

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

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

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## **Background**

Title V Needs Assessment. Title V of the Social Security Act is a federal-state partnership that provides for programs to improve the health of all mothers and children, including children with special health care needs. California currently receives approximately \$43.3 million in federal Title V funds that are jointly administered by the State's Maternal Child Adolescent Health (MCAH) Branch and the Children's Medical Services (CMS) Branch. Three population groups are served through Title V: pregnant women and infants less than 1 year of age; children ages 1 to 21 years; and children with special health care needs (CHSCN). Every five years the Federal Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau requires that each State MCH agency funded through the Federal Title V MCH Block Grant Program complete a needs assessment. California's MCAH Branch, which is a block grant recipient, must complete an assessment of the health problems and needs of the MCAH population and develop a FY2010-2015 5-year plan for addressing problems identified through this process. At least 30% of Federal Title V funds must be used for preventive and primary care services for children and at least thirty percent (30%) for services for CSHCN as specified in legislation. Based on this requirement it has been the practice that the CMS Branch would identify three priority needs for the California Children's Services (CCS) program that will be addressed in the 5-year plan and for which performance measures will be included.

As part of the broader planning process and the identification of the 3 priority CSHCN action areas, the Family Health Outcomes Project was contracted by CMS to conduct an assessment of the needs and systems issues related to delivering services to children and families eligible for CCS, California's CSHCN program, is a statewide program that treats children with certain physical limitations and chronic health conditions or diseases. CCS children are a subset of the nationally defined CSHCN. Other California agencies and departments, such as the California Departments of Developmental Services and Mental Health and the California Department of Education (CDE) provide services to other CSHCN and may provide some services to CCS-eligible children as well. While CMS and stakeholders recognize that Federal Title V guidance promotes assessment and planning for the broader CSHCN population, CMS is limited in its capacity to plan across programs and Departments by limited funds as well as California's separation of the responsibility for the delivery of health, mental health, developmental and social services for children and makes coordination among these services difficult. Other challenges faced by CMS included California's ongoing

fiscal crisis and reductions in programs staff due to layoffs and furloughs necessitated by the fiscal crisis. In addition, the needs assessment was conducted against the backdrop of the need for reauthorization of California's Medicaid 1115 Hospital/Uninsured Waiver and the Department of Health Care Services' goal of developing pilot projects to explore potential redesign options for the CCS program.

CMS recognized that a critical aspect of the assessment process is to encourage and facilitate participation by stakeholders throughout the state to assist in identifying health and health systems problems/needs, prioritizing among the identified issues, developing strategies to intervene in prioritized issue areas and evaluating the effectiveness of intervention strategies. Accordingly, CMS established a CCS Needs Assessment Stakeholders Group and contracted with the Family Health Outcomes Project (FHOP) to facilitate a stakeholder process to determine Action Priorities to be addressed during FY2010-2015 and to assist in identifying the most important and potentially effective areas in which CCS can improve services for CCS-eligible children.

CCS Program. In fiscal year 2008-2009, a total of 173,555 California children ages birth to 21 years received services through the CCS program. CCS-eligible CSHCN are children who are under 21 years old; have or may have a medical condition that is covered by CCS (such as cancer, spina bifida, sickle cell disease, cerebral palsy, metabolic problems and congenital defects); are a resident of California; and whose families meet financial eligibility requirements. The family must have a family income of less than \$40,000 as reported as the adjusted gross income on the state tax form, or the out-of-pocket medical expenses for a child who qualifies are expected to be more than 20 percent of family income, or the child has Medi-Cal or Healthy Families coverage.

CCS may authorize and/or pay for:

- Treatment, such as doctor services, hospital and surgical care, physical therapy and occupational therapy, laboratory tests, X-rays, orthopedic appliances and medical equipment.
- Medical case management to authorize appropriate health care services for an eligible child's medical condition when medically necessary, and referral to other agencies, including public health nursing and regional centers.
- Medical Therapy Program (MTP) services including physical therapy and/or occupational therapy provided in public schools for medically-eligible children.

## **Assessment Framework and Process**

FHOP proposed a framework and process for conducting the CCS Title V Assessment and facilitating the participation of a diverse group of Stakeholders identified by CMS. FHOP recommended an inclusive and systematic process of developing methods and issues to be assessed, gathering both primary and secondary data, analyzing and

presenting data, identifying issues and needs and setting priorities among them. This general framework has been used successfully for work with large planning groups with diverse membership.<sup>1</sup> CMS approved the framework and it was shared with CCS program Stakeholders at the first stakeholder meeting. Key elements of the framework include the following processes and methods.

CCS CSHCN Stakeholder Process. There were two all day meetings of the Stakeholders for the purpose of identifying CCS CSHCN issues/needs and recruiting Stakeholders to participate in subcommittees during the needs assessment process and setting action priorities among the identified issue areas (see Appendix 1 for a list of Stakeholders). Prior to the first meeting, stakeholders were contacted by phone and asked for their input into what needs and issues they thought should be addressed in the assessment and the stakeholder process. The first meeting was held on September 9, 2009 and the second on May 10, 2010.

In addition to the two meetings, the Stakeholders participated in the following four subcommittees: Key Informant Interviews, Focus Groups, Surveys, and Data (including workgroups on program data, outcomes data, and other data sources). Between the first and second Stakeholder meetings, the subcommittees held a total of 13 conference call meetings and numerous e-mail follow-up communications as needed to review instruments and data (see Appendix 6 Needs Assessment Timeline for the schedule of meetings). Stakeholders were also invited to participate in a series of 8 webinars to provide them with additional data and information relevant to the needs assessment. Topics and presenters for the webinars included Melisasa Rowan, from Health Management and Associates (HMA) discussing HMA's report: "Considerations for Redesign of the California Children's Service Program"; Kathy Smith from UCLA presenting "The State of Children with Special Health Care Needs in California"; Tom Klitzner presenting "Benefits of Care Coordination for Children with Complex Disease: A Pilot Medical Home Project in a Resident Teaching Clinic;" and Clarissa Kripke presenting "Transition issues for youth with special health care needs" (a complete list of webinar topics and presenters is in Appendix 6). All the webinars were recorded and made available to Stakeholders via links on FHOP's website so Stakeholders who missed the initial presentation could watch it.

During the September 9 Stakeholders meeting, the group 1) received information about the CCS Title V 5-year needs assessment process, the stakeholder group's role and the process the group would participate in to select CCS Action Priorities from among identified issues/problems; 2) participated in the selection of the criteria that this group would use during its second meeting to determine the action priorities (weighting of the criteria was voted on after the meeting via an online survey); 3) was introduced to the iterative process FHOP would use to gather primary data from key informants, focus groups, and online surveys; 4) saw a slide show data on CSHCN in California and

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

nationally from the National Survey of Children with Special Health Care Needs; and 5) participated in a breakout group to assist CCS in the identification of issues/problems of concern to Stakeholders, relevant data, and potential data sources. (Please see Appendix 2 for the September Stakeholder meeting presentation).

During the May 10, 2010 meeting, the group 1) reviewed the criteria they had developed and weighted and the definitions and rating scales (see Appendix 3 for Prioritization Criteria), 2) saw a slide show presentation of highlights of data related the MCHB core outcome indicators for CSHCN and potential priorities to address key issues (see Appendix 18), 3) reviewed and modified the draft list of identified issue/need areas (see Appendix 30) 4) revised and agreed on a final issue/ objective list (see Appendix 31), and 5) received orientation to and used a method of rating and ranking the identified issues/objectives (see Appendix 4 for a copy of the Prioritization Scoring Tool).

To promote the success of this process, the State CMS Branch staff assured that representative Stakeholders were invited, provided the best and most appropriate data available (within CCS resources and the timeframe) to FHOP, were available to FHOP and Stakeholders to answer questions and articulated CCS program commitment to using the results where funding and legislation permit. The Stakeholders were asked to be open to the process, to provide their expertise during discussions, use data and expert knowledge to inform their decision-making and agree to honor the group outcome. FHOP's role was to provide the framework; collect, review and analyze data and prepare a data packet and presentation; provide opportunities for stakeholder input, and facilitate a rational, inclusive stakeholder process.

#### Problems/Issue Selection and Methods for Gathering Additional Data

FHOP used an iterative approach to collecting and analyzing data for the needs assessment process that included key informant interviews, focus groups, and online surveys of respondents from key constituent groups. The process of identifying and learning about issues/needs began with the review of available sources of information about the needs of CSHCN, e.g., the National Survey of CSHCN; a scan of relevant websites; interviews with CCS stakeholders; and review and clarification of information recorded during the CCS stakeholder meeting breakout groups. Key informant interviews and focus groups provided additional valuable opportunities to identify strengths of the CCS program and current issues and challenges, however, by their very nature, it is not appropriate to generalize from key informant interviews or focus groups. Therefore, web-based surveys were developed and completed by many more respondents to provide data that is more representative of the key constituent groups, including families, physicians, County CCS program and MTU administrators, children's hospitals, health plans, and durable medical equipment (DME) providers.

*Key Informant Interviews:* A Key Informant Subcommittee consisting of 10 members was convened by FHOP. The information initially gathered on issues/problems was shared with the Subcommittee and informed the development of the key informant interview guide (see Appendix 8) and selection of respondents to complete the key

informant interview. Participants selected to complete the key informant interview represented durable medical equipment providers, county administrators, county CCS programs, Medical Therapy Programs (MTPs), the Department of Developmental Services, specialty care physicians, primary care physicians, children's hospitals, health plans, special education, legislative staff from the state government and family advocates. A total of 16 key informant interviews were conducted with all interviews being conducted over the phone. See Appendix 9 for a summary of the information gathered from the key informant interviews.

*Focus Groups:* The focus group process was guided by a combination of subcommittee input, stakeholder coordination, and assessment of feasibility. Originally, it was planned for FHOP to conduct seven focus groups. Instead, FHOP conducted eight groups and community partners conducted two additional groups. FHOP convened a focus groups subcommittee, consisting of 14 members representing hospitals, health plans, families, family advocacy/support groups, and County CCS programs. The subcommittee began meeting in October to discuss the potential topics for and make-up of focus groups and to identify potential locations/contacts for the groups. The development and refinement of the focus group discussion guides created for each group category was informed by the findings from the key informant interviews and with input from the focus groups subcommittee (see Appendix 10 Focus Group Discussion Guides). The original list of potential groups was modified based on scheduling and on the availability of each group and FHOP staff.

Ten focus groups were conducted with a total of 107 participants (see Appendix 11 Focus Groups Data Summary). Three groups were held in Southern California: Families, Medical Therapy Program Administrators, and Specialty Care Providers. The family group was held at a County health department office on a rainy day. The County had recruited families through a mailing and phone calls, and they offered an incentive of refreshments and a gift card. Six women participated, including one Spanish-speaking woman who used a translator. The Medical Therapy Program Administrators group was held during a regular meeting of their group, and there were 15 participants representing 10 Counties. Participants took part in person and over the phone. A group with Specialty Care Providers was organized by one of the stakeholders. It was held early in the morning at a hospital. The stakeholder invited the participants and provided breakfast. 10 providers participated, including nurses and doctors specializing in Oncology, Gastroenterology, ICU, Neonatology, Endocrinology, HIV, and Psychology.

Seven groups were conducted in Northern California with Families, Transition Age Youth, CCS Administrators and Case Managers, CCS Medical Consultants, Medical Therapy Program Administrators, and administrators of Hospitals and Health Plans. The Subcommittee identified several potential organizations to contact about conducting a group with families. To gain additional perspective, a group with Spanish-speaking parents was held in a non-urban community. A family support agency recruited participants. Refreshments were provided and there was a translator. Eight mothers and fathers attended. A second family group was conducted by Family Voices and included 5 mothers and fathers. Transition-age youth were identified by the Subcommittee as an

important group to hear from. With the assistance of a community group and a County program, a group with five young adults was held at a local college where they were all enrolled. Participants received pizza and gift cards.

Also in northern California, a focus group was conducted with CCS Administrators and Case Managers during a regular meeting of their group, and there were 16 participants representing 10 counties. A focus group was conducted with CCS Medical Consultants during a regular meeting of their group, and there were 10 participants representing seven counties. A focus group with Medical Therapy Program Administrators was conducted on behalf of FHOP by the Children's Regional Integrated Services System (CRISS) included 20 participants representing 11 counties. Finally, a focus group with administrators from Hospitals and Health Plans across the state was held in Northern California. A stakeholder agency identified and invited representatives from children's hospitals and additional participants were identified from the larger Needs Assessment Stakeholder group. A hospital stakeholder set up a location at a community health center and refreshments were provided. There were 12 participants who attended in person and over the phone. Eight of the participants represented hospitals and four represented Health Plans.

*Online Surveys:* FHOP convened a Survey Subcommittee that included 7 members and using the data gathered in the key informant interviews and focus group, developed four web-based surveys administered to 1) physicians, 2) CCS and MTP administrators, children's hospitals and health plans, 3) families (available in both English and Spanish) who have a child covered by CCS, and 4) durable medical equipment providers. Topics covered in the online surveys include access to medical care and durable medical equipment, barriers to physician and DME providers participating in CCS and strategies to address the barriers, case management and the coordination of services, county variations in CCS services, conditions covered by CCS, transitioning of youth who age out of CCS, access to and satisfaction with the Medical Therapy Program and overall satisfaction with the CCS program. The family survey was available in Spanish and English and wording for most of the questions from this survey were taken from either the Family Voices Survey or the National Survey of Children with Special Health Care Needs. Findings from the survey have been incorporated into the data summary sheets for each MCHB core outcome measure that were prepared for Stakeholders (see Appendix 19).

Copies of the survey instruments are in Appendixes 12-16, and Appendix 29 contains a table comparing the number and percentage of respondents by county to the online surveys for CCS families, physicians, and county CCS and MTU program administrators and managers, hospitals, and health plans as well as the number and percentage of CCS cases by county.

The family surveys were online and open for completion for approximately one month. The English version of the family survey was completed by 331 respondents and the Spanish version was completed by 34 respondents. Responses from the English and Spanish versions were combined (see Appendix 25 for a summary of response). Family

Voices as well as many local CCS programs encouraged and assisted families in completing the online survey. While the use of a web-based survey for families can be a fairly quick and cost effective method of obtaining data, there are limitations to this approach. It can be very challenging for families without computer access to complete a survey, thus our survey sample is likely to over represent those CCS families that have a higher level of resources and education.

The Physician survey was online and open for completion for approximately three weeks. This survey was completed by 133 physicians; the vast majority of whom are currently CCS paneled physician specialists. Although efforts were made to get physicians throughout the state to complete the survey, efforts were more successful in Southern California with 68% of survey respondents indicating that their practice area includes Los Angeles. (See Appendix 26 for a report on responses to this survey.)

The survey for county CCS and MTU program administrators and managers, hospitals, and health plans was online for approximately two weeks and completed by 217 people. County CCS Program administrators/managers or Medical Consultants account for 41% of responses, 15% of the responses were from MTP administrators/managers, 10% were from Hospital administrators/managers/staffs, 8% were from Health Plan administrators/managers/staffs, and 27% were from others, including nurse case managers, public health nurses, and therapists. (See Appendix 27 for a report on responses to this survey.)

The survey for DME providers was online for approximately 3 weeks and completed by 14 DME providers. Between these 14 DME providers, the services area they provide equipment for cover the entire state of California. (See Appendix 28 for a report on the responses to this survey.)

#### Additional Data Sources

The major source for data on children with special health care needs in California is the National Survey of Children with Special Health Care Needs (NS-CSHCN). In addition, a request for data was submitted to CMS/CCS staff who then identified which data was available and provided the available data to FHOP. CMS Net and the paid claims data were the primary sources of CCS specific data. Several published UCLA reports as well as "Family Voices" were also sources of data, as was a survey on the availability of specialty care physicians and wait times conducted by the Children's Specialty Care Coalition. A description of the major data sources used is included in Appendix 17. The data was analyzed and summarized for stakeholder review. It was organized, using the six federal core CSHCN outcomes, into data summary sheets. A data packet was sent to the Stakeholders prior to the prioritization meeting, and an updated data packet was also provided at the meeting.

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

- Appendix 01. List of Stakeholders
- Appendix 02. CCS September Stakeholder Meeting Presentation with Data Slides
- Appendix 03. Prioritization Criteria
- Appendix 04. Prioritization Scoring Tool
- Appendix 05. CCS Issues and Topics to Address
- Appendix 06. Needs Assessment Timeline
- Appendix 07. Process Materials from Subcommittees
- Appendix 08. Key Informant Interview Guide
- Appendix 09. Key Informant Interviews Summary
- Appendix 10. Focus Group Discussion Guides
- Appendix 11. Focus Groups Data Summary
- Appendix 12. FHOP Survey of CCS Families – English Version
- Appendix 13. FHOP Survey of CCS Families – Spanish Version
- Appendix 14. FHOP Survey of Physicians
- Appendix 15. FHOP Survey of CCS Administrators, Hospitals, and Health Plans
- Appendix 16. FHOP Survey of DME Providers
- Appendix 17. Data Sources used in the CCS Needs Assessment 2010
- Appendix 18. CCS May Stakeholder Meeting Presentation
- Appendix 19. Issue briefs for MCHB Core Outcomes
- Appendix 20. CCS Expenditures and Highest Cost Conditions
- Appendix 21. CMS Net Data on Administrative Processing Times
- Appendix 22. CMS Net Data on Access to Special Care Centers
- Appendix 23. CMS Net Data on Primary Care Provider Address
- Appendix 24. Maps of CCS cases and Payer Types
- Appendix 25. Responses to FHOP Survey of CCS Families
- Appendix 26. Responses to FHOP Survey of Physicians
- Appendix 27. Responses to FHOP Survey of CCS Administrators, Hospitals and Health Plans
- Appendix 28. Responses to FHOP Survey of DME Providers
- Appendix 29. CCS Case Distribution and FHOP Survey Respondents
- Appendix 30. List of Potential Priorities

Appendix 31. Potential priorities and scores

Appendix 32. Top Priorities

## **Results of the CCS Needs Assessment and Prioritization Process**

Title V Needs Assessment Issues/Needs. An initial draft list of program priorities was developed by FHOP, in consultation with state staff, based on issues identified through the data collection and analyses processes discussed previously, as well as the list of program priorities developed during the 2005 needs assessment. This list was sent to Stakeholders prior to the May 10 Stakeholder meeting for feedback, and was then further modified and finalized by Stakeholders at the May 10 meeting following a presentation of data highlights from the needs assessment.

The final list of 13 objectives that the Stakeholders prioritized are:

1. Link families to information and support, build better connections to community based resources, such as family resource centers, and inform families about what CCS covers.
2. Increase family partnership in decision making and satisfaction with services through such things as: parent participation on advisory committees and parent liaisons, and financial support for participating in these activities. Increase family partnership in decision making in the MTP by collaborative goal setting and increase family participation in provision of therapy.
3. Conduct regular assessments of the level of parent/patient satisfaction as part of CCS outcomes.
4. Consider adjusting financial eligibility by indexing it to inflation.
5. Implement a standardized system of service delivery including consistent timeliness guidelines, access to special care center services, access to subspecialists and access to medical home services for ALL children with special health care needs regardless of insurance coverage or county of residence.
6. Develop and implement IT and other solutions to facilitate more rapid determinations of eligibility and authorizations and communication between CCS and providers –
  - a. Identify best practices
  - b. Support electronic referrals
  - c. Open physician portals to CCS staff
  - d. Use technology to collect data and monitor outcomes
  - e. Build on federal funding of electronic medical records
7. Increase access to adult health care services for transitioning CCS youth by

- a. Requiring CCS specialty care centers to incorporate adult specialist as part of their teams with written transition policies and procedures
  - b. Launching outreach effort and increase education (Fresno example) to recruit adult specialists for youth transitioning out of CCS
  - c. Working with medical providers to identify methods, materials and protocols to increase transition planning services provided to CCS youth
  - d. Exploring regulatory and policy options to increase services for transition age youth
  - e. Increase knowledge and provide education about community resources to adult psychiatrists about CP and other CCS developmental diagnoses.
8. CCS will work with appropriate partners to define and create and implement standards for Medical Homes for CCS children, including addressing the following issues:
    - a. Include certification (rural areas may need special consideration)
    - b. Authorization for CCS rates
    - c. Authorize and pay for care coordination services (in coordination with special care center not in lieu of SCC, addresses relationship with SCC)
    - d. Utilize previous work that was done on medical homes
    - e. Implement a system able to accurately reflect whether or not CCS children have medical homes
  9. Modify the CCS program, with appropriate funding, to cover the whole child.
  10. Expand the number of qualified providers of all types in the CCS program.
    - a. Simplify paperwork
    - b. Streamline and improve the process for paneling CCS providers, for example, by prioritizing the Medi-Cal registration for qualified CCS providers,
    - c. Ensure regular rate increases for CCS providers; preserve CCS physician rate enhancement; address problems with Fiscal Intermediary processing that results in no payment
    - d. Develop and implement strategies to facilitate reimbursing providers in a more timely fashion. (Correct problems at Fiscal Intermediary with processing claims for CCS services)
    - e. Look at appropriate use of physician extenders while maintaining CCS standards
    - f. Develop a system of electronic-consults for screening for referrals for certain conditions to reduce unnecessary referrals (subspecialists provide initial consult via telemedicine, electronic means)
  11. Preserve CCS role as state standard setter (including regionalization).
  12. Develop quality processes and structures to collect outcomes data.

13. Develop a system to implement and evaluate the quality of care provided by the CCS program with the goal of ensuring that each child gets the right care at the right time by the right providers.

Top Five Priority Objectives. The Stakeholders individually used the weighted criteria they had developed together and a tool provided by FHOP to rate each of the objectives. The individual rating scores were then summed resulting in an aggregate score used to rank the objectives. The resulting top five priorities follow. The complete ranking result is included in Appendix 31. Three priorities will be included as Title V MCAH priorities. CMS will address other priority objectives if resources and opportunities allow it to do so.

Rank	Priority Objectives
1	Modify the CCS program, with appropriate funding, to cover the whole child
2	Expand the number of qualified providers of all types in the CCS program
3	CCS will work with appropriate partners to define and create and implement standards for Medical Homes for CCS children
4	Develop and implement IT and other solutions to facilitate more rapid determinations of eligibility and authorizations and communication between CCS and providers
5	Develop a system to implement and evaluate the quality of care provided by the CCS program with the goal of ensuring that each child gets the right care at the right time by the right providers