

# California's Ailing System of Caring for Children With Special Health Care Needs

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May 2000

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## Executive Summary

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 is providing timely access to services for children eligible for the program.

The CCS program provides specialized health care services to children with qualifying health care conditions. CCS is one of the oldest health programs in the state, having been established in 1927 in the aftermath of the polio outbreaks of the early part of the 20<sup>th</sup> century.

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. A summary of SOR's principal findings and options was released January 3, 2000. On February 4, 2000, SOR convened a policy roundtable forum on the future of the CCS program, at which numerous stakeholder representatives presented additional information and perspectives on the needs of the program.

This paper summarizes SOR's main findings from the interviews and the roundtable forum and presents options for addressing growing barriers to services to families under the program.

## Principal Findings of Study

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 concludes that a number of problems limit the ability of the program to provide timely and seamless services to eligible children. In some cases, this produces very lengthy delays in children receiving services. These problems include:

- Growing problems with the adequacy of provider participation. The report finds that low reimbursement rates for CCS and Medi-Cal services are causing many physicians and other providers to cease seeing CCS/Medi-Cal patients or limit the number they will treat. As a result, waiting times of 3 – 6 months, and in some cases more, for services are not uncommon, depending on the subspecialty. Lengthy delays in claims reimbursement and claims editing procedures only serve to further reduce the effective rate of payment to providers. The report outlines 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, existing staffing standards permit staff-to-client ratios in excess of 500-to-1 in larger counties and in excess of 1,000-to-1 in the state centers serving smaller counties, far too high to permit timely eligibility determinations, treatment authorizations, and claims payment in many counties. Providers and families report having to wait months for treatment approval in some cases, while the child's condition goes untreated. The report recommends 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 are resulting in a lack of compliance in many counties with basic program standards, including timeliness standards. The report outlines a number of options for addressing this, including increasing the frequency of county and provider site reviews and expediting implementation of the CMS Net management-information system.
- Inadequate attention to family-centered care as a program goal. The report finds that lack of focus on family-centered approaches to care results in the CCS program being frequently confusing for families and difficult to participate in. The report identifies 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.
- Inconsistent county application of program standards. The report finds that county funding pressures may lead to an inconsistent application of program standards. This has 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 result in different financial obligations for similarly situated families. The report outlines 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 percent level that existed prior to the 1991 program realignment.
- **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 result. The report details 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.** 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 on it. At least 22,000, and perhaps as many as 130,000 additional children would be eligible for the program if the income standard were returned to \$100,000. The report puts forward options to increase or index the financial eligibility limit to a standard that more realistically reflects the financial burdens CCS conditions can 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 be 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 believe acts to exclude some children who could benefit from the services provided by the program. The report suggests requiring DHS to study the feasibility of developing alternative medical eligibility criteria.

## **Background**

According to some studies, 15 to 20 percent of all children have special health care needs, including serious and chronic health conditions, developmental disabilities, and mental illness, that require specialized health care services.

States, as a condition of receiving federal Title V Maternal and Child Health (MCH) block grant funds, are required to spend 30 percent of their MCH grant funds on programs for children with special health care needs. In California, children with defined serious or chronic physical health conditions who meet income and residency requirements are eligible for the California Children's Services (CCS) program, which is one of the programs by which California meets the federal requirement.

CCS provides medical diagnosis, treatment, case management, and therapies to children under age 21 with defined handicapping conditions that can be cured, ameliorated, improved, or stabilized through intervention.

To be eligible for CCS, children must be under 21 years of age, be California residents, have qualifying medical conditions, and meet income limits established for the program. Eligible medical conditions include birth defects, heart conditions, cleft palate, spina bifida, chronic illnesses, cancers, blood disorders, genetic diseases, perinatal conditions, and effects of serious injuries such as fractures, spinal cord injuries, and burns (See Appendix A for a more complete listing of eligible conditions).

Families must have gross incomes below \$40,000, as determined by their last tax return. Children eligible for no share-of-cost Medi-Cal or for the Healthy Families program automatically meet the financial eligibility requirements. In addition, families with incomes above \$40,000 can qualify for the program if expenses for a child's care exceed 20 percent of their adjusted gross incomes.

Services provided under the program are limited to those required to treat the condition and include medical diagnosis, medical and surgical treatment, hospitalization, physical and occupational therapy, durable medical equipment, prescriptions, and medical case management.

For uninsured and Medi-Cal-eligible children, CCS authorizes and arranges all care related to the condition. For privately insured children, CCS acts as a form of back-up coverage for the condition, covering services not provided by the plan, as well as deductibles and copayments, if any.

Services are provided to CCS-eligible children by a network of approved providers. Care for children with the most complex conditions – for example, congenital heart disease, inherited metabolic disorders, chronic lung disease, cancers, hemophilia, and craniofacial disorders – is provided or arranged by designated special care centers located throughout the state, most of which are located at academic or children's hospitals.

The program is overseen by the Children's Medical Services Branch within the state Department of Health Services, which sets guidelines and regulations for the program and approves health care providers for participation in the program. Twenty-six counties with populations in excess of 200,000 (referred to as independent counties) administer most aspects of the program including eligibility determinations, authorization of services, and case management. Smaller counties (known as dependent counties) rely on three state-administered regional offices for medical eligibility determinations, authorization of services, and case management, but handle financial and residence eligibility determinations.

## Caseload and Expenditure Trends

In the 1999–00 fiscal year, the estimated caseload for the program is 147,650 children. About 75 percent of these are Medi-Cal beneficiaries and the remainder are what's referred to as CCS-only cases. Figure 1 shows caseload trends for the CCS program from 1994-96 through 1997-98, the most recent year for which audited data is available. According to DHS, in 1995-96, 283,190 children were estimated to have conditions that would qualify for CCS coverage, of which 123,492 were eligible for the program in that year. According to DHS, the additional 159,698 children were generally ineligible because their family incomes were above the program's financial threshold.

**Figure 1**

**CCS Caseload Trends**

<b>Year</b>	<b>Total Caseload</b>	<b>Medi-Cal Eligible</b>	<b>CCS-Only</b>
<b>1994-95</b>	129,994	89,966	40,028
<b>1995-96</b>	123,473	89,066	34,408
<b>1996-97</b>	128,498	95,319	33,179
<b>1997-98</b>	133,302	99,642	33,660
<b>Percent Change 94-95 – 97-98</b>	2.5%	10.8%	-15.9%

In 1997-98, the last year for which full data is available, expenditures on CCS-covered services, including treatment and administration, totaled \$703 million, of which Medi-Cal paid about \$600 million, with the remainder paid 50/50 by the state and counties. In the current fiscal year, total expenditures (treatment and administration) for the non-Medi-Cal portion of the program are estimated to be \$114.3 million, with \$52.3 million coming from the General Fund, \$54.8 million from county funds, \$4.7 million from federal Title V MCH block grant funds, \$1.4 million from Federal Title XXI State Children's Health Insurance Program funds, and \$1.1 million from enrollment fees and funding adjustments.

## Findings

CCS is a highly specialized program which has successfully assisted thousands of children with special health care needs in gaining access to medical treatment and therapy necessary to restore and improve their functioning and long-term prognosis. Further, CCS serves children with complex and difficult-to-treat conditions and symptoms who, in the absence of the program, would face limited access to state-of-the-art treatments to address their conditions. Despite this, SOR's review concludes that a number of problems limit the ability of the program to provide timely and seamless services to eligible children and, in some cases, produce very lengthy delays in children being able to access services. These problems include:

- Growing problems with the adequacy of provider networks.
- Inadequate case management staffing.
- Need for better state oversight of and enforcement of program standards.
- Inadequate attention to family-centered care as a program goal.
- Inconsistent county application of program standards.
- Fragmented service delivery as a result of the exclusion of CCS services in managed care plan contracts.
- Outdated income eligibility standards.
- Need to develop more flexible medical eligibility standards.

(Note: Although the focus of this study was the CCS program, those who commented on earlier drafts pointed out that many problems hindering access to CCS services also apply to the Genetically Handicapped Persons Program (GHPP). GHPP is a highly specialized program serving adults with some, but not all, CCS-eligible conditions and operates in some respects differently from CCS. SOR has attempted to note throughout the text areas where problems or options apply to both programs. However, a focused review of GHPP, while warranted, was beyond the scope of this project.)

### **Growing Problems with Adequacy of Provider Networks**

CCS depends on an established network of physicians, therapists, and hospitals to provide care to the over 140,000 children enrolled in the program at any given time. Care for children with special health care needs, particularly those with the most complex cases, is fairly concentrated among providers in the state. For example, according to data supplied by the California Children's Hospital Association (CCHA), eight hospitals (generally children's hospitals and teaching hospitals) provided over 40 percent of all Medi-Cal-financed CCS hospital days in 1998. Similarly, approximately 140 special care centers statewide provide or arrange virtually all outpatient care for certain designated conditions, ranging from 14 such centers for spina bifida to 22 for treatment of craniofacial disorders.

Health care providers who participate in the CCS program are reimbursed at Medi-Cal rates for services. According to many sources, Medi-Cal pays far below rates paid by commercial plans or Medicare for comparable services. According to the American Academy of Pediatrics, services provided under Medicaid are reimbursed at rates 20 to 50 percent less than the same services provided under Medicare. According to a 1998 study of rates commissioned by the Medi-Cal Policy Institute, Medi-Cal fee-for-service payments for office visits are typically 40 percent of those of other payers, including Medicare and large commercial health plans. Reimbursement shortfalls for institutional providers serving CCS-eligible children for inpatient and outpatient care have been exacerbated by:

- Limits on reimbursement from managed care plans,
- Lack of a permanent funding source for reimbursement for graduate medical education costs for teaching hospitals serving Medi-Cal and CCS patients,
- A shift in case mix to more severe cases being referred for hospitalization, and
- Declines in reimbursement under other public programs these institutions rely on, such as the Medi-Cal disproportionate share hospital program (DSH).

This has decreased the ability of hospitals to support special care centers by providing staffing and facility support.

While physicians and medical groups had some ability to offset losses from seeing Medi-Cal and CCS patients through reimbursement from commercial payers in the 1980s and early 1990s, the rapid expansion of managed care and tightening of reimbursement under commercial plans has made that more difficult. Among specialties, pediatrics has been especially hard-hit by stagnating Medi-Cal payment rates because a higher percentage of children live under poverty and qualify for Medi-Cal than the population generally. Further, adult-patient practices have had access to relatively more generous Medicare reimbursement levels for treatment of elderly and disabled patients.

According to several sources, low reimbursement rates for CCS and Medi-Cal services are causing many physicians and other providers to cease seeing CCS/Medi-Cal patients, leave the state, or otherwise limit the number of CCS/Medi-Cal patients they will treat. In addition, medical groups, hospitals, and special care centers specializing in treatment of children with complex conditions report increasing difficulties hiring and retaining qualified subspecialists. SOR was informed of cases where it has taken centers years to fill vacant positions as well as cases where it has been impossible to fill positions.

The net result is growing waiting times for some subspecialty services. For example, according to data provided by CCHA, average waits for treatment of CCS-eligible conditions at special care centers and subspecialty clinics at three hospitals now last between a few days and several months. This includes up to two months in the case of craniofacial conditions, four months for diabetes/endocrine conditions, two months for nephrology, four months for neurology, three months for psychiatry, two months for pulmonary conditions, eight months for rehabilitative services, and two months for spina bifida.

According to physicians' groups, children with certain conditions have to wait three to six months for appointments. In Los Angeles, it is virtually impossible for children to find pediatric orthopedic services outside of academic, county, and other safety-net medical centers. Stakeholders told SOR that problems with reimbursement and

shortages of pediatric subspecialists are resulting in children with conditions amenable to treatment in an outpatient setting – for example, children with cancer who are receiving chemotherapy – in some cases being hospitalized because reimbursements are higher and they can receive care more expeditiously. Stakeholders stated that gaps and delays in access to services have in some cases resulted in patients' deaths and worsening of their conditions, in addition to the inconveniences and discomforts caused by delays in treatment.

Medi-Cal local initiative managed care plans also told SOR that in many counties plans have to contract with pediatric subspecialists at up to 200 percent of the Medi-Cal/CCS rates in order to maintain access to these services.

Stakeholders told SOR that many counties, particularly rural counties, have difficulties recruiting and retaining pediatric specialists at Medi-Cal payment rates and must refer children outside their counties for services. This finding is reinforced by the CCS needs-assessment survey DHS prepared in 1998, which focused on rural and semi-rural counties. It found that nearly 40 percent of families travel over 80 miles round trip to see a doctor/clinic authorized by CCS. However, it is not clear to what extent the travel distances reflect shortages of providers and to what extent they reflect referral patterns, particularly for tertiary and higher-level care.

In addition to being low generally, claims for reimbursement for CCS services are routinely reduced by the Medi-Cal fiscal intermediary, Electronic Data Systems (EDS), based on the frequency of the service for which reimbursement is being claimed and whether the visit is an initial or follow-up visit. The result is that rates for CCS services do not reflect that visits involving CCS-eligible children are more complex, more frequent, and more time-consuming than visits involving children in general. While rates have been augmented in recent budgets (including a 20 percent increase for preventive and primary care services in 1998 and a 5 percent adjustment for CCS physician services in the 1999-00 state budget), they are still considerably below standard rates for comparable services. Finally, few counties have the capacity to handle treatment authorization requests or claims electronically.

In many counties, providers report lengthy waits for claims reimbursement, both for claims submitted to EDS and to the county itself. (Several GHPP providers indicated similar problems with GHPP claims reimbursement.) Providers frequently cited lack of a process for electronic submission of claims. According to providers interviewed, the emphasis on paper submission of claims increases the potential for errors in reviewing the claims and delays in payment.

While most of the concern regarding reimbursement is focused on physicians and hospitals, stakeholders made it clear that low reimbursement levels are affecting children's access to virtually all services covered by CCS, including hearing aids, laboratory services, X-rays, dentists, orthodontists, audiologists, and pharmacy services.

***Options to deal with these problems include:***

- Establishing Medicare payment levels as a benchmark for CCS payments for services to children. This would recognize that treatment of CCS-eligible conditions is as complex and time-consuming as treatment of conditions common to elderly and adult disabled patients;
- Increasing Medi-Cal rates for CCS services to the Medicare level but not indexing them for changes in Medicare payment levels. This would permit initially an equivalent increase in rates but would not guarantee that the rates would maintain parity with Medicare rates over time;
- Requiring DHS to conduct periodic assessments of the adequacy of CCS payment rates vis-à-vis commercial rates, as well as the impact of CCS payment practices on provider participation and accessibility of services to CCS clients;
- Providing reimbursement to CCS (and GHPP) special care centers for case management, case coordination, and other nonphysician services;
- Making permanent the supplemental Medi-Cal reimbursement program for graduate medical education expenses administered by the California Medical Assistance Commission (CMAC), or establishing a separate supplemental payment program for children's hospitals;
- Requiring CMAC to develop a risk-adjusted system for Medi-Cal payments to hospitals for treatment of CCS-eligible conditions so that payment rates are linked to the complexity of the cases treated;

- Adjusting Medi-Cal disproportionate share hospital payment rates for children's hospitals to establish parity between children's and other disproportionate share hospitals in the amount of the daily cost cap covered by disproportionate share payments;
- Removing EDS claims-processing edits that result in denial of claims based on the frequency of services or that reduce reimbursements;
- Establishing a process for electronic submission of claims to counties and to the state;
- Requiring EDS to document claims turnaround times and establishing a time limit for processing clean claims.

### **Inadequate Case Management Staffing**

Delays in accessing services are compounded by county staffing standards that most stakeholders view as unrealistic. DHS establishes staffing standards for the program that are used to determine allowable state reimbursements for county administrative costs, including case management and program administration. Counties are free to exceed these standards on a case-by-case basis but bear part of the cost of doing so. Most observers agree the standards are out of date and result in case management ratios exceeding 500 clients per case manager in most independent counties and up to 1,000 clients per case manager in the state centers that serve dependent counties. This is far in excess of standards for comparable programs, such as regional centers, which serve developmentally disabled clients and the CalLearn program, which serves pregnant or parenting teenagers. In particular, stakeholders argue that the standards do not reflect changes that have occurred in the CCS program over time, including the increasing complexity of cases and newer mandates to coordinate care more closely with other systems such as Medi-Cal managed care plans, special education, county mental health, and regional centers.

According to material provided by DHS to the Senate Budget and Fiscal Review Committee, case handling ratios in the three regional CCS offices range from 500-to-1 in the Sacramento office to over 1,000-to-1 in the Southern California regional office. According to the material, the Sacramento regional CCS office requires 41 days to make an eligibility determination, open a case file, and authorize services, as well as five weeks to process treatment authorization requests.

DHS expects some administrative savings as a result of the planned implementation of the CMS Net project, an online information management system. This will free up county staff resources, particularly those devoted to billing and claims functions, for case management activities, but the extent of these savings is currently unknown. In addition, DHS is updating the CCS staffing standards but does not expect to have those standards in place until late 2000.

### ***Options to deal with this problem include:***

- Requiring CCS staffing standards to be updated regularly and to be consistent with those used in other case managed programs serving families or children and adolescents.

### **Need for Better State Oversight and Enforcement of Program Standards**

Although DHS has issued a detailed procedures manual for the CCS program and issues frequent directives concerning administration of the program to counties via program letters, it conducts very little formal oversight of county administration of the program to gauge compliance with program standards. Interviewees told SOR that county and provider site reviews are rarely conducted, generally only in response to highly publicized problems. Many expressed concern that CCS administrative functions, including program oversight and standard setting, are understaffed at the state level. As a result, counties routinely fail to comply with many program standards, including timeliness standards for eligibility determinations, authorization of services, and payment of claims. In some counties, large backlogs of unpaid claims exist.

The state-county linked management information system, CMS Net 47, being implemented by DHS will enable it to track enrollment, services, and program outcomes at the county level. Currently 44 counties participate in the system; however, efforts to include the remaining counties are hampered by county delays in computerizing client-tracking services, a reluctance among some counties to participate in the system, limits in the capacity of the state's hardware system, and a lack of state staffing to assess program outcomes.

In most counties, all claims for services to Medi-Cal-eligible children are submitted to the CCS county or state regional office for review and approval and then are submitted to the Medi-Cal billing intermediary, EDS. With the

completion of the CMS Net 47 system, all Medi-Cal claims for counties participating in the system will be sent directly to EDS. AB 2793 of 1994 required *all* independent counties to begin forwarding to EDS claims for services to CCS-only children submitted to EDS by January 1, 1999. Currently, 49 counties have met this requirement.

Stakeholders also cited problems with long backlogs in the credentialing or recredentialing of CCS hospitals, neonatal and pediatric intensive care units, special care centers, and individual health care providers, leading to barriers to services in some areas. According to materials provided to the Senate Budget Committee by DHS, in February 2000 a backlog of 452 facilities and providers was awaiting certification or recertification, as well as a backlog of 104 medical therapy units.

A variety of reasons were given by persons SOR interviewed for counties' problems with meeting CCS timeliness standards, including difficulties filling staffing vacancies, periodic county hiring freezes, and understaffing, in some cases driven by unrealistic staffing standards imposed by the state. Even when DHS officials are aware of problems, the lack of clear authority to sanction counties for failure to correct program deficiencies allows the problems to continue.

*Options to deal with these problems include:*

- Expediting implementation of the CMS Net 47 management information system;
- Requiring all counties to participate in the CMS Net 47 system by a target date as a condition of receiving state matching funding for CCS;
- Requiring DHS to conduct formal county site reviews and reviews of CCS (and GHPP) credentialed providers and special care centers at least once every two years;
- Providing additional funds and staffing for updating and enforcement of program eligibility, administration, and provider certification standards, and for regional office eligibility determinations and treatment authorizations;
- Providing funding to track and analyze program outcomes across counties, including gauging family and provider satisfaction and impacts of county CCS programs on school absenteeism, emergency room visits, and hospitalization rates;
- Giving DHS authority to issue corrective action notices and to impose financial sanctions on counties for failure to comply with the notices.

### **Inadequate Attention to Family-Centered Care as a Program Goal**

Federal law and guidelines require states to administer MCH block-grant funded programs, which includes CCS, in a family-centered manner – meaning in a manner that is inclusive of families and adapted to their needs. Despite this mandate, the CCS program remains a difficult program for families to understand and deal with, according to program administrators and family resource groups. In most counties interaction with the program is via cursory letters that are sometimes confusing to families. Application procedures and timelines are cumbersome and burdensome. Program materials, including applications, information packets, and notices are rarely provided in languages besides English. Translator services are generally limited to English and Spanish. Due to workloads, case managers frequently do not have time to return calls to families who are concerned about program determinations regarding their children. In many counties, children needing therapy are assigned to therapists without input from families and families are not involved in treatment decisions. For the most part, CCS does not provide therapy or treatment services in the home, although traveling to a medical treatment unit center or provider's office is often difficult for children with significant disabilities. Due to backlogs in the credentialing of CCS providers, satellite clinics have had difficulties getting established in several rural areas, requiring families to travel further distances to visit special care centers.

Families with children eligible for other state-administered programs and services – for example, regional center services and special education – face inconsistencies in eligibility standards and separate intake procedures for the programs. They must deal with multiple case managers, adding to the complexities of addressing their children's conditions. For example, eligibility for services under the CCS high-risk infant follow-up program is limited to birth to 24 months, while eligibility for services for children at risk of developmental disability under the Early Start program extends from birth to 36 months. Similarly, eligibility for special education extends until the 22<sup>nd</sup> birthday, while eligibility for CCS usually terminates at age 21.



In most cases, the only recourse for families who are confused by or wish to challenge a program decision is to make a formal appeal and have a case heard by an administrative hearing officer.

A survey of families conducted by DHS in 1998 as part of its MCH block-grant needs assessment also found that nearly 20 percent of families with CCS-eligible children have problems with transportation that make it difficult to keep medical appointments for their children. These range from lacking a reliable car or adequate bus fare to being unable to take time off work or facing difficulties transporting a disabled child. The same survey found that 35 percent of families ranked as very important additional parent education on rights and entitlements and 30 percent ranked as very important help in getting needed services and supplies.

Family representatives pointed out that families are disadvantaged by a variety of financial standards and requirements. For example, under existing statute, families must document their incomes using the previous year's income tax return, making it difficult for families whose income has recently declined to establish eligibility.

When a person is found eligible for Medi-Cal, coverage is generally retroactive for up to three months. However, family representatives report difficulties getting the Medi-Cal Health Insurance Payment Program (HIPP) to cover families' share of private health insurance premiums for the three months before eligibility is established for their children. Problems in getting CCS to pay for copayments and deductibles under private health insurance coverage also were cited by several groups.

County CCS administrative staff have informed SOR that statutorily required annual enrollment fees for families with incomes above \$25,000 act as a barrier to enrollment in some cases and are routinely waived by counties for hardship. These fees currently account for about 0.3 percent of CCS revenues.

DHS has taken some steps to address the issues outlined above, including hiring a family coordinator to provide families' perspectives on program administration issues and publishing a parent handbook that explains the CCS program in different languages. In addition, Children's Hospital Los Angeles has received a federal MCH grant to conduct training sessions for families of CCS-eligible children.

*Options to deal with these problems include:*

- Requiring DHS and counties to provide CCS materials and communications – including applications, information packets, correspondence, and telephone contacts – in threshold languages, consistent with Medi-Cal managed care regulations;
- Establishing a family ombudsperson and an 800 telephone number where families can informally try to resolve concerns and complaints prior to filing formal complaints about the program;
- Requiring county notices of CCS decisions or actions in specific cases to provide clear notice of the action being taken, the reasons for the action, and the family's appeal rights;
- Providing funds for county CCS programs to hire family coordinators at the county level to improve interaction between CCS and families;
- Providing funds for county CCS programs to contract with family resource centers to improve interaction between CCS and families;
- Requiring DHS to produce informational videotapes in several languages explaining the CCS program to be shown to families upon enrollment in the program;
- Requiring DHS and counties to review all program materials and application procedures to ensure that they are family-centered and easy to understand;
- Requiring DHS and the Department of Developmental Services to develop common application forms and integrated intake procedures for Medi-Cal, Healthy Families, CCS and the regional centers. Develop greater consistency in eligibility standards and better collaboration between different programs serving CCS-eligible children, including CCS, regional centers, and special education programs;

- Requiring DHS to establish standards for access to home services if traveling to treatment centers or providers' offices risks further complications of children's conditions;
- Allowing families to document their income using pay stubs, income tax returns, or county welfare office statements, similar to the verification documents used in the Healthy Families program;
- Establishing a process for electronic submission of treatment authorization requests to expedite the review of requests for treatment;
- Eliminating the annual enrollment fee for participating families;
- Establishing clearer standards regarding access to medical transportation services under CCS and better informing families of the availability of medical transportation services;
- Establishing a Medi-Cal administrative claiming program so counties can bill Medi-Cal for a greater variety of travel arrangements under CCS, including transportation provided by the family itself;
- Requiring the Medi-Cal HIPP to pay the family share of cost for private health insurance coverage for the two months preceding the date of determined CCS eligibility, similar to the policy for regular Medi-Cal.

### **Inconsistent County Application of Program Standards**

To be eligible for CCS, children must have a qualifying medical condition, be Medi-Cal eligible or meet family-income limits, and be a resident of the county in which they are seeking eligibility. According to stakeholders, in practice, inconsistent application of the standards leads to children with similar conditions being covered in some counties and not in others. For example, stakeholders told SOR that some counties adopt relatively liberal interpretations of the medical eligibility standards while others follow more restrictive interpretations. While this problem has been partially rectified by the recent issuance of new medical eligibility standards that better define which specific types of conditions are eligible for CCS, there are still many gray areas requiring county interpretation of standards.

Similarly, some counties require a determination of Medi-Cal eligibility for all applicants before admitting a child to the program, while others admit clients who meet medical and residence requirements pending a Medi-Cal determination. In practice, the Medi-Cal determination rarely affects eligibility for the program but instead affects the share of cost the county will be responsible for.

Finally, procedures and policies for treatment and authorization requests differ from county to county and between the state regional centers and individual counties. Large-volume CCS providers such as academic medical centers and children's hospitals indicated that they often have to deal with several different county eligibility and treatment authorization systems. Some urged that standardized forms be developed for all counties and regional offices for treatment authorizations and claims.

Results of focus group interviews conducted by DHS indicate that many families who move from one county to another have difficulty reestablishing services in the new county. Inconsistent application of program standards also burdens providers who see children from more than one county.

Many stakeholders expressed a belief that inconsistencies in county administration of the CCS program are the result of funding pressures on counties brought about by the increased county share of cost enacted as part of California's 1991 state-county realignment of health, mental health, and social services programs. Current law establishes a county financial maintenance-of-effort requirement of 25 percent of the 1990-91 baseline costs of the CCS program. In addition, counties receive realignment funds equal to 25 percent of the historical program costs. However, existing law also allows counties to reduce their funding contributions to below the maintenance-of-effort level if they can certify that a lesser amount is needed to pay 25 percent of the program costs.

In practice, many counties have been able to reduce their funding requirements due to greater shifting of caseload to Medi-Cal, the \$40,000 cap on income eligibility for the program, and the availability of enhanced federal funds for CCS services to children eligible for the Healthy Families program. However, these trends are being offset in many counties by increasing caseload and an increasing volume of services, especially medical therapy services. In essence, counties must make difficult trade-offs between committing county funds for CCS, which provides medical care for a limited number of children with extraordinary needs, versus other health and social service programs.

The state's plan to implement the federal children's health insurance program (Healthy Families in California) calls for the identification of CCS-eligible children who are also eligible for Healthy Families. It also assumes enhanced federal funding for CCS services provided to Healthy Families-eligible children. The enhanced funding effectively lowers the county and state share of cost for CCS services to Healthy Families-eligible children from 50 percent each to 17.5 percent each (assuming a federal matching rate of 65 percent).

In practice, counties have not been receiving the benefit of enhanced federal funding of CCS cases due to problems identifying Healthy Families-eligible children in the state's medical eligibility data system.

***Options to deal with these problems could include:***

- Funding additional regional coordination projects, similar to the Children's Regional Integrated Service System (CRISS) project in the San Francisco Bay area;
- Requiring DHS to conduct more frequent site reviews of county programs (see recommendation above);
- Requiring DHS to provide training for county CCS staff on CCS program standards and any changes in the standards. This could be carried out in conjunction with more frequent county site reviews;
- Establishing a program advisory body comprised of county, provider, and family representatives to identify and recommend solutions to disparities in counties' application of program standards and to advise the state on changes in eligibility and provider standards necessary to keep the CCS program current with accepted medical practice;
- Requiring DHS to develop and/or disseminate best treatment practices for specific conditions to increase consistency among counties in authorization decisions;
- Requiring continuous eligibility and continuous service delivery for clients who move from one county to another;
- Requiring counties to grant eligibility to applicants who are otherwise eligible while their Medi-Cal applications are pending;
- Returning to the 25 percent county share of costs for CCS that existed prior to realignment in 1991.

**Fragmented Service Delivery as a Result of Expansion of Managed Care**

Because CCS provides medical and therapy services related to a particular condition and does not provide overall medical care, it must coordinate its services with those of other providers of basic health care services. In the past, most children with other forms of health coverage had fee-for-service coverage. In these cases CCS could manage the services needed by a particular child. With the growth of managed care, with its gatekeeping system and defined networks of providers, that is more difficult.

Stakeholders told SOR that, in practice, a number of problems complicate the coordination of CCS services with basic health care services provided by managed care plans. First, for children who are covered by private managed care plans, CCS does not provide case management and instead limits services to those not covered by the private coverage. The reason for this policy is that managed care plans use their own networks of providers and the state believes that such plans should be responsible for both services and case management to enrolled children with special health care needs. This means that before CCS will authorize a particular service or therapy, the other plan must first deny coverage for it. Due to the reluctance of plans to make outright denials of coverage in many areas, including coverage of pediatric subspecialty care, lab work, X-rays, durable medical equipment, and pharmaceuticals, this process can take weeks and often months, while the family waits for services. In some cases, the denials are never provided, leaving the family indefinitely without access to services.

Second, due to concerns about the ability of managed care plans to provide CCS services, these services are currently excluded (carved out) from Medi-Cal managed care plans until August 2005, while the state undertakes and evaluates pilot projects to test the impact of full capitation on CCS-eligible children. Until earlier this year, DHS was in the process of implementing one such pilot in Los Angeles County, which was expected to enroll up to 6,000 CCS-eligible children on a voluntary basis in comprehensive managed care arrangements. However, LA Care, the

sponsor of the pilot project, recently discontinued its involvement after being unable to secure supplemental funding for case management services. As a result, the state has little data from which to judge whether including treatment of CCS conditions in managed care contracts would result in better or more seamless care for CCS-eligible children.

While many stakeholders believe that the carve out of CCS services ensures better access to services for children, they acknowledge that fragmentation of care can result. Most Medi-Cal managed care plans and plans contracting with the Healthy Families program must refer children with CCS-eligible conditions to CCS for services related to their condition, while retaining responsibility for other basic health care services unrelated to the condition. Stakeholders told SOR that, in practice, this leads to frequent cross-referrals of treatment requests between CCS and plans and frequent disagreements over what constitutes basic care and what constitutes care related to the CCS-eligible condition. CCS administrators and providers that SOR interviewed indicated that these cross referrals and disagreements frequently cause significant delays in families accessing services, as well as extra administrative costs. For children with serious medical conditions, for whom the lines between preventive and specialty care are often blurred, these delays can be harmful and even life-threatening.

Several Medi-Cal local initiative managed care plans expressed interest in the state pursuing additional CCS pilot projects and in the state providing supplemental funding for those pilots. The local initiatives pointed out several areas where they believe they could improve on the current level of care provided to CCS clients if given a chance, including greater access to providers as a result of higher reimbursement rates for subspecialists, and greater access to ancillary services such as translation, transportation, and home health care.

According to DHS, continuity of care for children enrolled in managed care plans is improving, both in Medi-Cal and in the Healthy Families program, as plans and providers gain more experience in implementing MOUs governing referral of CCS-eligible conditions between counties and the plans. The state has also received a federal grant to implement, on a pilot basis, a medical-home concept for CCS-eligible children, which would assign primary care responsibilities to either family care providers or special care centers depending on the nature of the condition.

***Options to deal with these issues include:***

- Implementing a medical-home concept for CCS-eligible children, in which responsibility for primary care and care coordination would be assigned to either primary care providers or special care centers, depending on the nature of the condition.
- Establishing disincentives for managed-care plans to abuse the CCS referral process under the existing CCS carve-out system, for example by over-referring to CCS non-CCS-eligible conditions.
- Requiring External Quality Review audits of Medi-Cal managed care plans to include an assessment of the adequacy of care coordination by the plans for CCS-eligible children.
- Excluding children with more serious conditions from mandatory enrollment in Medi-Cal managed care plans, or allowing CCS-eligible children to opt out of mandatory enrollment in managed care plans under Medi-Cal, similar to the process proposed by AB 469 (Papan) of 1999, which was vetoed by the governor.
- Requiring DHS to contract for a study of the medical outcomes, family satisfaction, and health status of CCS-eligible children currently or previously enrolled in managed care plans for all of their health care needs. This would include Kaiser's geographic managed-care plan in Sacramento County, the three county organized health systems that are capitated for CCS care (Santa Barbara, San Mateo, and Solano), and private managed care plans. This would enable DHS to better assess the impact of managed care on children with special health care needs.
- Establishing CCS as a standard of care for children with special health care needs in all health plans under Knox-Keene HMO licensing standards.
- Requiring or encouraging counties to use blanket or extended authorization processes for certain ongoing services to avoid the need for separate authorizations for each service provided.

**Outdated Income Eligibility Standards**

Up until 1982, eligibility for CCS was extended to families with annual gross incomes up to \$100,000. As part of the

fiscal relief package enacted in 1982, eligibility was lowered to \$40,000. Families can qualify for CCS with incomes over that amount only if their medical expenses reach 20 percent of their incomes. Over time, the effect of this reduction has been to reduce the number of children eligible for the program and it is most likely one of the reasons for the decline in the non-Medi-Cal-eligible portion of the caseload since the early 1990s. In 1999-00, budget trailer legislation extended financial eligibility to families with children eligible for the Healthy Families program, which allows some (generally larger) families with incomes in excess of \$40,000 to be eligible for the program. But the same provision does not exist for non-Healthy Families-eligible children who otherwise meet the Healthy Families income limits (generally 250 percent of the federal poverty level). In addition to lowering of the income threshold, the lack of any inflation adjustment mechanism acts to exclude more families from the program over time.

Other programs serving clients with significant health and social needs generally incorporate higher income ceilings than \$40,000 and sometimes no ceiling. For example, the Aids Drug Assistance Program (ADAP) provides drug therapies with no share of cost to individuals with AIDS with incomes below \$50,000 (equivalent to an income limit of 600 percent of the federal poverty level). Regional center services are provided to persons with developmental disabilities generally without regard to family income; there is a family share of cost requirement for 24-hour out-of-home placement.

### ***Options to address this include:***

- Redefining financial eligibility for CCS as a percentage of the poverty level, similar to the approach used by other state-administered health programs, including Medi-Cal, Healthy Families, and the Access for Infants and Mothers (AIM) programs. A level of 300 percent of poverty would include most families who would currently meet the \$40,000 limit while providing a built-in inflation adjustment. To avoid excluding any family that would otherwise meet the \$40,000 limit, the redefinition could extend eligibility to families with incomes below 300 percent of the federal poverty level or \$40,000, whichever is greater.
- Adjusting the \$40,000 ceiling for inflation since 1982, when the standard was first imposed, as well as for future cost-of-living changes.
- Reestablishing \$100,000 as the income ceiling for the program. According to the Legislative Analyst's Office, roughly 22,000 additional children would be eligible if this change were made.
- Eliminating the income ceiling and instead institute a sliding-scale fee schedule for families with incomes above a certain level.

### **Need to Develop More Flexible Medical Eligibility Standards**

Eligibility under CCS is generally limited to children with defined medical conditions, including congenital heart defects, cerebral palsy, cancers, craniofacial abnormalities, and HIV. The exception to this is newborn infants who require specified neonatal intensive care services but who do not have identified CCS-eligible conditions. A number of health care providers and CCS program administrators that SOR spoke with stated that children with a variety of medical conditions would benefit from access to CCS services, but don't have diagnosed conditions meeting CCS eligibility criteria. An example is newborns who fail to thrive in early weeks of life and are not eligible for neonatal intensive care services under the CCS neonatal care program. Many expressed a desire to see CCS medical eligibility eventually based on more general criteria, including functional status, level of condition, or need for specialized services. Many see this as a way to increase the program's flexibility to adapt to emerging conditions and treatments.

In addition, some stakeholder groups expressed interest in expanding conditions eligible for treatment under the GHPP to include other conditions that continue into adulthood and have similar implications for insurability and the need for highly specialized and coordinated treatment to other conditions covered by GHPP.

*One option to deal with this issue is:*

- Require DHS to study the feasibility of developing alternative medical eligibility criteria based on functional status, level of condition, or need for specialized services.

### **Conclusions**

CCS is a successful and multi-faceted program serving children with complicated health care needs. Although the purpose and basic structure of the program are sound, numerous growing problems prevent timely access to services for many CCS-eligible children, including fragmentation of services, outdated standards, limited state

oversight of the program, and erosion of the provider infrastructure serving the program. The Legislature and governor may wish to consider additional reforms and funding for the CCS program to ensure that eligible children receive care in a seamless and timely manner.

## **Acknowledgments**

The authors would like to acknowledge several persons who provided comments on earlier drafts of the report and valuable technical expertise. They include Laurie Soman, Center for the Vulnerable Child, Oakland Children's Hospital; Erin Aaberg Givens, Pediatric Management Group; Susan Maddox, President and Chief Executive Officer, California Children's Hospital Association; Terri Cowger, legislative representative, California Children's Hospital Association and the California Children's Lobby; Dr. Maridee Gregory, Chief, Children's Medical Services Branch, Department of Health Services; Diane Van Maren, principal consultant, Senate Budget and Fiscal Review Committee; Marilyn Holle, staff attorney, Protection and Advocacy, Inc.; Hellan Roth Dowden, Local Health Plans of California; and Dan Rabovsky, Legislative Analyst's Office.

The authors also wish to thank those who participated in SOR's California Children's Services Roundtable Forum on February 4, 2000, and whose remarks provided a basis for many of the findings and options presented in this report.

Finally, the authors would like to acknowledge the comments and input received from numerous other persons and organizations, including those who agreed to be interviewed for this report. (See the appendices for complete listings.)

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## **Appendix A**

### **Medical Conditions Covered by the CCS Program**

Please see hard copy of report.

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## **Appendix B**

### **CCS Policy Roundtable Agenda**

February 4, 2000, 1:00 – 4:00  
State Capitol, Room 112

#### **Introduction**

**Peter Hansel, Senate Office of Research, Moderator**

#### **1:10 Adequacy of CCS Provider Networks**

CCS depends on an established network of physicians, therapists, and hospitals to provide care to the over 100,000 children enrolled in the program at any point in time. Currently, health care providers who participate in CCS are reimbursed at Medi-Cal rates for services. According to several sources, low reimbursement rates for CCS and Medi-Cal services are causing many physicians to cease seeing CCS/Medi-Cal patients or otherwise limit the number of patients they will treat. The result is growing waiting times for some subspecialty services, ranging from weeks to months, depending upon the service. In some cases, children with conditions which are treatable on an outpatient basis are being hospitalized in order to receive treatment more expeditiously.

In addition, claims for reimbursement for CCS services are routinely edited by the Medi-Cal fiscal intermediary, EDS, based on the frequency of the service for which reimbursement is being claimed and based on whether the visit is an initial or follow-up visit. The result is that rates for CCS services do not reflect that visits involving CCS-eligible children are more complex, more frequent, and more time-consuming than visits involving children in general. Finally, providers report lengthy waits for claims reimbursement in many counties.

While CCS physician rates have been augmented in recent budgets, including a 20 percent increase for preventive and primary care services in 1998 and a five percent adjustment in the 1999-00 budget, they are still considerably below standard rates for comparable services.

Presenters

Erin Aaberg Givans

Director of Government Affairs

Pediatric Management Group

Peter DuBois

President and CEO

Pediatric Management Group

Kathryn Anderson, M.D.

University Children's Medical Group

Robert Haining, M.D.

Director of Pediatric Rehabilitation

Oakland Children's Hospital

James Feusner, M.D.

Director of Pediatric Oncology

Oakland Children's Hospital

Lucy Crain, M.D.

Chair, American Academy of Pediatrics, California District

Steven Cederbaum, M.D.

Professor of Psychology and Pediatrics

UCLA

Sue Maddox

President and Chief Executive Officer

California Children's Hospital Association

### **2:00 Updating and Achieving Consistent Application of Program Standards**

In the view of many stakeholders, many CCS program standards are in need of updating. For example, the \$40,000 income limit for the program has not been updated since 1982, resulting in a declining number of families who meet the financial eligibility standards over time.

In addition, according to several sources, CCS case management ratios exceed 500 clients per case manager in most independent counties and 1,000 in the state centers serving dependent counties, far in excess of standards for comparable programs, such as the regional centers and the CalLearn program. Stakeholders argue that the standards do not reflect changes that have occurred in the CCS program over time, including the increasing complexity of cases and newer mandates to coordinate care more closely with other systems of care, including Medi-Cal managed care plans, special education, county mental health, and regional centers.

Many stakeholders support a more flexible and responsive process for updating medical eligibility standards. Many support creation of an ongoing standards advisory group to recommend changes in medical eligibility needed to keep the program abreast of changes in medical practice. Many expressed a desire to see CCS medical eligibility eventually based on more general criteria, including functional status, level of condition, or need for specialized services as a way to increase the program's flexibility to adapt to emerging conditions and treatments.

Finally, inconsistent application of program standards results in children with similar conditions being covered in some counties and not in others. According to many stakeholders, some counties adopt relatively liberal interpretations of the medical eligibility standards while others follow more restrictive interpretations. While this problem has been partially rectified by the recent issuance of new medical eligibility standards, which better define which specific types of conditions are eligible for CCS, there are still many gray areas requiring county interpretation of standards.

Presenter

Laurie Soman

Center for the Vulnerable Child

Oakland Children's Hospital

### **2:30 Need to Develop a More Family-Centered Approach**

The CCS program is a difficult program for families to understand and deal with according to program administrators and family resource groups. In most counties interaction with the program is via cursory letters that are sometimes confusing to families. Application procedures and timelines are cumbersome and burdensome. Program materials, including applications, information packets, and notices are rarely provided in languages besides English. Translator services are generally limited to English and Spanish. Due to workloads, case managers frequently do not have time to return calls to families who are concerned about program determinations regarding their child. In many counties, children needing therapy are assigned to therapists without input of families and families are not involved in treatment decisions. For the most part, CCS does not provide therapy or treatment services in the home, although traveling to a medical treatment unit center or provider's office is often difficult for children with significant disabilities.

Families with children eligible for other state-administered programs and services, for example regional center services and special education, face problems of inconsistency of eligibility standards and separate intake procedures between the programs, as well as problems of dealing with multiple case managers, adding to the complexity of dealing with their children's condition.

Presenter

Claire Gover

Matrix Parent Network and Family Resource Center

### **3:00 Managed Care Carve-Out Issues**

With the passage of 1999-00 budget and trailer legislation, CCS services are currently excluded (carved-out) from Medi-Cal managed care contracts until August 1, 2005. While many stakeholders believe that the current carve-out of CCS services ensures better access to services for children, in practice the carve-out leads to frequent cross-referrals of treatment requests between CCS and plans and frequent disagreements over what constitutes basic care and care related to the CCS-eligible condition. These cross referrals and disagreements frequently cause significant delays in families accessing services, as well as extra administrative costs.

According to the Department of Health Services, continuity of care for children enrolled in managed care plans is improving, both in Medi-Cal and in the Healthy Families program, as plans and providers gain more experience in



implementing MOUs governing referral of CCS-eligible conditions between counties and the plans. The department has also received a federal grant to implement, on a pilot basis, a medical home concept for CCS-eligible children, which would assign primary care responsibilities to either family care providers or special care centers depending on the nature of the condition.

Presenters

Linda Burden, M.D.

California Children's Lobby

Leona Butler

CEO

Santa Clara Family Health Plan

Helen DuPlessis, M.D., M.P.H.

Chief Medical Officer

LA Care Health Plan

### **3:45 Oversight and Enforcement of Program Standards**

Although the Department of Health Services has issued a detailed procedures manual for the CCS program and issues frequent directives concerning administration of the program to counties via program letters, it conducts very little formal oversight of county administration of the program to gauge compliance with program standards. Interviewees told SOR that site reviews are rarely conducted, generally only in response to highly publicized problems. Many expressed concern that CCS administrative functions, including program oversight and standard setting, are understaffed at the state level. As a result, counties routinely fail to comply with many program standards, including timeliness standards for eligibility determinations, authorization of services, and payment of claims. In some counties, large backlogs of unpaid claims exist. While DHS is in the midst of implementing an online management information system that will enable it to track enrollment, services, and program outcomes at the county level, the effort is beset by numerous obstacles, including delays at the county level in computerizing client tracking services, the reluctance of some counties to participate in the system, and the lack of state staffing to assess program outcomes.

Presenter

Peter Hansel

Senate Office of Research

### **4:00 Conclusion**

#### **List of Attendees**

Helen M. DuPlessis, MD, MPH

LA Care

Betsy Lyman

CMS, DHS

Maridee Gregory, MD

CMS, DHS

Arwen Chenery

Assemblywoman Susan Davis

Melissa Rodgers

Legal Aid Society of San Mateo County

Diana M. Lee

Sickle Cell Community Health Network

Jeannine Woods

Sickle Cell Community Health Network

Mary Sheehan

Valley Mt. Regional Center

Wendell Uychutin

UCPA

Cyndi Kettmann

Sutter Health

Mickey Richie

DHS – Local Liaison

Terri Cowger

California Children's Lobby/

California Children's Hospital Association

Leona Butler

Santa Clara Family Health Plan

Hellan Roth Dowden

Local Health Plans of California

Richard Ikeda, MD

Health For All

Joel Cohen

California Research Bureau

Michael Dimmitt

California Health Care Association

Shawn Jones, MD

Adult Sickle Cell Program, Berkeley

Son Nguyen

Midwestern University

Virginia Knowlton

Protection and Advocacy, Inc.

Lou Vismara, MD

California State Children and Families Commission

Robin Miller

CCS Administrator, Solano County

Laurie Soman

Center for the Vulnerable Child

Children's Hospital, Oakland

Bob Frangenberg

L.A. County Health Department

Nicole Garro

L.A. Medical Home Project

Mary Hurts

Sacramento Sickle Cell, Inc.

Robert L. Nolan, MD

CCS Contra Costa County

Robin Thomas

CCS Contra Costa County

Diana Cunnison

Contra Costa County CCS

Linda Burden, MD

California Partnership for Children

Diana Obrinsky

Alameda County CCS

Rosita Saw, Director

Santa Clara County CCS

Barbara Johnston  
Kaiser Permanente  
Stephen Cederbaum, MD  
UCLA  
James Feusner, MD  
Children's Hospital Oakland  
Rita Huppe  
Lynn Suter and Associates  
Peter DuBois  
Pediatric Management Group  
Kathryn Anderson, MD  
University Children's Medical Group  
Naomi Meyer  
Consumers Union  
Jack Keating, MD  
Health Net  
Marilyn Holle  
Protection and Advocacy  
Robert Haining, MD  
Oakland Children's Hospital  
Lucy Crain, MD  
American Academy of Pediatrics, California District  
Sue Maddox  
California Children's Hospital Association  
Claire Gover  
Matrix Parent Network and Family Resource Center

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## **Appendix C**

### **List of Persons Interviewed or From Whom Comments Were Received**

Erin Aaberg Givans  
Director of Government Affairs

Pediatric Management Group

Marilyn Backlund

Coordinator

California Children's Services Program

Stanislaus County

James Bartley, MD, Ph.D

Redlands, CA

Peggy Baxter

Director

Government and Community Relations

Children's Hospital Oakland

Linda Burden, MD, MPP, MPH

California Children's Lobby

Leona Butler

Chief Executive Officer

Santa Clara Family Health Plan

Ann Cirimele

Director

Family Resource Network

Thomas Coates, MD

Associate Professor of Pediatrics and Pathology

Children's Center for Cancer and Blood Diseases

Teri Cowger

Cowger and Associates

Lucy Crain, MD

Chair

American Academy of Pediatrics, California District

Diane Cummins

Office of California Senate President Pro Tempore John Burton

Marian Dalsey, MD

Director

Program Standards and Quality Assurance Section

Children's Medical Services Branch

Marge Deichman

Director

California Children's Services

Alameda County

Helen DuPlessis, MD, MPH

Chief Medical Officer

LA Care Health Plan

Juno Duenas

Executive Director

Support for Families

Robert Frangenberg

Director

California Children's Services Program

Los Angeles County

Susan Garland

Administrator

California Children's Services Program, Solano County

Dale Garrel, MD

Chair

Department of Pediatrics

University of Southern California

Nicole Garro, MPH

Research Specialist

The Los Angeles Medical Home Project for Children with Special Health Care Needs

Claire Gover

Matrix Parent Network and Family Resource Center

Maridee Gregory, MD

Chief

Children's Medical Services Branch

Martha Guerrero, MSW

Legislative Analyst

LA Care Health Plan

Robert Haining, MD

Director of Pediatric Rehabilitation

Children's Hospital, Oakland

Marilyn Holle

Attorney

Protection and Advocacy

Leslie Holve, MD

Santa Rosa, CA

M.E. Hurley, MD

Department of Orthopedic Surgery

Kaiser Permanente, Fontana

Richard Ikeda, MD

Elisabeth Jameson, JD

Institute for Health Policy Studies

University of California, San Francisco

Kathy Jew, RN, MPH

Carol Kamjou, RN, MPH

Michelle Fox, CGC, MS

Division of Genetics

UCLA School of Medicine

Sally Johnson

Supervisor

California Children's Services Program, Imperial County

Barbara Johnston, MSNL&M

CCS Coordinator

Kaiser Permanente Medical Group

Sharon Jones, MD

Director, Adult Sickle Cell Program

Alta Bates Medical Center

Jack Keating, MD

Health Net

Kathleen Keon

Harbor Regional Center

Carol Kerfoot

Barbara Rice

California Children's Service Program

Santa Cruz County

David Kerns, MD

Virginia Knowlton

Protection & Advocacy, Inc.

Dan Little

Fiscal Forecasting and Data Management Branch,

DHS

Sheila Lawler

Director, State Programs Compliance

Kaiser Foundation Health Plan

Elizabeth Lyman

Assistant Chief

Children's Medical Services Branch

Susan Maddox

President and CEO

California Children's Hospital Association

Debra Mansfield

Bakersfield, CA

William Mentzer, MD



Professor

Department of Pediatrics

University of California, San Francisco

Patty Moore

Family First Program

Robert Nolan, MD

Medical Consultant

California Children's Services Program, Contra Costa County

Diana Obrinsky, MD

Medical Director

California Children's Services, Alameda County

Robyn Phelps

Administrator

California Children's Services Program, San Diego County

Diane Quinn

Program Manager

San Mateo County

Melissa Rodgers

Attorney at Law

Legal Aid Society of San Mateo County

Hellen Roth Dowden

Local Health Plans of California

Rosita Saw

Director

California Children's Services Program

Santa Clara County

Mary Sheehan

Valley Mt. Regional Center

Laurie Soman

Senior Policy Analyst

Center for the Vulnerable Child

Oakland Children's Hospital

Claudia Spencer

Administrator

California Children's Services Program, San Bernardino County

Margie Swartz

Western Center on Law and Poverty

Diane Van Maren

Principial Consultant

Senate Budget Committee

Louis Vismara, MD

Commissioner

California Children and Families Commission

Nora Wells

Family Voices

Irv White

Chief

Program Support Division

Children's Medical Services Branch

Elinor Zorn, MD

Associate Director

Valley Children's Hospital

Julie Zumwalt

Parent Coordinator

Children's Medical Services Branch