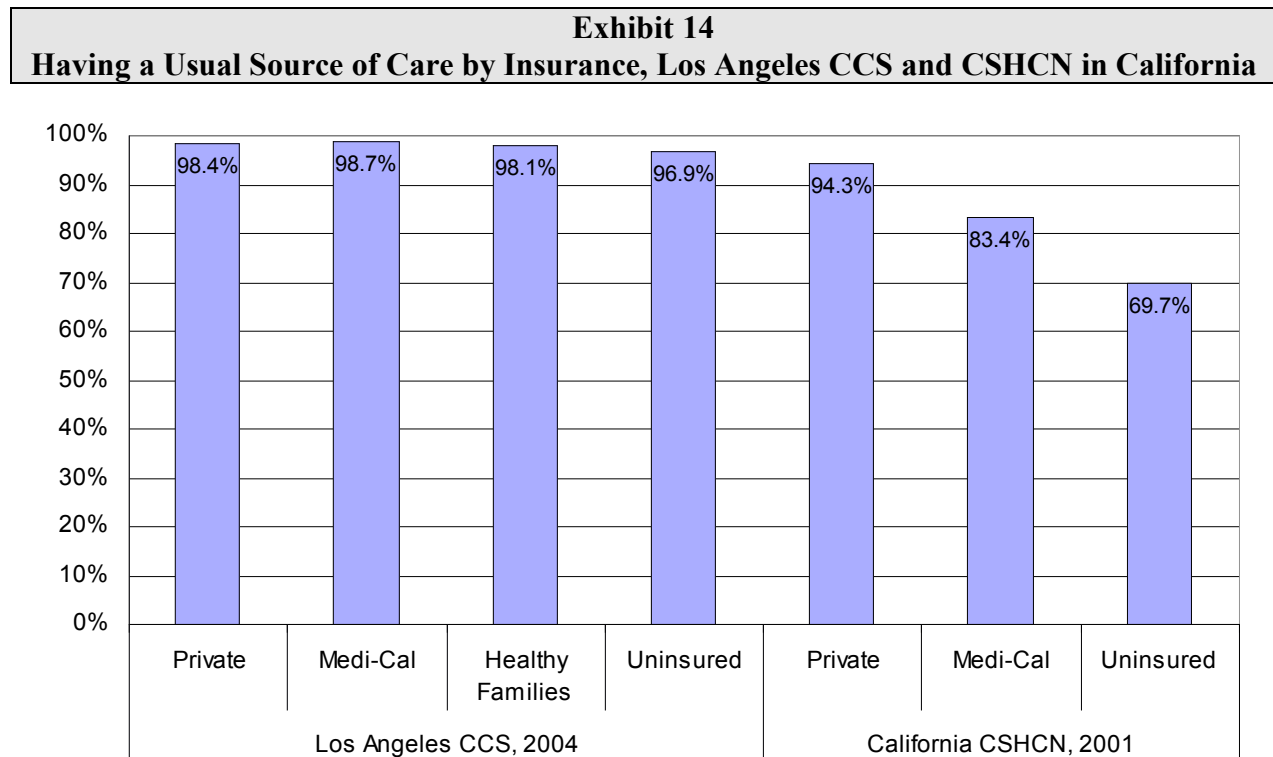
- ❖ The Medical Home Concept
 - ❖ Setting of Health Care
 - ❖ Having a Personal Health Care Provider
 - ❖ Interpreter Services
- ❖ Family Centered Care/Quality of Interpersonal Relationship
 - ❖ Coordination Among Physicians and Programs
- ❖ Health Care Self-Management and Transitions for Adolescents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

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.

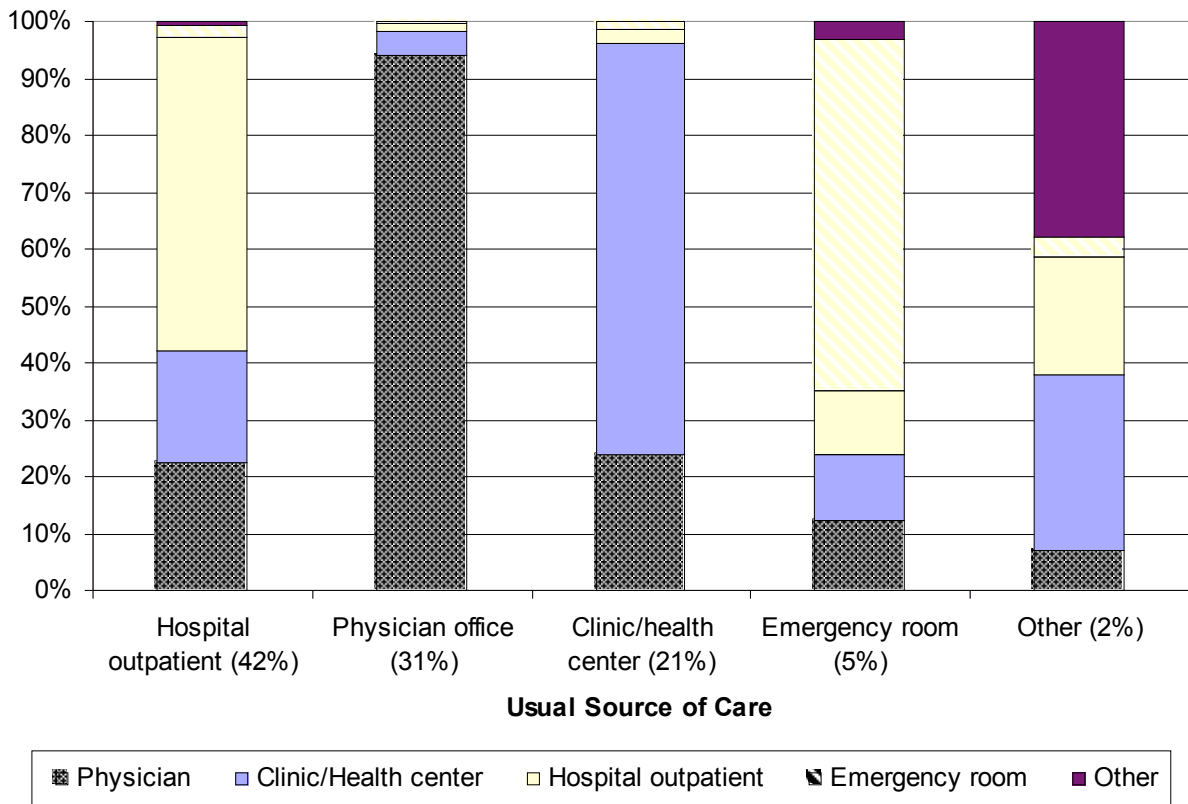
Having a Personal Health Care Provider

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

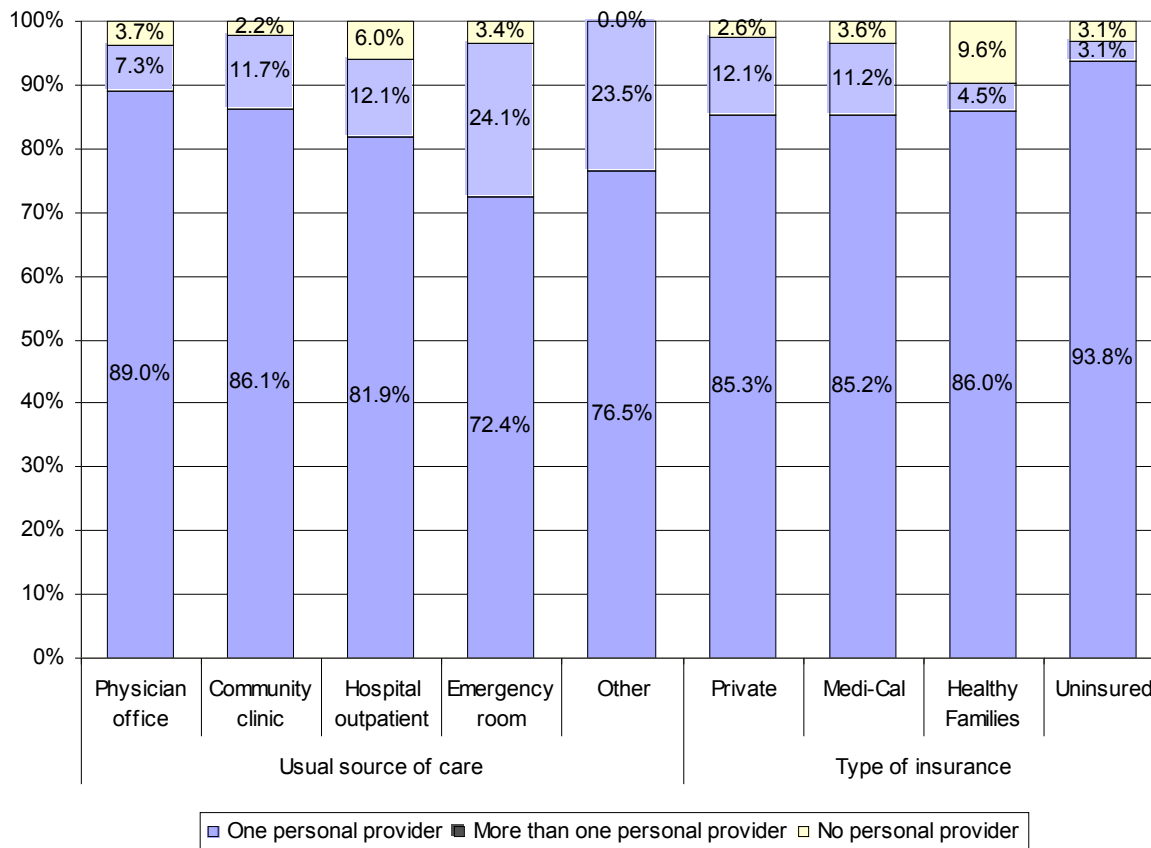


*Percentages are among children with a usual place for care when sick or advice needed about the child's health.
Source: Los Angeles CCS Survey, 2005*

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

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.

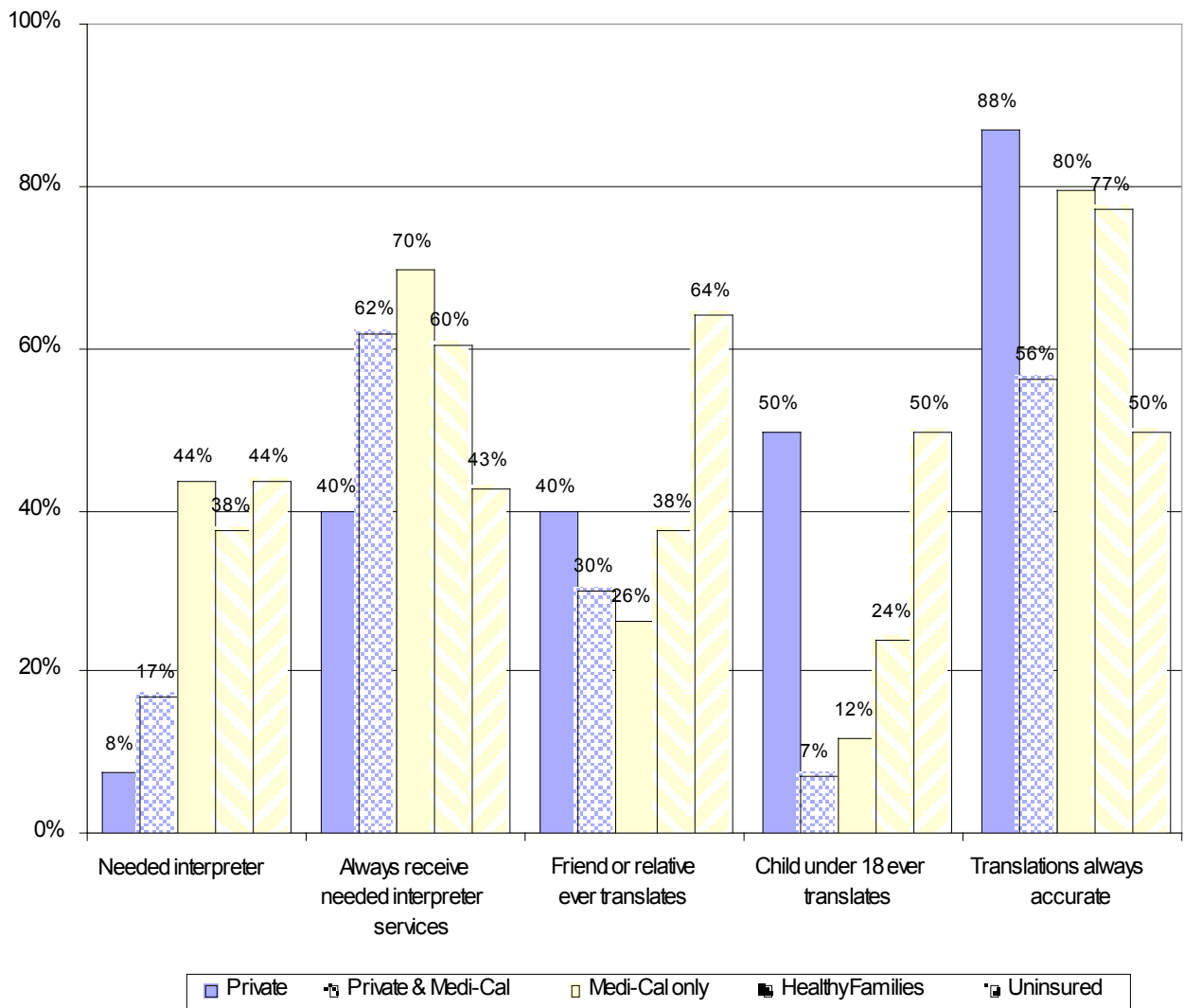
- About three-quarters (75.4%) of parents always received interpreter services when needed.
- Most parents (86%) said that they were always confident that translated information between the parent and the child’s providers (by professional interpreters, relatives, or children) is accurate. Parents are 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 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

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**).

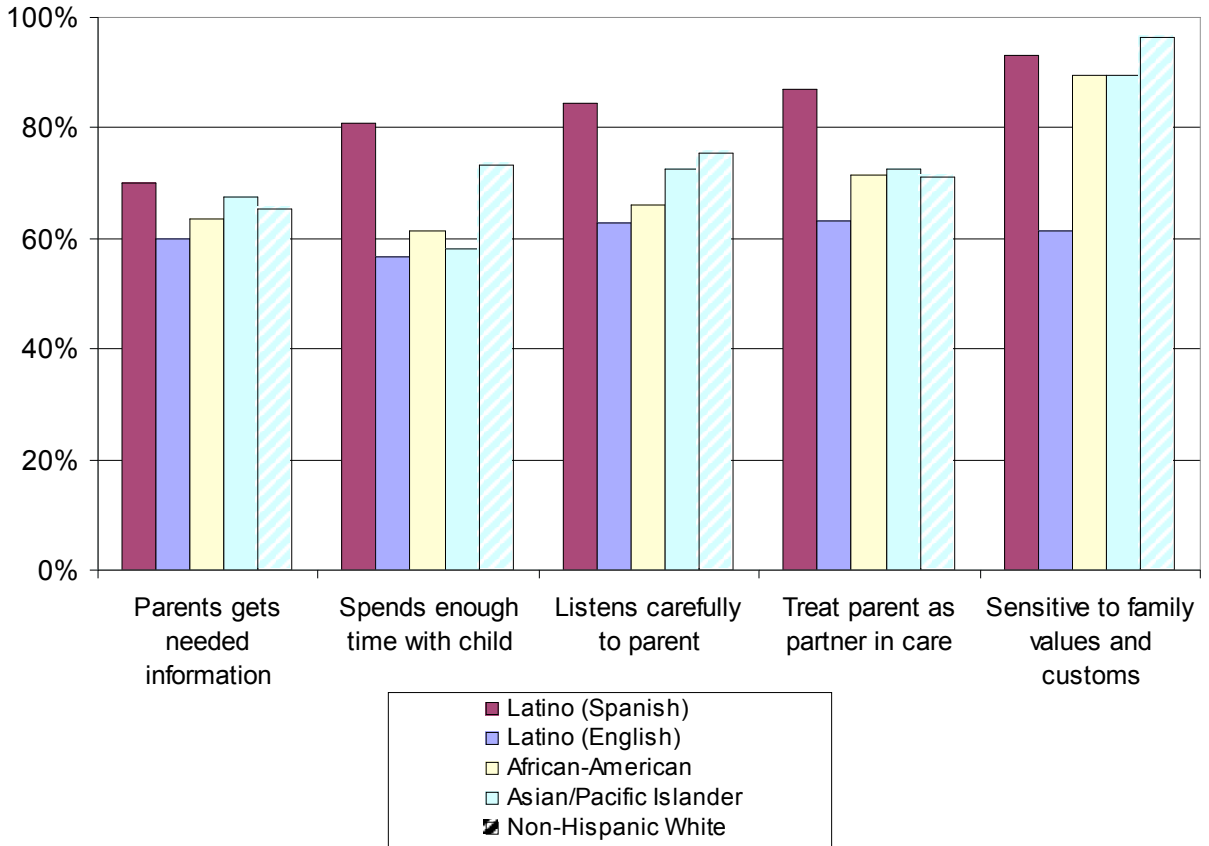
Listening carefully Nearly three-quarters of parents (72.5%) reported that their child’s providers always listen carefully to them. The highest ratings were from parents of Latino children surveyed in Spanish (84.6%) and parents of non-Hispanic white children (75.6%).

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

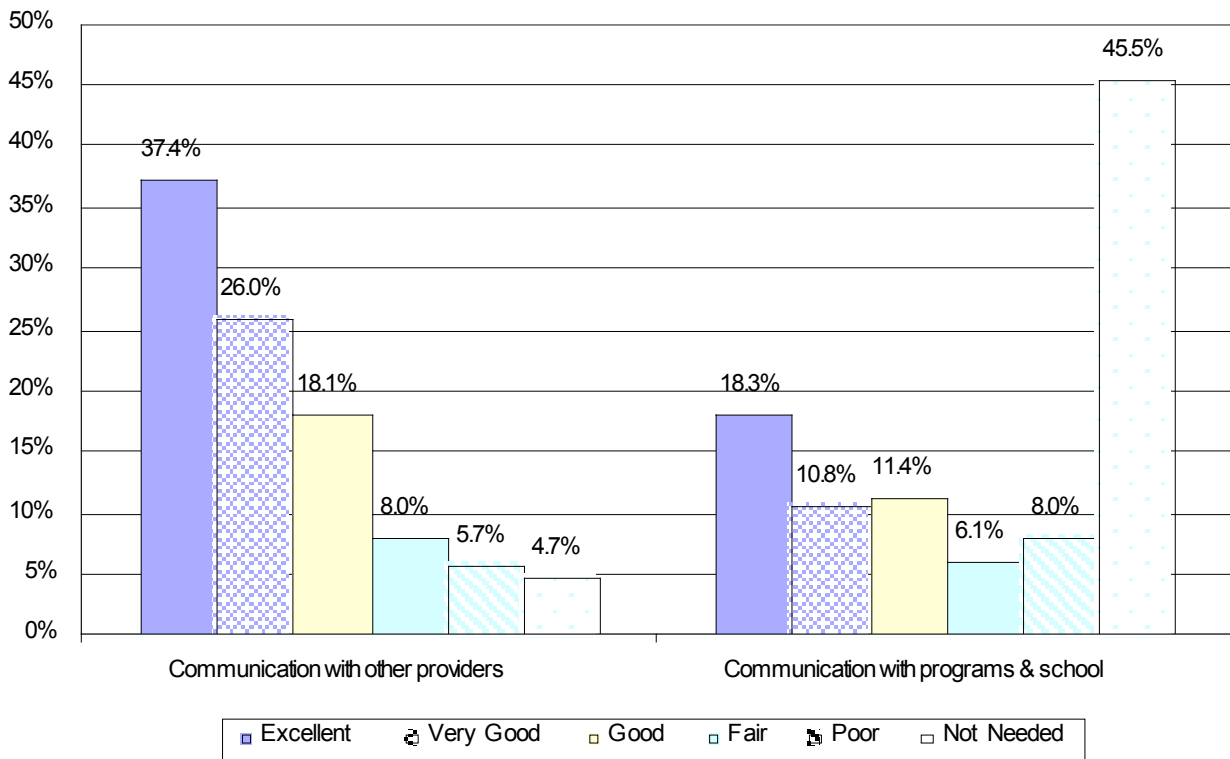
For many children, communication between the child's doctor and other health care providers, such as specialists, is important but not sufficient. Some CSHCN need treatment or special accommodations in their school or child care arrangement. This requires attention and good communication about the child's 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).

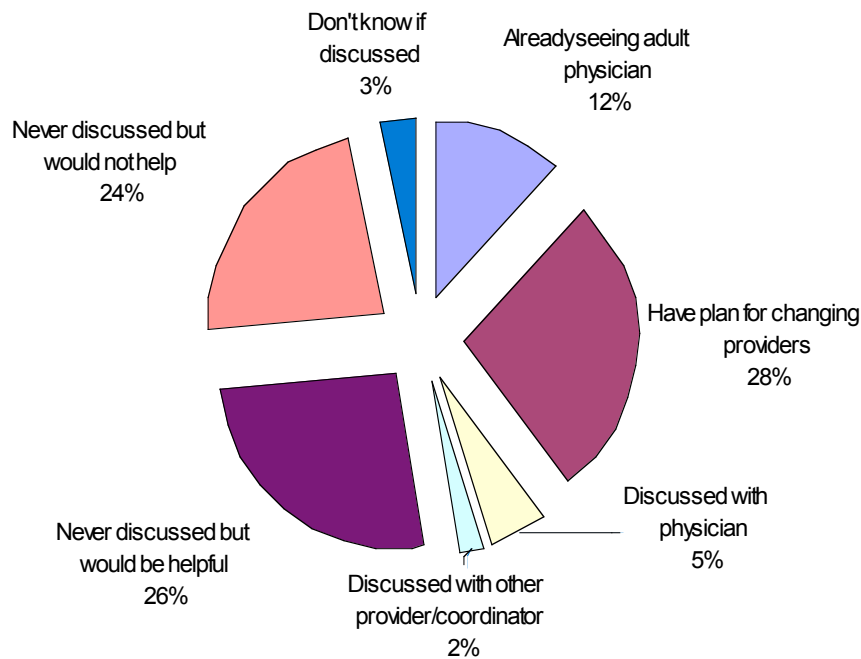
- Among young adults age 18-21, about 69.8% were always encouraged to take responsibility for self-management, which is somewhat higher than the rate for those age 13-17 years (53.5%).
- Most parents (77%) of those 13-18 years who have never been encouraged to take more responsibility said that it would 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

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.

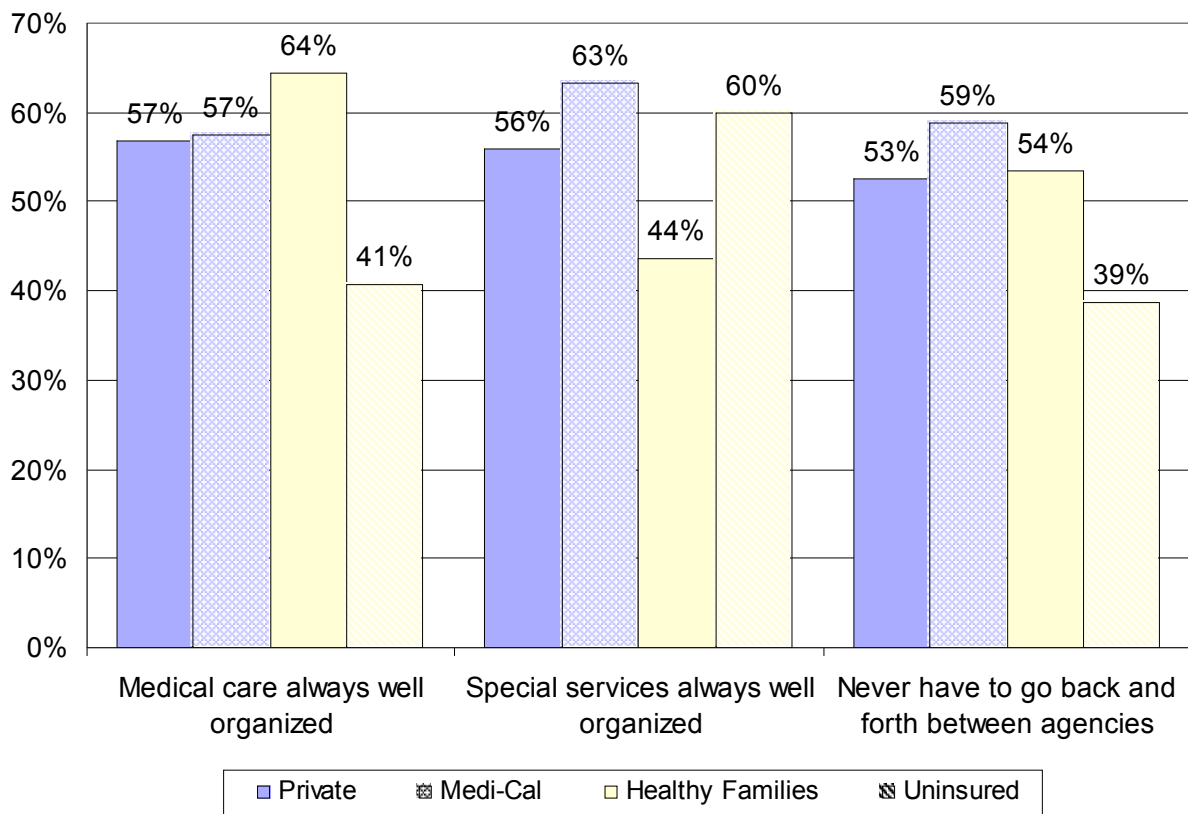
Exhibit 21 compares parent reports of organization of medical care, organization of special services (for those needing such services), and needing to go back and forth between agencies or programs, by the child's health insurance coverage.

- 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

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.

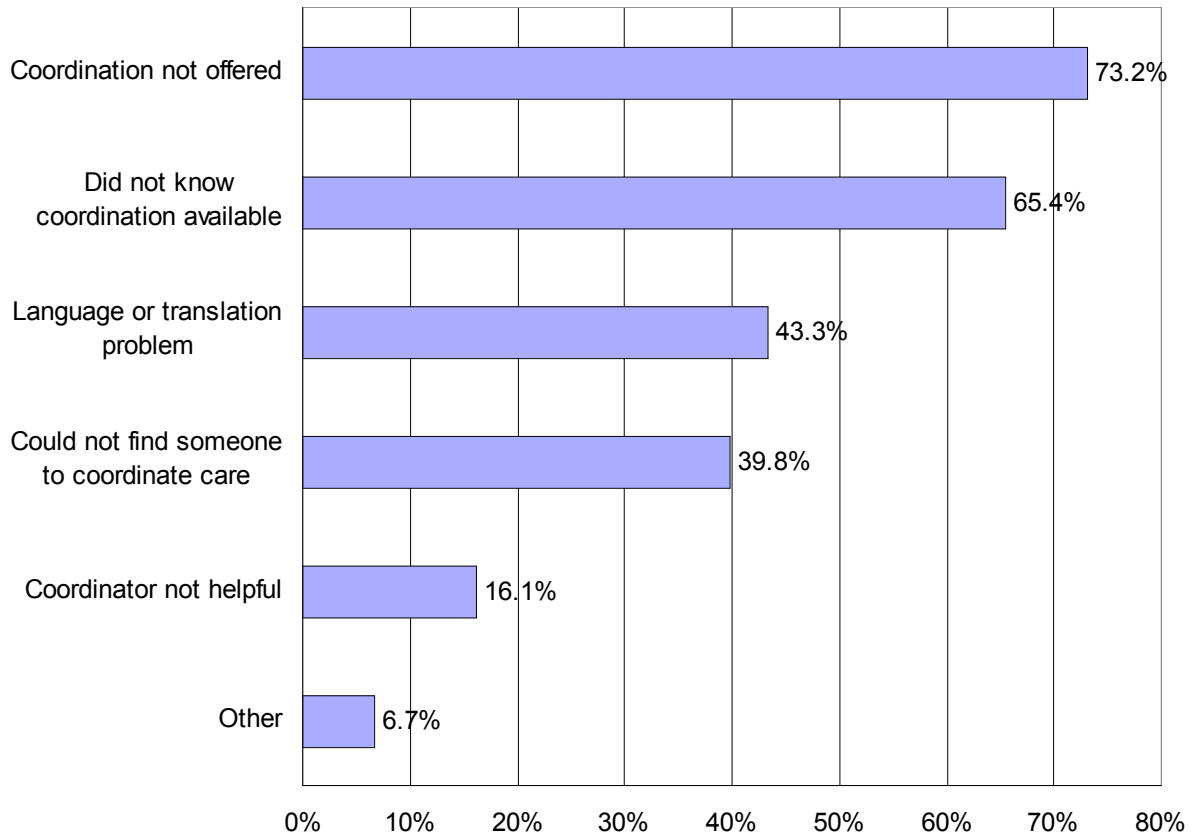
About half of parents (52.4%) said that they received help arranging or coordinating their child's medical care in the past year.

- 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

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.

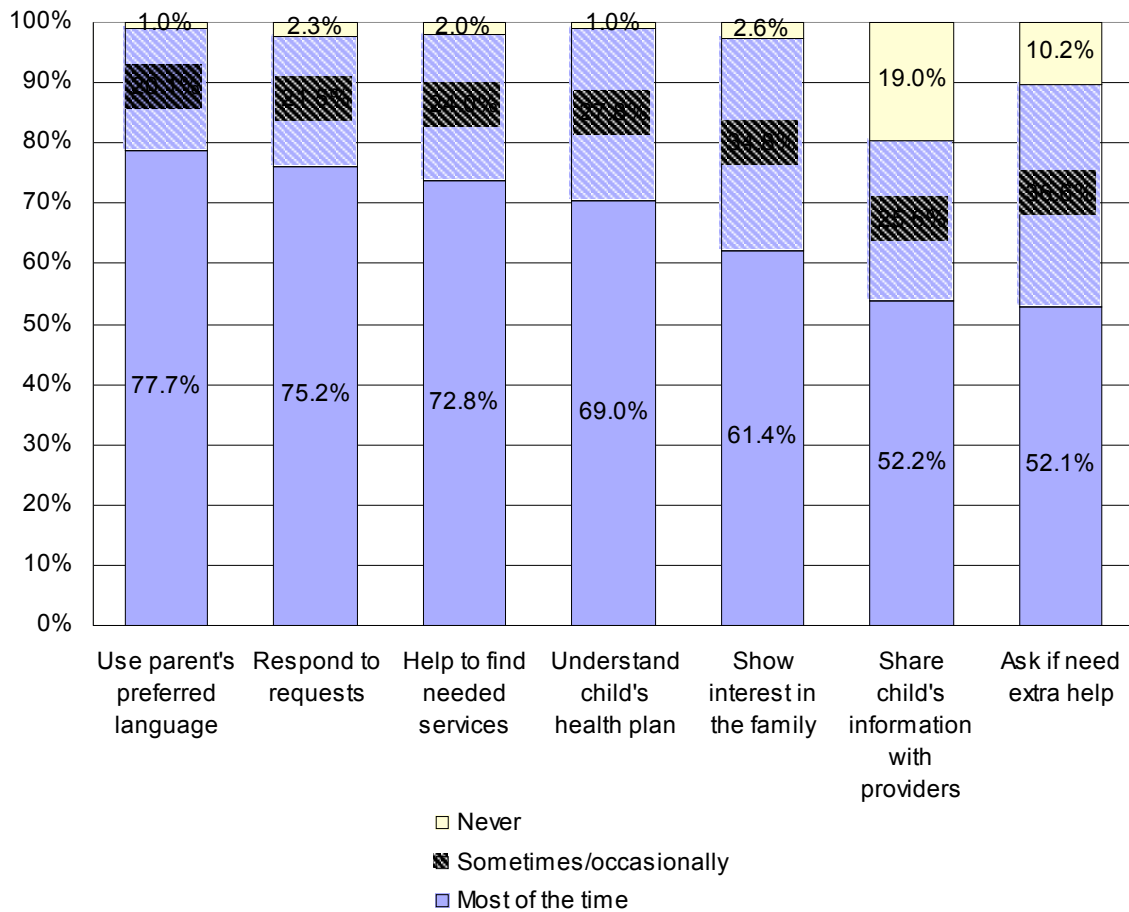
Experiences with the CCS Program

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



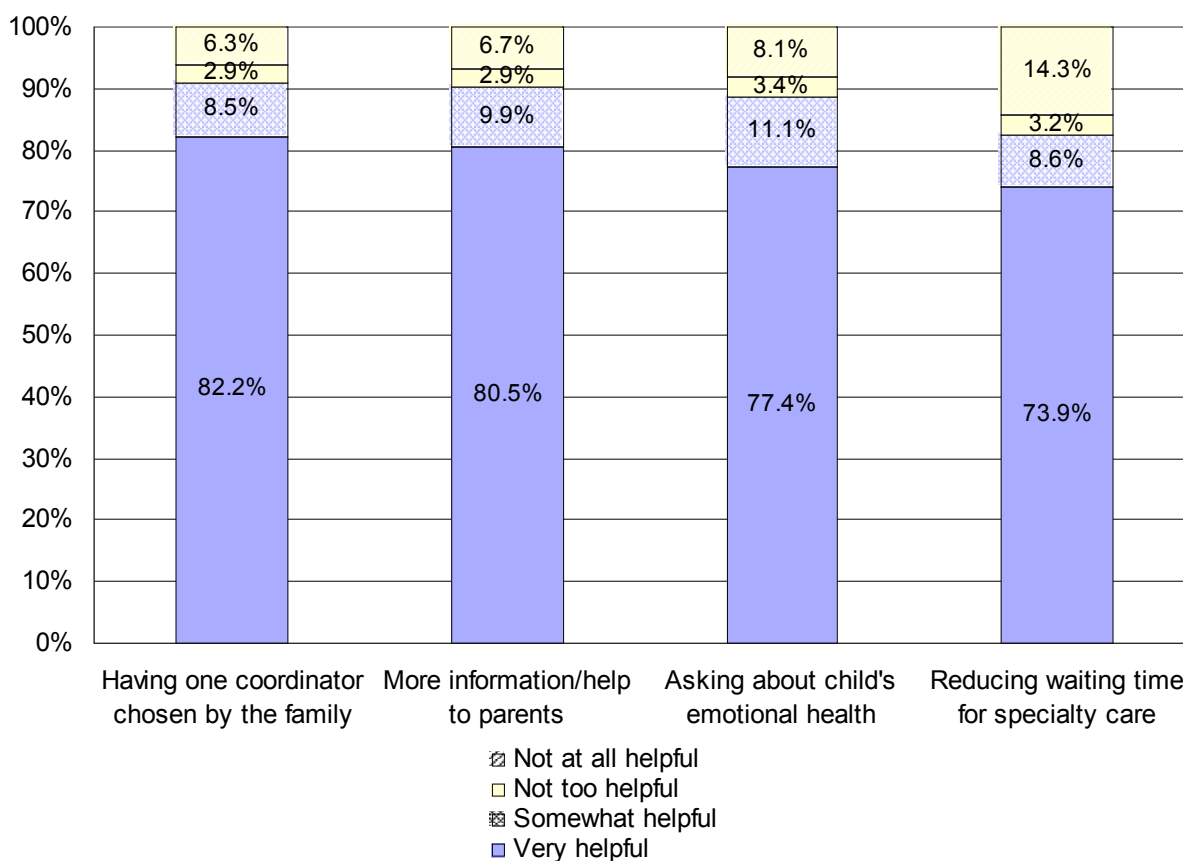
Source: Los Angeles CCS Survey, 2005

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

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

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.

Exhibit 25				
Access to Care for Children 0-17 Years, Los Angeles CCS Program and CSHCN in California				
	Los Angeles CCS		CSHCN in California	
	Total (%)	In Medi-Cal only (%)	Total (%)	In Medi-Cal only (%)
Usual Source of Health Care				
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
Medical Home				
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
Specialty Care				
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
Ease of Accessing Services				
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

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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**APPENDIX 11: TITLE V CHILDREN WITH SPECIAL HEALTH CARE
NEEDS (CSHCN) NEEDS ASSESSMENT REPORT: CALIFORNIA
CHILDREN'S SERVICES (CCS) PROGRAM SYSTEMS ISSUES AND
PRIORITY ACTION OBJECTIVES**

REPORT SUBMITTED BY FAMILY HEALTH OUTCOMES PROJECT, MAY 23, 2005

**Title V Children with Special Health Care Needs (CSHCN)
Needs Assessment Report:
California Children's Services (CCS) Program Systems
Issues and Priority Action Objectives**

May 23, 2005

Report Submitted by
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Title V CSHCN Needs Assessment Report: California Children's Services (CCS) Program Systems Issues and Priority Action Objectives

Submitted by the
Family Health Outcomes Project
May 23, 2005

Background

Title V Needs Assessment. Title V of the Social Security Act is a federal-state partnership that provides for programs to improve the health of all mothers and children. California currently receives approximately \$48 million in federal Title V funds that are jointly administered by the State's Maternal Child Adolescent Health (MCAH) Branch and the Children's Medical Services (CMS) Branch. Three population groups are served through Title V: pregnant women and infants less than 1 year of age, children ages 1 to 21 years, and children with special health care needs (CSHCN). Every five years the Federal Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau requires that each State MCH agency funded through the Federal Title V MCH Block Grant Program complete a needs assessment. California's MCAH and CMS Branches must complete an assessment of the health problems and needs of the target population groups and develop a FY2005-2010 5-year plan for addressing problems identified through this process. At least thirty percent (30%) of Federal Title V funds must be used for preventive and primary care services for children and at least thirty percent (30%) for services for CSHCN as specified in legislation. Based on this requirement it was decided that California Children's Services (CCS), California's CSHCN program, would identify three priority needs that will be addressed in the 5-year plan and for which action strategies and performance measures will be included.

As part of the broader planning process and the identification of the 3 priority CSHCN action areas, CMS has conducted an assessment of the needs and systems issues related to delivering services to children and families eligible for the CCS program. CCS is a statewide program that provides case management and health care services for children with certain physical limitations and chronic health conditions or diseases. CCS children are a subset of the nationally defined CSHCN. Other California programs, such as the California Department of Developmental Services, provide services to other CSHCN and may provide some services to CCS-eligible children as well. While CMS recognizes that Federal Title V guidance promotes assessment and planning for the broader CSHCN population, it is limited in its capacity to plan across programs by limited funds as well as California's fragmented Health and Human Services structure that separates health, mental health, developmental and social services and makes coordination among these services difficult. A recently funded HRSA initiative to develop a plan for an integrated system of care for the CSHCN population has been

initiated to address these issues. The Champions for Progress grant will utilize the CCS Needs Assessment Stakeholders Group to develop an action plan to address the priority areas identified in this needs assessment process. The Stakeholders will develop a long-term strategic plan for serving CSHCN, identify resources in California to carry out the activities in the strategic plan, and develop a monitoring and evaluation strategy to assure continued improvement and progress toward achievement in the priority areas.

CMS recognized that a critical aspect of the assessment process is to encourage and facilitate participation by stakeholders throughout the State to assist in identifying health and health systems problems/needs, prioritizing among the identified issues, developing strategies to intervene in prioritized issue areas and evaluating the effectiveness of intervention strategies. Accordingly, CMS established a CCS Needs Assessment Stakeholders Group. It contracted with the Family Health Outcomes Project (FHOP) 1) to identify and analyze data for the purpose of targeting the most important and potentially effective areas in which CCS can improve services for CCS-eligible children and 2) to facilitate the stakeholder process for providing input into problem/issue identification and determining the Action Priorities that will be addressed during FY2005-2010.

CCS Program. In 2004, a total of 170,880 of California children ages birth to 21 years received services delivered or paid for by CCS. CCS-eligible CSHCN are children who are under 21 years old; have or may have a medical condition that is covered by CCS (such as cancer, spina bifida, sickle cell disease, cerebral palsy, metabolic problems and congenital defects); are a resident of California; and whose families meet financial eligibility requirements. The family must have a family income of less than \$40,000 as reported as the adjusted gross income on the state tax form, or the out-of-pocket medical expenses for a child who qualifies are expected to be more than 20 percent of family income, or the child has Healthy Families coverage.

CCS may pay for or provide:

- Treatment, such as doctor services, hospital and surgical care, physical therapy and occupational therapy, laboratory tests, X-rays, orthopedic appliances and medical equipment.
- Medical case management to assure appropriate health professionals and multidisciplinary teams provide medically necessary services for the child, and referrals are made to other agencies, including public health programs and Regional Centers.
- Medical Therapy Program (MTP) services including physical therapy and/or occupational therapy provided in public schools for medically-eligible children.

Assessment Framework and Process

FHOP proposed a framework and process for conducting the CCS Title V Assessment. They recommended an inclusive and systematic process of selecting indicators and issues to be assessed, analyzing and presenting data, identifying issues and needs and setting priorities among them. This framework has been used successfully for work with large planning groups with diverse membership.¹ CMS approved the framework and it was shared with CCS program stakeholders prior to the first stakeholder meeting. The framework is included in Appendix A.

CCS CSHCN Stakeholder Process. There were two all day meetings of the Stakeholders for the purpose of identifying CCS CSHCN issues/needs and setting action priorities among the identified issue areas. Prior to the first meeting, stakeholders were contacted and asked for their input about what needs and issues they thought should be addressed in the assessment and the stakeholder process. The first meeting was held on January 27, 2005 and the second on April 28, 2005. In addition to the two meetings, the stakeholders participated in telephone or e-mail follow-up communications as needed and reviewed a data packet. During the January 27 stakeholders meeting, the group 1) received information about the CCS Title V 5-year needs assessment process, the stakeholder group's role and the process the group would participate in to select CCS Action Priorities from among identified issues/problems; 2) participated in the selection and weighting of the criteria that this group would use during its second meeting to determine the action priorities; 3) was introduced to the indicator selection and data collection process by which CSHCN issues/problems would be identified; and 4) participated in either a Providers, County CCS, Family and Advocates, or Collaborating Agencies breakout group to assist CCS in the identification of issues/problems of concern to stakeholders, relevant data, and potential data sources. Also, a teleconference meeting was held to provide information to stakeholders who were unable to participate in the first meeting and wished to participate in the second meeting.

During the April 28, 2005 meeting, the group 1) reviewed the criteria they had developed and weighted at the first meeting and the definitions and rating scale developed by staff, 2) reviewed the list of identified issue/need areas, 3) saw a slide show presentation of 15 identified issue/need areas and data relevant to those areas, 4) revised and agreed on a final issue/objective list, and 5) received orientation to and used a method of rating and ranking the identified issues/objectives. The results were presented, discussed and confirmed by the group.

To promote the success of this process, the State CCS program staff assured that representative stakeholders were invited, provided the best data available (within CCS resources and the timeframe) to FHOP, were available to FHOP and stakeholders to

¹ The process is adapted from a method included in the University of North Carolina, Program Planning and Monitoring Self-Instructional Manual, "Assessment of Health Status Problems" and described in the University of California at San Francisco Family Health Outcome Project (FHOP) "Developing an Effective MCH Planning Process: A Guide for Local MCH Programs".

answer questions and articulated CCS program commitment to using the results where funding and legislation permit. The Stakeholders were asked to be open to the process, to provide their expertise during discussions, use data and expert knowledge to inform their decision-making and agree to honor the group outcome. FHOP's role was to provide the framework; review and analyze data and prepare a data packet and presentation; provide opportunities for stakeholder input, and facilitate a rational, inclusive stakeholder process.

Indicator/Issue Selection and Organization and Presentation of Data and Issue Areas.

The process of identifying and learning about issues/needs began with the review of available sources of information about the needs of CSHCN, e.g., the National Survey of CSHCN; a scan of relevant websites; discussion with other State CCS Program Directors; interviews with CCS CSHCN stakeholders and a short e-mail survey of the stakeholders; and review and clarification of information recorded during the CCS stakeholder meeting breakout groups. Then indicators were selected using criteria (see Appendix D for the indicator selection criteria). A major source of data was "The National Survey of Children with Special Health Care Needs" (NS-CSHCN). In addition a data request was submitted to CMS/CCS staff who reviewed the request and provided the data that was available to FHOP. CMS Net and the State Performance Measures data were the primary sources of CCS specific data. Several published UCLA reports as well as "Family Voices" were also sources. A description of these data sources is included in Appendix F. The data was analyzed and summarized for stakeholder review. It was organized, using the six federal core CSHCN outcomes, into data summary sheets. A data packet was sent to the Stakeholders prior to the prioritization meeting. CMS and FHOP, based on available data and stakeholder input, identified 15 major CCS issues/systems problems affecting CCS and CCS-eligible children and families. CMS wanted to promote a positive action-oriented process; therefore, the issue/need areas were framed into objectives. Performance measures can be identified later, when the strategies to achieve the objectives have been developed.

Materials and Documentation. In addition to the development of the framework, assistance in identifying Title V CCS CSHCN issues/needs, and the facilitation of the priority setting process, FHOP produced materials and documentation, which are included in appendices as follows:

- Appendix A Framework for Identifying and Prioritizing the Title V Health and Health Systems Access and Capacity Needs of CCS-Eligible Children and Their Families
- Appendix B Stakeholder Invitee List
- Appendix C Title V CSHCN Stakeholder Telephone Questionnaire
- Appendix D CSHCN Needs Assessment Indicator Selection Criteria
- Appendix E Data Request Submitted to Children's Medical Services
- Appendix F Data Sources Used in the CCS Needs Assessment

Appendix G	Data Sheets Provided to CCS Stakeholders in Preparation for the Priority-Setting Meeting
Appendix H	Tables of County Level CCS Data
Appendix I	County Level CCS Maps
Appendix J	CSHCN Slide Show Presented to Stakeholders at the Title V Needs Assessment Stakeholders Meeting, April 28, 2005
Appendix K	Proposed CCS Program Objectives for Priority Consideration
Appendix L	CCS Stakeholder Criteria, Definitions and Rating Scales for Prioritizing Among Identified CSHCN Issues/Objectives
Appendix M	CCS Stakeholder Issue/Objective Prioritization Rating Tool
Appendix N	CCS Stakeholder's Priority Issue/Objective Rating Scores (spreadsheet)
Appendix O	California Children's Services (CCS) Stakeholders Meeting: Priority Objectives (Ranked Scores)
Appendix P	Data Development Notes from the CCS Title V Needs Assessment Stakeholder Meeting, April 28, 2005

Results of the CCS Needs Assessment and Prioritization Process

Title V Needs Assessment Issues/Needs Identified. There were 15 major systems issues identified through examination of the data, Stakeholder interviews/questionnaires, from the January 27, 2005 Stakeholder meeting breakout workgroups, and by CCS staff. As described, previously, the issue/need areas identified were developed by CMS and FHOP into action objectives. These were presented to the Stakeholders at the April meeting and, following a data presentation and discussion, the Stakeholders prioritized the issue areas/objectives. Performance indicators for the priority action objectives will be identified later, when strategies to achieve the objectives have been developed. Two overarching principles were identified.

- CCS will address disparities in impact and outcomes by gender, age, geographic location and race/ethnicity issues when developing strategies and tracking priority objective outcomes.
- The CCS program shall ensure that children participating in CCS have access to and receive services from appropriately trained pediatric providers and shall develop and apply standards of care intended to lower morbidity and mortality rates among eligible children (This overarching principle was added at the Stakeholder meeting by consensus of the group).

The 15 objectives, organized under the federal Title V CSHCN core outcomes and presented to the Stakeholders were:

Medical Home

1. Increase the number of family-centered medical homes for CSHCN and the number/% of CCS children who have a designated medical home.

Family Involvement and Satisfaction

2. Increase family access to educational information and information about accessing CCS services, including availability of and access to services offered by health plans
3. Increase family partnership in decision making and satisfaction with services

Screening

4. Increase the % of infants born in California who receive newborn hearing screening services

Insurance Coverage and Access to Care

5. Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists
6. Increase access of CCS children to preventive health care services (primary care, well child care, immunizations, screening) as recommended by the AAP
7. Increase access to CCS services by increasing the financial eligibility limit (\$40,000 limit)
8. Increase access to services for CCS youth, 17-21 years of age

Organization of Services

9. Facilitate the timely referral of foster care children with CCS eligible medical conditions to CCS services
10. Decrease the time between referral to CCS and receipt of CCS services.
11. Decrease the time between referral to the Medical Therapy Program and receipt of MTP services
12. Improve the uniform application of CCS authorization and referral policies across the state
13. Implement a system of standards of service delivery for all children with CCS medically eligible conditions regardless of payor source, including sharing of data.
14. Coordinate to develop and implement a system of timely referral between mental health and CCS systems for CCS eligible children.

Transition to Adulthood

15. Increase capacity of local CCS programs to develop and implement transition plans for adolescents transitioning to adult services

Top Five Priority Objectives. The Stakeholders individually used the weighted criteria they had developed together and a tool provided by FHOP to rate each of the objectives. The individual rating scores were then summed resulting in an aggregate score used to rank the objectives. The resulting top five priorities, discussed and agreed upon with the stakeholders follow. The complete ranking result is included in Appendix O. There are three objectives ranked as number four (4), as the aggregate scores were within a few points of each other. Three priorities will be included as Title V CSHCN priorities. CMS will address other priority objectives if resources and opportunities allow it to do so.

Rank	Priority Objectives
1	Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists
2	Coordinate to develop and implement a system of timely referral between mental health, developmental services, social services, special education services and CCS
3	Increase number of family-centered medical homes for CSHCN and the number/% of CCS children who have a designated medical home
4	Increase access of CCS children to preventive health care services (e.g., primary care providers, well child care, immunizations, screening) as recommended by the AAP
4	Increase family access to educational information and information about accessing CCS services, including availability of and access to services offered by health plans
4	Increase access to services for CCS youth, 17-21 years of age
5	Decrease the time between referral to CCS and receipt of CCS services

FHOP Recommendations for Data Development

While the effort to identify and examine data for CSHCN and CCS enrolled children was enthusiastically supported by both CMS program staff and stakeholders and a significant amount of data was compiled in a short time period, there were many issues identified pertaining to the need for data development. Problems encountered in conducting the needs assessment included limited data available specific to the CCS enrolled and eligible population, lack of standard definitions and consistency in the entry of data in CMS Net data fields, and lack of availability of data on the CCS population over time and across the multiple agencies serving these children. There were also

inconsistencies between the Federal HRSA definition of CSHCN and California's narrower focus on the CCS subset of CSHCN, and in defining a medical home.

CMS is currently working on expanding and improving the CMS Net information system and asked FHOP to take advantage of this needs assessment effort to obtain recommendations regarding data collection. At the April 28, 2005 meeting, the stakeholders were asked to identify data issues and data development recommendations relevant to the priority objectives that were identified at the meeting. At the conclusion of the data development discussion, ***it was agreed that the first CCS data development step will be to develop a matrix of the data available for children covered by CMS/CCS.*** The notes from the meeting are included as Appendix P.

The following data development recommendations are based on the experiences and challenges of this year's needs assessment process:

CMS Net Data

Examine data and monitor service delivery disparities by race and age

- From the National Survey of CSHCN, we know that there are often disparities between different race/ethnic and age groups when it comes to having a medical home or having services organized in a way that makes them easy to access or use. It is important to examine CMS Net data by race/ethnic groups to identify, address, and monitor race/ethnic disparities in care for CCS children.
- During this assessment, data on services provided to children ages 16-21 years was not available, therefore, making it difficult to determine how well the needs of this age group are being met. Anecdotal data indicates a lack of services specific to this population group.

Regularly update diagnosis data

- It is difficult to get an accurate picture from the CMS NET data of the medical conditions affecting CSHCN because the diagnosis fields are not consistently updated when diagnoses are modified or when new conditions are identified. It would be useful if these fields could be updated to reflect changes in medical condition or a new diagnosis on a regular basis.

Implement AAP Medical Home definition and expand data collection fields

- To achieve the goal of all CSHCN having a medical home, it will be important to implement the AAP definition of medical home and train county personnel and those doing data entry for CMS Net to use the AAP definition. Separate fields in CMS Net for primary care physicians, specialists, and medical home also need to be created in recognition that having a medical home is not the same as

having a primary care provider and that many physicians are not providing the level of care coordination necessary to meet the AAP definition of medical home. There should also be a mechanism for regularly updating medical home information.

Collect data on the percent of children participating in the CCS program receiving preventive services (e.g., immunization, well child exams)

- For this current needs assessment, there was no data available to evaluate the regularity at which children served by the CCS program are receiving regular preventive services.

State Performance Measures

Implement the American Association of Pediatrics (AAP) definition of Medical Home in State Performance Measures

- Implement the AAP definition of medical home and have State Performance Measure #5 reflect that definition. It would be useful to expand the number of items used to assess whether or not a child has a medical home, as done in the National CSHCN Survey.

Develop measures to monitor timely authorizations and eligibility determinations

- Consider creating a new performance measure based on to-be-established goals for times between determination of eligibility and authorization for services and from referral to determination of eligibility for services (i.e., eligibility determination shall be made within one week). Then, for future needs assessments, the data can be examined by County to see what percentage of CCS cases met this goal.

CCS-Paneled Physicians

Restructure and regularly update the database

- Restructure the database of CCS-paneled physicians to have counties in rows and different specialties in columns. Establish a mechanism to indicate whether or not each CCS-paneled physician is willing to take new clients. Regularly update the database and determine why there is so little consistency with the list of Board Certified Physicians in California.

Recommendations for Future Needs Assessments

Increase the California sample size for the National CSHCN Survey

- To better understand how well California is meeting the needs of all its CSHCN, it would be useful to have additional respondents in California to the National Survey of CSHCN so that data may be examined for specific subsets of the population (i.e., different race/ethnic groups) to determine how well their needs are being met.

Establish baseline data

- Utilize the data collected for the current needs assessment as baseline measures to be used for comparisons and analysis of trends in future needs assessments. When implementing new data elements/fields, establish a baseline as soon as possible.

Develop and monitor outcomes data

- Identify measurable outcomes to monitor the quality of services for CCS enrolled children.

Framework for Identifying and Prioritizing the Title V Health and Health Systems Access and Capacity Needs of CCS Eligible Children and their Families

Background:

Title V of the Social Security Act is a federal-state partnership that provides for programs to improve the health of all mothers and children, including children with special health care needs. California currently receives approximately \$48 million in federal Title V funds that are jointly administered by Maternal and Child Health (MCH) Branch and the California Medical Services (CMS) Branch. Three population groups are served through Title V: pregnant women and infants less than 1 year of age; children ages 1 to 21 years; and children with special health care needs (CHSCN). The California Children's Services (CCS) program, California's CSHCN program, provides case management and payment of services for program-eligible CSHCN and promotes family-centered, community-based, coordinated care for these children.

CMS has established its CCS Needs Assessment Stakeholders Group, and contracted with Family Health Outcomes Project (FHOP) to assist in identifying needs related to CCS eligible children and their families and facilitating the process of problem identification and prioritization of those problems/needs. The process being used is an inclusive and systematic process of data presentation and analysis, identification of problems and setting priorities. This process has been used successfully for work with large planning groups with a diverse membership.¹

Purposes of the Problem Identification and Prioritization Process

- Promote rational allocation of resources
- Create a systematic, fair and inclusive process
- Focus decision-making if there are many problems/issues identified
- Challenge participants to objectively and critically review data
- Document the process and results

The outcome of this process will be a 5 year needs assessment report and the selection of statewide performance measures to evaluate the results of our interventions. The report will be submitted in July 2005, as part of California's 2005-06 Title V Maternal and Child Health Block Grant application. CCS is committed to addressing the selected priorities, within our budgetary and legislative constraints.

Description of the Problem Identification and Prioritization Process

There will be two meetings of the CCS Needs Assessment Stakeholders Group for the purpose of setting priorities among identified needs. The first meeting is on January 27, 2005 and the second is planned for April or early May, 2005. In addition to the two meetings, the group members will review documents and participate in telephone or e-mail communications in the time period between the two large group meetings to review data, and provide input to assist in

¹ The process is adapted from a method included in the University of North Carolina, Program Planning and Monitoring Self-Instructional Manual, "Assessment of Health Status Problems" and described in the University of California at San Francisco Family Health Outcome Project (FHOP) "Developing an Effective MCH Planning Process: A Guide for Local MCH Programs".

identifying significant problems. After reviewing and analyzing data on selected indicators, identified problems/issue will be submitted to the group for consideration in the overall prioritization process. During the April 2005 meeting, the full group will review the list of identified problems, review data about these problems/issues, agree on a final problem list, and receive orientation to and use a method of rating and ranking the identified problems. The results will be presented, discussed and confirmed by the group. The table below shows the steps of the process.

Steps in the CCS Needs Assessment Stakeholder Group Process for Prioritizing Problems/Needs	
I.	Meeting January 27, 2005
	Introductions/Share information
	CMS / FHOP present overall objectives of the Needs Assessment, scope, background and the recommended process for prioritization
	FHOP facilitates process of selecting up to 7 criteria that will be used by the Group members to assist in the ranking/prioritization of problems <ul style="list-style-type: none"> - Develop criteria - Develop criteria rating scales - Determine weights for each criterion (how important each criterion is relative to the other criterion)
	FHOP reviews criteria for selecting indicators with the group, receives input, and orients group to how data will be presented for their review.
	FHOP asks participants (key informants) to divide into groups. Groups will discuss how the core outcomes and issues identified through FHOP's indicator research, brief interviews with Stakeholders and e-mail survey can be assessed (e.g., suggests possible indicators, instruments, data sources). Their input is recorded and shared with the larger group, and this will be incorporated into the identification of the final list of indicators.
II.	Work is done by the Group in the months between meetings (can be accomplished by e-mail, phone or smaller group meetings):
	Review and input by Group Members of data collected and analyzed by FHOP/CMS Review and input by Group members of problem/issue list developed based on data
III	Meeting in April or early May, 2005:
	Group members agree on the final problem/issue list to be prioritized
	The Group sets priorities among the final problem list. These priorities will be the focus of the Title V, 5 Year Action Plan. <ul style="list-style-type: none"> • Group Participants use the agreed upon weighted criteria to score problems • Sum participants' scores / rank problems • Discuss and confirm results

Stakeholders for CMS Title V Needs Assessment

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Stakeholders						
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PICU TAC	Lorry Frankel, M.D.	Lucille Packard Children's Hosp	750 Welch Road, Suite	Palo Alto	94304	650-723-5495
Cardiac TAC	Thomas	UCLA School of Medicine	B2-427 MDCC, Box	Los Angeles	90095-1743	310-825-5296
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American Academy of Pediatrics	Kris Calvin	853 Ramona Ave		Albany	94706	323-254-1740
American Academy of Pediatrics	Marc Lerner, M.D.	University of California, Irvine	1 Medical Plaza Dr., ZOT	Irvine	92697-0001	714-456-7011
California Healthcare Association	Sheree Kruckenberg	1215 K Street, Suite 800		Sacramento	95814	916-552-7576
Dept. of Developmental Services	Rick Ingraham	Children and Family Services	P.O. Box 944202, MS 3-8	Sacramento	94244-2020	916-654-2773
Designee for 1/27 pm	Eileen McCauley					916-654-1470
Regional Center of Orange Count	Arleen Downing, M.D.	P.O. 22010		Santa Ana	92702-2010	714-796-5257
California Dept of Education	Jim Bellotti	Special Education Division	P.O. Box 944272	Sacramento	94244-2720	916-323-6711
Designee for process		Special Education Division	1430 N Street, Suite 2104	Sacramento	95814	
Department of Mental Health	Penny Knapp, M.D.	1600 Ninth Street, Room 151		Sacramento	95814	916-654-2309
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CCS Executive Committee						
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Stakeholders for CMS Title V Needs Assessment

Appendix B

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Family Voices of California	Juno Duenas	2601 Mission Street, Suite 606		SanFran.	94110	415-282-7494
CRISS	Laurie Soman	725 Welch Road, MC 5524		Palo Alto	94304	510-428-3783
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California Medical Home Project	Kathryn Smith	5000 W. Sunset Blvd.	Suite 510	Los Angeles	90027	323-913-4400
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CHEAC (County Administrators)	Judith Reigel	1127 11th Street, Suite 309		Sacramento	95814	916-327-7540
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MCAH Directors	Troy Jacobs, M.D.	P.O. Box 6099		Santa Ana	92706-6099	714-834-8411
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Designee	Dale Mentink	100 Howe Avenue, Suite 235N		Sacramento	95825	916-488-9950
Parents						
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	Diana Vergil-Bolling					
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Title V CSHCN Stakeholder Telephone Questionnaire

I am calling from The Family Health Outcomes Project. We are assisting CMS in its Title V assessment process.....: Thank you for agreeing to participate or I am calling to follow up on Dr. Dalsey's e-mail to you. provide information as needed

The process is:

Any questions?

If they have not previously committed to join the planning group, ask now if they are willing. If not, can they suggest someone to represent them/their organization/interest group?

If they can commit, but can't come to the meeting in January, ask availability for the following week. Availability _____

I'd like to ask you a few questions

1. What is your role/interest in planning for children with special health care needs?
2. Are there particular indicators or issues you think should be assessed? Do you have suggestions about data to look at? Prompt:
3. Have you been part of a previous CMS assessment process? If so how do you think the process went? The outcome?
4. Do you have suggestions regarding the current process?
5. Is there anything you would like to add?

CSHCN Needs Assessment Indicator Selection Criteria

The Family Health Outcomes Project (FHOP), in consultation with the CMS Staff, will be selecting a finite number of indicators for which data can be collected, analyzed and presented to the Stakeholders group for prioritization and subsequently included in the Children with Special Health Care Needs (CSHCN) portion of the Maternal Child and Adolescent (MCAH) Assessment and 5 Year Plan. These indicators will be defined as population-based measures of either the entire population or a defined population subgroup that may assess general health status, a particular health condition, health access, or health system effectiveness and are measured at a specified point in time. Where possible they will be compared to a standard or benchmark, such as the national CSHCN outcome measures or Healthy People 2010 goals. The following criteria will be used by FHOP to identify the final set of indicators:

The indicator is a valid measure of access to or utilization of CCS services

Indicator data is easily available and is either representative of the general population, or taken from a representative sample of CSHCN, or the CCS eligible or CSN population in question

The indicator is relevant and informative to stakeholders. (“relevant” and “informative” means that the stakeholders can use the indicator to monitor services and outcomes for CSHCN and their families)

The indicator data provides information on conditions or service limitations that lead to functional constraints among the CCS-eligible and/or CCS served population

The indicator reveals disparities in service access and/or delivery to CCS-eligible children

The indicator relates to one of the core national or State CSHCN performance outcomes

Data Request Submitted to Children's Medical Services

General Comments

For all data requested, the data should, as possible, be further broken down by urban/rural, and race/ethnicity. Data from past years would also be useful to assist in identifying trends.

Screening:

Hearing

Newborn Hearing Screening Program Data. As many years as possible in order to look at trends. Data in spreadsheets would be most useful.

Is there any data available for screening on infants born outside of certified hospitals? Interested in assessing births in the state which occur in non CCS-certified hospitals.

Genetic Diseases

1. Genetic Disease Branch data for all children screened
2. How many children screened by the GDB that have CCS eligible conditions are referred to CCS?
3. How many CCS eligible children who are screened by the GDB get referred to CCS?
4. Time frames for the following:
 - a. Time between screening and referral to GDB Specialty Center
 - b. Time between receipt of GDB referral by Specialty Center to referral of medically eligible children to CCS
 - c. Time between CCS receipt of referral and CCS authorization to treat
 - d. Time from authorization to treat and first appointment

Developmental Screening

From Medi-Cal billing data:

1. How many developmental screenings were paid for this year by type of screening by provider
2. Of those, how many children were screened and how many screenings did each child have?

What is the Medi-Cal policy for developmental screening? What kinds of screening do they pay for and how often?

Medical Home

1. From the CMSnet, number of CCS children with a medical home (and the total number of CCS children) and the definition of medical home that is used to make that determination. If possible, we would also like to get breakdowns for rural vs. urban and race/ethnicity

2. Performance Measure 1 submitted to the state by the counties, including the number of CCS children by county that have a medical home (and the total number of CCS children by county) and the definition of medical home that is used to make that determination

Access to Care

1. Access of CCS children to preventive and well child care in Medi-Cal managed care organizations, both where CCS is carved in and where it is carved out
 - a. % of CCS eligible children who had the recommended periodic CHDP exams and screening
 - b. % of CCS eligible children up to date for immunizations
 - c. Average waiting time for primary care appt.
2. Timeliness of initial care
 - a. Time between referral data and when CCS determines eligibility
 - b. Time from determination of eligibility to authorization
 - c. Time from authorization to first appointment for care
3. Timeliness of referrals
 - a. Time between referral for care within the system and when services are authorized and time between authorization and services received
 - b. Time between referral for care to programs/services outside the systems and when services are received
4. Fragmentation of services
 - a. Average number of providers (primary and specialty) of care by type and by site per CCS child
5. Duplication of Services
 - a. For DME, look at claims and billing data to see if children are getting the same equipment from multiple providers
6. Adequate supply of providers certified for the CCS panel
 - a. Time from provider application to be on the panel and approval by state
 - b. Number of board certified pediatricians per county
 - c. Number of board certified pediatricians on CCS panel by county
 - d. Number of board certified MDs in essential medical specialties by county
 - e. Number and % board certified MDs in essential medical specialties that are certified to provide services to CCS eligible children by county
7. CCS Children in foster care
 - a. # and % of CCS children in foster care
 - b. # and % of foster Care children eligible for CCS services?
 - c. # and % of CCS children in foster care that receive CCS services

8. % of CCS children that received dental care last year
9. Cultural Competency
 - a. Is there any information available on cultural competency? (i.e., language capabilities of providers, availability of translators, cultural competency trainings)

Access to Specialty Care

1. Timeliness of referrals
 - a. Time between referral to a Specialty Care Center and when services are received for CCS children who are NOT registered with a Specialty Care Center
 - b. Time between Specialty Care request for authorization for care and when CCS approves the authorization
2. Timeliness of specialist care within Specialty Care Center
 - a. # of CCS children on the waiting list for specialty care
 - b. Time between referral and eligibility determination
 - c. Time between eligibility determination and authorization
 - d. Time between authorization and service delivery
3. Specialty Care Centers
 - a. % of CCS children with a Specialty Care diagnosis who are registered with a Specialty Care Center – by county
 - b. % of CCS children registered with a Specialty Care center who have had an annual or semi-annual visit
4. Access for CCS eligible to needed medical specialty services (outside of Specialty Care Center)
 - a. Waiting time for appointments to see CCS panel MDs
 - b. Time between referral to eligibility determination - eligibility determination to authorization – authorization to service
5. Adequacy of Medical Therapy Programs
 - a. Waiting time for evaluation by MTU after referral
 - b. # and % of children receiving MTU services and # and % referred to vendor for services
 - c. Number of appeals of MTU decisions by county; results of appeals
6. Tertiary care facilities
 - a. Number of tertiary care and trauma centers in California by county and age ranges served and number of CCS approved tertiary care and trauma centers by county and the age ranges served, percent of tertiary care and trauma centers that are CCS certified
 - b. Number and % of CCS approved specialty hospital centers (e.g. NICU, PICU, Burn, Rehab, etc) and tertiary and trauma centers and the age ranges served

- c. Number and % of tertiary care and trauma centers that opt out due to refusal to meet standards
7. Mental health care
 - a. # and % of CCS children referred for mental health counseling
 - b. % of children by county in MHS referred and accepted to CCS program
 8. Access to Orthodontic care
 - a. Average time until assignment
 9. Access to ancillary services and equipment
 - a. Waiting time for in-home support services (i.e., nutrition care, nursing)
 - b. Waiting time for recommended equipment

QUESTION: Have counties had problems finding care for adolescents in a CCS approved facility?

Transition to Adulthood

- a. # of transition clinics county and age groups served by the clinics
- b. Average length of time between a request for appointment and the actual appointment
- c. % of CCS transitioning children with an adult PCP identified
- d. % CCS children with a transferable GHPP eligible condition that make the transition to GHPP
- e. % of children that transition out of CCS coverage that obtain other insurance coverage by payer type
- f. % of transitioning children that have vocational plans collaboratively developed by DDS, Department of Vocational Rehabilitation and CCS as applicable
- g. % of transitioning children served by MTU/CCS that have a discharge plan

Prevalence and Outcomes

- a. # of CCS children by diagnosis
- b. # of children born with a CCS eligible condition
- c. % of children with a CCS eligible birth defect that are enrolled in CCS
- d. % of CCS children with a birth defect by type of services received
- e. Severity of cases: % of CCS conditions that require high intensity treatment vs. lower intensity treatments (definition?)
- f. Services received by type of service
- g. Services authorized/paid by type (# paid by Medi-Cal, # Healthy Families, paid by CCS, paid by others??)
- h. % of CCS children with up-to-date immunizations

Family Roles

- a. The degree to which the CMS program demonstrates family participation (data from Performance Measure 4)

Organization of Services – Collaborative relationships among local program

- a. The degree to which local CCS, CHDP, and HCPCFC programs maintain collaborative relationships internally and externally (data from Performance Measure 1)

Data Sources used in the CCS Needs Assessment

The National Survey of Children with Special Health Care Needs (NS-CSHCN)

The National Survey of Children with Special Health Care Needs, sponsored by the Maternal and Child Health Bureau, provides national and state-level information about the numbers of children and youth, 0 - 17 yrs old, in the population with special health care needs. In addition, the survey asked 750 families of CYSHCN (Children and Youth with Special Health Care Needs) in each state about:

- Access to health care and unmet needs
- CYSHCN health and functioning
- Health care quality and satisfaction
- Impact of child's health on family activities, finances, and employment
- Adequacy of health insurance to cover needed services

In each state, telephone interviewers screened at least 3,000 households with children to identify CYSHCN. In-depth interviews were conducted with the parents of approximately 750 CYSHCN per state. Although 759 interviews were completed in California, for some questions on the survey, the sample size was much smaller and severely limited the statistical power needed for detecting significant differences when making comparisons between subgroups.

The screening questions used in the survey to identify children with special health care needs included five major components: In addition to the existence of a condition that has lasted or is expected to last at least one year, one of the following: the use of or need for prescription medication; the use of or need for more medical care, mental health services, or education services than other children of the same age; the use of or need for treatment or counseling for an emotional, developmental or behavioral problem; a limitation in the child's ability to do the things most children of the same age do; or the use of or need for special therapy, such as physical, occupational, or speech therapy. (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2001*. Rockville, Maryland: U.S. Department of Health and Human Services, 2004.)

Data on selected indicators is presented comparing California with the nation. (Source: <http://www.cshcndata.org/DesktopDefault.aspx>)

CMS Net Data

CMS Net is a full-scope case management system for California Children's Services (CCS). The State's CMS Net resides at the Health and Human Services Data Center (HHSDC). Data from CMS Net are active cases through 3/15/05. Los Angeles, Orange County and Sacramento, home to approximately 45% of the State's CCS children, do not yet have data in the CMS Net system, but plans are underway to include these counties.

Orange, Los Angeles, and Sacramento County also provided data, similar to that provided from CMS Net, from their databases for their counties.

State Performance Measures Data

Reporting on the CMS performance measures is a Scope of Work requirement. Starting in Fiscal Year (FY) 2002-03, CMS local programs have been using tracking systems and other data collection methods to measure their work with communities, provider networks, and target populations. Data presented are from fiscal year 2003-2004.

Other Data Sources:

Inkelas M, Ahn P, Larson K. 2003. *Experiences with health care for California's children with special health care needs*. Los Angeles, CA: UCLA Center for Healthier Children, This chartbook provides California data on access to care for CSHCN, comparing care of children in Medi-Cal to care received by other children in California and to other State Medicaid programs. It presents data from the National Survey of Children with Special Health Care Needs (NS-CSHCN) and the California Health Interview Survey (CHIS). Both surveys are based on parent report in telephone interviews, as reported in 2001. Figures, tables, and text present California and national averages; statistical comparisons are between California and all other states excluding California. Comparisons made in the report text between CSHCN in Medi-Cal and other CSHCN are statistically significant ($p < 0.05$) unless otherwise indicated. Due to larger sample size nationally (more than 36,000 children) than in California (750 children), subgroup comparisons often detect statistical differences nationally but not in California.

Wells, N., Doksum, T., Martin, L., Cooper, J. 2000 *What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants*. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

"Your Voice Counts!!" was conducted in 1998 by Family Voices and Abt Associates Inc., to assess the health care experiences of children with special health care needs and their parents. This survey was distributed to a random sample of 7,100 families from CCS mailing lists and 6 California family resource organizations. 954 Families returned the survey, 153 of which were in Spanish. In order to get a sample that was more geographically representative of California, respondents came from Los Angeles, San Diego, Fresno, Sacramento, and two rural areas in the state. Family Voices states that the findings from the survey should be interpreted with caution for two reasons – the low response rate (13%) means that the survey may not be representative of all children from the CCS and family organizations in the sample, and the children from participating organizations may not represent all children with special health care needs in California.

Halfon N., Inkelas M., Flint R., Shoaf K., Zepeda A., Franke T. 2002. *Assessment of factors influencing the adequacy of health care services to children in foster care*. UCLA Center for Healthier Children, Families and Communities.

This study examines the "readiness" of state and local child welfare, child health, mental health, and Medicaid agencies to systematically meet the needs of children in foster care. Gaps between best practices developed by AAP and the Child Welfare League of America (CWLA) and current agency performance are examined, and agency policies and administrative procedures are evaluated for their ability to achieve Adoption and Safe Families Act of 1997 (ASFA) objectives and improve children's well-being. The study evaluates performance on basic standards, and

collaboration and performance monitoring activities, and provides a foundation on which new policies can be developed to address problems with performance and other challenges faced by agencies.

Data Sheets Provided to CCS Stakeholder in Preparation for Priority-Setting Meeting

Introduction to Packet

Included for stakeholder review are the following materials:

- The April 28 Stakeholder Meeting Agenda
- The Criteria selected and agreed upon by the Stakeholders at the January 27, 2005 meeting. A 5-point rating scale has been developed for each of the criteria. This rating sheet will be used by each stakeholder during the meeting to assist in rating the identified CCS issues/goals.
- Data which has been organized according to the six National CSHCN outcome areas. CSHCN prevalence data is also included.

Overview Information:

Based on 2001 data (data extracted from Inkelas M., Ahn P., Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities):

- About 10% of children in California have special health care needs
- About 7.4% of the children enrolled in Medi-Cal and 3.5% of the children enrolled in Healthy Families in 2001 were children with special health care needs
- Most children in CCS have Medi-Cal coverage while a small number have Healthy Families, private coverage, or lack insurance coverage. **Nearly 80% Of CCS children are Medi-Cal beneficiaries**
- About 21% of CSHCN in CA were covered by Medi-Cal, 2% were covered by Healthy Families
- About 15% of California's CSHCN receive specialty care through the CCS program (about 150,000 children annually)

Definitions useful for your review of the data:

The federal definition of Children With Special Health Care Needs (CSHCN) defines CSHCN as "children 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 was developed by the Maternal and Child Health Bureau (MCHB)It is purposefully broad and inclusive, recognizing that children with many different diagnoses and conditions have some important, common needs. MCHB's goal in developing this definition was to help States carry out the mission given them under Title V of the Social Security Act to develop and implement comprehensive, community-based systems to serve children and families with special needs. This mission has been affirmed in the President's New Freedom Initiative and in the Surgeon General's report *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental*

Retardation. The definition was published in Pediatrics in July 1998 and has been accepted and used extensively in the child health arena. However, because this definition is so broad, it is not appropriate for every purpose or program.” (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.) Much of the data included for review is data about this larger group.

California Children’s Services (CCS) program, California’s CSHCN program, provides case management and payment of services for program-eligible CSHCN and promotes family-centered, community-based, coordinated care for these children. 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 share the operation of their program with state CCS regional offices in Sacramento, San Francisco, and Los Angeles. *You are participating, as a Stakeholder, in the CCS Program’s Title V needs assessment and priority-setting process.*

CCS-eligible CSHCN are children who are under 21 years old, have or may have a medical condition that is covered by CCS (such as cancer, spina bifida, sickle cell disease, cerebral palsy, metabolic problems and congenital defects); are a resident of California; and have a family income of less than \$40,000 as reported as the adjusted gross income on the state tax form or the out-of-pocket medical expenses for a child who qualifies are expected to be more than 20 percent of family income; or the child has Healthy Families coverage. CCS serves a subset of the nationally defined CSHCN. Other California Programs, such as the California Department of Developmental Services, provide services to other CSHCN and may provide some services to CCS-eligible children as well.

There is limited data available specific to the CCS-eligible population. The data included is primarily from CMSNet, the Title V State Performance Reports and Paid Claims Data.

Organization of the Data:

In general, the data is organized using the six National Core CSHCN outcomes. These desired outcomes can serve as indicator categories toward creating a system of care for CSHCN. In addition, prevalence and expenditure data is provided:

- Screening. All children will be screened early and continuously for special health care needs.
- Family Centered Care and Satisfaction. Families of CSHCN will participate in decision making at all levels and will be satisfied with the services they receive.
- Coordinated Care—Access to Care and Medical Home. All CSHCN will receive coordinated, ongoing, comprehensive care in a medical home.
- Health Insurance Coverage. All CSHCN will be adequately insured for the services they need.

- Organization of Services. Services for CSHCN will be organized so families can use them easily.
- Transition. All youth with special health care needs will receive services needed to support the transition to adulthood (Information on transition indicators is limited and we are still in the process of obtaining it, some data will be presented at the meeting)
- CSHCN Prevalence
- CCS Expenditure Data

Description of primary data sources:

The National Survey of Children with Special Health Care Needs (NS-CSHCN).

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- Access to health care and unmet needs
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The following data sheets are included:

	<u>Part</u>
Prevalence and Diagnosis Data	A
Medical Home and Access to Care Data	B
Insurance Coverage Data	C
Screening Data	D
Organization of Services Data	E
Family Center Care, Participation, and Satisfaction	F
Transition to Adulthood Data	G
CCS Selected Expenditures Data	H



Children with Special Health Care Needs Prevalence Information

Prevalence of CSHCN Population

From the National Survey of CSHCN 2001ⁱ

- 10.3% of CA children were identified as having special health care needs vs. 12.8% Nationwide. This is a statistically significant difference ($p < .05$).

From the “Experiences with health care for California’s children with special health care needs”ⁱⁱ

- About 7.4% of the children enrolled in Medi-Cal and 3.5% of the children enrolled in Healthy Families in 2001 were children with special health care needs.
- About 15% of California’s CSHCN receive specialty care through the CCS program. (150,000 annually).

Prevalence of CSHCN Population by Race/Ethnicity

From the National Survey of CSHCN 2001

	Hispanic	White	Black	Multiracial	Other
California %:	7.6	13.7	15.7	10.2	6.9
Sample Size:	339	472	75	30	47
Est. Pop.:	313,648	462,157	95,424	29,636	66,118
Nationwide %:	8.5	14.2	13.0	15.1	7.8
Sample Size:	4,320	35,950	5,036	1,581	1,658
Est. Pop.:	1,077,970	6,401,832	1,133,566	275,998	239,361

- There are no significant differences between CA and the nation in terms of prevalence of CSHCN by race/ethnicity

Race/Ethnicity of CSHCN Population in CA and Nationally

From the National Survey of CSHCN 2001

	<u>Hispanic</u>	<u>White</u>	<u>Black</u>	<u>Multiracial</u>	<u>Other</u>
California %:	32.3*	47.7*	9.8*	3.1	6.8
Nationwide %:	11.5	68.4	14.2	2.9	2.6

- Consistent with the racial/ethnic composition of CA compared to the nation, significantly more of the CSHCN in CA are Hispanic, and significantly fewer are white or black.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Prevalence of CSHCN Population by age

From the National Survey of CSHCN 2001

	<u>0 – 3 yrs.</u>	<u>4 – 7 yrs.</u>	<u>8 – 11 yrs.</u>	<u>12 – 14 yrs.</u>	<u>15 – 17 yrs.</u>
California %:	4.3*	8.4*	12.5*	15.0	11.8
Nationwide %:	6.5	11.4	15.5	16.2	14.7

- Compared to the nation, significantly fewer children ages 0 to 3, 4 to 7, and 8 to 11 years old are identified as CSHCN

Prevalence of CSHCN Population by Household Income

From the National Survey of CSHCN 2001

	<u>0 - 99% FPL</u>	<u>100 - 199% FPL</u>	<u>200 - 399% FPL</u>	<u>400% FPL or greater</u>
California %:	7.5*^	9.7*	11.0	13.0^
Nationwide %:	13.6	13.6	12.8	13.6

Note: FLP = Federal Poverty Level

- The poorest children in CA (199% of the FPL or less) are significantly less likely than the poorest children in the nation to be identified as CSHCN
- Within California, children in households earning 99% or less of the FPL are significantly less likely to be identified as a CSHCN than children in households earning 400% or greater than the FPL

Prevalence of CSHCN by Criteria for Qualifying as a CSHCN

From the National Survey of CSHCN 2001

- In CA, significantly fewer children qualify as CSHCN based on use of prescription medication screening criteria (6.7% in CA vs. 9.5% nationally)
- In CA, significantly fewer children qualify as CSHCN based on the elevated need/use of medical, mental health or educational services criteria (4.9% in CA vs. 5.8% nationally)
- CA has similar rates of children that qualify as CSHCN based on the functional limitation screening criteria (2.2% in CA vs. 2.7% nationally)
- CA has similar rates of children that qualify as CSHCN based on the need/use of specialized therapies screening criteria (1.7% in CA vs. 2.2% nationally)
- CA has similar rates of children that qualify as CSHCN based on the emotional, developmental or behavioral conditions screening criteria (3.4% vs. 3.7%)

Prevalence of CSHCN by Specific Types of Special Health Needs

From the National Survey of CSHCN 2001

- 2.2% of CA children have conditions that result in functional limitations and does not differ significantly from the national rate of 2.7%
- Significantly fewer CA children (3.1%) have a CSHCN condition managed by prescription medication than the national rate of 4.7%

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

- CA and the nation of have similar rates of children whose CSHCN condition requires above routine use of medical, mental health or other services (2.7% for CA, 2.3% nationally)
- CA has significantly fewer children whose CSHCN condition required prescription medicine and above routine use of services
- CA has significantly fewer CSHCN with no qualifying emotional, behavioral or developmental issues (6.9%) than the national rate of 9.1%

From the “Your Voice Counts!!” Surveyⁱⁱⁱ:

- Most children were affected by more than one condition. 37% had two or three conditions, 53% had four or more conditions. Fourteen percent of the children were technology dependent or assisted, needed things such as a feeding tube, shunt, or ventilator, etc.

Impact of Health Conditions

From the National Survey of CSHCN 2001

- 36.2% of CSHCN in CA never have their daily activities limited or affected by their health condition, 39.9% have their daily activities moderately affected and 24% have them consistently affected. Nationally, rates are very similar
- 49.8% of CSHCN in CA missed 0 – 3 days of school due to illness, 18.8% missed 4 to 6 days, 15.1% missed 7 to 10 days, and 16.2% missed 11 or more days

From the “Your Voice Counts!!” Survey^{iv}:

- 97% of the children needed prescription medications; 85% needed therapy services, 43% needed durable medical equipment; 21% needed home health services, and 11% needed mental health services.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Diagnoses among CCS clients

From CMS Net Active Cases through 3/15/03

Primary Diagnosis for CCS Cases* Active through 3/15/05

Diagnosis	N	%
Undiagnosed Condition	325	0.3%
Infectious Diseases	495	0.5%
Neoplasms	3868	4.2%
Endocrine, Nutritional, Metabolic Disease, Immun. Disorder	6583	7.1%
Disease of Blood and Blood-Forming organs	2029	2.2%
Mental Disorders and Mental Retardation	140	0.2%
Diseases of the Nervous System	12785	13.7%
Diseases of the Eye	3673	3.9%
Diseases of the Ear and Mastoid	8489	9.1%
Diseases of the Circulatory System	2721	2.9%
Diseases of the Respiratory System	1257	1.4%
Diseases of the Digestive System	4824	5.2%
Diseases of the Genitourinary System	2704	2.9%
ICD.9 Codes 630-679	46	0.0%
Diseases of Skin and Subcutaneous Tissues	266	0.3%
Diseases of Musculoskeletal System and Connective Tissue	4016	4.3%
Congenital Anomalies	21291	22.9%
Perinatal Morbidity and Mortality	6587	7.1%
ICD.9 Codes 780-799	2657	2.9%
Accidents, Poisonings, Violence, and Immunization Reactions	8283	8.9%
Total	93039	100.0%

Source: CMS Net - Data are for current Active cases effective 3/31/05

*Data does not include Los Angeles, Orange and Sacramento Counties

* Difference between CA and Nation significant at $p < .05$ ** Differences within the Nation significant at $p < .05$ ^ Difference within the State significant at $p < .05$

Birth Defects Data:

CALIFORNIA			
Estimated cases for 529,245 total livebirths			
	Estimated Cases	Rate per 1000	Frequency
All Structural Birth Defects	16,038	30.3	1 in 33
Specific Conditions			
Serious heart defects	1,348	2.55	1 in 390
- Conotruncal heart defects	389	0.73	1 in 1,360
Chromosome abnormalities	694	1.31	1 in 760
- Down syndrome	538	1.02	1 in 980
Oral clefts	720	1.36	1 in 730
- Cleft lip with/without cleft palate	497	0.94	1 in 1,060
- Cleft palate	232	0.44	1 in 2,280
Intestinal atresia/imperforate anus	275	0.52	1 in 1,930
Neural tube defects	262	0.49	1 in 2,020
- Anencephaly	138	0.26	1 in 3,800
- Spina bifida	189	0.36	1 in 2,800
Abdominal wall defects	236	0.45	1 in 2,250
- Gastroschisis	185	0.35	1 in 2,860
- Omphalocele	47	0.09	1 in 11,320
Limb defects	217	0.41	1 in 2,440
Infant deaths with birth defects	1588	~3.00	1 in 333
Mental retardation, school age	2646	5.00	1 in 200
Source: Estimates use registry data and California birth totals			

ⁱ National Survey of CSHCN, 2001

ⁱⁱ Inkelas M, Ahn P, Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

ⁱⁱⁱ Wells, N., Doksum, T., Martin, L., Cooper, J. (2000) What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

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Children with Special Health Care Needs Medical Home and Access to Care

Medical Home

From the National CSHCN Surveyⁱ:

The National Survey of CSHCN implements the American Academy of Pediatrics definition of a medical home – medical care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective and delivered or directed by a well-trained primary care or specialty physician who helps to manage and facilitate essentially all aspects of care for the child. The medical home variable is derived from responses to questions about having a usual source of care, having a personal doctor or nurse, having no problems receiving referrals when needed, and family centered care.

- 55% of CSHCN in California are lacking a medical home. Significantly more CSHCN in California are lacking a medical home when compared to the National rate of 47.3% of CSHCN without a medical home
- Only about half of children surveyed had a case manager, most of whom were employed by the regional centers (35%) or CCS (28%). Only 3% of the case managers were employed by a health insurance plan.

From the “Experiences with health care for California’s children with special health care needs” 2003ⁱⁱ

- Fewer CSHCN in Medi-Cal than in other state Medicaid programs had a usual source of health care, with much greater use of community and hospital clinics than doctor’s offices a month those with a usual source. Fewer in California than other states had a personal doctor or nurse.

From CMS Netⁱⁱⁱ

In CMS Net, having a medical home is defined as having a primary care provider.

CA Counties vary widely in their percentages of CCS children with a medical home.

- in 35% of counties, 80% or more of their CCS children have medical homes
- in 24% of counties, between 60 to 79% of their CCS children have medical homes
- in 22% of counties, between 40 to 59% of their CCS children have medical homes
- in 5% of counties, between 20 and 39% of their CCS children have medical homes
- in 15% of Counties have fewer than 20% of their CCS children with medical homes.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Medical Home by Race/Ethnicity

From the National Survey of CSHCN, 2001

- In California, Hispanics are significantly more likely than whites to be without a medical home (64.9% vs. 47.9%)
- In California, children with an “Other” race/ethnicity are significantly more likely than whites to be without a medical home (77.8% vs. 47.9%) (For African Americans, the sample size was too small to test for significant differences. Asians were included in the “other” category.)
- Rates for CA CSHCN lacking a medical home for race/ethnic groups are not significantly different than national rates for racial/ethnic groups

Medical Home and Insurance Status

From the National Survey of CSHCN, 2001

- Significantly more insured CSHCN in California are lacking a medical home compared to national rates for insured CSHCN (54.3% vs. 46.5%)
- 73.5% of uninsured CSCHN in California are lacking a medical home. This rate does not differ significantly from the national rate of 62.8%

Medical Home and Special Health Needs

From the National Survey of CSHCN, 2001

- In CA, children with functional limitations are significantly more likely to lack a medical home than are children with health needs managed by prescription drugs (64.8% vs. 41.7%)
- In CA, children with above routine needs and use of services are significantly more likely to lack a medical home than children whose needs are managed by prescription drugs (68.6% vs. 41.7%)

From the “Experiences with health care for California’s children with special health care needs” 2003

- Fewer CSHCN in Medi-Cal (83%) than with private insurance (94%) were reported to have a usual source of health care. Further, fewer CSHCN in Medi-Cal (72% than with private insurance (91%) had a personal doctor or nurse. California’s Medi-Cal program lags behind other state Medicaid programs on this important indicator.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Providing Effective Case Management to Eligible Children

From State Performance Measures^{iv}

This summary performance measure is designed to demonstrate that CCS, CHDP, and HCPCFC programs provide effective case management. The measure combines responses to 7 questions regarding CCS children having a documented medical home/primary care provider, children in out-of-home placement have a preventive health and dental exam within the past year documented in the health education passport, children referred to CCS have their program eligibility determined with prescribed guidelines per 2001 Procedures Manual, children enrolled in CCS whose conditions require CCS special care center services are seen at least annually at appropriate Special Care Centers, fee-for-service Medi-Cal eligible children whose CHDP screening exams reveal a condition requiring follow-up care receive it, and non-Medi-Cal eligible children whose CHDP screening exams reveal a condition requiring follow up care receive it.

In 56 CA counties, the percentages of points counties received on this measure ranged from 0 to 100% with an average of 72% of possible points.

- 32% of counties scored 80% or more of possible points
- 45% of counties scored between 60 to 79% of possible points
- 23% of counties scored less than 60% of possible points

Unmet Medical Needs

Unmet need is a direct measure of access to health care services. Unmet service needs 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.

- CSHCN in CA are significantly more likely to have unmet needs for health care services (23.1%) than are CSHCN nationwide (17.7%)*

Unmet Medical Needs by Race

From the National Survey of CSHCN 2001

- Nationwide, Black, Hispanic, and multiracial CSHCN are significantly less likely to report no unmet needs for health care than are Whites (84.8% for Whites vs. 77.3% for Blacks, 76.2% for Hispanics, and 74.2% for multiracial).** CA data reflects this same pattern, although the small sample size prevents these differences from achieving statistical significance. A larger CA sample would likely reveal that Blacks and Multi-racial CSHCN are significantly less likely to have no unmet needs.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Unmet Medical Needs by Medical Home

From the National Survey of CSHCN 2001

- Compared to CSHCN nationwide with medical homes, those without medical homes are significantly more likely to have unmet need for health care services (24.6% for those without medical homes vs. 10.5% for those with). CA data again reflects the same pattern, but differences fail to achieve statistical significance (26.6% for those without medical homes vs. 15.9% with).

Unmet Medical Needs by Insurance Status

From the National Survey of CSHCN 2001

- In both CA and nationwide, CSHCN without insurance are significantly more likely to report unmet medical needs than those with insurance.^{^,**} There were no significant differences between CA and the nation.
- In CA, 21.6% of those currently insured report unmet needs compared to 57.2% without insurance[^]
- Nationwide, 16.1% of those currently insured report unmet needs compared to 46.2% of those not insured^{**}

From the “Experiences with health care for California’s children with special health care needs” 2003

- Nearly half of children in Medi-Cal (43%) were reported having at least one unmet need. Rates of unmet need among those children in Medi-Cal requiring a particular service were high for mental health (42%) and specialty care (10%). Among all CSHCN in California, the highest reported rates of unmet need were for respite care (35%), family counseling or mental health services (23%) and mental health services for the child (22%)
- Most health services needed by CSHCN in Medi-Cal are covered benefits of the federal Medicaid program. Unlike adult services, children’s benefits in Medi-Cal come from the expansive federal Early and Periodic Screening Diagnosis and Treatment (EPSDT) requirements. The medical necessity definition in EPSDT requires the state Medicaid program to provide children with any federal Medicaid benefit that is needed to ameliorate a condition. Moreover, the CCS program covers specialty care for those children in Medi-Cal or Healthy Families with severe or disabling conditions. CCS also pays for some specialty services for commercially insured children whose health plans limit benefits:
 - Fewer parents of CSHCN in Medi-Cal (61%) compared to those with private insurance (86%) reported that their child’s needs are met by insurance benefits.
 - Parents of 18% of CSHCN in Medi-Cal said that the benefits “never” meet their child’s health care needs.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

[^] Difference within the State significant at $p < .05$

Unmet Need for Family Support Services

From the National Survey of CSHCN 2001

- 25.1% of CSHCN families in CA who needed respite care, genetic counseling and/or mental health services did not get all the support services that were needed (vs. 23.1% nationwide, difference not significant)
- Nationally, there were no statistically significant differences in unmet needs for family support services by race. In CA, the sample is too small to detect any significant differences.

Access

From the “Experiences with health care for California’s children with special health care needs” 2003

- In general parents of CSHCN in Medi-Cal report experiencing more access problems than parents of CSHCN in other state Medicaid programs. (Nearly 80% of CCS children are Medi-Cal beneficiaries.)

Access to Specialty Care

From the “Experiences with health care for California’s children with special health care needs” 2003

- Parents of CSHCN in Medi-Cal more frequently reported difficulty obtaining a referral (54%) if their child is significantly affected by their medical condition.
- Most children eventually got needed specialty care even when they had problems with referrals. Parents of 9% of the CSHCN who needed a specialist (about 44,000 children) said that the child did not receive the needed care, with no differences between children in Medi-Cal (10%) and children in private insurance (8%)

Problems Getting Referrals

From the National Survey of CSHCN 2001

Problems getting Referral for Specialty care

- In CA, 27.5% of CSHCN who needed specialty care had problems getting a referral (vs. 21.9% nationwide, difference not significant)

Problems getting Referral for Specialty Care by presence of a Medical Home

- CSHCN in CA and nationwide with a medical home were significantly more likely than those without a medical home to report no problems getting referrals for needed specialty care (100% with medical homes in CA and national vs. 54.6% of CSCHN in CA and 58.8% nationwide without a medical home)**.^^. CA rates did not differ significantly from national rates.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Problems getting Referral for Specialty care by Type of Health Problem

- Nationally, CSHCN managed by prescription drugs (Rx meds) who needed specialty care were significantly more likely to report no problems getting a referral (86.4%) than CSCHN who have functional limitations and need a referral (72.5%), or CSHCN who have above routine needs/use of services (72.6%), or CSHCN who are managed by Rx meds and have above routine needs/use of services (78.4%)** In CA, data reflect a similar pattern, however differences are not statistically significant due to small sample size.

Problems getting Referral for Specialty care by Insurance Adequacy

- In both CA and nationally, CSHCN not having adequate insurance were significantly less likely to report having no problems getting a referral for need specialty care (58.5% for CA and 66.9% nationally) than were CSCHN with adequate insurance (81.4% in CA, 85.2% nationally)

Waiting times from referral to first authorization for CCS services

From CMS Net

In 54 CA counties, average waiting times for referral to authorization vary from 55 to 227 days, with an average of 127 days.

- in 26% of counties, average waiting time was between 55 to 98 days
- in 41% of counties, average waiting time was between 99 to 141 days
- in 24% of counties, average waiting time was between 142 to 184 days
- in 9% of counties, average waiting time was between 185 to 227 days

Access to Ancillary Services

From CMS Net

Wait time between request for in-home support services and authorization

- Average Wait time between request for and authorization for in-home support services ranges from 0 to 1469 days, with average being 24 days, the mode (most frequent value) being 0 days and the median (middle value) being 5 days.

Access to Equipment

From CMS Net

Wait time between request for equipment (wheelchairs) and authorization

- Average Wait time between request for and authorization of equipment ranges from 0 to 1838 days, with average being 29 days, the mode (most frequent value) being 0 days and the median (middle value) being 12 days.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Provider Certification

From CMS Branch

- The length of time between when a provider application is received and when it is approved for paneling is 5 to 7 weeks. This time frame is based on the assumption that the provider has an active Medi-Cal number in good standing along with all the required documentation to fully complete the provider's paneling application

ⁱ National Survey of CSHCN, 2001

ⁱⁱ Inkelas M, Ahn P, Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

ⁱⁱⁱ CMS Net

^{iv} State performance measures

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$



Children with Special Health Care Needs Health Insurance Coverage

Research shows that for children generally, retention of coverage is important for health care continuity, quality of care, parent adherence to medical advice and parent self-management of children's conditions.

Current Insurance Coverage for CSHCN

From the National Survey of CSHCN, 2001ⁱ

	<u>Private or employer- based insurance only</u>	<u>Medicaid, SCHIP, Title V, or other public insurance only</u>	<u>Combination of public and private insurance</u>	<u>Uninsured at time of survey</u>
California %:	72.2*	16.6*	6.9	4.3
Nationwide %:	64.9	21.7	8.1	5.2

- CSHCN in CA are significantly more likely than CSCHN nationally to have private or employer based only and significantly less likely to have public insurance only

From the "Your Voice Counts!!" Surveyⁱⁱ:

- More than half (53%) of children were enrolled in Medi-Cal managed care, 26% were enrolled in private managed care plans, 20% were enrolled in Medi-Cal fee for service, and 1% in private fee for service plans.
- Although nearly half (46%) of the families did not know whether their child was in a managed care plan, most of the children (72%) were in a plan with at least one feature of managed care, such as having a network of doctors or requiring a primary care physician.

No Insurance Coverage during Past Year

From the National Survey of CSHCN, 2001

- 9.9% of CSHCN in CA and 11.6% nationally were without health insurance at some point during the year prior to the survey. Differences are not significant.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Current Insurance Inadequate

From the National Survey of CSHCN, 2001

- 36.5% of CSHCN in CA and 33.8% nationally report that their current insurance is not adequate. Differences are not significant.

Current Insurance inadequate by Race

	<u>Hispanic</u>	<u>White</u>	<u>Black</u>	<u>Multiracial</u>	<u>Other</u>
California %:	46.1**	33.2	21.6	45.6	37.2
Nationwide %:	46.7	31.5	34.2	35.5	36.6

- Nationally, Hispanics were more likely than all other groups to not have adequate insurance for their CSHCN
- CA data reflects a similar pattern, although small sample sizes result in Hispanics only differing significantly from Blacks, but not from Whites.

From the “Your Voice Counts!!” Survey:

- Of children needing home health care, 39% reported problems. Of those, half had insurance that wouldn't pay for home health care. Fifty one percent of families reporting problems had trouble getting payment for enough home health care hours.
- Of children needing therapies, 35% reported problems. The most common problem for children who needed some kind of therapy was that they did not get the therapy they needed. Lack of coverage for occupational therapy and speech therapy was the second most common problem followed by difficulty getting a referral and an adequate number of visits to meet their child's needs.

Current Insurance by Specific Types of Special Health Needs

From the National Survey of CSHCN, 2001

- Nationally, CSHCN managed by prescription drugs are significantly more likely to have adequate insurance (73.7%) than CSHCN who have functional limitations (57.3%), above routine needs/use of services (59.7%) or both above routine needs/use of services and use of prescription drugs (66.9%)
- CA data reflect similar patterns, but only CSHCN who are managed by prescriptions drugs are significantly more likely to have adequate insurance than CSHCN who have above routine need/use of services (76.2% vs. 47.2%). With a larger sample size, other differences would likely be significant.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Reasonableness of Costs Not Covered by Insurance

From the National Survey of CSHCN, 2001

- In CA, 30.7% of CSHCN have costs that are not covered by insurance that are never or sometimes reasonable, 28.8% have costs that are usually reasonable and 40.5% have costs that are always reasonable. National data reflect a similar pattern and did not differ significantly from CA.

From the “Experiences with health care for California’s children with special health care needs”, 2003:

- Recent expansions of Medi-Cal and the Healthy Families program have improved children’s financial access to health care. However, having insurance coverage does not guarantee that CSHCN are covered for all the services that they need.
- In 2001, the rate of uninsurance for CSHCN (4%) was similar to the uninsurance rate among all children 0-17 years in California (55)
- However, a larger proportion of CSHCN (10%) was currently uninsured or experienced a gap in coverage. Although gaps in insurance may be temporary, changes in coverage disrupt services.
- Most health services needed by CSHCN in Medi-Cal are covered benefits of the federal Medicaid program. Unlike adult services, children’s benefits in Medi-Cal come from the expansive federal Early and Periodic Screening Diagnosis and Treatment (EPSDT) requirements. The medical necessity definition in EPSDT requires the state Medicaid program to provide children with any federal Medicaid benefit that is needed to ameliorate a condition. Moreover, the CCS program covers specialty care for those children in Medi-Cal or Healthy Families with severe or disabling conditions. CCS also pays for some specialty services for commercially insured children whose health plans limit benefits:
 - Fewer parents of CSHCN in Medi-Cal (61%) compared to those with private insurance (86%) reported that their child’s needs are met by insurance benefits.
 - Parents of 18% of CSHCN in Medi-Cal said that the benefits “never” meet their child’s health care needs.

Needs Met By Insurance

From the “Experiences with health care for California’s children with special health care needs”, 2003

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Access to Care for Children with Special Health Care Needs Ages 0-17, California 2001

	All CSHCN (%)	CSHCN in Medi-Cal(%)
Insurance benefits usually meet child's needs.	81.4	60.9
Have enough information about how health plan works.	88.0	72.4
Non-covered costs reasonable.	69.4	57.5
Insurance usually allows child to see needed providers.	80.1	60.5
Would switch health plan if could.	33.4	44.9
Health plan is good for CSHCN.	80.3	80.1

Note: All differences are statistically significant

- Fewer parents of CSHCN in Medi-Cal (61%) compared to those with private insurance (86%) reported that their child's needs are met by insurance benefits. Parents of 18% of CSHCN in Medi-Cal said that the benefits "never" meet their child's health care needs. The report says "The NS-CSHCN shows that although medical benefits in Medi-Cal are generally more comprehensive than benefits in private insurance, this does not mean that children are always able to obtain these services. Parents of children in Medi-Cal more frequently perceived that the coverage does not meet their child's needs. Yet most health services needed by CSHCN in Medi-Cal are covered benefits of the federal Medicaid program.

Impact of Coverage System on Families

From the "Your Voice Counts!!" Survey:

- Over half of the parents reported spending some time each week providing health care at home. One-fifth spent 20 or more hours per week providing this care.
- One third of the parents reported that their child's health conditions caused financial problems; 28% said they stopped working; and 37% cut down the hours they worked.
- Almost half the parents reported spending between \$500 and \$3000 out of their own pocket for the special health care needs of their child in the past year. One-tenth said they spent \$3000 or more.

ⁱ National Survey of CSHCN, 2001

ⁱⁱ Wells, N., Doksum, T., Martin, L., Cooper, J. (2000) What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$



Children with Special Health Care Needs Screening

Newborn Screening

From Title V Reports, 2001-2003ⁱ

In CA, all newborns are screened for 4 conditions: phenylketonuria, congenital hypothyroidism, galactosemia, and sickle cell disease. Nationwide, the number of screenings states mandate range from 4 to 36. California is in the process of mandating screening for an additional 26 conditions.

- CA has high rates of screening for the 4 conditions it mandates: 99.9% in 2001, 99.0% in 2002, and 98.5% in 2003
- In CA, very high percentages of those needing treatment for each of these conditions receive it, with 100% of those needing treatment for PKU, congenital hypothyroidism, and galactosemia in 2003 receiving. Rates for receiving needed treatment of sickle cell disease are slightly lower and have been increasing for the last three years: 2001 = 94%, 2002 – 95.9%, 2003 – 97.6%
- In CA in 2003, 709 infants had a presumptive positive screen for congenital hypothyroidism and there were 275 confirmed cases; 164 infants had a presumptive positive screen for PKU and there were 34 confirmed cases; 93 infants had a presumptive positive screen for galactosemia and there were 6 confirmed cases; and 86 infants had presumptive positive screens for sickle cell disease and there were 84 confirmed cases

California Newborn Hearing Screening

From Title V reports – Statewide data

	1999	2000	2001	2002	2003*
Annual Indicator	9.8%	13.7%	21.6%	52.2%	52.2%
Annual Performance Objective	10%	10%	15%	40%	60%

* Projected

From the State Newborn Hearing Screening Program (NHSP) Dataⁱⁱ

- In CA, all newborns born at CCS-approved hospitals are required to be offered hearing screening and all infants in CCS-approved NICUs must be screened. In

2003, approximately 74% of all newborns born in the state were born at a CCS approved hospital.

- In 2003, 90.7% of newborns at CCS-approved hospitals received hearing screening at birth, and 94.3% did so in 2004
- Screening rates in WBN in CCS approved hospitals that were certified to participate in the NHSP were 97.1% in 2004 and 97.2% in 2003
- Screening rates in CCS approved NICU that were certified to participate in the NHSP were 91% in 2004 and 86.3% in 2003
- In 2004, 0.9/1000 of those screened in WBN identified with hearing loss, and 5.5/1000 of those screened in NICU
- There were some regional variations in NICU screening rates, with Regions A and B reporting the lowest levels of screening (Region A: 2003 = 85.9%, 2004 = 87.9%; Region B: 2003 = 73.4%, 2004 = 86%, and Region D reporting the highest: 2003 = 99.3%, 2004 = 98%)
- Regional screening rates for WBN ranged from 96.4% to 98.1%

ⁱ Data are from California's Title V Application 2005,

ⁱⁱ Data are from the California Newborn Hearing Screening Program, 2003 and 2004



Children with Special Health Care Needs Organization of Services

Organization of Services

From the National Survey of CSHCN, 2001ⁱ

Community-Based Service Systems Organized for Easy Use

- In CA, the National MCHB outcome of having community-based service systems organized so families can use them easily was successfully achieved for 65.9% of CSHCN (vs. 74.3% nationally, difference is not significant)

Community-Based Service Systems Organized for Easy Use by Race

- Nationally, this outcome was more likely to be achieved for Whites (77.4%) than for Hispanics (66.4% and Blacks (65.3%), or other (59.2).
- In CA, the sample size is very small, but generally reflects the pattern of the national data

From “Experiences with health care for California’s children with special health care needs”ⁱⁱ:

- In general, parents of CSHCN in Medi-Cal reported more difficulty in navigating the system of services and obtaining the health care benefits needed by the child than did parents of CSHCN in other state Medicaid programs.

From the “Your Voice Counts!!” Survey:

- Most parents were dissatisfied with the lack of “family-centeredness” of their primary health plan. Parents were most dissatisfied with the lack of information or newsletters about issues of interest or resources outside of their plan. Many were dissatisfied with or did not know whether their plan offered parent support groups or gave parents an opportunity to give advice to the plan.

Care Coordination and Communication Among Providers

From the “Experiences with health care for California’s children with special health care needs”:

Care coordination involves sharing of medical information between providers as well as helping parents navigate service systems. Parents of children with complex conditions often need help coordinating multiple appointments and services. The health needs of many CSHCN are also relevant to their ability to attend school or child care as well as their need for referral to public programs such as early intervention, CCS, and Regional Centers.

- Most parents who received professional care coordination said they were generally satisfied with it, suggesting that professional care coordination based at public programs, health plans and even provider offices is helping children access needed care.

Coordination and consistency of care for children in foster care

From the UCLA Health Services Assessment for Children in Foster Care:ⁱⁱⁱ

- Fewer than one third of agencies report that judges review a child's health plan when making decisions about a child's placement.

ⁱ National Survey of CSHCN, 2001

ⁱⁱ Inkelas M, Ahn P, Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

ⁱⁱⁱ Halfon N, Inkelas M, Flint R, Shoaf K, Zepeda A, Franke T. 2002. Assessment of factors influencing the adequacy of health care services to children in foster care. UCLA Center for Healthier Children, Families and Communities.



Children with Special Health Care Needs Family-Centered Care, Participation, and Satisfaction

Family partnership in decision-making

From the National Survey of CSHCN 2001ⁱ:

- The MCHB core outcome: Families of CSHCN will partner in decision-making and will be satisfied with the services they receive, was successfully achieved for 57.5% of CSHCN nationwide, and by 47.6% in CA. This difference is almost statistically significant.

Family partnership in decision-making by race

- Nationally, for 55.8% of Hispanic CSHCN, 51.6% of Black CSHCN, and 56.5% of other CSHCN, the MCHB outcome of families partnering in decision-making and being satisfied with the services they received was NOT successfully achieved. Compared to Whites (37% did not achieve this outcome), Hispanic, Black, and other CSHCN are significantly less likely to achieve this outcome. In CA, the data reflect a similar pattern with even large percentages of Hispanic, Black and other CSHCN for whom this outcome was not achieved. However, there are very small numbers in the CA sample for this item and only Hispanic CSHCN differ significantly from White CSHCN.

Family Participation

From State Performance Measuresⁱⁱ

This summary performance measure is designed to assess the degree to which the CMS program demonstrates family participation. The measure combines responses to 6 questions regarding family member participation on advisory committees or task forces, offering of financial support for parent activities or groups, providing opportunities for family members to provide feedback regarding their satisfaction with services received through CCS program, involving family members in in-service trainings of CCS staff and providers, hiring family advocates for their expertise as paid staff or consultants to the CCS program, and involving family members of diverse cultures in all the above activities.

In 51 CA counties, the percentage of points counties received on this measure ranged from 0 to 100% with an average of 41% of possible points.

- 6% of counties scored 80% or more of possible points
- 18% of counties scored between 60 to 79% of possible points
- 22% of counties scored between 40 to 59% of possible points
- 29% of counties scored between 20 to 39% of possible points
- 26 of counties scored less than 20% of possible points

Understanding How Health Plans Work

From the “Experiences with health care for California’s children with special health care needs”ⁱⁱⁱ

- About $\frac{3}{4}$ (73%) of parents of CSHCN in Medi-Cal said that they have enough information about how their child’s health insurance plan works, compared to 92% of parents of privately insured children.
- Among parents of the children most severely affected by their condition, 56% of those in Medi-Cal reported having enough information about their health insurance plan compared to 92% of privately insured children.

From the “Your Voice Counts!!” Survey^{iv}:

- Nearly half (46%) of families surveyed did not know whether their child was in a managed care plan, though most (72%) were in fact in a plan with at least one managed care feature, such as a network of doctors or required primary care doctor.

Satisfaction with Services/Care

From the “Your Voice Counts!!” Survey

- 44% of families said they were “very satisfied” with their child’s primary plan; 42% were “somewhat satisfied”, 12% were “somewhat dissatisfied” and 2% were “very dissatisfied.”
- Parents of children in Medi-Cal managed care plans were most satisfied with their doctor’s overall quality of care than those in private managed care plans.

Quality of the Provider-Parent Relationship

From the “Experiences with health care for California’s children with special health care needs”

Research generally shows that a good interpersonal relationship between the provider and parent/child improves adherence to medical advice, patient satisfaction, self-rated access to care, fewer unmet needs and fewer emergency department visits.

- Fewer children in Medi-Cal (62%) than with private insurance (82%) were reported to have enough time with their providers.
- Most indicators show lower parent ratings of how well the child’s provider understand the child’s unique needs and provides the information needed by the family about the child’s condition

Access to Care for Children with Special Health Care Needs, Ages 0-17, California 2001

	All CSHCN (%)	CSHCN in Medi-Cal(%)
Child has a personal doctor or nurse.	86.8	72.2
Doctors communicate well (among children receiving professional care coordination).	66.2	82.0
Provider communicates well with school, early intervention, programs, provider.	52.6	56.1
Provider is sensitive to family values and customs.	84.5	75.0
Provider spends enough time with child.	77.8	62.3
Provider gives specific information needed.	72.3	61.1

Note: All differences are statistically significant

From the “Your Voice Counts!!” Survey:

- Parents who responded in Spanish were less satisfied in terms of overall quality of care from their doctors, their doctor’s overall communication with the family, and their waiting times. Spanish respondents were more satisfied with their doctor’s respect for their child and the family than those responding in English

ⁱ National survey of CSHCN 2001

ⁱⁱ State performance measures

ⁱⁱⁱ Inkelas M, Ahn P, Larson K. 2003. “Experiences with health care for California’s children with special health care needs.” Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

^{iv} Wells, N., Doksum, T., Martin, L., Cooper, J. (2000) What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.



Children with Special Health Care Needs Transition to Adulthood

From CMS Net

Number of CCS Clients Age 20 with Insurance

- Out of the CCS cases active as of 3/15/05, there were a total of 2746 clients 20 years of age. Within 52 CA counties, the percentages of these clients with insurance range from 1 to 100% with an average of 22% having insurance.

Expenditure data for CCS program
By Selected Diagnosis
FY 2003-2004

ICD-9 Codes	Medi-Cal	HF	CCS-only	Total
Congenital Heart Disease (754-747)	\$48,200,000	\$4,000,000	\$1,800,000	\$54,000,000
Cleft Lip/Palate (749)	\$3,900,000	\$539,000	\$727,000	\$5,166,000
Cerebral Palsy (343)	\$32,190,000	\$363,000	\$4,583,000	\$37,136,000
Hearing Loss (389)	\$4,700,000	\$496,000	\$945,000	\$6,141,000
Hemophilia (286)	\$80,200,000	\$8,279,000	\$5,510,000	\$93,989,000
Acute Lymphocytic Leukemia (204)	\$15,800,000	\$2,220,000	\$981,000	\$19,001,000
Brain Cancer (191)	\$8,722,000	\$1,158,000	\$586,000	\$10,466,000
Cystic Fibrosis (277)	\$8,245,000	\$372,000	\$532,000	\$9,149,000
Total	\$201,957,000	\$17,427,000	\$15,664,000	\$235,048,000

Expenditure and Beneficiary data for CCS program
By Selected Service Provided
FY 2003-2004

Procedure Codes	Medi-Cal	# M/C	HF	# HF	CCS-only	# CCS	Total	Total #
Developmental Screening	\$67,700		\$1,700		\$5,900		\$75,300	
96110	\$30,400		\$920		\$3,600		\$34,920	
96111	\$37,300		\$780		\$2,300		\$40,380	
Hearing Aids	\$2,024,000	1,635	\$249,000	187	\$507,000	405	\$2,781,822	2,227
Z5946	\$832,000		\$135,000		\$230,000		\$1,197,000	
V5030-V5255	\$1,192,000		\$114,000		\$277,000		\$1,583,000	
Equipment (Wheelchairs)	\$6,693,000		\$132,000		\$554,000		\$7,379,000	
E0950-1030	\$295,000		\$7,700		\$28,000		\$330,700	
E1050-E1298	\$793,000	2,574	\$23,000	160	\$78,000	284	\$897,018	3,018
E1399	\$5,900,000		\$109,000		\$476,000		\$6,485,000	
Home Health Services	\$1,600,000		\$109,000		\$114,000		\$1,823,000	
Z6900-Z6916	\$1,600,000		\$109,000		\$114,000		\$1,823,000	
Inpatient Services	\$581,264,000	27,441	\$40,492,000	2,031	\$14,839,000	976	\$636,624,472	30,448
099-219	\$581,000,000		\$40,400,000		\$14,800,000		\$636,200,000	
250-949	\$264,000		\$92,000		\$39,000		\$395,000	
NICU	\$187,000,000		\$580,000		\$1,300,000		\$188,880,000	
170-175	\$187,000,000		\$580,000		\$1,300,000		\$188,880,000	
ICU	\$120,000,000		\$12,000,000		\$3,800,000		\$135,800,000	
PICU	\$80,700,000		\$7,200,000		\$2,000,000		\$89,900,000	
Factor	\$79,000,000	382	\$8,500,000	50	\$5,331,000	64	\$92,831,496	496
J7190-J7195 & Z5230	\$79,000,000		\$8,500,000		\$5,331,000		\$92,831,000	

Appendix H

Tables of County Level CCS Data

	<u>Page</u>
Table of CCS Cases by County	2
Table of Percent of Children receiving CCS Services with a Medical Home by County	3
Table of CCS-Paneled Pediatricians by County and Number of Pediatricians per 100 Children Served by CCS	4
Table of CCS-Paneled Specialists by County and Number of Pediatricians per 100 Children Served by CCS	5
Table of Average Number of Days between Referral to CCS and Eligibility Determination by County	6
Table of Average Number of Days between Referral to CCS and Authorization for services by County	7
Table of Number of Children Age 20 Served by CCS and Number and % with Insurance	8
Table of Diagnosis Data for Los Angeles County CCS	9

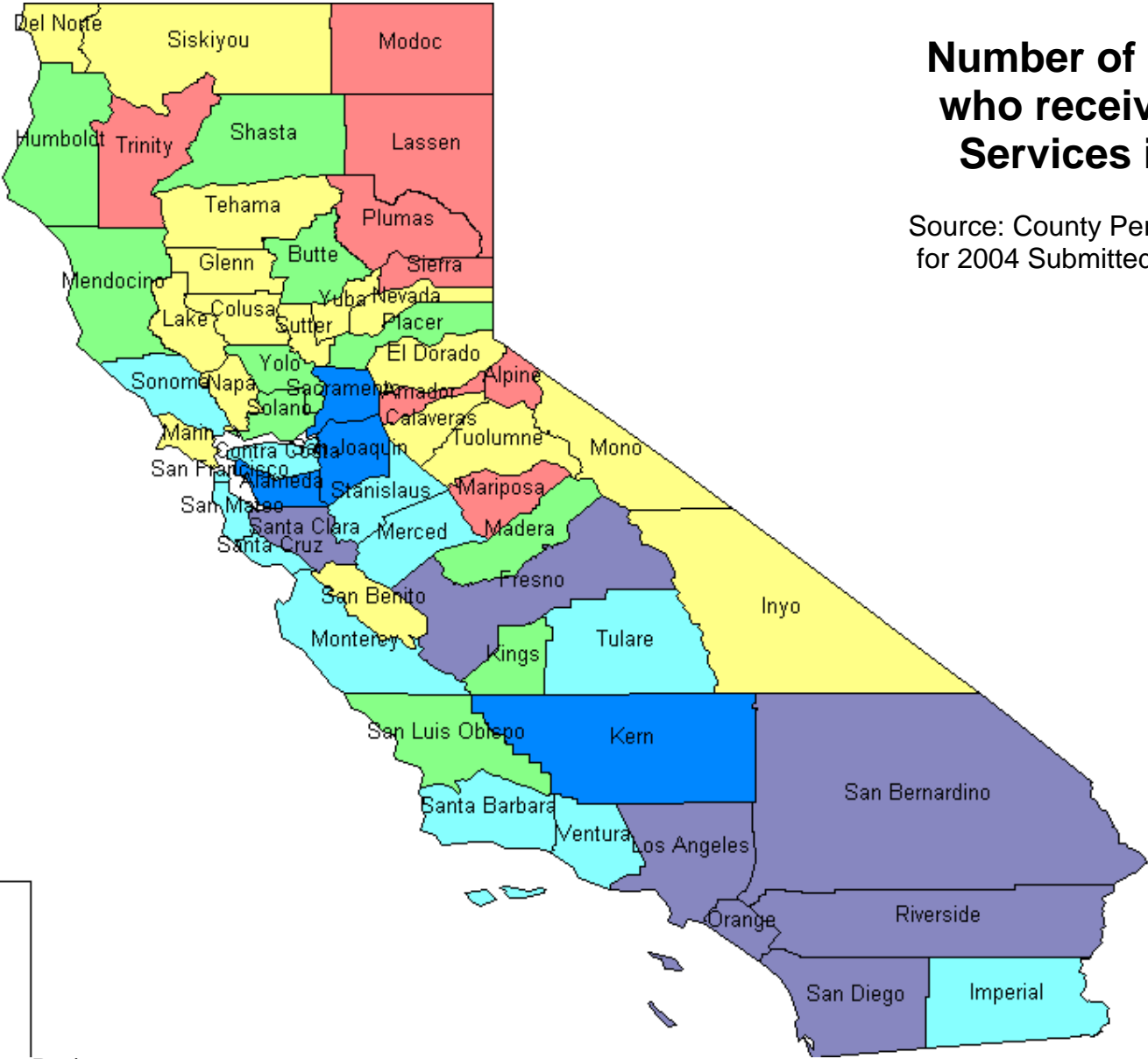
Appendix I

Maps of County Level CCS Data

	Page
Number of Children who received CCS Services in 2004 – Color Map	2
Number of Children who received CCS Services in 2004 – Black and White Map	3
Percent of Children Served by CCS in 2004 with a Medical Home – Color Map	4
Percent of Children Served by CCS in 2004 with a Medical Home – Black and White Map	5
CCS-Paneled Pediatricians by CCS Cases for 2004 – Black and White Map	6
Key CCS-Paneled Specialists by CCS Cases for – Black and White Map	7
CCS-Approved Facilities by Number of Children Receiving CCS Services in 2004 – Color Map	8

Number of Children who received CCS Services in 2004

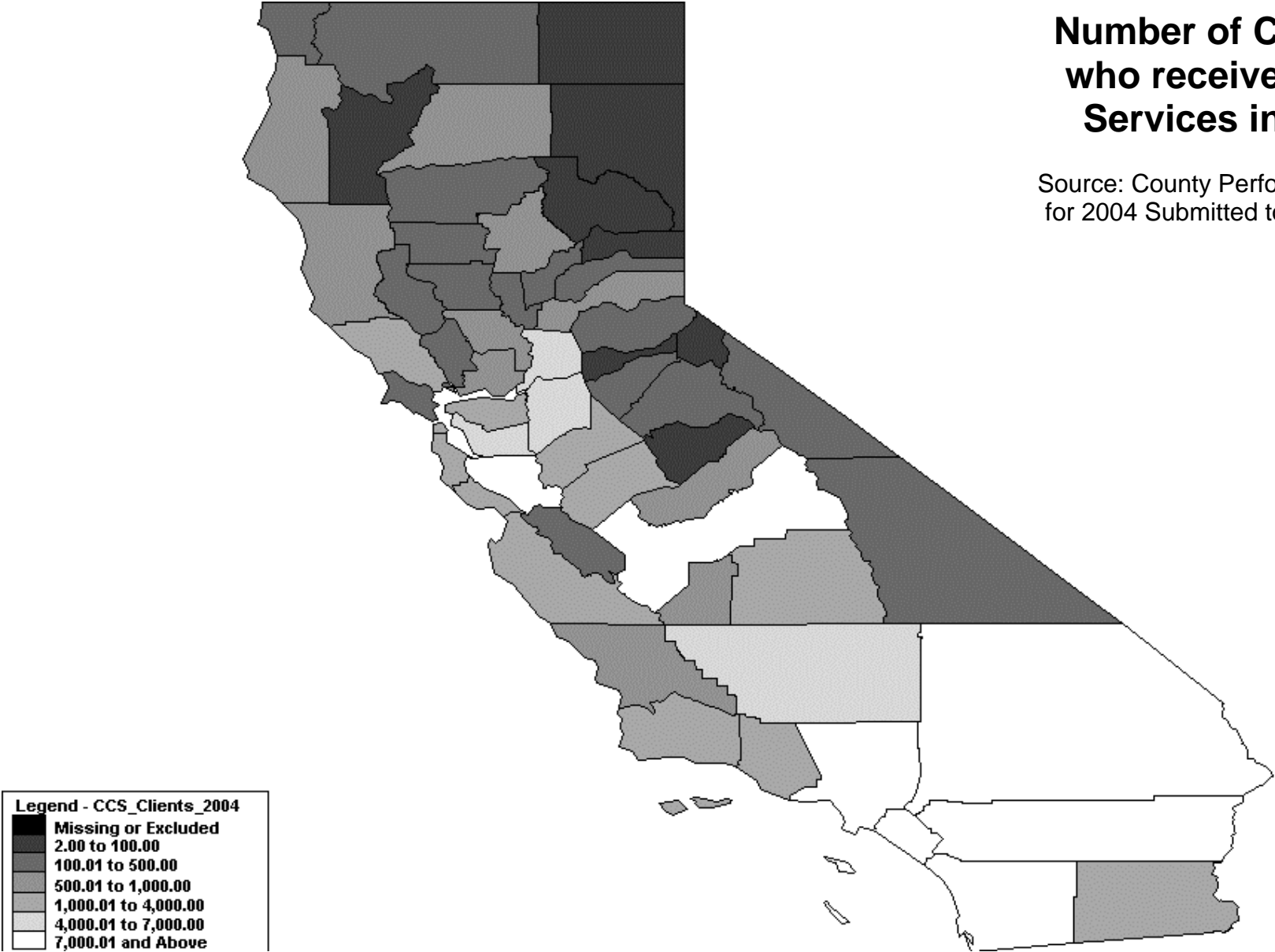
Source: County Performance Data for 2004 Submitted to State CMS



Legend - CCS_Clients_2004	
[White Box]	Missing or Excluded
[Red Box]	2.00 to 100.00
[Yellow Box]	100.01 to 500.00
[Light Green Box]	500.01 to 1,000.00
[Cyan Box]	1,000.01 to 4,000.00
[Blue Box]	4,000.01 to 7,000.00
[Dark Blue/Purple Box]	7,000.01 and Above

Number of Children who received CCS Services in 2004

Source: County Performance Data for 2004 Submitted to State CMS



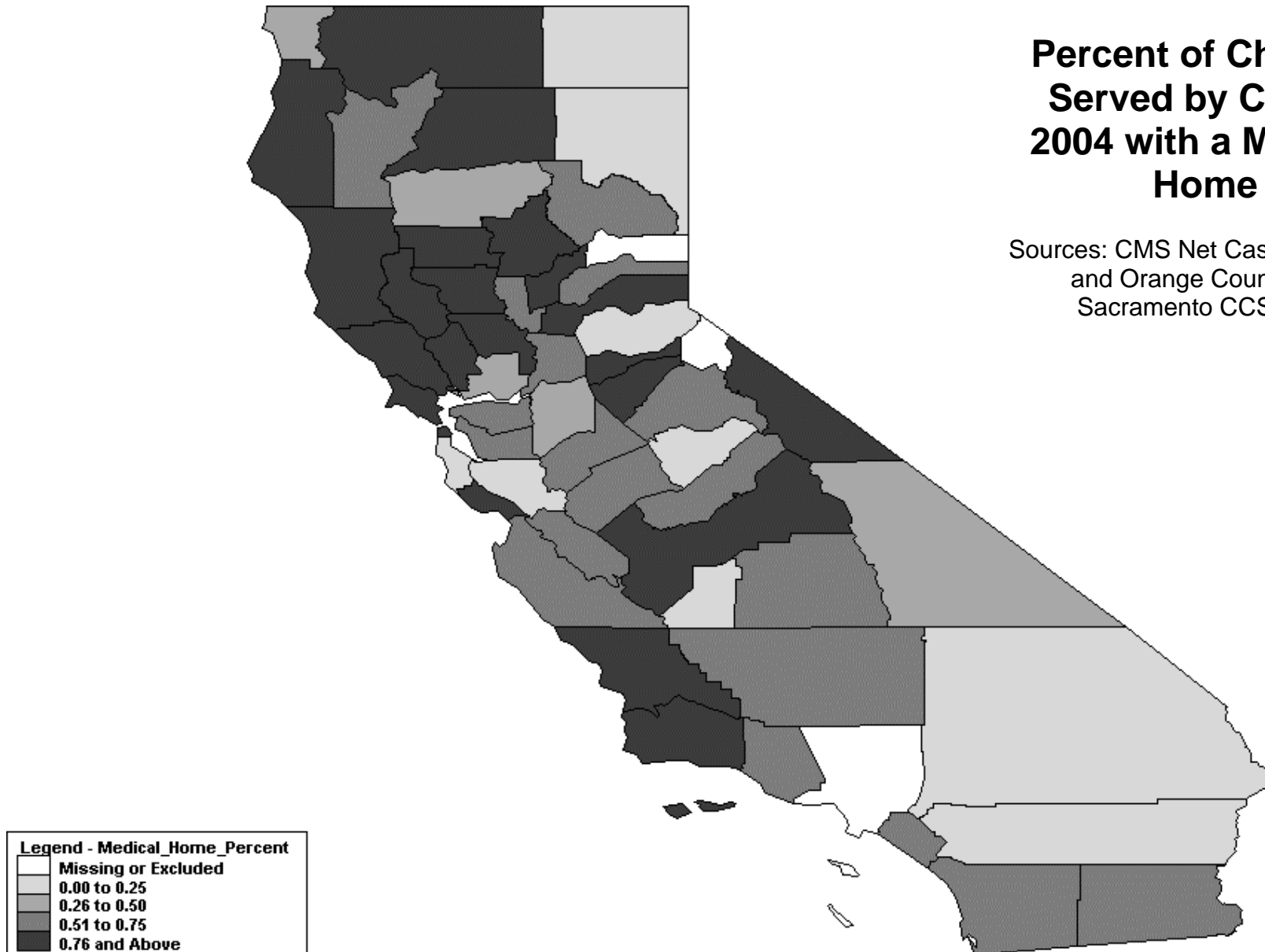
Percentage of Children Served by CCS in 2004 with a Medical Home

Sources: CMS Net Cases for 2004, and Orange County and Sacramento CCS Data



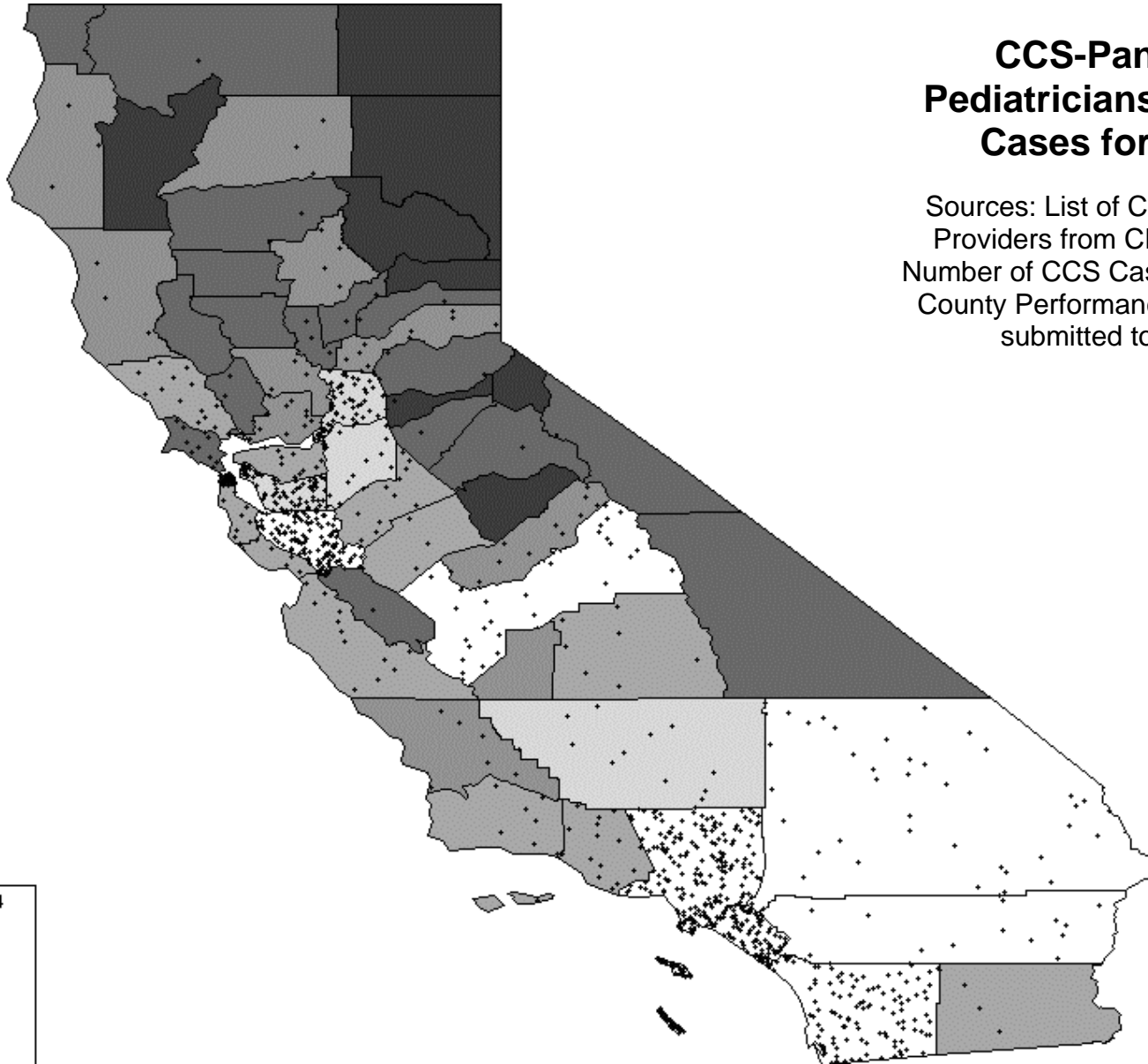
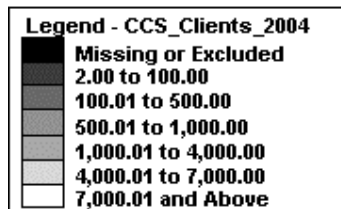
Percent of Children Served by CCS in 2004 with a Medical Home

Sources: CMS Net Cases for 2004,
and Orange County and
Sacramento CCS Data



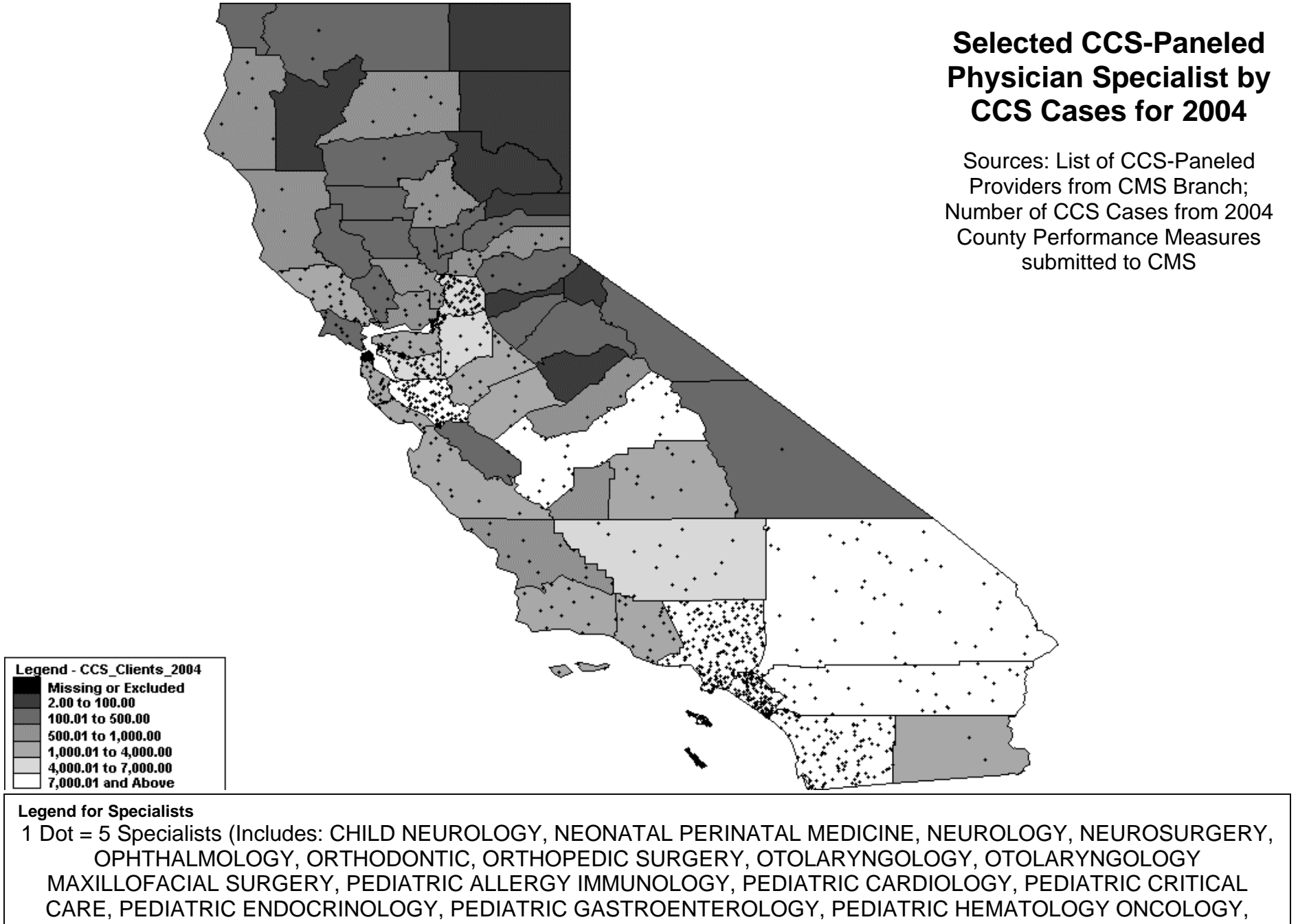
CCS-Paneled Pediatricians by CCS Cases for 2004

Sources: List of CCS-Paneled
Providers from CMS Branch;
Number of CCS Cases from 2004
County Performance Measures
submitted to CMS



Selected CCS-Paneled Physician Specialist by CCS Cases for 2004

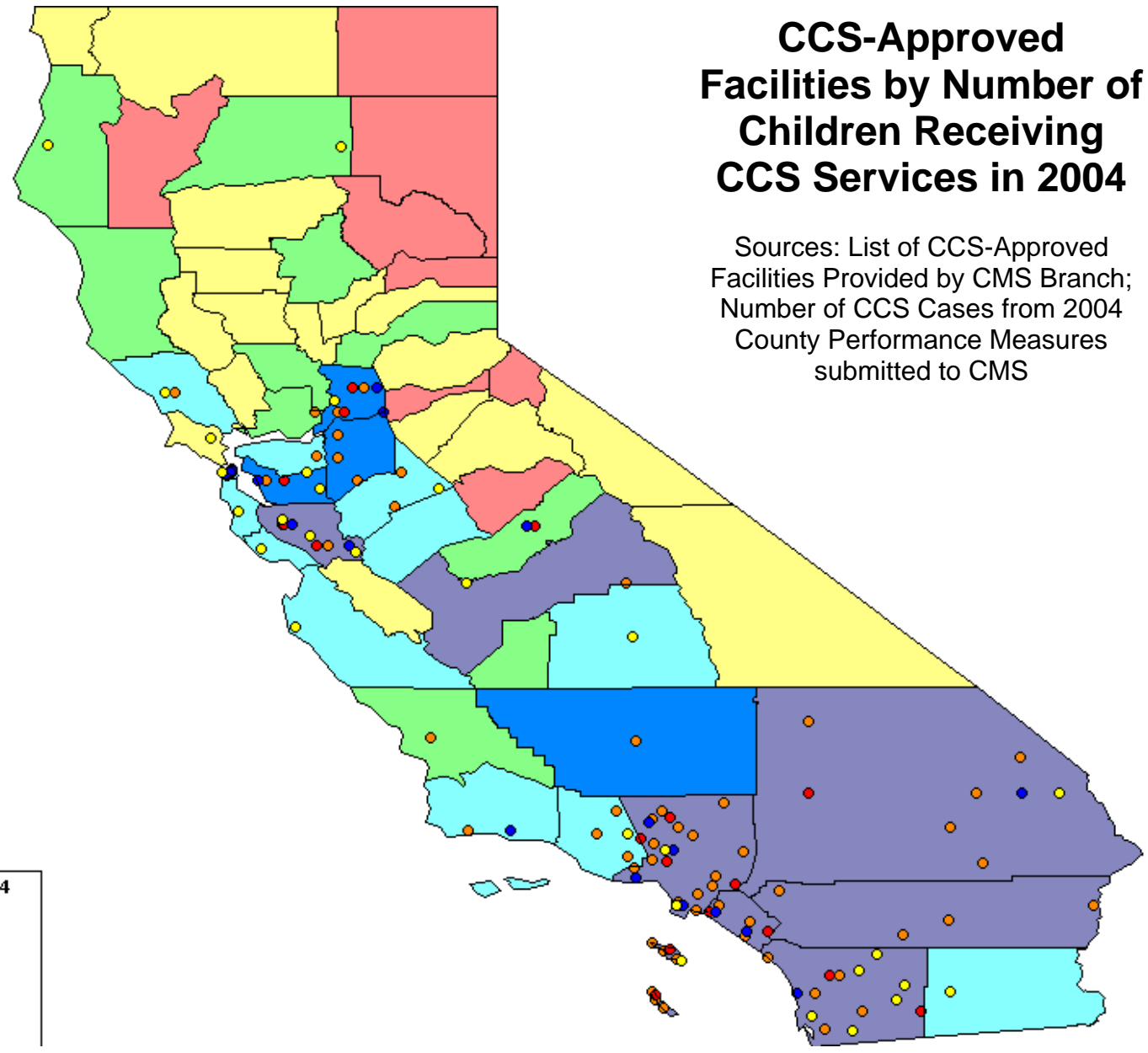
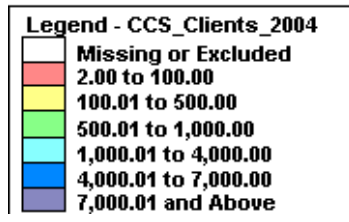
Sources: List of CCS-Paneled
Providers from CMS Branch;
Number of CCS Cases from 2004
County Performance Measures
submitted to CMS



- = Regional
- = Community
- = Intermediate
- = PICU

CCS-Approved Facilities by Number of Children Receiving CCS Services in 2004

Sources: List of CCS-Approved
Facilities Provided by CMS Branch;
Number of CCS Cases from 2004
County Performance Measures
submitted to CMS



Appendix J

Slide Show Presentation, April 28, 2005
CCS Title V CSHCN Stakeholder Meeting



Setting CCS Action Priorities for California's Title V 5-Year Plan

Family Health Outcomes Project (FHOP)

April 28, 2005

Why Are We Here?

To identify 3 priority areas that will:

1. Be incorporated into the Title V MCAH block grant application
2. Be used by CCS to focus program efforts for the next 5 years



How will we do it?

- We will follow a formal, rational and inclusive process
- This will involve using predefined criteria to prioritize issue areas identified by the stakeholders group and CCS

Review of Process to Date

- Stakeholders met (1/05)
 1. Reviewed objectives and process
 2. Selected criteria for setting priorities
 3. Weighted criteria
 4. Reviewed how data will be presented
 5. Met in groups to identify issues/data sources

Review of Process to Date

- Between meetings
 1. Break-out group members reviewed summaries / gave additional input
 2. Data requests / Data collection / Data review and analysis
 3. Criteria rating scales developed
 4. Materials sent to Stakeholders for review
 5. Issue areas / objectives identified

Today's Objectives

- Stakeholders will use criteria to prioritize among identified issues / objectives
- FHOP will facilitate identification of data development agenda
- All stakeholders will have an understanding of and accept the prioritized areas
- Meeting will lay ground work for next steps in the planning process

Purposes of the Process Today

- Assure that each stakeholder has equal input to final selection of priorities
- Provide a systematic, rational decision-making process that can be communicated to others
- Provide a way for stakeholders to incorporate both knowledge and values
- Provide stakeholders the same decision-making tools and information
- Assist in selecting a manageable number of priorities

Today's Prioritization Process

April 28, 2005

1. Review priority-setting criteria
2. Presentation of data and issue / objective list
3. Review Data and agree on final objective list
4. Review rating method
5. Rate problems
6. Tally scores to produce a group ranking
7. Discuss and confirm results
8. Brainstorm / discuss data development

Review of Criteria

- Criteria: the values or standards the group selected and will use to make decisions about priorities
- Each criterion was given a weight, for example:
 - 1 = important
 - 2 = more important
 - OR
 - 3 = extremely important



Stakeholder Criteria

1. **Problem has great impact on families** 3
(quality of life / functionality)
2. **Problem is important to consumers** 3
3. **Problem results in great cost to program and/or society** 2
(great fiscal impact)
4. **Addressing the problem maximizes opportunity to leverage resources / relationships** 2
5. **Addressing the problem would increase equity and fairness** 2
6. **Likelihood of successful intervention and political will** 1

Criterion Scoring Scales

A numerical scale was developed for each criterion with an explicit definition for each value. Example:

Criterion: Problem is important to consumers :

- 1 = Addressing the problem is not important to consumers
- 2 =some importance to consumers
- 3 =moderate Importance to consumers
- 4 =important to consumers
- 5 = Addressing the problem is a very high priority for consumers

List of Objectives to Prioritize

- CCS is taking an action-oriented approach
- Issue areas were identified and translated into objectives
- Review list of objectives (in packet)

Indicators

How selected

- Interviews
- Breakout groups
- Availability of data

Most frequently mentioned:

- Access to medical specialists
- Coordination and communication between providers
- Family access to information

Identified CCS Issues / Objectives

Definitions

- CSHCN – children 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
- Title V CSHCN program in CA is CCS
- CCS children - CCS enrolled children are children who have an eligible medical conditions and whose families meet financial eligibility requirements

Data Request

- Requested data from State CMS and from Los Angeles, Orange, and Sacramento counties

Sources of Data

- The National Survey of Children with Special Health Care Needs (NS-CSHCN), 2001
- CMSNet Data
- State Performance Measures Data
- California's Title V Application 2005
- California Newborn Hearing Screening Program, 2003 and 2004
- Data from Los Angeles, Sacramento, and Orange County

Data Sources (cont.)

- Inkelas M., Ahn P., Larson K. 2003. *Experiences with health care for California's children with special health care needs*. Los Angeles, CA: UCLA Center for Healthier Children.
- Wells, N., Doksum, T., Martin, L., Cooper, J. 2000 *What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants*.
- Halfon N., Inkelas M., Flint R., Shoaf K., Zepeda A., Franke T. 2002. *Assessment of factors influencing the adequacy of health care services to children in foster care*. UCLA Center for Healthier Children, Families and Communities.

Prevalence Information

- 10.3% of CA children are identified as having special health care needs (vs. 12.8% nationally, $p < .05^*$
- About 15% of CA's CSHCN receive specialty care through the CCS program (approx. 150,000 annually)**
- 80% of CCS children are covered by Medi-Cal**
- Most children were affected by more than one condition:
 - 37% had 2 or 3 conditions
 - More than 50% had 4 or more conditions

Source: *National Survey of CSHCN 2001, ** ** Experiences with Health Care for California's CSHCN, **Your Voice Counts!! Survey.

Prevalence Information

Total 2004 CCS Cases = 170,880*

Active CCS Cases and percent by diagnosis:**

- Accidents, poisoning, violence, and immunization reactions: 10160; 13.5%
- Perinatal morbidity and congenital anomalies: 10,088 (13.4% and 11.9%)
- Undiagnosed condition: 10289 (13.7%)

Source: *State Performance Measures, **CMS Net as of 3/15/05

Prevalence Information

- Compared to the nation, fewer CA children ages 0 to 3, 4 to 7, and 8-11 are identified as CSHCN
- Significantly more of CA CSHCN are Hispanic and fewer are black or white than nationally
- The poorest children in CA (below 199% FPL) are significantly less likely than the poorest children in the nation to be identified as CSHCN

Source: National Survey of CSHCN, 2001

CSHCN in CA by Race

	Hispanic	White	Black	Multiracial	Other
California %:	7.6	13.7	15.7	10.2	6.9
Sample Size:	339	472	75	30	47
Est. Pop.:	313,648	462,157	95,424	29,636	66,118
Nationwide %:	8.5	14.2	13	15.1	7.8
Sample Size:	4,320	35,950	5,036	1,581	1,658
Est. Pop.:	1,077,970	6,401,832	1,133,566	275,998	239,361

Source: National Survey of CSHCN, 2001

Prevalence Information

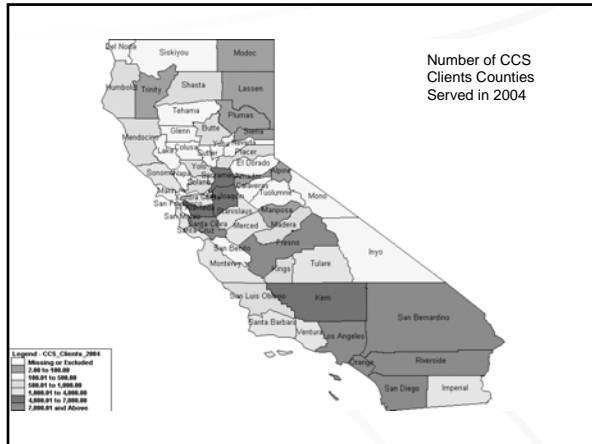
- 97% of CA CSHCN needed prescription medications
- 85% needed therapy services
- 43% needed durable medical equipment
- 21% needed home health services
- 11% needed mental health services

Source: Your Voice Counts!! Survey

Prevalence Information

- 24% of CA CSHCN have their daily activities consistently limited or affected by their condition, 40% are moderately affected, 39% are never limited by their condition
- 50% of CA CSHCN missed 0-3 days of school due to illness. 20% missed 4-6 days, 15% 7-10 days, and 16% missed 11 or more days

Source: National CSHCN Survey, 2001



Medical Home

American Academy of Pediatrics definition:

Medical care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, culturally effective, and delivered or directed by a well-trained primary care or specialty physician who helps to manage and facilitate essentially all aspects of care for the child.

Medical Home

Objective: Increase number of family-centered medical homes for CSCHN and the number/% of CCS children who have a designated medical home

- 55% of CSHCN children in CA lack a medical home; significantly more than national rate of 47.3%
- Significantly more insured CSHCN in CA lack a medical home (54.3%) compared to national rates for insured CSHCN (46.5%)

Source: National CSHCN Survey, 2001

Medical Home

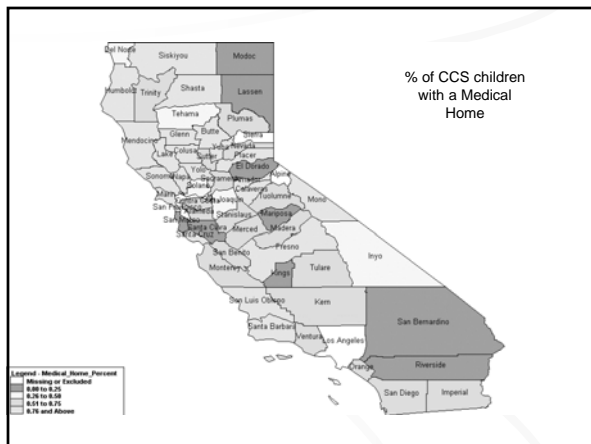
- 73.5% of uninsured CSCHN in CA lack a medical home
- In CA, CSCHN without medical homes are significantly more likely to have unmet need for health care services (26.6%) than those without a medical home (15.9%)

Source: National CSCHN Survey, 2001

In CMS Net, medical home is defined as having a primary care provider.

CA Counties vary widely in their percentages of CCS children with a medical home (range 0-100%, average 61%)

- in 33% of counties, 80% had a medical home
- in 25% of counties, between 60 to 79% had a medical home
- in 23% of counties, between 40 to 59% had a medical home
- in 5% of counties, between 20 and 39% had a medical home
- in 14% of Counties have fewer than 20% had a medical home



Family Involvement and Satisfaction Goal

Objective 2: Increase family access to educational information and information about accessing CCS services, including availability of and access to services offered by health plans

MCHB Core Outcome: Community-Based Service Systems Organized for Easy Use

- In CA, this outcome was successfully achieved for 65.9% of CSHCN (vs. 74.3% nationally, difference is not significant)
- Nationally by race, Hispanic, Black and other were significantly less likely to achieve the outcome. CA follows the pattern, but only statistically significant for Hispanic

Source: National CSHCN Survey, 2001

- By race Nationally, Hispanic, Black and other are significantly less likely to achieve the outcome. CA follows the pattern, but SS only for Hispanic*
- Parents of CSHCN in Medi-Cal reported more difficulty navigating system of services and obtaining health care benefits for child than did parents of CSHCN in other state Medicaid programs**
- 46% of Family Voices survey respondents did not know whether their child was in a managed care plan, while 72% were in a plan with at least one feature of managed care (i.e., such as having a network of doctors or requiring a primary care physician)**

*Source: National CSHCN Survey, 2001. ** Experiences with Health Care for California's CSHCN. *** From the "Your Voice Counts!!!" Survey

3. Increase family partnership in decision making and satisfaction with services

- Most parents dissatisfied with lack of "family centeredness" of their primary health plan*
- CA had significant more CSHCN without family center care – MCHB core outcome** (43.7% vs. 33.2 nationally)
- Parents were most dissatisfied with the lack of information or newsletters about issues of interest or resources outside of their plan*
- Many were dissatisfied with or did not know whether their plan offered parent support groups or gave parents an opportunity to give advice to the plan*

Source: *Family Voices, **National CSHCN Survey, 2001

- Fewer children in Medi-cal (62%) than with private insurance (82%) report enough time with provider*

CMS Performance Data Family Participation Measure (advisory committees, task forces, evaluation)

- Involving family members: Statewide average - 41% of total possible points
- Slightly more than half (55 %) of Counties had less than 40% of possible points

Source: *Experiences with Health Care for CA CSHCN, **HRSA

Screening

Objective 4: Increase the % of infants born in CA who receive newborn hearing screening services.

- 74% of newborns in the state were born at CCS approved hospitals
- In 2003, 90.7% of newborns at CCS-approved hospitals received hearing screening at birth, and 94.3% did so in 2004

Screening Data

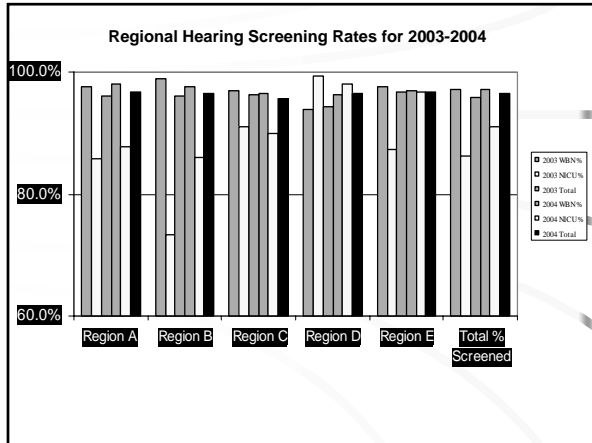
• % of total newborns screened has increased every year since 1999. Title V estimated 52% were screened in 2003

	1999	2000	2001	2002	2003*
Annual Indicator	9.80%	13.70%	21.60%	52.20%	52.20%
Annual Performance Objective	10%	10%	15%	40%	60%

Source: From Title V reports – Statewide data

Screening

- Screening rates in CCS NICU certified to participate in NHSP were 86% in 2003 and 91% in 2004.
- There were variations in rates, with Region A (Bay Area and coastal CA) reporting 88%, Region B 86% (northwestern and central CA) and Region C 98% (south eastern CA)



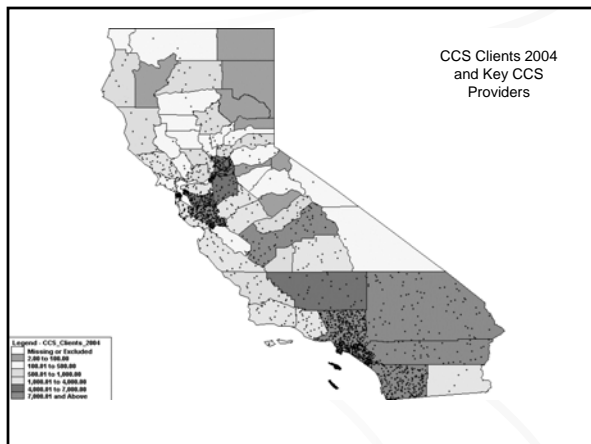
Insurance Coverage and Access to Care

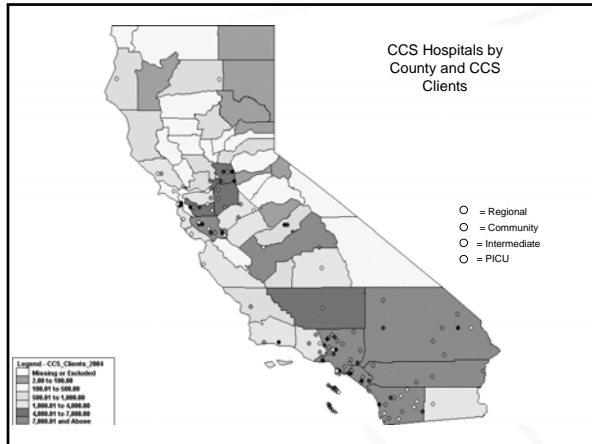
Objective 5. Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists

Number of Key CCS-Paneled Medical Providers

	# Approved Providers
CHILD NEUROLOGY	57
NEONATAL PERINATAL MEDICINE	16
NEUROLOGY	464
NEUROSURGERY	409
OPHTHALMOLOGY	1484
ORTHODONTIC	733
ORTHOPEDIC SURGERY	1663
OTOLARYNGOLOGY	839
OTOLARYNGOLOGY MAXILLOFACIAL SURGERY	13
PEDIATRIC	6005
PEDIATRIC ALLERGY IMMUNOLOGY	44
PEDIATRIC CARDIOLOGY	96
PEDIATRIC CRITICAL CARE	6
PEDIATRIC ENDOCRINOLOGY	43
PEDIATRIC GASTROENTEROLOGY	2
PEDIATRIC HEMATOLOGY ONCOLOGY	93
PEDIATRIC INFECTIOUS DISEASE	2
PEDIATRIC NEONATOLOGY	286
PEDIATRIC NEPHROLOGY	37
PEDIATRIC NEUROLOGY	5
PEDIATRIC NEUROSURGERY	1
PEDIATRIC PULMONOLOGY	1
PEDIATRIC SURGERY	28
PSYCHIATRY & NEUROLOGY	67
Total	12394

- Number of key providers per 100 CCS clients varies widely, with a low of 0 in Sierra and a high of 32 in San Francisco
- Average of 8 providers per 100 CCS children
- Uncertain which of these approved providers is currently accepting CCS clients
- Problems with CCS provider list





Objective 6. Increase access of CCS children to preventive health care services (primary care, well child care, immunizations, screening) as recommended by the AAP

- Currently, CCS does not collect this data

Objective 7. Increase access to CCS services by increasing the financial eligibility limit (\$40,000 limit)

Recent expansions of Medi-Cal and the Healthy Families program have improved children's financial access to health care. However, having insurance coverage does not guarantee that CSHCN are covered for all the services that they need.

Source: *Experiences with Health Care for CA CSHCN

•CSHCN in CA are significantly more likely than CSHCN nationally to lack adequate public or private insurance – MCHB core outcome(40.7% vs. 59.3%)

	<u>Private or employer-based</u>	<u>Medicaid, SCHIP, Title V, or other</u>	<u>Combination of public and private</u>	<u>Uninsured at time of survey</u>
California %:	72.2*	16.6*	6.9	4.3
Nationwide %:	64.9	21.7	8.1	5.2

• CSHCN in CA are significantly more likely than CSHCN nationally to have private or employer based only and significantly less likely to have public insurance only

Source: National CSHCN Survey, 2001

Objective 8: Increase access to services for CCS youth, 17 – 21 years

• Currently no data available

Organization of Services

Objectives 9: Facilitate the timely referral of foster care children with CCS eligible medical conditions to CCS services

• Fewer than 1/3 of local agencies report that judges review a child’s health plan when making decisions about that child’s foster care placement.

Source: UCLA Health Services Assessment for Children in Foster Care

Organization of Services

Objective 10: Decrease the time between referral to CCS and receipt of CCS Services

- In 53 counties, the average waiting times from referral to eligibility vary from 2 to 107 days, with an average of 50 days:
 - 14% less than 25 days
 - 39% between 26 and 50 days
 - 8% between 51 and 75 days
 - 17% between 76 or more

Source: CMS Net

- Many 'negative' time periods between 1st referral and eligibility determination

- In 54 counties, the average waiting times from referral to authorization vary from 55 to 227 days, with an average of 127 days:
 - 26% between 55 and 98 days
 - 41% between 99 and 141 days
 - 24% between 142 and 184 days
 - 9% between 185 and 227 days

Objective 11. Decrease the time between referral to the Medical Therapy Program and receipt of MTP services

- Data not currently collected

Objective 12. Improve the uniform application of CCS authorization and referral policies across the state

Objective 13. Implement a system of standards of service delivery for all children with CCS medically eligible conditions regardless of payor source, including sharing of data.

Objective 14: Coordinate to develop and implement a system of timely referral between mental health and CCS systems for CCS eligible children.

- Children with CCS problems accessing mental health service
Children who are CSS enrollees and MediCal beneficiaries are covered for specialty mental health services under terms of specialty mental health carve-out.
- Children with mental health problems in need of CCS services
All county Mental Health Plans have MOU with a health plan. If child is eligible for CSS services, child should have a medical home, and mental health plan should be able to exchange information and share care with the health plan.

Transition to Adulthood

Objective 15: Increase capacity of local CCS programs to develop and implement transition plans for adolescents transitioning to adult services

- Over 90% of children with special health care needs now live to adulthood, but are less likely than their non-disabled peers to complete high school, attend college, or be employed.
- Health and health care are two of the major barriers to making successful transitions

Source: HRSA

- Out of the CCS cases active as of 3/15/05, there were a total of 2,746 clients 20 years of age. Within 52 CA counties, the percentages of these clients with insurance range from 1 to 100%, with an average of 24% having insurance

- The transition of youth to adulthood has become a priority issue nationwide, as evidenced by the President's 2002 "New Freedom Initiative"***

Source: *CCS Data, **HRSA

Rating the Issues / Objectives

Individuals Rate Objective Areas

Apply the criteria using the agreed upon scoring and weighting values.

Apply the criteria to the objective by:

- Determining the numeric “score” (1 to 5) for the criterion
- Multiplying the numeric score by the “weight” for that criterion, that is:
 - 1 = Important
 - 2 = Very important
 - 3 = Extremely important

Example of individual scoring:

Issue / Objective	CRITERIA (Weight)		TOTAL
	Great impact on families (2)	Addressing would increase equity (3)	
Children have medical home	4 x 2 = 8	4 x 3 = 12	20
Family access to information	5 x 2 = 10	2 x 3 = 6	16

Scores are Summed to Produce a Group Ranking

Issue / Objective	PARTICIPANTS				TOTAL
	1	2	3	4	
Medical homes	16	12	9	6	43
Family access to information	10	10	6	12	38
Family partnership / satisfaction	4	6	12	8	30
Universal new-born hearing screening	20	15	12	15	62

Rank Objective Areas & Confirm Agreement

Highest Score = Top Ranked Problem

From previous example:

- Universal new-born hearing screening **62**
- Medical homes **38**
- Family partnership / satisfaction **36**
- Universal new-born hearing screening **30**



Proposed CCS Program Objectives for Priority Consideration at the Stakeholder Meeting, April 28, 2005

These objectives have been developed to address the problems identified through data, interviews, the Stakeholder breakout workgroups, and CCS staff.

Overarching Principle: Address disparity issues when developing strategies and tracking priority objective outcomes.

Medical Home

1. Increase number of family-centered medical homes for CSCHN and the number/% of CCS children who have a designated medical home.

Family Involvement and Satisfaction

2. Increase family access to educational information and information about accessing CCS services, including availability of and access to services offered by health plans
3. Increase family partnership in decision making and satisfaction with services

Screening

4. Increase the % of infants born in California who receive newborn hearing screening services

Insurance Coverage and Access to Care

5. Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists
6. Increase access of CCS children to preventive health care services (primary care, well child care, immunizations, screening) as recommended by the AAP
7. Increase access to CCS services by increasing the financial eligibility limit (\$40,000 limit)
8. Increase access to services for CCS youth, 17-21 years of age

Organization of Services

9. Facilitate the timely referral of foster care children with CCS eligible medical conditions to CCS services
10. Decrease the time between referral to CCS and receipt of CCS services.
11. Decrease the time between referral to the Medical Therapy Program and receipt of MTP services
12. Improve the uniform application of CCS authorization and referral policies across the state
13. Implement a system of standards of service delivery for all children with CCS medically eligible conditions regardless of payor source, including sharing of data.
14. Coordinate to develop and implement a system of timely referral between mental health and CCS systems for CCS eligible children.

Transition to Adulthood

15. Increase capacity of local CCS programs to develop and implement transition plans for adolescents transitioning to adult services

**CCS Stakeholder Criteria, Definitions and Rating Scales for prioritizing among
identified CSHCN issues/objectives
(April 28, 2005)**

1. **Criterion Name: Problem has great impact on families (quality of life, functionality)**
Weight: 3
Definition/Concepts: This means that the child and the family's quality of life and functionality are affected by the problem. Examples are a parent cannot work; a child cannot go to school.
Rating Scale: 3
 - 1= Problem is not affecting the quality of life or functionality of the family
 - 2= Problem is minimally or occasionally affecting the quality of life or functionality of the family
 - 3= Problem is moderately and/or frequently affecting the quality of life or functionality of the family
 - 4= Problem is negatively impacting the family's quality of life and functionality most of the time.
 - 5= Problem is severely negatively impacting the family's quality of life and functionality most or all of the time

2. **Criterion Name: Addressing the problem is important to consumers**
Weight: 3
Definition/Concepts: Addressing the problem is important to the recipients or potential recipients of services: child, siblings, parents, extended family
Rating Scale:
 - 1= Addressing the problem is not important to consumers
 - 2= Addressing the problem is of some importance to consumers
 - 3= Addressing the problem is of moderate Importance to consumers
 - 4= Addressing the problem is important to consumers
 - 5= Addressing the problem is a very high priority for consumers

3. **Criterion Name: Problem results in great cost to program and/or society, there is a significant fiscal impact of not addressing it**
Weight: 2
Definition/Concepts: If problem is not addressed the result will be increased monetary costs, e.g., health care and/or social services costs to the CCS program or to society and loss of education and productivity of individuals because of chronic illness, disability or premature death.
Rating Scale:
 - 1= Economic / societal cost is minimal
 - 2= There is some potential increased costs
 - 3= There is likely to be moderate increased costs
 - 4= There is likely to be substantial increased costs
 - 5= There will be great economic and societal cost

4. Criterion Name: Addressing the problem maximizes opportunity to leverage resources and relationships for effective system change.

Weight: 2

Definition/Concepts: There is opportunity for Agencies or Collaborative Partners to plan together or pool resources to address the problem and/or there is opportunity to build new relationships. Allows us to take advantage of opportunities to leverage resources and relationships to affect systems change

Rating Scale:

- 1= No known opportunity to collaborate
- 2= There may be opportunities to collaborate
- 3= There are opportunities to collaborate
- 4= There are opportunities to collaborate and some collaboration is already occurring
- 5= Major collaborative efforts are already underway

5. Criterion Name: Addressing the problem would increase equity and fairness

Weight: 2

Definition/Concepts: This means that one or more population subgroups as defined by race/ethnicity, income, insurance status, gender or geography, diagnosis are more impacted than the general group. Addressing the problem or issues would promote equity and reduce disparities.

Rating Scale:

- 1= No group is disproportionately affected by the problem
- 2= It appears that one or more groups is disproportionately affected by the problem, but differences are not statistically significant
- 3= Statistically significant differences exist in one group
- 4= Statistically significant differences exist in more than one group
- 5= Very large statistically significant differences exist in one or more groups

6. Criterion Name: There is likelihood of success. Problem is amenable to prevention or intervention, and/or there is political will to address it

Weight: 1

Definition/Concepts: This means that there is a good chance that the strategies used to intervene in the identified problem will result in an improvement in outcomes. The intervention strategies are shown in research literature, by experts or by National, State or program experience to be effective or promising. The group also indicated this criterion would incorporate political will, e.g., the problem is a national or regional priority

- 1= No known intervention available
- 2= Promising intervention with limited impact (not effecting a wider array of problems), little political will
- 3= Proven intervention with limited impact, moderate political will
- 4= Promising or proven intervention with broad impact and moderate political will
- 5= Proven intervention with broad impact and strong political will

CCS Stakeholder Issue/Objective Prioritization Rating Tool

Appendix M

CRITERION #1: PROBLEM HAS GREAT IMPACT ON FAMILIES (QUALITY OF LIFE, FUNCTIONALITY)				CRITERION #5: ADDRESSING THE PROBLEM WILL INCREASE EQUITY AND FAIRNESS				
CRITERION #2: ADDRESSING PROBLEM IS IMPORTANT TO CONSUMERS				CRITERION #6: LIKELIHOOD OF SUCCESS / AMMENABLE TO INTERVENTION AND POLITICAL WILL				
CRITERION #3: PROBLEM RESULTS IN GREAT COST TO PROGRAM AND/OR SOCIETY (FISCAL IMPACT)								
CRITERION #4: ADDRESSING PROBLEM MAXIMIZES OPPORTUNITY TO LEVERAGE RESOURCES								
Issue/Objective	In the line below each criterion number (e.g. C1), the assigned weight is Then, For each issue area score each criterion (1 through 5) and multiply the score by the assigned weight. Add weighted criterion scores to obtain Total Score for Issue/objective.							Total Score For Issue / Objective
	C1	C2	C3	C4	C5	C6		
	3	3	2	2	2	1		
1. Children have medical homes								
2. Families have educational and access to services information								
3. Family partnership in decision-making and satisfaction with services								
4. Newborns receive hearing screening services								
5. Access to qualified providers (#)								
6. Access to preventive health services (primary care, screening)								
7. Higher financial eligibility limit								
8. Access to services for youth ages 17-21								
9. Timely referral of foster care children to CCS								
10. Time between referral to and receipt of CCS services								

CCS Stakeholder Issue/Objective Prioritization Rating Tool

CRITERION #1: PROBLEM HAS GREAT IMPACT ON FAMILIES (QUALITY OF LIFE, FUNCTIONALITY)	CRITERION #5: ADDRESSING THE PROBLEM WILL INCREASE EQUITY AND FAIRNESS								
CRITERION #2: ADDRESSING PROBLEM IS IMPORTANT TO CONSUMERS	CRITERION #6: LIKELIHOOD OF SUCCESS / AMMENABLE TO INTERVENTION AND POLITICAL WILL								
CRITERION #3: PROBLEM RESULTS IN GREAT COST TO PROGRAM AND/OR SOCIETY (FISCAL IMPACT)									
CRITERION #4: ADDRESSING PROBLEM MAXIMIZES OPPORTUNITY TO LEVERAGE RESOURCES									
Issue / Objective	In the line below each criterion number (e.g. C1), the assigned weight is Then, For each issue area, score each criterion (1 through 5) and multiply the score by the assigned weight. Add weighted criterion scores to obtain Total Score for Problem.								Total Score For Issue / Objective
	C1	C2	C3	C4	C5	C6			
	3	3	2	2	2	1			
11. Time between referral to & receipt of Medical Therapy Program services									
12. Uniform application of CCS authorization and referral policies									
13. System of standards of service delivery (all payors and share data)									
14. Timely referral between mental health and CCS									
15. Local CCS program capacity to transition adolescents to adult services									
16.									
17.									
18.									
19.									
20.									
21.									

CCS Stakeholder's Priority Issue / Objective Rating Scores

Initials	Medical homes	Family access to information	Family partner-ship/satisfaction	Newborn screening	Access to providers (#)	Access to preventive health	Higher financial eligibility	Access to services (17-21)	Referral of Foster Care children	Time between referral and receipt of services	Time between referral & receipt of MTP	Uniform application of auth & policies	System of standards of service	Coord. system of referrals to/from	Capacity to transition adol to adult services
ek	44	58	55	28	51	40	37	33	28	35	34	33	53	60	39
tk	59	39	39	24	61	40	28	43	26	37	29	47	39	40	44
	44	49	59	61	61	57	35	53	40	44	33	35	33	43	49
ct	50	50	51	46	54	53	50	47	48	49	46	37	37	45	45
mu	30	29	38	35	46	41	35	34	44	58	51	61	63	64	33
tb	54	51	50	48	61	62	47	54	46	50	46	50	49	49	51
da	43	54	38	39	58	58	40	70	48	55	54	49	36	46	53
hh	29	43	38	40	55	56	52	51	44	37	43	48	30	48	48
sr	58	51	45	59	40	51	42	46	45	45	42	35	45	55	35
ps	48	34	26	50	63	29	48	56	61	36	39	56	54	49	56
	53	41	36	36	50	52	37	42	48	45	45	38	60	55	44
	33	38	48	37	56	31	37	35	36	40	27	37	28	46	43
	50	59	40	31	62	41	39	36	42	43	36	58	49	44	34
ml	49	47	37	52	53	43	39	41	47	50	37	41	48	53	34
fm	45	37	36	31	41	35	36	35	29	34	34	31	38	39	32
ks	41	40	32	36	53	36	33	51	35	39	34	29	33	50	47
jd	63	63	63	17	63	63	14	64	64	64	63	63	63	65	65
	45	40	36	57	62	62	34	46	45	59	50	31	29	55	45
	51	39	40	39	42	33	31	35	33	32	34	36	35	31	28
	41	46	52	49	60	39	36	51	47	36	38	36	55	45	45
ew	53	51	53	36	55	44	53	46	47	51	49	29	43	54	46
las	50	58	56	33	53	52	37	46	58	52	37	54	60	52	56
Totals	1033	1017	968	884	1200	1018	840	1015	961	991	901	934	980	1088	972

California Children's Services (CCS) Title V Stakeholders Meeting
Priority Objectives (Ranked Scores)
April 28, 2005

Overarching Principles:

- CCS will address disparity issues when developing strategies and tracking priority objective outcomes.
- The CCS program shall ensure that children with CCS eligible health care needs have access to and receive services from appropriately trained pediatric providers and shall develop and apply standards of care intended to lower morbidity and mortality rates among eligible children.

Rank	Score	Proposed Objective
1	1200	Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists
2	1088	Coordinate to develop and implement a system of timely referral between mental health, developmental services, social services, special education services and CCS
3	1033	Increase number of family-centered medical homes for CSCHN and the number / % of CCS children who have a designated medical home
4	1018	Increase access of CCS children to preventive health care services (primary care providers, well child care, immunizations, screening) as recommended by the AAP
4	1017	Increase family access to educational information and information about accessing CCS services, including availability of and access to services offered by health plans
4	1015	Increase access to services for CCS youth, 17-21 years of age
5	991	Decrease the time between referral to CCS and receipt of CCS services
6	980	Implement a system of standards of service delivery for all children with CCS medically eligible conditions regardless of payor source, including sharing of data
7	972	Increase capacity of local CCS programs to develop and implement transition plans for adolescents transitioning to adult services
8	968	Increase family partnership in decision-making and satisfaction with services
9	961	Facilitate the timely referral of foster care children with CCS eligible medical conditions to CCS services
10	934	Improve the uniform application of CCS authorization and referral policies across the state
11	901	Decrease the time between referral to the Medical Therapy Program and receipt of MTP services
12	884	Increase the % of infants born in California who receive newborn hearing screening services
13	840	Increase access to CCS services by increasing the financial eligibility limit (\$40,000 limit)

**Data Development Notes from
CCS Title V Needs Assessment Stakeholder Meeting
April 28, 2005**

Stakeholders were asked to identify data issues and data development recommendations relevant to the priority objectives identified during the priority-setting portion of the meeting. At the conclusion of this discussion, ***it was agreed that the first CCS data development step will be to develop a matrix of data available for children covered by CMS/CCS*** (Troy Jacobs offered to assist with this process).

The three priority objectives identified by the group were:

- Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists and nutritionists
- Coordinate to develop and implement a system of timely referral between mental health, developmental services, social services, special education services and CCS
- Increase the number of family-centered medical homes for CSHCN and the number/% of CCS children who have a designated medical home

The group's input on data development issues and recommendations relevant to these priorities is documented below. Other comments (made verbally and in written notes) were collected during the meeting and have also been included in the data issues/development sections below.

Assessing Access to Providers

- Availability of providers (paneled and non-paneled) by county and by region (use health care region) broken down by sub-specialties and how many paneled providers are accepting CCS enrolled children
- Assess need vs. availability of providers (paneled and non-paneled, by county and by health care region): number of CCS children, diagnostic breakdown, number of providers by pediatric specialty, number of orthodontists, etc.
- Clean up the provider list so the data becomes meaningful – eliminate dead, moved, retired providers from the list; identify the providers that are taking new patients
- Send approved providers copies of their CCS applications annually to have them review and update their information (e.g., address, specialties, accepting patients)
- Restructure CCS-paneled provider data base (Counties in rows, types of providers in columns – use standardized provider types across all counties)
- Collect/enable analysis of event vs. person data

- In progress – Business Objects to help access data. Need user friendly access, by county
- Assess waiting times between referral, eligibility determination, authorization and services received
- Map flow patterns of where children go to receive care (can get from OSHPD data set for hospitalizations, claims paid data (*Tom Klitzner* offered to help with methods)
- Track barriers to provider access. Can local programs identify problem areas with access? Can CMS keep track of these?
- Collect complaints data
- Implement survey to assess CCS clients' satisfaction with providers, such as the CAHPS survey questions for CSHCN
- Quality of care data, mortality statistics need to be looked at when considering lowering standards to increase provider participation

Developing a Coordinated System of Timely Referrals Among Programs Serving CCS Children

- Develop a MATRIX of available data across existing CSHCN programs (*Troy Jacobs*, offered to help with developing the method/matrix for obtaining this information)
- Link data across programs, i.e., track CCS children across systems. Work towards establishing common program fields across state programs – *Juno Duenas* may be helpful. Use identifying information. Consider using a uniform confidentiality form across programs.
- Look at other states and see what they do to collect data across programs

Assessing Access and Function of a Medical Home

- Need to define medical home; who decides; levels; types of medical home, services medical home provides. Use and compare continuity of care scores for children in medical homes – and those not in medical homes
- Agree upon and institute a consistent definition of medical home, consistent recording of information across counties
- Important once definition is established to get baseline data on “medical home” in order to monitor progress towards accomplishment of the medical home objective
- How many CCS children/adolescents have an AAP medical home?
- Make sure that those who are authorized as medical home providers know what they are supposed to be doing
- How are counties completing the “medical home” field? Make it a required field
- Every system should be required to identify the patient's medical home
- Use connections with other state groups to work on establishing medical homes
- Monitor whether/when children get comprehensive assessments

- Medical Home: roundtables to do case management across medical homes – collect data via roundtables
- Medical Home index
- Continuity of care scores
- Problem of tracking patients as they change medical homes
- Collect / Analyze data regarding medical homes and related outcomes: school attendance, lost days of work by parents, hospitalizations and re-hospitalization; need *baseline data* first
- Consider using the national medical home survey questions to gather California data – may help guide counties to ask appropriate questions

Data on Children with Special Health Care Needs (CSHCN)

- Explore possibility of Increasing California sample size for National CSHCN SURVEY
- Get data support (data, demonstration funds) from federal MCH – look across CSHCN diagnostic and eligibility criteria

Overarching and Other Data Development Concerns and Recommendations

- CMS Net data should be collected and analyzed by age and race
- Assess accuracy of diagnostic codes / how to increase accuracy
- Need accurate numbers of pediatric specialists (total vs. paneled)
- Assess duplication of patient data
- Need data on CSHCN from health plans—can we get it?
- Need to document other types of service-related data available, e.g., various audits to document care and provider surveys
- Need data regarding provision of non-CCS services by providers
- Clarify encounter data in both fee-for-service and capitated delivery systems – look at encounter data in Medi-Cal Managed Care (MCMC)
- Look to “outside” agencies for assistance in collecting data (e.g., MCMC, Specialists, AAP, Children’s Hospitals)
- Look at what/how data is collected across programs in other States
- Collect and analyze all data by counties / jurisdictions to extent possible
- What % of children in Healthy Families has CCS vs. what % of children in Medi-Cal has CCS coverage? Is the Healthy Families population underrepresented in CCS? Are providers making referrals to CCS?

**APPENDIX 12: CHILDREN'S MEDICAL SERVICES BRANCH,
CALIFORNIA DEPARTMENT OF HEALTH SERVICES CALIFORNIA
STATEWIDE STRATEGIC PLAN FOR CHILDREN WITH SPECIAL
HEALTH CARE NEEDS, 2006-2010**

**Children's Medical Services Branch, California Department of Health Services
California Statewide Strategic Plan for Children with Special Health Care Needs
2006 - 2010**

Introduction

In August 2005, the State Children's Medical Services Branch (CMS) of the California Department of Health Services convened a nine-month strategic planning process on behalf of children with special health care needs (CSHCN). The planning effort was funded by the federal Champions for Progress, a Maternal and Child Health Bureau (MCHB) initiative to support state efforts to develop a statewide strategic plan to meet the needs of CSHCN. California's state plan is intended to assist the state in reaching the national MCHB core performance measures for CSHCN. These core performance measures are:

- 1. Families of CSHCN will partner in decision-making at all levels and will be satisfied with the services they receive.**
- 2. All CSHCN will receive regular ongoing comprehensive care within a medical home.**
- 3. All families of CSHCN will have adequate private and/or public insurance to pay for the services they need.**
- 4. All children will be screened early and continuously for special health care needs.**
- 5. Community-based service systems will be organized in ways that families can use them easily.**
- 6. All youth with special health care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence.**

The federal MCHB definition of CSHCN is broad and includes children "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." In California, these children and their families are served by a variety of public and private agencies and many children are clients of more than one of these programs, each with its unique procedures for eligibility determination, referral and data collection. This plan focuses on those children eligible for the state California Children's Services (CCS) program within the CMS Branch, while recognizing the importance of improving communication and coordination among systems serving all CSHCN and their families.

The state strategic plan for CSHCN is part of a three-pronged effort by the Children's Medical Services Branch to achieve a statewide system of care for these children:

1. State Children's Medical Services Branch Needs Assessment

The Champions planning process is built on a needs assessment for CSHCN conducted in 2005 by the Family Health Outcomes Project (FHOP) at UCSF for the Children's Medical Services Branch as part of the state's Title V Block Grant application. The needs assessment employed a broadly representative stakeholder group to identify the top priority issues for the Branch (see the list of priorities in the Appendix).

2. Champions for Progress State Strategic Plan

The Champions project convened the stakeholders group from the needs assessment project in order to develop the strategic plan (see stakeholder list in the Appendix). The stakeholder group adopted the following vision statement, developed by an earlier Task Force on Children with Special Health Care Needs, in which many of the Champions members participated, that

was convened by the State Medi-Cal Managed Care Division to improve the quality of care of CSHCN enrolled in managed care plans:

Vision for Children with Special Health Care Needs: All children with special health care needs will be identified and will have access to quality health care that is:

- ***family-centered and supportive***
- ***community-based***
- ***coordinated and seamless***
- ***effective, appropriate, and efficient***
- ***culturally and linguistically effective. (August, 2003)***

The Champions stakeholder group met seven times over nine months in professionally facilitated work group meetings to consider strategies that would assist the state to achieve the six MCHB core performance measures and to meet the priorities identified by the state in its needs assessment process. The core performance measures serve as the goals for the plan, with specific and measurable objectives and action steps, and assignments of responsibility for implementing the objectives. (Note: Some of the performance measures/goals include a section with recommended strategies that require legislative action. While these recommendations are beyond the purview of the State CMS Branch, they may be adopted and pursued by advocacy groups.)

Each stakeholder was charged with assisting in developing strategies for action, circulating draft documents within member organizations for feedback and support, and reaching consensus within the group on a final plan. The Champions planning process was convened by Dr. Marian Dalsey, chief of the Children's Medical Services Branch; facilitated by Carolyn Verheyen of Moore Iacofano Goltsman; and staffed by Juno Duenas, Family Voices of California; Kathryn Smith, Los Angeles Partnership for Special Needs Children; and Laurie A. Soman, Children's Regional Integrated Service System (CRISS) Project.

3. Federal MCHB Grant: "Implementing Integrated Systems of Care for CSHCN"

This federally funded project, conducted by Juno Duenas, Kathryn Smith, and Laurie A. Soman under the auspices of the USC University Center of Excellence in Developmental Disabilities at Children's Hospital Los Angeles in collaboration with Children's Medical Services, will promote implementation of the state plan strategies both statewide and regionally. The Champions stakeholder group will serve as the advisory group to the MCHB grant and will continue to meet on a quarterly basis to review and comment on implementation progress through June, 2008.

Glossary of Terminologies

Acronyms/Abbreviations	
AAP	American Academy of Pediatrics
AAFP	American Academy of Family Physicians
CAFP	California Academy of Family Physicians
CCHA	California Children's Hospital Association
CCS	California Children's Services
CDE	California Department of Education
CHA	California Hospital Association
CHDP	Child Health and Disability Prevention Program
CHEAC	County Health Executives Association of California
CMA	California Medical Association
CMS	Children's Medical Services
CPT	Current Procedural Terminology
CRISS	Children's Regional Integrated Services System
CSCC	Children's Specialty Care Coalition
CSHCN	Children with Special Health Care Needs
CSIM	California Society of Internal Medicine
DMH	Department of Mental Health
DDS	Department of Developmental Services
DME	Durable Medical Equipment
DOR	Department of Rehabilitation
DSS	Department of Social Services
EDS	Electronic Data Systems Corporation
FPL	Federal Poverty Level
FRC	Family Resource Center
FRCN	Family Resource Center Network
FVCA	Family Voices of California
HMO	Health Maintenance Organization
GHPP	Genetically Handicapped Persons Program
HRIF	High Risk Infant Follow-up
ICC	Interagency Coordinating Council
IEP	Individual Education Plan
HRSA/MCHB	Health Resources and Services Administration/Maternal and Child Health Bureau
KP	Kaiser Permanente
LAPSNC	Los Angeles Partnership for Special Needs Children
MH	Medical Home
MC/MC	Medi-Cal Managed Care
MNIHA	Medically Necessary Interperiodic Health Assessment
MOD	March of Dimes
MOU	Memorandum of Understanding
MRMIB	Managed Risk Medical Insurance Board (administers Healthy Families program)
MTP	CCS Medical Therapy Program
NICU	Neonatal Intensive Care Unit
OSHPD	Office of Statewide Health Planning and Development
PAI	Protection and Advocacy, Inc
PHL	Parent Health Liaison
PHN	Public Health Nurse
PPO	Preferred Provider Organization
RC	Regional Center

SCC	Special Care Center
Special Ed	Special Education
SPOE	Single Point of Entry
YSHCN	Youth with Special Health Care Needs
Other Terms	
100% Campaign	A coordinated effort of Children Now, Children's Defense Fund, Children's Partnership, and the California Endowment to ensure that all children in California have access to affordable, comprehensive health insurance.
CAHMI CSHCN Screener©	The CSHCN Screener© is a five item, parent survey-based tool for identifying CSHCN and was developed through the efforts of the Child and Adolescent Health Measurement Initiative (CAHMI), based on the MCHB definition for CSHCN. Children are identified on the basis of experiencing one or more current functional limitations or service use needs that are the direct result of an on-going physical, emotional, behavioral, developmental or other health condition.
First Five California	First Five California is designed to provide, on a community-by-community basis, all children prenatal to five years of age with a comprehensive, integrated system of early childhood development services. Approved by voters in 1998, Proposition 10 was the ballot initiative that established the California Children and Families Program and the State Commission, and authorized the establishment of county commissions, since renamed First Five.
Screening	The examination of a group of usually asymptomatic individuals to detect those with a high probability of having or developing a given disease or condition.
Surveillance	A type of observational study that involves continuous monitoring of disease or condition occurrence within a population.

Core Measure — FAMILY PARTNERSHIP/SATISFACTION: Families of children with special health care needs (CSHCN) will partner in decision-making at all levels and will be satisfied with the services they receive.

S T R A T E G I E S A N D A C T I O N S

1. Promote family-centered care at the local level by creating and promoting best practices standards for relationships between county California Children's Services (CCS) and local Family Resource Centers (FRC):
 - A. Require Parent Health Liaison (PHL) positions with % FTE in state staffing standards
 - Establish family advisory group with regular meetings
 - Consider contracts with local FRCs for position
 - Evaluate best practices for working with family organizations
 - Assist in educating local administrators and supervisors re: importance of funding position
 - B. Conduct random sample interviews with families regarding CCS services
 - C. Develop standard statewide survey to evaluate family satisfaction with CCS services.
 - D. Promote better communications between CCS and families to improve understanding of program and decisions through family contact on all new applications (i.e., person to person) and follow-up phone calls to families regarding official letters (denial for services, service changes)

Responsibility: State CMS, Family Voices of California (FVCA), County Health Executives Association of California (CHEAC)
2. Promote family friendly CCS service delivery in CCS Special Care Centers (SCC) by building standards for family-centered care into SCC standards, e.g.:
 - A. Ensure family participation in SCC team meetings
 - B. Educate families regarding SCC process and services
 - C. Educate professionals regarding family issues
 - D. Include attention to linguistic/cultural appropriateness
 - E. Provide training to SCC office staff in family friendly concepts and approaches

Responsibility: State CMS, Health Resources and Services Administration/ Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB) grant staff
3. Design and implement strategies so that families (including youth) are represented and will partner at all levels, e.g.:
 - A. Collect existing research and analyze prior surveys and focus groups with families to inform strategies
 - B. Consider currently used models such as family-to-family team based decision-making model used for children in out of home placement (Annie E. Casey Foundation) and parent/professional team teaching model
 - C. Customize information for individual child and family
 - D. Determine and communicate a range of opportunities for parent involvement at each level of decision making, including State CMS/FVCA advisory committee
 - E. Involve families in assessing CMS current level of practice and efficacy in family participation and satisfaction
 - F. Increase resources of FRC Councils to expand parent involvement and coordination for families
 - G. Survey different service systems to determine involvement of families in decision-making
 - H. Assess family satisfaction with cross-systems services

Responsibility: State CMS, FVCA, CCS Executive Committee with local programs

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

STRATEGIES AND ACTIONS (FAMILY PARTNERSHIP/SATIS. continued)

4. Design and implement education for families and youth when family/youth enter program and offer ongoing to make sure families stay involved.

** See the Appendix on "Training and Outreach" for details*

Responsibility: State CMS, Family Advisory Council to State CMS, FVCA

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

Core Measure — **MEDICAL HOME**: All children with special health care needs (CSHCN) will receive regular ongoing comprehensive care within a medical home.

S T R A T E G I E S A N D A C T I O N S

1. **Collect data on pediatricians/other medical providers serving CSHCN:**
 - A. **Collect data on number of pediatricians, pediatric sub-specialties, and other providers in the state and by region, their availability geographically and by payer source (including Medi-Cal), percentage of CSHCN seen by pediatricians, etc., e.g. from American Academy of Pediatrics (AAP), Children’s Specialty Care Coalition (CSCC), California Children’s Hospital Association (CCHA), and other sources**
 - B. **Collect information from HMOs/Medi-Cal Managed Care (MC/MC)/Healthy Families/Healthy Kids plans on how they identify CSHCN and policies for assigning CSHCN to primary care providers (PCP)**

Responsibility: State CMS as lead, Electronic Data Systems Corporation (EDS), Office of Statewide Health Planning and Development (OSHPD), AAP, California Medical Association (CMA), CSCC, MC/MC, Managed Risk Medical Insurance Board (MRMIB), Health Plans, CCHA
2. **Identify strategies to retain/increase number of California Children’s Services (CCS) providers (including pediatric specialists, PTs/OTs, and vendored services such as DME), e.g. via work with AAP and CSCC; Identify appropriate pediatric and pediatric sub-specialty providers who are not paneled and assist them in paneling**

Responsibility: State Children’s Medical Services (CMS) as lead, CSCC, AAP

3. **Activate state Medi-Cal billing codes for care coordination**
 - A. **Establish definitions of and standards for care coordination for medical home providers**
 - B. **Collect information regarding Special Care Center (SCC) care coordination billing, e.g., how it is billed, payment received**
 - C. **Determine how to implement use of care coordination Current Procedural Terminology (CPT) codes for billing**

Responsibility: State CMS, Family Voices of California (FVCA)
4. **Define medical home, PCP, and care coordination, including CCS role in each**

Responsibility: State CMS, FVCA

5. **Promote a system that assures that care coordination appropriate to each child is provided (e.g. establishment of a primary care coordinator for each child)**

Responsibility: State CMS, FVCA advisory committee

6. **Ensure that all CSHCN have a PCP and/or medical home (MH)**
 - A. **Develop a set of questions to ask parents to identify the child’s medical home for use by all service systems**
 - B. **Local CCS programs will work with Child Health and Disability Prevention (CHDP) program, health plans, and Healthy Families staff to identify PCP/MH for every CSHCN**
 - C. **Establish PCP/MH as a required field in CMS-Net with at least annual updates**
 - D. **Encourage all systems to ask families regarding their access to a PCP/MH**

Responsibility: State CMS, local CCS/CHDP programs, local CMS, health plans, with Department of Mental Health (DMH), Department of Developmental Services (DDS), etc., FVCA
7. **Ensure that CCS-approved major hospital facilities have on-site CCS care coordinators who can work across county lines and address all children regardless of county of residence.**

Responsibility: State CMS

Items that appear in bold overlap with goals outlined in California’s FFY 2006-2010 Title V Implementation Plan.

STRATEGIES AND ACTIONS (MEDICAL HOME continued)
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8. Enhance CCS SCC standards to include expectations regarding communication with PCPs and provide training to SCC staff regarding strategies to achieve better communication (e.g. improving information flow to specialists from PCPs and reports back to PCPs from specialists)
Responsibility: State CMS
9. **Develop and conduct continuing education and trainings on medical home and system of care for CSHCN**, building on existing trainings and adapting or develop additional materials as necessary, and addressing the following:
 - A. **Providers** including how to partner with clients
 - B. Family and youth regarding medical homes and how to partner with others
 - C. CCS staff training regarding what a medical home is, how to talk about it, and how to partner

** See the Appendix on "Training" for details*
Responsibility: State CMS, Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB) implementation grant staff, FVCA, AAP, Health Plans, county CCS programs
10. Conduct training programs on the use of parent notebooks to enhance records organization and to increase communication between parents and providers
Responsibility: State CMS, HRSA/MCHB grant staff, FVCA
11. Locate funding to support local medical home projects with family and CCS participation
Responsibility: State CMS

Priority Issues that Require Legislative Action

The following recommendations were identified as priorities but require action in the legislative arena. State CMS will monitor progress on these recommendations and provide technical assistance when requested:

1. Pursue separate appropriation/additional funds for care coordination for medical home providers
Responsibility: CSCC, AAP, CCHA, CMA, other advocates
2. Streamline approval process for obtaining Medi-Cal provider number to reduce 180-day wait for PCPs and specialists
Responsibility: CSCC, CCHA
3. Maintain existing carve-out of CCS services from Medi-Cal and Healthy Families managed care plans
Responsibility: CSCC, AAP, CCHA, CMA, other advocates

It is understood that all groups suggested to undertake implementation of legislative priorities must take recommendations to their boards/leadership groups in order to set priorities for legislative action.

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

Core Measure — INSURANCE: All families of children with special health care needs (CSHCN) will have adequate private and/or public insurance to pay for the services they need.

STRATEGIES AND ACTIONS

1. Change California Children's Services' (CCS) program policy to refer all children to all sources of available insurance, including Healthy Families, county Healthy Kids programs, Kaiser Permanente (KP) Cares for Kids, and Medicaid waiver programs
** See the Appendix on "Outreach" for details on outreach strategies*
Responsibility: State Children's Medical Services (CMS)
2. Promote CMS participation in health care financing discussions at all levels of state government
Responsibility: State CMS, advocacy groups, health plans
3. Link state and local CCS programs and other agencies serving CSHCN with funded outreach programs and projects promoting insurance coverage for children (e.g. Governor's coverage initiatives, other campaigns)
Responsibility: CMS
4. Review existing Medicaid waivers and consider opportunities for expansion to include additional youth, e.g. for Medi-Cal "deeming" for additional youth with special health care needs (YSHCN)
Responsibility: CMS, Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB) implementation grant staff

Priority Issues that Require Legislative Action

The following recommendations were identified as priorities but require action in the legislative arena. State CMS will monitor progress on these recommendations and provide technical assistance when requested:

1. Protect and increase access to the CCS program via the following legislative steps:
 - A. Deem children enrolled in Healthy Kids programs eligible for CCS
 - B. Restore CCS financial eligibility limit to \$100,000
 - C. Link CCS financial eligibility to Federal Poverty Level (FPL) to consider family size and income*Responsibility: California Children's Hospital Association (CCHA), Children's Specialty Care Coalition (CSCC), American Academy of Pediatrics (AAP), other advocates*
2. Amend State Insurance Code to require private Health Maintenance Organizations (HMO)/Preferred Provider Organizations (PPO) to meet CCS pediatric standards of care
Responsibility: CCHA, CSCC, AAP, other advocates
3. **Increase Medi-Cal and Healthy Families reimbursement for practitioners serving CSHCN and protect against rate cuts**
Responsibility: CSCC, CCHA, AAP, other advocates
4. Ensure insurance coverage for all uninsured CSHCN, regardless of income
 - A. Strengthen and standardize Healthy Kids programs by setting statewide standards and financial eligibility criteria
 - B. Create state buy-in for Medi-Cal for CSHCN (modeled on the federal Family Opportunities Act)
 - C. Eliminate pre-existing condition barriers under private individual insurance coverage for youth aging out of CCS*Responsibility: Advocates*

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

S T R A T E G I E S A N D A C T I O N S (INSURANCE continued)
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5. Advocate for accessible health coverage for YSHCN:
- A. Modify financial eligibility for Medi-Cal for YSHCN, e.g. by increasing percentage of FPL covered for youth
 - B. Extend benefits for YSHCN under parental coverage to specific age (e.g., 24 years)
 - C. Consider extending CCS-type coverage for certain medical conditions for YSHCN > 21 years of age, e.g.:
 - Maintain coverage for CCS-eligible children with metabolic conditions beyond age 21
 - Cover adrenal hyperplasia/other conditions identified in newborn screenings
 - Add other chronic conditions requiring continued specialty care

Responsibility: AAP, CSCC, CCHA, California Medical Association (CMA), American Academy of Family Physicians (AAFP), California Society for Internal Medicine (CSIM), California Hospital Association (CHA), 100% Campaign, Protection and Advocacy Inc (PAI), other advocates

It is understood that all groups suggested to undertake implementation of legislative priorities must take recommendations to their boards/leadership groups in order to set priorities for legislative action.

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

Core Measure — SCREENING: All children will be screened early and continuously for special health care needs.

S T R A T E G I E S A N D A C T I O N S

1. Ensure that children get both periodic and inter-periodic visits as needed
 - A. Broaden/publicize opportunities for inter-periodic screenings for Child Health and Disability Prevention (CHDP) program for children without other coverage
 - B. Educate providers regarding maximum visits available under CHDP and Medi-Cal (including continuous screening for health, developmental, mental health issues) and how to use Medically Necessary Interperiodic Health Assessment (MNIHA)

Responsibility: American Academy of Pediatrics (AAP)
2. Identify and implement standardized screening tool to identify Children with Special Health Care Needs (CSHCN), e.g., Child and Adolescent Health Measurement Initiative (CAHMI) screener, Health Net screener

Responsibility: State Children’s Medical Services (CMS), Medi-Cal Managed Care (MC/MC), Managed Risk Medical Insurance Board (MRMIB), health plans, Department of Mental Health (DMH)
3. Institutionalize funding and billing mechanism(s) for administration of developmental, behavioral and mental health screenings, using existing standardized tools accepted in the field
 - A. Include screening in annual Special Care Center (SCC) evaluations and institutionalize in SCC standards
 - B. Ensure that appropriate staff, including SCC staff, are trained to administer tools

Responsibility: State CMS, Medi-Cal, County Mental Health Directors, State First 5, Department of Developmental Services (DDS), California Department of Education (CDE), Department of Mental Health (DMH), MRMIB
4. Implement strategies to increase resources for follow-up when screens identify problems
 - A. Identify existing treatment and support resources in communities
 - B. Mobilize existing resources (including other families) to assist families whose children are identified with problems
 - C. Identify service gaps and strategies to address them
 - D. Increase provider knowledge about resources**

Responsibility: State CMS, Los Angeles California Children’s Services (LA CCS) Workgroup, Children’s Regional Integrated Services System (CRISS)
5. Ensure that HRIF and Early Start programs are coordinated by such strategies as HRIF identifying appropriate children and ensuring their referral to Early Start and to the CCS Medical Therapy Program

Responsibility: State CMS, DDS, CDE
6. Create and implement an outreach and education plan to promote early and continuous screening and surveillance for health problems

* See the Appendix for details on “Outreach” and “Training”

Responsibility: State CMS (CCS/CHDP) as lead, local CHDP and CCS, CHDP Executive Committee, Health Education subcommittee, Provider Relations Subcommittee, provider group community, managed care plans, American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), National Association of Pediatric Nurse Practitioners (NAPNAP), children’s insurance plans, Family Voices of California (FVCA), Infant Care Center (ICC), California School Nurses Association (CSNA)

Items that appear in bold overlap with goals outlined in California’s FFY 2006-2010 Title V Implementation Plan.

S T R A T E G I E S A N D A C T I O N S (SCREENING continued)
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Priority Issues that Require Legislative Action

The following recommendations were identified as priorities but require action in the legislative arena. State CMS will monitor progress on these recommendations and provide technical assistance when requested:

1. Align, via budget process, CHDP periodicity schedule with current AAP schedule
Responsibility: 100% Campaign, Children's Specialty Care Coalition (CSCC), AAP, AAFP
2. Create risk-adjusted screening periodicity schedule for CSHCN with number of visits beyond current AAP periodicity schedule, while maintaining current AAP periodicity schedule
Responsibility: AAP
3. Create state performance standards for early/continuous screenings (e.g., CHDP Health Assessment Guidelines) for public and private plans/insurance/HMOs/PPOs, including use of accepted developmental and mental health screening tools
Responsibility: AAP and other advocates
4. Make newborn hearing screening universal by seeking legislation to require that all hospitals that deliver babies participate in the screening program
Responsibility: March of Dimes (MOD), AAP

It is understood that all groups suggested to undertake implementation of legislative priorities must take recommendations to their boards/leadership groups in order to set priorities for legislative action.

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

Core Measure — ORGANIZED SERVICES: Community-based service systems will be organized in ways that families can use them easily.

S T R A T E G I E S A N D A C T I O N S

1. **Create a statewide interdepartmental coordinating body with Departments of Health, Mental Health, Social Services, Developmental Services, Education, etc., to address cross-systems issues, in partnership with family organizations, advocates, and representatives of county departments**

Responsibility: State Children’s Medical Services (CMS) as lead, with other departments, Family Voices of California (FVCA) begin discussions via Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB) implementation grant

2. Increase consistency in inter-county interpretation of state laws/regulations/California Children’s Services (CCS) procedures regarding program and benefits eligibility by such strategies as:
 - A. Conducting regional meetings of CCS staff, followed by state regional office meetings
 - B. Presenting statewide webcasts
 - C. Conducting regional planning with involvement of family organizations and providers

Responsibility: State CMS

3. Develop and implement strategies, including funding, to improve coordination of services used by CCS children, including:

- A. **Local “roundtables” or other interagency planning bodies to coordinate care and ensure that services are obtained**
- B. **“Single point of entry” (SPOE) mechanisms to ensure that families can locate and access services**
- C. **Special Care Center (SCC) sponsored multidisciplinary team meetings to coordinate care with other agencies** (with ability to bill CCS)
- D. **Neonatal Intensive Care Unit (NICU) discharge planning meetings with all agencies involved with child**
- E. **Universal consent form with parents to facilitate information sharing among agencies**
- F. CCS Public Health Nurse (PHN) for positions (modeled after Foster Care PHNs) to **coordinate between CCS and schools**, identify other services needed, facilitate referrals, and act as resource person for families
- G. Increase support component within CCS (through CCS social workers and/or Parent Health Liaison (PHL) positions)
- H. Models for a “system navigator” and/or CMS ombudsperson to advise parents on accessing service across systems (e.g. troubleshooting, problem-solving)

Responsibility: CMS with local CCS programs, Department of Developmental Services (DDS), Department of Social Services (DSS), Department of Mental Health (DMH), California Department of Education (CDE), foster care nurses

4. Ensure that families have a hard copy and/or electronic health record for their children and tools to assist them in tracking their medical care, including child health notebooks, and develop training in the use of these tools by reviewing existing materials and tools and adapting or developing additional materials as needed

Responsibility: State CMS as lead, HRSA/MCHB implementation grant

Items that appear in bold overlap with goals outlined in California’s FFY 2006-2010 Title V Implementation Plan.

STRATEGIES AND ACTIONS (ORGANIZED SERVICES continued)
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5. Ensure timely CCS responses to requests for services through such actions as:
 - A. Identifying factors influencing the length of time from CCS referral to authorization to receipt of services
 - B. Considering strategies to reduce the length of time from referral to receipt of services, e.g.:
 - Allowing pediatrician to do 2 to 3 visit referral to a specialist before going through lengthy CCS authorization process
 - Outstationing CCS workers in hospitals
 - Letting hospitals start the CCS application process
 - Facilitating provision of medical and financial information from families and providers to expedite eligibility determination and service authorizations

Responsibility: State CMS

6. **Provide education to families, youth and all providers to help them know how services are organized, e.g.:**
 - A. **Distribute materials summarizing different programs**, what is covered, how they interact, timelines, referral requirements, links to other programs, etc.
 - B. Design interactive tool/database to help identify which program is appropriate for each child, e.g. through links to other agencies on state CCS website
 - C. **Design education/training** to meet the needs of families, youth and providers with the assistance of stakeholders representing these target populations

* See the Appendix for details on "Training" for details

Responsibility: State CMS, FVCA, Family Resource Centers (FRC)

Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.

Core Measure — TRANSITION: All youth with special health care needs (YCHCN) will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence.

S T R A T E G I E S A N D A C T I O N S

1. Create an effective and coordinated transition process for youth including but not limited to the following elements:
 - A. Design structure of transition plans, determine distribution plan, and implement transition process:
 - Develop or adapt existing transition checklist, including access to adolescent well-child care in transition plan (e.g. identifying appropriate primary care physician (PCP) as youth leave pediatric providers) and sensitive issues
 - Create “flag” in Children’s Medical Services network system (CMS-Net, state California Children’s Services (CCS) database) to identify all children at age 14 and trigger assessment of their need for transition plan
 - Reevaluate transition plan in even years to age 18, then annually, e.g. at ages 14, 16, 18, 19, 20, then six months before transition out of CCS
 - Hold exit interviews for CCS enrollees between ages 20 and 21, including anonymous evaluations by clients
 - Complete a checklist for the Medical Therapy Program (MTP) for all youth at age 17 and address, at minimum, conservatorship and application for rehabilitation services
 - B. Establish coordination mechanisms across multiple systems to support transition:
 - Determine transition policies and timelines of other relevant agencies (e.g. California Department of Education (CDE), Regional Centers (RC), Department of Mental Health (DMH), etc)
 - Establish periodic group meetings with transition coordinators identified for their special expertise, at local, regional, and state level; coordinators should participate in transition planning meetings held by other agencies that involve adolescents and invite participation of PCPs and other care providers, including Special Care Center (SCC)
 - Include discussion regarding transition issues at quarterly meetings with managed care plans
 - Work with family resource centers (FRC) to plan transition education meetings for parents
 - Develop a memorandum of understanding (MOU) to bring Department of Rehabilitation (DOR) and Regional Centers into transition process for Medical Therapy Program (use Individual Education Plan (IEP) model)
 - C. Develop and implement training and outreach to support transition:
 - Create manual describing transition benefits available
 - Provide counseling to youth and families regarding benefits, timelines, activities, and continuum of needs (e.g., equipment), and resources available in communities (e.g. other support services)

Responsibility: State CMS, Family Voices of California (FVCA), state interdepartmental coordinating body, Health Resources and Services Administration/Maternal and Child Health Bureau HRSA/MCHB) grant staff
2. **Strengthen network and capacity of adolescent-oriented adult-oriented providers to serve youth and adults with special health care needs** through such strategies as:
 - A. Collect information about transition population such as numbers of youth affected, medical conditions, and other service needs

Items that appear in bold overlap with goals outlined in California’s FFY 2006-2010 Title V Implementation Plan.

- B. Consider possible incentives to maintain and build provider network, including reimbursement and non-reimbursement approaches
- C. Create position in CCS for physician recruitment, including recruitment of adult-oriented providers
- D. Encourage the American Academy of Pediatrics (AAP) to work with the American Academy of Family Physicians (AAFP) and the California Society of Internal Medicine (CSIM) to increase knowledge of/familiarity with YSHCN
- E. **Work with adult primary care and specialty groups to identify providers and ensure understanding of youth and adults with special health care needs, and the medical home model**
- F. Provide mechanisms to assist providers in creating disability-friendly practice environments (e.g. ergonomic review) and consider using existing resources such as Medical Therapy Program staff expertise

Responsibility: State CMS, FVCA

- 3. Incorporate transition standards into SCC standards

Responsibility: State CMS, FVCA

- 4. Consider strategies to assist with transition such as funding of system navigators at FRCs

Responsibility: State CMS, FVCA; state interdepartmental coordinating body

Priority Issues that Require Legislative Action

The following recommendation was identified as a priority but requires action in the legislative arena. State CMS will monitor progress on this recommendation and provide technical assistance when requested:

- 1. Secure provider rates and other incentives to fortify provider network for YSHCN, e.g. by applying increased CCS specialty rate to Genetically Handicapped Persons Program (GHPP) specialists and to other non-physician CCS providers, including Durable Medical Equipment (DME) vendors, etc.

Responsibility: AAP, Children's Specialty Care Coalition (CSCC), California Children's Hospital Association (CCHA), California Medical Association (CMA), AAFP, CSIM, California Hospital Association (CHA), 100% Campaign, Protection and Advocacy, Inc (PAI), other advocates

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Items that appear in bold overlap with goals outlined in California's FFY 2006-2010 Title V Implementation Plan.