



Assessing the California Children's Services Program

Introduction

The California Children's Services (CCS) program provides coverage for essential health care services to more than 165,000 children with special health care needs, including cancer, diabetes, and conditions related to premature birth. Established in 1927, it is one of the oldest health coverage programs in the nation and preceded the federal mandate under Title V of the Social Security Act. Today, it is perhaps California's most complex health program in terms of financing structure, administration, and care delivery.

The CCS program is at a crossroads. For almost a decade, providers, families, and many policymakers have been calling for reform of CCS, not just to control costs but to improve delivery of essential care.¹ The state's fiscal crisis has increased pressure on state and county administrators to rein in CCS program expenditures, which continue to rise despite few changes in enrollment. Indeed, the state budget for 2009–10 directs the California Department of Health Care Services to develop a proposal for the federal government to restructure Medi-Cal for children with significant medical needs in order to better serve these children and slow the long-term growth of the program.

This issue brief provides an overview of the CCS program, including eligibility and coverage policies, program administration and financing, the delivery system, the size and characteristics of the enrolled population, and expenditures and spending trends. It also discusses the state of the CCS program, describing its strengths and the challenges it is facing. The final section argues

for an overhaul of the program and outlines key areas for further analysis and action on the part of policymakers.

The Fundamentals of CCS

Eligibility

Children under the age of 21 in California qualify for CCS if they meet specific residential, medical, and financial criteria. A child must have what is defined by the state as a "CCS-qualifying condition." These conditions are defined in the California Code of Regulations and generally include serious, chronic, and disabling medical conditions such as congenital anomalies, cerebral palsy, hearing loss, cancer, and diabetes.² The California program's limited definition of children with special health care needs, which includes only physical conditions, is different from many other states' Title V programs. The federal definition of this population is "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."³ Many other states include children who are developmentally disabled or mentally ill.

Children are considered financially eligible for CCS if they are:

- Enrolled in Medi-Cal;
- Enrolled in Healthy Families;
- Uninsured with an annual family income of less than \$40,000; or

- Projected to require more than 20 percent of annual adjusted gross family income for treatment of the CCS condition.

Children in California also may be eligible for the CCS Medical Therapy Program (MTP). The program operates Medical Therapy Units staffed by CCS physical and occupational therapists in designated public schools. Children are eligible for services at no cost if they meet specific medical eligibility criteria or have Independent Education Plans that include MTP services.⁴ There is no income requirement for this program because federal disability law requires states to provide children with “free appropriate public education” and necessary related services.⁵

Coverage

The CCS program pays for diagnosis and treatment of qualifying conditions, as well as care coordination and utilization management. Each county or regional office authorizes services that may include specialty and subspecialty care, outpatient and inpatient care, physical therapy, oral health, and prescription drugs. CCS does not cover health care services unrelated to the child’s CCS condition. Consequently, families with a child in CCS often do not experience it as a distinct program but rather as one payer amid a much larger system that may include services from regional centers, services provided by special education programs, in-home support services, mental health treatment, and other services. Many children with a CCS-eligible condition who are eligible for Medi-Cal, and all children with a CCS-qualifying condition enrolled in Healthy Families, are enrolled in a managed health care plan. Services related to the CCS condition are generally carved out of health plans’ payments and responsibilities.⁶

Administration

The California Department of Health Care Services (DHCS) administers the CCS program.⁷ Administration of the program was decoupled from other Title V-funded programs in California following the reorganization in

2007 of the state Department of Health Services. The CCS program was placed within DHCS, which also administers Medi-Cal, while other Title V programs are administered by the Department of Public Health.

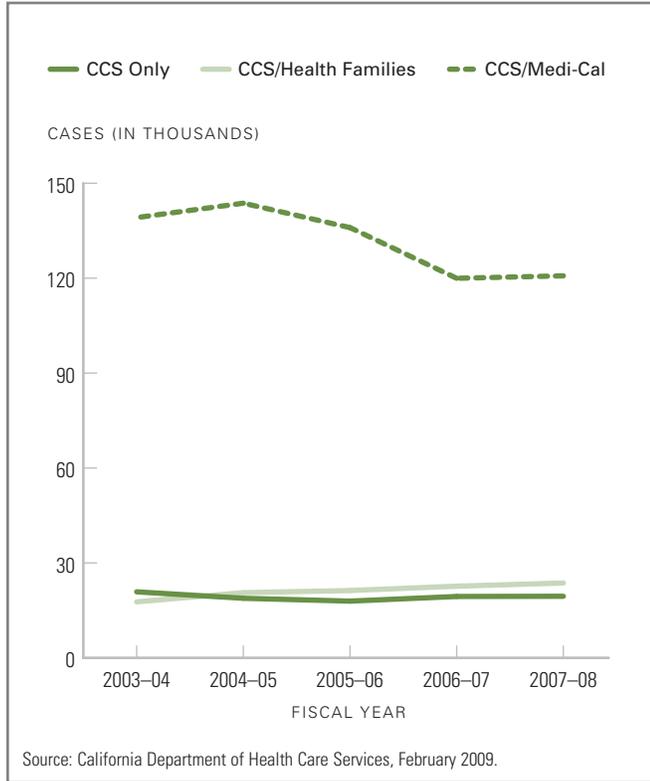
The state administers the program through policy letters and regulation. The state’s primary CCS functions are approving participating providers, facilitating payment of providers, and developing and implementing quality standards for providers.⁸ Other administrative functions include eligibility determination, authorization of services, and case management of enrollees. These functions are county-administered in mid-size and large counties. For counties with populations under 200,000—referred to as dependent counties—program administration is shared between the county and one of three state regional offices. The number of case managers and level of case management services varies by county, and staffing standards are developed by the state. Due to changes in state funding allocations for administration, many counties reduced case management positions in fiscal year 2008–09. In Los Angeles County, 54 case management positions were cut: As of May 2009, there were approximately 124 full-time case managers in Los Angeles County and 49,350 enrolled children.

Caseload and Conditions

As of December 2008, 163,845 children were enrolled in CCS, excluding children who receive MTP services.⁹ The majority (74 percent) were CCS/Medi-Cal recipients, yet CCS children are a very small population (3 percent) among all children in Medi-Cal. According to the best data available, the total number of children in CCS appears to have declined 8 percent since FY2003–04 (see Figure 1 on page 3). However, DHCS attributes the decline to the implementation of a statewide master eligibility file in 2004 that purged inactive cases from local and state records, as well as a change in policy to exclude pending cases. Despite a lack of wholly comparable data, it appears that the proportion of CCS children enrolled in CCS/Healthy Families has

increased significantly, perhaps as much as 34 percent since FY2003–04, but still this group accounted for only 14 percent of the total CCS population in 2008.

Figure 1. CCS Caseload, by Payer, FY03–04 to FY07–08



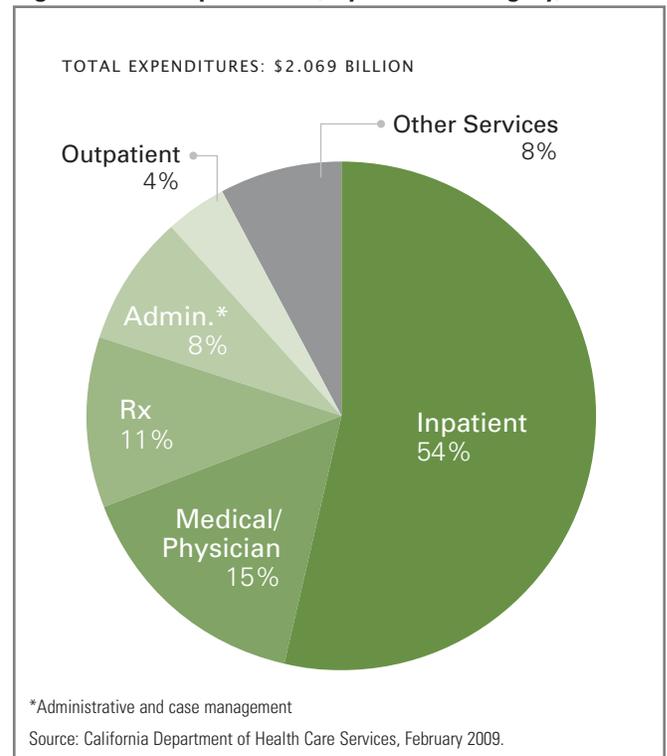
Children enrolled in CCS present with a wide variety of conditions, including a very small number of rare conditions, many of which are unique to pediatric medicine. The top five conditions are congenital anomalies, congenital heart disease, cerebral palsy, hearing loss, and fractures (excluding head injuries). Examples of other CCS-qualifying conditions include cystic fibrosis, muscular dystrophy, and spina bifida. Each of these conditions requires intensive and high-cost long-term treatment. Treatment for many conditions, such as cancer and cystic fibrosis, is rapidly changing as research efforts result in more efficacious protocols and higher rates of survival. The true impact on CCS caseload is unknown. For example, some children whose conditions improve, such as some cancer survivors, become ineligible for CCS. Others, such as those with cystic fibrosis, may survive

longer and will remain enrolled in CCS until they are no longer eligible for the program at age 21.

Expenditures

Total CCS expenditures in 2007-2008 were \$2.1 billion. Expenditures for services—diagnosis or treatment—were \$1.9 billion and averaged about \$11,000 per child.¹⁰ Approximately 8 percent of expenditures were for administration, including case management (Figure 2). CCS/Medi-Cal recipients make up 74 percent of the CCS caseload yet account for 89 percent of total CCS diagnosis and treatment expenditures. CCS/Healthy Families expenditures for diagnosis and treatment have doubled over the past five years; however, when adjusted for caseload, expenditures per recipient have increased more for CCS/Medi-Cal (47 percent) than for CCS/Healthy Families (33 percent) during the same time period.

Figure 2. CCS Expenditures, by Service Category, FY07–08



Inpatient care is the largest major expenditure area in CCS, followed by medical/physician expenses.

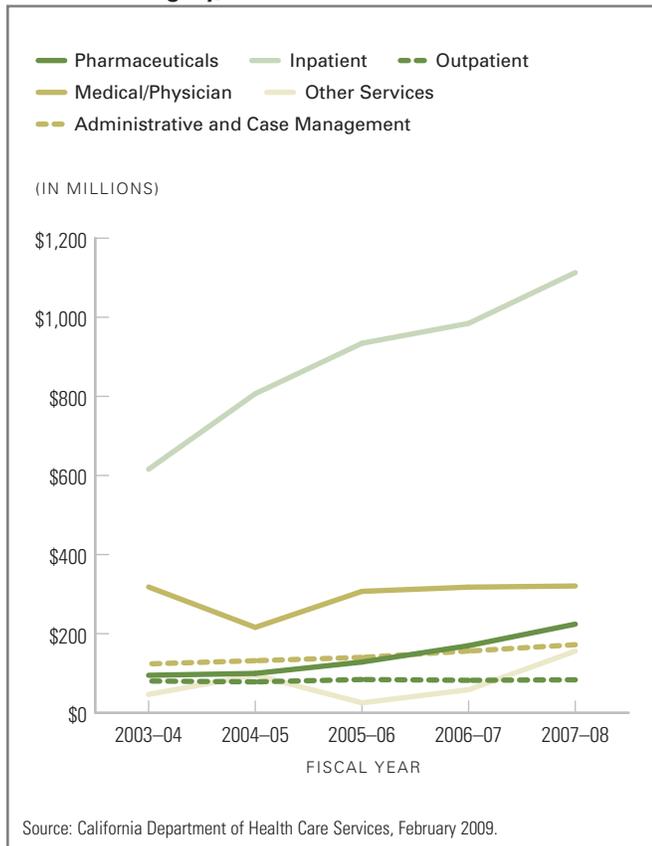
While pharmaceuticals account for only about 11 percent of CCS program expenditures (before rebates), spending on prescription drugs increased 136 percent over the five-year period from FY2003–04 to FY2007–08. Although expenditures for inpatient care did not grow as quickly during this period, the 81 percent growth in spending for inpatient care had a much bigger impact, adding nearly \$500 million to CCS expenditures (Figure 3). The largest increase in spending—236 percent—was for the DHCS expenditure category “Other Services.” Additional data were not available, but examples of costs in this category are in-home nursing services, transportation, optometry, and dental care.

Despite relatively few changes in caseload, CCS expenditures for diagnosis and treatment have increased at an average annual rate of 8.6 percent during this period. Administrative costs have increased at an average annual rate of 6.3 percent. CCS expenditures for particular conditions have increased dramatically, with the two largest increases for cystic fibrosis (84 percent) and premature births (56 percent).

Financing

CCS is financed by a combination of federal, state, and county funds. The financing formula is different for each specific CCS program. With the exception of CCS-only, the federal government provides at least half of all funding for administration and services. California is required to spend 30 percent of funds from its Title V Maternal and Child Health Block Grant on children with special health care needs, and a portion of these federal funds is allocated to the CCS program.

Figure 3. Total Program Expenditures, by Service Category, FY03–04 to FY07–08



The financing structure for the non-Medi-Cal-funded CCS program changed significantly in 1991 with the realignment of state and county health, social service and mental health program responsibilities. Realignment increased the counties’ share of funding for CCS-only diagnosis and treatment from 25 percent to 50 percent. In addition, a statutory maintenance-of-effort requirement for the county share of cost was established based on 1991 program costs. Each year counties contribute funds well beyond their maintenance-of-effort requirement, roughly \$50 million in aggregate. In 2008, due to state budget pressures, DHCS implemented a new methodology for allocating state and federal funding to counties for CCS administration, capping the funding available to individual counties.

Medical System of Care

Specialty medical care for children in California is organized quite differently from adult care. In general, pediatric specialty care is delivered within a small number of large pediatric tertiary care facilities designed to

serve large areas of the state rather than just individual communities. This care model stems from recognition in the 1980s of the need for a regional approach toward treating critically and chronically ill children due to the rare and complex nature of their conditions. Regional models were developed prior to the growth of managed care. Many of the CCS-designated Special Care Centers and hospitals with pediatric tertiary serve CCS children from multiple counties. In contrast, CCS administration, including medical eligibility determinations and treatment authorization for services, is county-based with the exception of the small dependent counties.

DHCS approves individual providers and institutions for participation in the CCS program based on a set of established standards. All providers must also participate in Medi-Cal. CCS providers are paid by the state on a fee-for-service basis. Historically, CCS physicians were paid the Medi-Cal rate. In 2001, in response to concerns about a shortage of specialty providers participating in CCS, the California Legislature approved a supplemental physician payment rate for services provided to CCS children equivalent to the Medi-Cal rate plus 39 percent. This increase applies to specified physician services only. Hospital inpatient services, medical equipment, prescription drugs, and other CCS services continue to be paid at the Medi-Cal rate.

It is important to note that CCS is one piece of a much larger system that parents and caregivers navigate for children with special health care needs. Obtaining all of the care necessary for comprehensive treatment of a complex condition often requires services from programs administered by other state agencies or departments such as the departments of developmental services, mental health, education, and rehabilitation.

The State of the CCS Program

In December 2008, the California HealthCare Foundation commissioned a series of more than 30 interviews with selected stakeholders to identify the greatest challenges facing the CCS program. Stakeholders included consumer advocates, providers, health plans, state and county program administrators, and policymakers. This research also explored other states' programs for children with special health care needs; examined proposed CCS-related legislation; and reviewed state and national policy research into the population.

Program Strengths

The CCS program plays an essential role in the California health care system. It has been implemented as an entitlement program and in many cases it is the only source of health coverage for some of the state's sickest children. CCS estimates that approximately 61 percent of CCS families had a medical home in 2005 while only 42 percent of all families with such children in California reported having a medical home that same year.^{11,12}

There was general consensus among stakeholders that CCS is a unique program with a mission that must be preserved. Stakeholders agree that CCS covers necessary treatment for qualifying benefits. Relative to other states, CCS coverage for required medical equipment is considered good. Among all families with children who have special health care needs—not just those with CCS—California fares better than the national average when it comes to the percentage who report that their child's condition causes financial problems for the household (15.5 percent in California versus 18.1 percent in the United States).¹³

CCS provides direct access to high-quality providers for children regardless of income. Unlike Medi-Cal for adults with disabilities or chronic but intensive health needs, CCS children have access to the same centers of excellence as do privately insured children. Through the approval of providers, CCS serves as the primary

credentialing entity for all pediatric specialty care. The program establishes the quality and care standards for all children with special health care needs in California.

Program Challenges

Stakeholders identified multiple challenges the program presents to families, providers, and policymakers. Many of these challenges echoed findings from earlier assessments of the CCS program from the Senate Office of Research and the Legislative Analyst's Office.¹⁴ The increased fiscal strain on the state and counties has heightened stakeholders' concern about the sustainability of the program in its current form.

Program variation across counties. Due to the financing and administrative structure of the CCS program, counties effectively operate very different CCS programs across the state. Not surprisingly, the most significant differences, according to those interviewed, are in those areas administered by counties: medical eligibility determinations, needs assessments, and case management.

CCS medical directors in each county determine medical eligibility by applying their interpretations of qualifying conditions. Providers who serve children from multiple counties report having the same diagnosis repeatedly denied by some counties yet accepted by others. Some managed care plans and providers maintain lists of eligible conditions by county to avoid these denials. A group of pediatric provider organizations and hospitals, family support organizations, and county CCS programs in 14 counties in Northern California—the Children's Regional Integrated Service System—is working to standardize the medical eligibility process and has implemented processes for CCS medical directors to communicate privately with one another and compare cases. The state participates in a workgroup with these stakeholders and is aware of the need for broader standardization.

There are no standard tools for the needs assessments conducted by CCS case managers. In some counties the needs assessment is limited to required authorizations, while other counties use the process to develop a larger plan for care coordination. These variations are directly linked to each county's definition of the case management function. Many stakeholders are concerned that recent changes in state funding and capped allocations to counties for CCS administration will further reduce care coordination as staff cuts result in increased caseload for individual case managers.

Complex and burdensome financing structure.

There is a strong desire among stakeholders to simplify and streamline funding sources. Stakeholders generally agree that the current funding structure is unnecessarily complicated and outdated.

Many say multiple funding streams and the payment reconciliation process between counties and the state has created an inflexible and inefficient system. Stakeholders described the amount of time spent on budgeting, claiming, reconciling, and reporting that could be spent instead on addressing many other areas of the program. Providers also expressed concerns about the ability to make any kind of systematic change or improve standards of care when faced with a patchwork of funding mechanisms. In addition, the current structure places much of the financial risk, particularly for CCS-only cases, on counties. County-level CCS treatment costs can vary significantly from year to year. For small counties, one unanticipated premature infant hospitalized for six months might use the bulk of an annual CCS budget. Several stakeholders expressed concern that the new caps on state funding allocations would further decrease budget flexibility within county CCS programs.

Inefficient authorization processes. There was general consensus among stakeholders that the authorization process for CCS services, though varied by county, is unnecessarily long and complicated. Recent budget woes

probably will exacerbate this problem if left unaddressed. Lengthy authorizations may lead to delays in accessing appropriate care, unnecessarily long hospitalizations, loss of funds for providers, and increased administrative expenses for health plans. Stakeholders reported waiting two or three months for an authorization for service. Delays in authorizations for outpatient care appear to be greater than those for inpatient care. Some stakeholders believe this creates an incentive for services to be provided in the more costly hospital settings. This is consistent with findings from a report issued by the Legislative Analyst's Office in 2004.¹⁵

The extent of authorization delays varies by county, with state regional offices reportedly having the greatest difficulties. The most significant concerns relate to cases requiring multiple authorizations for similar services or continual care. CCS authorization standards are more stringent than Medi-Cal program standards. In addition, there is no retroactive CCS coverage for children with Healthy Families, which also differs from the rules for children with Medi-Cal. Many stakeholders expressed a desire to see a simplified authorization processes across counties with the hope that CCS case management staff could be redeployed to care coordination functions.

Provider access problems. California parents of children with special health care needs report significantly higher rates of difficulty getting a referral for care than elsewhere in the country.¹⁶ The rare and unique type of medical conditions, compounded by geographic disparities and historically low provider rates, have created what one stakeholder described as a “perfect storm” for a shortage of participating specialists and subspecialists. Unlike specialists who care for adults, many of these specialists have a lower proportion of privately insured patients to offset lower Medi-Cal rates.

There is also a shortage of primary care physicians capable of handling the complexities of primary care services for these children. These shortages are particularly acute

in rural areas, and can result in longer than necessary hospitalizations for children who must wait to be discharged until an appropriate provider can be located in the child's community. With tertiary care centers also reporting bed shortages, unnecessary hospitalizations not only have financial consequences for CCS but may also delay care for non-CCS children.

The extent to which CCS program standards and operations affect provider access is not clear. Many stakeholders reported delays in the CCS provider certification process for both hospitals and individual providers. Hospital site visits, required for certification or recertification, are often delayed due to staffing shortages at the state level. Some stakeholders expressed concerns that the process of becoming a certified provider was unnecessarily restricting the pool of CCS providers. Other stakeholders, however, stated that particular subspecialties may have shortages reflecting physician supply issues unrelated to the CCS program, and the pool is generally adequate.

Lack of monitoring and oversight. Although the federal government funds more than half of CCS expenditures through Medicaid, Healthy Families, and Title V, it provides states with a high level of discretion when it comes to implementing systems of care for children with special health care needs. The lack of state leadership in ensuring access to quality health care for children in CCS was an often-repeated criticism. Many stakeholders were particularly concerned that the state does not monitor administrative standards related to eligibility and authorization timeliness. As a result, access to coverage and care may differ dramatically by county. The “need for better state oversight and enforcement of program standard” was a central finding in the Senate Office of Research report on CCS in 2000.¹⁷ Some state policymakers point to financing structure, lack of regulatory authority, and staffing shortages as major obstacles to playing a larger role in monitoring and oversight of counties' CCS activities.

Lack of information and data. Many stakeholders were also concerned about the lack of data on quality of care and on services certified, authorized, and paid for by CCS. There was consensus that policy discussions about CCS are driven by entrenched and narrow interests and often are not informed by updated information based on national research regarding family-centered care. Further analysis of CCS-related data could be very instructive for not only monitoring quality and performance but also highlighting what is working well in the CCS program. Concerns about cost-shifting between programs that serve children with special health care needs continue to be raised. Increased access to information and data analysis may validate these concerns or provide better information on how to approach cost-containment.

Other issues. Individual stakeholders raised additional issues that warrant further exploration:

- The income eligibility level for the CCS-only program has not been adjusted since the 1970s;
- There is a need to revisit eligible diagnoses as well as incentives for inpatient versus outpatient procedures;
- Medical advancements in cancer treatment, neonatal care, and other areas translate into a rapidly growing number of CCS children needing assistance with the transition to adulthood;
- There is potential for cost-shifting of MTP children as state education and county CCS budgets face increasing fiscal pressures; and
- Access to durable medical equipment is becoming increasingly difficult for children in this population.

Into the Future

California can no longer afford to spend more than \$2 billion a year on a vital program without better understanding and managing the care, costs, and health outcomes for the children it is designed to serve. CCS faces many of the same challenges of the larger health care systems in California, including rapidly increasing costs and a shortage of some types of physicians in some areas of the state, as well as several challenges specific to CCS, including an outdated administrative and financing structure that hasn't kept pace with changes in health care delivery. The CCS program doesn't simply need updating: It needs an overhaul. CCS reform must account for the current and future needs of the children who depend upon it; anticipate the changing health care environment; incorporate incentives for evidence-based, family-centered care; and acknowledge the interconnection between CCS services and other public programs. Reforming the CCS program, while necessary, must be done with careful consideration of the impact on financing and care delivery for all children who need special health care services, not just those in CCS.

The mission of CCS is sound but the system needs policymakers' focused attention. The future requires state leadership and a dedicated group of stakeholders willing to collaborate, innovate, and advocate on behalf of children with special health care needs.

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ABOUT THE FOUNDATION

The California HealthCare Foundation is an independent philanthropy committed to improving the way health care is delivered and financed in California. By promoting innovations in care and broader access to information, our goal is to ensure that all Californians can get the care they need, when they need it, at a price they can afford. For more information, visit www.chcf.org.

ENDNOTES

1. Senate Office of Research. May 2000. *California's Ailing System of Caring for Children with Special Health Care Needs*; Hansel, P., C. Reiffman, and Legislative Analyst's Office. 2003. *Missed Opportunities for General Fund Savings in the CCS Program, in Analysis of the 2003–04 Budget Bill*.
2. 22 California Code of Regulations §§ 41800–41872.
3. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. 2008. *The National Survey of Children with Special Health Care Needs Chartbook 2005–2006*.
4. California Government Code § 7575 (a)(1).
5. U.S. Department of Education, Office for Civil Rights. 2007. *Free Appropriate Public Education for Students With Disabilities: Requirements Under Section 504 of the Rehabilitation Act of 1973*.
6. With the exception of residents of Napa, San Mateo, Santa Barbara, Solano, and Yolo counties.
7. California Health and Safety Code §§ 123800–123995.
8. California contracts with Electronic Data Systems for provider payment.
9. DHCS MTP case data includes cases counted in other payer categories.
10. Excludes MTP expenditures.
11. California Department of Health Services, Children's Medical Services. July 2005. *California Five-Year Needs Assessment for Children with Special Health Care Needs 2006–2010, Appendix 8*.
12. See note 3.
13. See note 3.
14. See note 1.
15. Hansel, P., C. Reiffman, and Legislative Analyst's Office. 2003. *Missed Opportunities for General Fund Savings in the CCS Program, in Analysis of the 2003–04 Budget Bill*.
16. See note 3.
17. See note 1.