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

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

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

May 23, 2005

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

Submitted by the
Family Health Outcomes Project
May 23, 2005

Background

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

As part of the broader planning process and the identification of the 3 priority CSHCN action areas, CMS has conducted an assessment of the needs and systems issues related to delivering services to children and families eligible for the CCS program. CCS is a statewide program that provides case management and health care services for children with certain physical limitations and chronic health conditions or diseases. CCS children are a subset of the nationally defined CSHCN. Other California programs, such as the California Department of Developmental Services, provide services to other CSHCN and may provide some services to CCS-eligible children as well. While CMS recognizes that Federal Title V guidance promotes assessment and planning for the broader CSHCN population, it is limited in its capacity to plan across programs by limited funds as well as California's fragmented Health and Human Services structure that separates health, mental health, developmental and social services and makes coordination among these services difficult. A recently funded HRSA initiative to develop a plan for an integrated system of care for the CSHCN population has been initiated to address these issues. The Champions for Progress grant will utilize the CCS Needs Assessment Stakeholders Group to develop an action plan to address the priority areas identified in this needs assessment process. The Stakeholders will develop a long-term strategic plan for serving CSHCN, identify resources in California to carry out the activities in the strategic plan, and develop a monitoring and evaluation strategy to assure continued improvement and progress toward achievement in the priority areas.

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

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

CCS may pay for or provide:

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

Assessment Framework and Process

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

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

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

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

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

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

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

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

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

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

Results of the CCS Needs Assessment and Prioritization Process

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

- CCS will address disparities in impact and outcomes by gender, age, geographic location and race/ethnicity issues when developing strategies and tracking priority objective outcomes.

- The CCS program shall ensure that children participating in CCS have access to and receive services from appropriately trained pediatric providers and shall develop and apply standards of care intended to lower morbidity and mortality rates among eligible children (This overarching principle was added at the Stakeholder meeting by consensus of the group).

The 15 objectives, organized under the federal Title V CSHCN core outcomes and presented to the Stakeholders were:

Medical Home

1. Increase the number of family-centered medical homes for CSHCN and the number/% of CCS children who have a designated medical home.

Family Involvement and Satisfaction

2. Increase family access to educational information and information about accessing CCS services, including availability of and access to services offered by health plans
3. Increase family partnership in decision making and satisfaction with services

Screening

4. Increase the % of infants born in California who receive newborn hearing screening services

Insurance Coverage and Access to Care

5. Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists
6. Increase access of CCS children to preventive health care services (primary care, well child care, immunizations, screening) as recommended by the AAP
7. Increase access to CCS services by increasing the financial eligibility limit ($40,000 limit)
8. Increase access to services for CCS youth, 17-21 years of age

Organization of Services

9. Facilitate the timely referral of foster care children with CCS eligible medical conditions to CCS services
10. Decrease the time between referral to CCS and receipt of CCS services.
11. Decrease the time between referral to the Medical Therapy Program and receipt of MTP services
12. Improve the uniform application of CCS authorization and referral policies across the state
13. Implement a system of standards of service delivery for all children with CCS medically eligible conditions regardless of payor source, including sharing of data.
14. Coordinate to develop and implement a system of timely referral between mental health and CCS systems for CCS eligible children.

Transition to Adulthood

15. Increase capacity of local CCS programs to develop and implement transition plans for adolescents transitioning to adult services

Top Five Priority Objectives. The Stakeholders individually used the weighted criteria they had developed together and a tool provided by FHOP to rate each of the objectives. The individual rating scores were then summed resulting in an aggregate score used to rank the objectives. The resulting top five priorities, discussed and agreed upon with the stakeholders follow. The complete ranking result is included in Appendix O. There are three objectives ranked as number four (4), as the aggregate scores were within a few points of each other. Three priorities will be included as Title V CSHCN priorities. CMS will address other priority objectives if resources and opportunities allow it to do so.

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

FHOP Recommendations for Data Development

While the effort to identify and examine data for CSHCN and CCS enrolled children was enthusiastically supported by both CMS program staff and stakeholders and a significant amount of data was compiled in a short time period, there were many issues identified pertaining to the need for data development. Problems encountered in conducting the needs assessment included limited data available specific to the CCS enrolled and eligible population, lack of standard definitions and consistency in the entry of data in CMS Net data fields, and lack of availability of data on the CCS population over time and across the multiple agencies serving these children. There were also inconsistencies between the Federal HRSA definition of CSHCN and California's narrower focus on the CCS subset of CSHCN, and in defining a medical home.

CMS is currently working on expanding and improving the CMS Net information system and asked FHOP to take advantage of this needs assessment effort to obtain recommendations regarding data collection. At the April 28, 2005 meeting, the stakeholders were asked to identify data issues and data development recommendations relevant to the priority objectives that were identified at the meeting. At the conclusion of the data development discussion, ***it was agreed that the first CCS data development step will be to develop a matrix of the data available for children covered by CMS/CCS.*** The notes from the meeting are included as Appendix P.

The following data development recommendations are based on the experiences and challenges of this year's needs assessment process:

CMS Net Data

Examine data and monitor service delivery disparities by race and age

- From the National Survey of CSHCN, we know that there are often disparities between different race/ethnic and age groups when it comes to having a medical home or having services organized in a way that makes them easy to access or use. It is important to examine CMS Net data by race/ethnic groups to identify, address, and monitor race/ethnic disparities in care for CCS children.
- During this assessment, data on services provided to children ages 16-21 years was not available, therefore, making it difficult to determine how well the needs of this age group are being met. Anecdotal data indicates a lack of services specific to this population group.

Regularly update diagnosis data

- It is difficult to get an accurate picture from the CMS NET data of the medical conditions affecting CSHCN because the diagnosis fields are not consistently updated when diagnoses are modified or when new conditions are identified. It would be useful if these fields could be updated to reflect changes in medical condition or a new diagnosis on a regular basis.

Implement AAP Medical Home definition and expand data collection fields

- To achieve the goal of all CSHCN having a medical home, it will be important to implement the AAP definition of medical home and train county personnel and those doing data entry for CMS Net to use the AAP definition. Separate fields in CMS Net for primary care physicians, specialists, and medical home also need to be created in recognition that having a medical home is not the same as having a primary care provider and that many physicians are not providing the level of care coordination necessary to meet the AAP definition of medical home. There should also be a mechanism for regularly updating medical home information.

Collect data on the percent of children participating in the CCS program receiving preventive services (e.g., immunization, well child exams)

- For this current needs assessment, there was no data available to evaluate the regularity at which children served by the CCS program are receiving regular preventive services.

State Performance Measures

Implement the American Association of Pediatrics (AAP) definition of Medical Home in State Performance Measures

- Implement the AAP definition of medical home and have State Performance Measure #5 reflect that definition. It would be useful to expand the number of items used to assess whether or not a child has a medical home, as done in the National CSHCN Survey.

Develop measures to monitor timely authorizations and eligibility determinations

- Consider creating a new performance measure based on to-be-established goals for times between determination of eligibility and authorization for services and from referral to determination of eligibility for services (i.e., eligibility determination shall be made within one week). Then, for future needs assessments, the data can be examined by County to see what percentage of CCS cases met this goal.

CCS-Paneled Physicians

Restructure and regularly update the database

- Restructure the database of CCS-paneled physicians to have counties in rows and different specialties in columns. Establish a mechanism to indicate whether or not each CCS-paneled physician is willing to take new clients. Regularly update the database and determine why there is so little consistency with the list of Board Certified Physicians in California.

Recommendations for Future Needs Assessments

Increase the California sample size for the National CSHCN Survey

- To better understand how well California is meeting the needs of all its CSHCN, it would be useful to have additional respondents in California to the National Survey of CSHCN so that data may be examined for specific subsets of the population (i.e., different race/ethnic groups) to determine how well their needs are being met.

Establish baseline data

- Utilize the data collected for the current needs assessment as baseline measures to be used for comparisons and analysis of trends in future needs assessments. When implementing new data elements/fields, establish a baseline as soon as possible.

Develop and monitor outcomes data

- Identify measurable outcomes to monitor the quality of services for CCS enrolled children.

Appendix A

Framework for Identifying and Prioritizing the Title V Health and Health Systems Access and Capacity Needs of CCS Eligible Children and their Families

Background:

Title V of the Social Security Act is a federal-state partnership that provides for programs to improve the health of all mothers and children, including children with special health care needs. California currently receives approximately $48 million in federal Title V funds that are jointly administered by Maternal and Child Health (MCH) Branch and the California Medical Services (CMS) Branch. Three population groups are served through Title V: pregnant women and infants less than 1 year of age; children ages 1 to 21 years; and children with special health care needs (CHSCN). The California Children's Services (CCS) program, California's CSHCN program, provides case management and payment of services for program-eligible CSHCN and promotes family-centered, community-based, coordinated care for these children.

CMS has established its CCS Needs Assessment Stakeholders Group, and contracted with Family Health Outcomes Project (FHOP) to assist in identifying needs related to CCS eligible children and their families and facilitating the process of problem identification and prioritization of those problems/needs. The process being used is an inclusive and systematic process of data presentation and analysis, identification of problems and setting priorities. This process has been used successfully for work with large planning groups with a diverse membership.[1]

Purposes of the Problem Identification and Prioritization Process

- Promote rational allocation of resources
- Create a systematic, fair and inclusive process
- Focus decision-making if there are many problems/issues identified
- Challenge participants to objectively and critically review data
- Document the process and results

The outcome of this process will be a 5 year needs assessment report and the selection of statewide performance measures to evaluate the results of our interventions. The report will be submitted in July 2005, as part of California's 2005-06 Title V Maternal and Child Health Block Grant application. CCS is committed to addressing the selected priorities, within our budgetary and legislative constraints.

Description of the Problem Identification and Prioritization Process

There will be two meetings of the CCS Needs Assessment Stakeholders Group for the purpose of setting priorities among identified needs. The first meeting is on January 27, 2005 and the second is planned for April or early May, 2005. In addition to the two meetings, the group members will review documents and participate in telephone or e-mail communications in the time period between the two large group meetings to review data, and provide input to assist in

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

identifying significant problems. After reviewing and analyzing data on selected indicators, identified problems/issue will be submitted to the group for consideration in the overall prioritization process. During the April 2005 meeting, the full group will review the list of identified problems, review data about these problems/issues, agree on a final problem list, and receive orientation to and use a method of rating and ranking the identified problems. The results will be presented, discussed and confirmed by the group. The table below shows the steps of the process.

	Steps in the CCS Needs Assessment Stakeholder Group Process for Prioritizing Problems/Needs
I.	Meeting January 27, 2005
	Introductions/Share information
	CMS / FHOP present overall objectives of the Needs Assessment, scope, background and the recommended process for prioritization
	FHOP facilitates process of selecting up to 7 criteria that will be used by the Group members to assist in the ranking/prioritization of problems - Develop criteria - Develop criteria rating scales - Determine weights for each criterion (how important each criterion is relative to the other criterion)
	FHOP reviews criteria for selecting indicators with the group, receives input, and orients group to how data will be presented for their review.
	FHOP asks participants (key informants) to divide into groups. Groups will discuss how the core outcomes and issues identified through FHOP's indicator research, brief interviews with Stakeholders and e-mail survey can be assessed (e.g., suggests possible indicators, instruments, data sources). Their input is recorded and shared with the larger group, and this will be incorporated into the identification of the final list of indicators.
II.	Work is done by the Group in the months between meetings (can be accomplished by e-mail, phone or smaller group meetings):
	Review and input by Group Members of data collected and analyzed by FHOP/CMS Review and input by Group members of problem/issue list developed based on data
III	Meeting in April or early May, 2005:
	Group members agree on the final problem/issue list to be prioritized
	The Group sets priorities among the final problem list. These priorities will be the focus of the Title V, 5 Year Action Plan. • Group Participants use the agreed upon weighted criteria to score problems • Sum participants' scores / rank problems • Discuss and confirm results

Stakeholders for CMS Title V Needs Assessment

Appendix B

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Monterey County CCS	Dyan Apostolos	1441 Constitution Blvd.	Bldg 400, Suite 200	Salinas	93906-3195	831-755-5508
Santa Clara County CCS	Heidi Hudson	720 Empey Way		San Jose	95128-4705	408-793-6266

Updated 3/21/05

Stakeholders for CMS Title V Needs Assessment

Appendix B

Santa Barbara County CCS	Elizabeth Kasehagen	1111 Chapala Street, Suite 200		San.Barbara	93101	805-681-5133
Family Voices of California	Juno Duenas	2601 Mission Street, Suite 606		SanFran.	94110	415-282-7494
CRISS	Laurie Soman	725 Welch Road, MC 5524		Palo Alto	94304	510-428-3783
Parent Links	Sandy Harvey	4708 Roseville Road, Suite 111		N. Highlands	95660	916-349-7500
California Medical Home Project	Kathryn Smith	5000 W. Sunset Blvd.	Suite 510	Los Angeles	90027	323-913-4400
Department of Health Services	Linda Rudolph, M.D.	Medi-Cal Managed Care Division	P.O. Box 997413, MS 44	Sacramento	95899-7413	916-449-5149
Designee	Penny Horper					916.449.5161
MRMIB	Lesley Cummings	P.O. Box 2769		Sacramento	95812-2769	916-324-4695
Designee for Process	Valetta Lewis					
Medically Vulnerable Infant Prog.	Arlene Cullum	5151 F Street, 2 South		Sacramento	95819-3295	916-733-8442
Early Hearing Detection and Inter	Shirley Russ, MBChB	Cedars-Sinai Medical Center	8700 Beverly Blvd, Rm 1	Los Angeles	90048	310-544-6289
CHEAC (County Administrators)	Judith Reigel	1127 11th Street, Suite 309		Sacramento	95814	916-327-7540
Designee	Iantha Thompson	Medical Care Services	260 East 15th Street	Merced	95340	209-381-1227
MCAH Directors	Troy Jacobs, M.D.	P.O. Box 6099		Santa Ana	92706-6099	714-834-8411
Protection and Advocacy	Marilyn Holle	3580 Wilshire Blvd, Suite 902		Los Angeles	90010-2512	213-427-8747
Designee	Dale Mentink	100 Howe Avenue, Suite 235N		Sacramento	95825	916-488-9950
Parents						
	Mara McGrath	725 Welch Road, MC 5524		Palo Alto	94304	510-540-8293
	Diana Vergil-Bolling					
	Yolanda Parie-Jones	43320 Gadsden Ave, Apt. 225		Lancaster	93534	661-940-4577
	Sandra West					916-361-7861(h)
(alternate)	Debra Capers	31814 3rd Street		Acton	93510	61-269-0472(h)
MCAH Branch Staff (mailings)						
	Shabbir Ahmad, DVM	1615 Capitol Ave, MS 8304	P.O. Box 997420	Sacramento	95899-7420	916-650-0319
	Gretchen Caspary	1615 Capitol Ave, MS 8304	P.O. Box 997420	Sacramento	95899-7420	916-650-0333
	Mike Curtis	1615 Capitol Ave, MS 8304	P.O. Box 997420	Sacramento	95899-7420	916-650-0320

Updated 3/21/05

Title V CSHCN Stakeholder Telephone Questionnaire

I am calling from The Family Health Outcomes Project. We are assisting CMS in its Title V assessment process……….: Thank you for agreeing to participate or I am calling to follow up on Dr. Dalsey's e-mail to you. provide information as needed

The process is:

Any questions?

If they have not previously committed to join the planning group, ask now if they are willing. If not, can they suggest someone to represent them/their organization/interest group?

If they can commit, but can't come to the meeting in January, ask availability for the following week. Availability ____________________________________

I'd like to ask you a few questions

1. What is your role/interest in planning for children with special health care needs?

2. Are there particular indicators or issues you think should be assessed? Do you have suggestions about data to look at? Prompt:

3. Have you been part of a previous CMS assessment process? If so how do you think the process went? The outcome?

4. Do you have suggestions regarding the current process?

5. Is there anything you would like to add?

CSHCN Needs Assessment Indicator Selection Criteria

The Family Health Outcomes Project (FHOP), in consultation with the CMS Staff, will be selecting a finite number of indicators for which data can be collected, analyzed and presented to the Stakeholders group for prioritization and subsequently included in the Children with Special Health Care Needs (CSHCN) portion of the Maternal Child and Adolescent (MCAH) Assessment and 5 Year Plan. These indicators will be defined as population-based measures of either the entire population or a defined population subgroup that may assess general health status, a particular health condition, health access, or health system effectiveness and are measured at a specified point in time. Where possible they will be compared to a standard or benchmark, such as the national CSHCN outcome measures or Healthy People 2010 goals. The following criteria will be used by FHOP to identify the final set of indicators:

The indicator is a valid measure of access to or utilization of CCS services

Indicator data is easily available and is either representative of the general population, or taken from a representative sample of CSHCN, or the CCS eligible or CSN population in question

The indicator is relevant and informative to stakeholders. (“relevant” and “informative” means that the stakeholders can use the indicator to monitor services and outcomes for CSHCN and their families)

The indicator data provides information on conditions or service limitations that lead to functional constraints among the CCS-eligible and/or CCS served population

The indicator reveals disparities in service access and/or delivery to CCS-eligible children

The indicator relates to one of the core national or State CSHCN performance outcomes

Data Request Submitted to Children's Medical Services

General Comments
For all data requested, the data should, as possible, be further broken down by urban/rural, and race/ethnicity. Data from past years would also be useful to assist in identifying trends.

Screening:

Hearing

Newborn Hearing Screening Program Data. As many years as possible in order to look at trends. Data in spreadsheets would be most useful.

Is there any data available for screening on infants born outside of certified hospitals? Interested in assessing births in the state which occur in non CCS-certified hospitals.

Genetic Diseases

1. Genetic Disease Branch data for all children screened
2. How many children screened by the GDB that have CCS eligible conditions are referred to CCS?
3. How many CCS eligible children who are screened by the GDB get referred to CCS?
4. Time frames for the following:
    a. Time between screening and referral to GDB Specialty Center
    b. Time between receipt of GDB referral by Specialty Center to referral of medically eligible children to CCS
    c. Time between CCS receipt of referral and CCS authorization to treat
    d. Time from authorization to treat and first appointment

Developmental Screening

From Medi-Cal billing data:
1. How many developmental screenings were paid for this year by type of screening by provider
2. Of those, how many children were screened and how many screenings did each child have?

What is the Medi-Cal policy for developmental screening? What kinds of screening do they pay for and how often?

Medical Home

1. From the CMSnet, number of CCS children with a medical home (and the total number of CCS children) and the definition of medical home that is used to make that determination. If possible, we would also like to get breakdowns for rural vs. urban and race/ethnicity

2. Performance Measure 1 submitted to the state by the counties, including the number of CCS children by county that have a medical home (and the total number of CCS children by county) and the definition of medical home that is used to make that determination

Access to Care

1. Access of CCS children to preventive and well child care in Medi-Cal managed care organizations, both where CCS is carved in and where it is carved out
    a. % of CCS eligible children who had the recommended periodic CHDP exams and screening
    b. % of CCS eligible children up to date for immunizations
    c. Average waiting time for primary care appt.

2. Timeliness of initial care
    a. Time between referral data and when CCS determines eligibility
    b. Time from determination of eligibility to authorization
    c. Time from authorization to first appointment for care

3. Timeliness of referrals
    a. Time between referral for care within the system and when services are authorized and time between authorization and services received
    b. Time between referral for care to programs/services outside the systems and when services are received

4. Fragmentation of services
    a. Average number of providers (primary and specialty) of care by type and by site per CCS child

5. Duplication of Services
    a. For DME, look at claims and billing data to see if children are getting the same equipment from multiple providers

6. Adequate supply of providers certified for the CCS panel
    a. Time from provider application to be on the panel and approval by state
    b. Number of board certified pediatricians per county
    c. Number of board certified pediatricians on CCS panel by county
    d. Number of board certified MDs in essential medical specialties by county
    e. Number and % board certified MDs in essential medical specialties that are certified to provide services to CCS eligible children by county

7. CCS Children in foster care
    a. # and % of CCS children in foster care
    b. # and % of foster Care children eligible for CCS services?
    c. # and % of CCS children in foster care that receive CCS services

8. % of CCS children that received dental care last year

9. Cultural Competency
    a. Is there any information available on cultural competency? (i.e., language capabilities of providers, availability of translators, cultural competency trainings)

Access to Specialty Care

1. Timeliness of referrals
    a. Time between referral to a Specialty Care Center and when services are received for CCS children who are NOT registered with a Specialty Care Center
    b. Time between Specialty Care request for authorization for care and when CCS approves the authorization

2. Timeliness of specialist care within Specialty Care Center
    a. # of CCS children on the waiting list for specialty care
    b. Time between referral and eligibility determination
    c. Time between eligibility determination and authorization
    d. Time between authorization and service delivery

3. Specialty Care Centers
    a. % of CCS children with a Specialty Care diagnosis who are registered with a Specialty Care Center – by county
    b. % of CCS children registered with a Specialty Care center who have had an annual or semi-annual visit

4. Access for CCS eligible to needed medical specialty services (outside of Specialty Care Center)
    a. Waiting time for appointments to see CCS panel MDs
    b. Time between referral to eligibility determination - eligibility determination to authorization – authorization to service

5. Adequacy of Medical Therapy Programs
    a. Waiting time for evaluation by MTU after referral
    b. # and % of children receiving MTU services and # and % referred to vendor for services
    c. Number of appeals of MTU decisions by county; results of appeals

6. Tertiary care facilities
    a. Number of tertiary care and trauma centers in California by county and age ranges served and number of CCS approved tertiary care and trauma centers by county and the age ranges served, percent of tertiary care and trauma centers that are CCS certified
    b. Number and % of CCS approved specialty hospital centers (e.g. NICU, PICU, Burn, Rehab, etc) and tertiary and trauma centers and the age ranges served

  c. Number and % of tertiary care and trauma centers that opt out due to refusal to meet standards

7. Mental health care
   a. # and % of CCS children referred for mental health counseling
   b. % of children by county in MHS referred and accepted to CCS program

8. Access to Orthodontic care
   a. Average time until assignment

9. Access to ancillary services and equipment
   a. Waiting time for in-home support services (i.e., nutrition care, nursing)
   b. Waiting time for recommended equipment

QUESTION: Have counties had problems finding care for adolescents in a CCS approved facility?

Transition to Adulthood

a. # of transition clinics county and age groups served by the clinics
b. Average length of time between a request for appointment and the actual appointment
c. % of CCS transitioning children with an adult PCP identified
d. % CCS children with a transferable GHPP eligible condition that make the transition to GHPP
e. % of children that transition out of CCS coverage that obtain other insurance coverage by payer type
f. % of transitioning children that have vocational plans collaboratively developed by DDS, Department of Vocational Rehabilitation and CCS as applicable
g. % of transitioning children served by MTU/CCS that have a discharge plan

Prevalence and Outcomes

a. # of CCS children by diagnosis
b. # of children born with a CCS eligible condition
c. % of children with a CCS eligible birth defect that are enrolled in CCS
d. % of CCS children with a birth defect by type of services received
e. Severity of cases: % of CCS conditions that require high intensity treatment vs. lower intensity treatments (definition?)
f. Services received by type of service
g. Services authorized/paid by type (# paid by Medi-Cal, # Healthy Families, paid by CCS, paid by others??)
h. % of CCS children with up-to-date immunizations

Family Roles

a. The degree to which the CMS program demonstrates family participation (data from Performance Measure 4)

Organization of Services – Collaborative relationships among local program

a. The degree to which local CCS, CHDP, and HCPCFC programs maintain collaborative relationships internally and externally (data from Performance Measure 1)

Data Sources used in the CCS Needs Assessment

The National Survey of Children with Special Health Care Needs (NS-CSHCN)

The National Survey of Children with Special Health Care Needs, sponsored by the Maternal and Child Health Bureau, provides national and state-level information about the numbers of children and youth, 0 - 17 yrs old, in the population with special health care needs. In addition, the survey asked 750 families of CYSHCN (Children and Youth with Special Health Care Needs) in each state about:

- Access to health care and unmet needs
- CYSHCN health and functioning
- Health care quality and satisfaction
- Impact of child's health on family activities, finances, and employment
- Adequacy of health insurance to cover needed services

In each state, telephone interviewers screened at least 3,000 households with children to identify CYSHCN. In-depth interviews were conducted with the parents of approximately 750 CYSHCN per state. Although 759 interviews were completed in California, for some questions on the survey, the sample size was much smaller and severely limited the statistical power needed for detecting significant differences when making comparisons between subgroups.

The screening questions used in the survey to identify children with special health care needs included five major components: In addition to the existence of a condition that has lasted or is expected to last at least one year, one of the following: the use of or need for prescription medication; the use of or need for more medical care, mental health services, or education services than other children of the same age; the use of or need for treatment or counseling for an emotional, developmental or behavioral problem; a limitation in the child’s ability to do the things most children of the same age do; or the use of or need for special therapy, such as physical, occupational, or speech therapy. (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2001*. Rockville, Maryland: U.S. Department of Health and Human Services, 2004.)

Data on selected indicators is presented comparing California with the nation. (Source: http://www.cshcndata.org/DesktopDefault.aspx)

CMS Net Data

CMS Net is a full-scope case management system for California Children's Services (CCS). The State’s CMS Net resides at the Health and Human Services Data Center (HHSDC). Data from CMS Net are active cases through 3/15/05. Los Angeles, Orange County and Sacramento, home to approximately 45% of the State’s CCS children, do not yet have data in the CMS Net system, but plans are underway to include these counties.

Orange, Los Angeles, and Sacramento County also provided data, similar to that provided from CMS Net, from their databases for their counties.

State Performance Measures Data

Reporting on the CMS performance measures is a Scope of Work requirement. Starting in Fiscal Year (FY) 2002-03, CMS local programs have been using tracking systems and other data collection methods to measure their work with communities, provider networks, and target populations. Data presented are from fiscal year 2003-2004.

Other Data Sources:

Inkelas M, Ahn P, Larson K. 2003. *Experiences with health care for California's children with special health care needs*. Los Angeles, CA: UCLA Center for Healthier Children,

This chartbook provides California data on access to care for CSHCN, comparing care of children in Medi-Cal to care received by other children in California and to other State Medicaid programs. It presents data from the National Survey of Children with Special Health Care Needs (NS-CSHCN) and the California Health Interview Survey (CHIS). Both surveys are based on parent report in telephone interviews, as reported in 2001. Figures, tables, and text present California and national averages; statistical comparisons are between California and all other states excluding California. Comparisons made in the report text between CSHCN in Medi-Cal and other CSHCN are statistically significant ($p<0.05$) unless otherwise indicated. Due to larger sample size nationally (more than 36,000 children) than in California (750 children), subgroup comparisons often detect statistical differences nationally but not in California.

Wells, N., Doksum, T., Martin, L., Cooper, J. 2000 *What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants.* Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

"Your Voice Counts!!" was conducted in 1998 by Family Voices and Abt Associates Inc., to assess the health care experiences of children with special health care needs and their parents. This survey was distributed to a random sample of 7,100 families from CCS mailing lists and 6 California family resource organizations. 954 Families returned the survey, 153 of which were in Spanish. In order to get a sample that was more geographically representative of California, respondents came from Los Angeles, San Diego, Fresno, Sacramento, and two rural areas in the state. Family Voices states that the findings from the survey should be interpreted with caution for two reasons – the low response rate (13%) means that the survey may not be representative of all children from the CCS and family organizations in the sample, and the children from participating organizations may not represent all children with special health care needs in California.

Halfon N., Inkelas M., Flint R., Shoaf K., Zepeda A., Franke T. 2002. *Assessment of factors influencing the adequacy of health care services to children in foster care. UCLA Center for Healthier Children, Families and Communities.*

This study examines the "readiness" of state and local child welfare, child health, mental health, and Medicaid agencies to systematically meet the needs of children in foster care. Gaps between best practices developed by AAP and the Child Welfare League of America (CWLA) and current agency performance are examined, and agency policies and administrative procedures are evaluated for their ability to achieve Adoption and Safe Families Act of 1997 (ASFA) objectives and improve children's well-being. The study evaluates performance on basic standards, and collaboration and performance monitoring activities, and provides a foundation on which new policies can be developed to address problems with performance and other challenges faced by agencies.

Data Sheets Provided to CCS Stakeholder in Preparation for Priority-Setting Meeting

Introduction to Packet

Included for stakeholder review are the following materials:

- The April 28 Stakeholder Meeting Agenda
- The Criteria selected and agreed upon by the Stakeholders at the January 27, 2005 meeting. A 5-point rating scale has been developed for each of the criteria. This rating sheet will be used by each stakeholder during the meeting to assist in rating the identified CCS issues/goals.
- Data which has been organized according to the six National CSHCN outcome areas. CSHCN prevalence data is also included.

Overview Information:

Based on 2001 data (data extracted from Inkelas M., Ahn P., Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities):

- About 10% of children in California have special health care needs
- About 7.4% of the children enrolled in Medi-Cal and 3.5% of the children enrolled in Healthy Families in 2001 were children with special health care needs
- Most children in CCS have Medi-Cal coverage while a small number have Healthy Families, private coverage, or lack insurance coverage. **Nearly 80% Of CCS children are Medi-Cal beneficiaries**
- About 21% of CSHCN in CA were covered by Medi-Cal, 2% were covered by Healthy Families
- About 15% of California's CSHCN receive specialty care through the CCS program (about 150,000 children annually)

Definitions useful for your review of the data:

<u>The federal definition of Children With Special Health Care Needs (CSHCN</u>**)** defines CSHCN as "children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. This definition was developed by the Maternal and Child Health Bureau (MCHB) …….It is purposefully broad and inclusive, recognizing that children with many different diagnoses and conditions have some important, common needs. MCHB's goal in developing this definition was to help States carry out the mission given them under Title V of the Social Security Act to develop and implement comprehensive, community-based systems to serve children and families with special needs. This mission has been affirmed in the President's New Freedom Initiative and in the Surgeon General's report *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental*

Retardation. The definition was published in Pediatrics in July 1998 and has been accepted and used extensively in the child health arena. However, because this definition is so broad, it is not appropriate for every purpose or program." (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.) Much of the data included for review is data about this larger group.

California Children's Services (CCS) program, California's CSHCN program, provides case management and payment of services for program-eligible CSHCN and promotes family-centered, community-based, coordinated care for these children. CCS can authorize and pay for specific medical services and equipment provided by CCS-approved specialists. The California Department of Health Services manages the CCS program. Larger counties operate their own CCS programs, while smaller counties share the operation of their program with state CCS regional offices in Sacramento, San Francisco, and Los Angeles. *You are participating, as a Stakeholder, in the CCS Program's Title V needs assessment and priority-setting process.*

CCS-eligible CSHCN are children who are under 21 years old, have or may *have a medical condition* that is covered by CCS (such as cancer, spina bifida, sickle cell disease, cerebral palsy, metabolic problems and congenital defects); are a resident of California; and have a family income of less than $40,000 as reported as the adjusted gross income on the state tax form or the out-of-pocket medical expenses for a child who qualifies are expected to be more than 20 percent of family income; or the child has Healthy Families coverage. CCS serves a subset of the nationally defined CSHCN. Other California Programs, such as the California Department of Developmental Services, provide services to other CSHCN and may provide some services to CCS-eligible children as well.

There is limited data available specific to the CCS-eligible population. The data included is primarily from CMSNet, the Title V State Performance Reports and Paid Claims Data.

Organization of the Data:

In general, the data is organized using the six National Core CSHCN outcomes. These desired outcomes can serve as indicator categories toward creating a system of care for CSHCN. In addition, prevalence and expenditure data is provided:

- Screening. All children will be screened early and continuously for special health care needs.
- Family Centered Care and Satisfaction. Families of CSHCN will participate in decision making at all levels and will be satisfied with the services they receive.
- Coordinated Care—Access to Care and Medical Home. All CSHCN will receive coordinated, ongoing, comprehensive care in a medical home.
- Health Insurance Coverage. All CSHCN will be adequately insured for the services they need.

- Organization of Services. Services for CSHCN will be organized so families can use them easily.
- Transition. All youth with special health care needs will receive services needed to support the transition to adulthood (Information on transition indicators is limited and we are still in the process of obtaining it, some data will be presented at the meeting)
- CSHCN Prevalence
- CCS Expenditure Data

Description of primary data sources:

The National Survey of Children with Special Health Care Needs (NS-CSHCN).
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The following data sheets are included:

	Part
Prevalence and Diagnosis Data	A
Medical Home and Access to Care Data	B
Insurance Coverage Data	C
Screening Data	D
Organization of Services Data	E
Family Center Care, Participation, and Satisfaction	F
Transition to Adulthood Data	G
CCS Selected Expenditures Data	H

Children with Special Health Care Needs
Prevalence Information

Prevalence of CSHCN Population

From the National Survey of CSHCN 2001[i]

- 10.3% of CA children were identified as having special health care needs vs. 12.8% Nationwide. This is a statistically significant difference ($p < .05$).

From the "Experiences with health care for California's children with special health care needs"[ii]

- About 7.4% of the children enrolled in Medi-Cal and 3.5% of the children enrolled in Healthy Families in 2001 were children with special health care needs.
- About 15% of California's CSHCN receive specialty care through the CCS program. (150,000 annually).

Prevalence of CSHCN Population by Race/Ethnicity

From the National Survey of CSHCN 2001

	Hispanic	White	Black	Multiracial	Other
California %:	7.6	13.7	15.7	10.2	6.9
Sample Size:	339	472	75	30	47
Est. Pop.:	313,648	462,157	95,424	29,636	66,118
Nationwide %:	8.5	14.2	13.0	15.1	7.8
Sample Size:	4,320	35,950	5,036	1,581	1,658
Est. Pop.:	1,077,970	6,401,832	1,133,566	275,998	239,361

- There are no significant differences between CA and the nation in terms of prevalence of CSHCN by race/ethnicity

Race/Ethnicity of CSHCN Population in CA and Nationally

From the National Survey of CSHCN 2001

	Hispanic	White	Black	Multiracial	Other
California %:	32.3*	47.7*	9.8*	3.1	6.8
Nationwide %:	11.5	68.4	14.2	2.9	2.6

- Consistent with the racial/ethnic composition of CA compared to the nation, significantly more of the CSHCN in CA are Hispanic, and significantly fewer are white or black.

* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Prevalence of CSHCN Population by age

From the National Survey of CSHCN 2001

	0 – 3 yrs.	4 – 7 yrs.	8 – 11 yrs.	12 – 14 yrs.	15 – 17 yrs.
California %:	4.3*	8.4*	12.5*	15.0	11.8
Nationwide %:	6.5	11.4	15.5	16.2	14.7

- Compared to the nation, significantly fewer children ages 0 to 3, 4 to 7, and 8 to 11 years old are identified as CSHCN

Prevalence of CSHCN Population by Household Income

From the National Survey of CSHCN 2001

	0 - 99% FPL	100 - 199% FPL	200 - 399% FPL	400% FPL or greater
California %:	7.5*^	9.7*	11.0	13.0^
Nationwide %:	13.6	13.6	12.8	13.6

Note: FLP = Federal Poverty Level

- The poorest children in CA (199% of the FPL or less) are significantly less likely than the poorest children in the nation to be identified as CSHCN
- Within California, children in households earning 99% or less of the FPL are significantly less likely to be identified as a CSHCN than children in households earning 400% or greater than the FPL

Prevalence of CSHCN by Criteria for Qualifying as a CSHCN

From the National Survey of CSHCN 2001

- In CA, significantly fewer children qualify as CSHCN based on use of prescription medication screening criteria (6.7% in CA vs. 9.5% nationally)
- In CA, significantly fewer children qualify as CSHCN based on the elevated need/use of medical, mental health or educational services criteria (4.9% in CA vs. 5.8% nationally)
- CA has similar rates of children that qualify as CSHCN based on the functional limitation screening criteria (2.2% in CA vs. 2.7% nationally)
- CA has similar rates of children that qualify as CSHCN based on the need/use of specialized therapies screening criteria (1.7% in CA vs. 2.2% nationally)
- CA has similar rates of children that qualify as CSHCN based on the emotional, developmental or behavioral conditions screening criteria (3.4% vs. 3.7%)

Prevalence of CSHCN by Specific Types of Special Health Needs

From the National Survey of CSHCN 2001

- 2.2% of CA children have conditions that result in functional limitations and does not differ significantly from the national rate of 2.7%
- Significantly fewer CA children (3.1%) have a CSCHN condition managed by prescription medication than the national rate of 4.7%

* Difference between CA and Nation significant at $p < .05$
** Differences within the Nation significant at $p < .05$
^ Difference within the State significant at $p < .05$

- CA and the nation of have similar rates of children whose CSHCN condition requires above routine use of medical, mental health or other services (2.7% for CA, 2.3% nationally)
- CA has significantly fewer children whose CSHCN condition required prescription medicine and above routine use of services
- CA has significantly fewer CSHCN with no qualifying emotional, behavioral or developmental issues (6.9%) than the national rate of 9.1%

From the "Your Voice Counts!!" Survey[iii]:

- Most children were affected by more than one condition. 37% had two or three conditions, 53% had four or more conditions. Fourteen percent of the children were technology dependent or assisted, needed things such as a feeding tube, shunt, or ventilator, etc.

Impact of Health Conditions

From the National Survey of CSHCN 2001

- 36.2% of CSHCN in CA never have their daily activities limited or affected by their health condition, 39.9% have their daily activities moderately affected and 24% have them consistently affected. Nationally, rates are very similar
- 49.8% of CSHCN in CA missed 0 – 3 days of school due to illness, 18.8% missed 4 to 6 days, 15.1% missed 7 to 10 days, and 16.2% missed 11or more days

From the "Your Voice Counts!!" Survey[iv]:

- 97% of the children needed prescription medications; 85% needed therapy services, 43% needed durable medical equipment; 21% needed home health services, and 11% needed mental health services.

Diagnoses among CCS clients

From CMS Net Active Cases through 3/15/03

Primary Diagnosis for CCS Cases* Active through 3/15/05

Diagnosis	N	%
Undiagnosed Condition	325	0.3%
Infectious Diseases	495	0.5%
Neoplasms	3868	4.2%
Endocrine, Nutritional, Metobalic Disease, Immun. Disorder	6583	7.1%
Disease of Blood and Blood-Forming organs	2029	2.2%
Mental Disorders and Mental Retardation	140	0.2%
Diseases of the Nervous System	12785	13.7%
Diseases of the Eye	3673	3.9%
Diseases of the Ear and Mastoid	8489	9.1%
Diseases of the Circulatory System	2721	2.9%
Diseases of the Respitory System	1257	1.4%
Diseases of the Digestive System	4824	5.2%
Diseases of the Genitourinary System	2704	2.9%
ICD.9 Codes 630-679	46	0.0%
Diseases of Skin and Subcutaneous Tissues	266	0.3%
Diseases of Musculoskeletal System and Connective Tissue	4016	4.3%
Congenital Anomalies	21291	22.9%
Perinatal Morbidity and Mortality	6587	7.1%
ICD.9 Codes 780-799	2657	2.9%
Accidents, Poisonings, Violence, and Immunization Reactions	8283	8.9%
Total	93039	100.0%

Source: CMS Net - Data are for current Active cases effective 3/31/05

*Data does not include Los Angeles, Orange and Sacramento Counties

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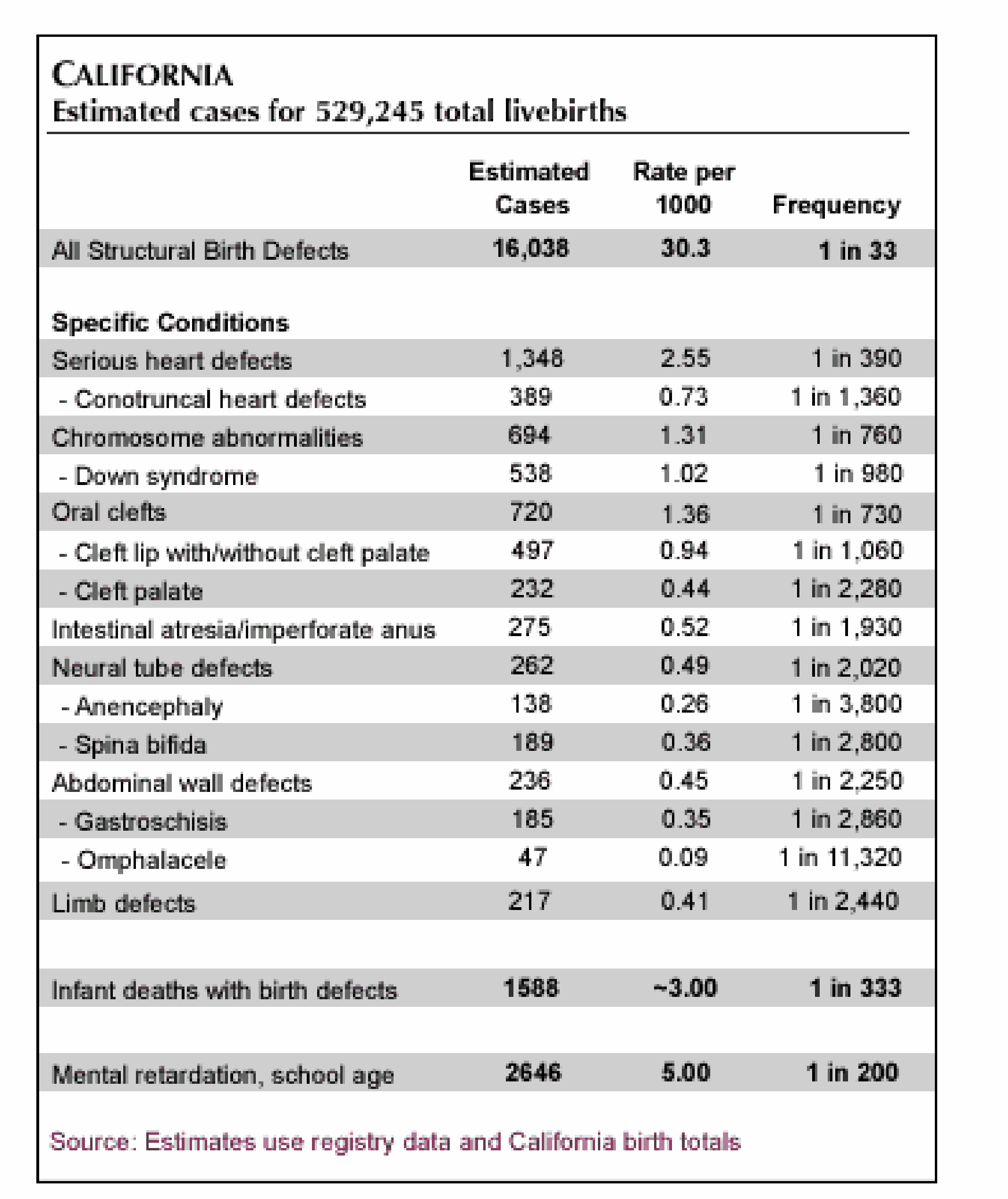
* Difference between CA and Nation significant at *p* < .05
** Differences within the Nation significant at *p* < .05
^ Difference within the State significant at *p* < .05

Birth Defects Data:



CALIFORNIA
Estimated cases for 529,245 total livebirths

	Estimated Cases	Rate per 1000	Frequency
All Structural Birth Defects	**16,038**	**30.3**	**1 in 33**
Specific Conditions			
Serious heart defects	1,348	2.55	1 in 390
- Conotruncal heart defects	389	0.73	1 in 1,360
Chromosome abnormalities	694	1.31	1 in 760
- Down syndrome	538	1.02	1 in 980
Oral clefts	720	1.36	1 in 730
- Cleft lip with/without cleft palate	497	0.94	1 in 1,060
- Cleft palate	232	0.44	1 in 2,280
Intestinal atresia/imperforate anus	275	0.52	1 in 1,930
Neural tube defects	262	0.49	1 in 2,020
- Anencephaly	138	0.26	1 in 3,800
- Spina bifida	189	0.36	1 in 2,800
Abdominal wall defects	236	0.45	1 in 2,250
- Gastroschisis	185	0.35	1 in 2,860
- Omphalacele	47	0.09	1 in 11,320
Limb defects	217	0.41	1 in 2,440
Infant deaths with birth defects	**1588**	**~3.00**	**1 in 333**
Mental retardation, school age	**2646**	**5.00**	**1 in 200**

Source: Estimates use registry data and California birth totals

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[i] National Survey of CSHCN, 2001

[ii] Inkelas M, Ahn P, Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

[iii] Wells, N., Doksum, T., Martin, L., Cooper, J. (2000) What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

[iv] Wells, N., Doksum, T., Martin, L., Cooper, J. (2000) What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

Children with Special Health Care Needs
Medical Home and Access to Care

Medical Home

From the National CSHCN Survey[i]:

The National Survey of CSHCN implements the America Academy of Pediatrics definition of a medical home – medical care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective and delivered or directed by a well-trained primary care or specialty physician who helps to manage and facilitate essentially all aspects of care for the child. The medical home variable is derived from responses to questions about having a usual source of care, having a personal doctor or nurse, having no problems receiving referrals when needed, and family centered care.

- 55% of CSHCN in California are lacking a medical home. Significantly more CSHCN in California are lacking a medical home when compared to the National rate of 47.3% of CSHCN without a medical home
- Only about half of children surveyed had a case manager, most of whom were employed by the regional centers (35%) or CCS (28%). Only 3% of the case managers were employed by a health insurance plan.

From the “Experiences with health care for California’s children with special health care needs” 2003[ii]

- Fewer CSHCN in Medi-Cal than in other state Medicaid programs had a usual source of health care, with much greater use of community and hospital clinics than doctor’s offices a month those with a usual source. Fewer in California than other states had a personal doctor or nurse.

From CMS Net[iii]

In CMS Net, having a medical home is defined as having a primary care provider.

CA Counties vary widely in their percentages of CCS children with a medical home.
- in 35% of counties, 80% or more of their CCS children have medical homes
- in 24% of counties, between 60 to 79% of their CCS children have medical homes
- in 22% of counties, between 40 to 59% of their CCS children have medical homes
- in 5% of counties, between 20 and 39% of their CCs children have medical homes
- in 15% of Counties have fewer than 20% of their CCs children with medical homes.

Medical Home by Race/Ethnicity

From the National Survey of CSHCN, 2001

- In California, Hispanics are significantly more likely than whites to be without a medical home (64.9% vs. 47.9%)
- In California, children with an “Other” race/ethnicity are significantly more likely than whites to be without a medical home (77.8% vs. 47.9%) (For African Americans, the sample size was too small to test for significant differences. Asians were included in the “other” category.)
- Rates for CA CSHCN lacking a medical home for race/ethnic groups are not significantly different than national rates for racial/ethnic groups

Medical Home and Insurance Status

From the National Survey of CSHCN, 2001

- Significantly more insured CSHCN in California are lacking a medical home compared to national rates for insured CSHCN (54.3% vs. 46.5%)
- 73.5% of uninsured CSCHN in California are lacking a medical home. This rate does not differ significantly from the national rate of 62.8%

Medical Home and Special Health Needs

From the National Survey of CSHCN, 2001

- In CA, children with functional limitations are significantly more likely to lack a medical home than are children with health needs managed by prescription drugs (64.8% vs. 41.7%)
- In CA, children with above routine needs and use of services are significantly more likely to lack a medical home than children whose needs are managed by prescription drugs (68.6% vs. 41.7%)

From the “Experiences with health care for California’s children with special health care needs” 2003

- Fewer CSHCN in Medi-Cal (83%) than with private insurance (94%) were reported to have a usual source of health care. Further, fewer CSHCN in Medi-Cal (72% than with private insurance (91%) had a personal doctor or nurse. California’s Medi-Cal program lags behind other state Medicaid programs on this important indicator.

* Difference between CA and Nation significant at $p < .05$
** Differences within the Nation significant at $p < .05$
^ Difference within the State significant at $p < .05$

Providing Effective Case Management to Eligible Children

From State Performance Measures[iv]

This summary performance measure is designed to demonstrate that CCS, CHDP, and HCPCFC programs provide effective case management. The measure combines responses to 7 questions regarding CCS children having a documented medical home/primary care provider, children in out-of-home placement have a preventive health and dental exam within the past year documented in the health education passport, children referred to CCS have their program eligibility determined with prescribed guidelines per 2001 Procedures Manual, children enrolled in CCS whose conditions require CCS special care center services are seen at least annually at appropriate Special Care Centers, fee-for-service Medi-Cal eligible children whose CHDP screening exams reveal a condition requiring follow-up care receive it, and non-Medi-Cal eligible children whose CHDP screening exams reveal a condition requiring follow up care receive it.

In 56 CA counties, the percentages of points counties received on this measure ranged from 0 to 100% with an average of 72% of possible points.
- 32% of counties scored 80% or more of possible points
- 45% of counties scored between 60 to 79% of possible points
- 23% of counties scored less than 60% of possible points

Unmet Medical Needs

Unmet need is a direct measure of access to health care services. Unmet service needs may affect severity of the disease, lead to more urgent care contacts and greater emergency department utilization, and ultimately reduce children's physical and mental well-being.

- CSHCN in CA are significantly more likely to have unmet needs for health care services (23.1%) than are CSHCN nationwide (17.7%)*

Unmet Medical Needs by Race

From the National Survey of CSHCN 2001

- Nationwide, Black, Hispanic, and multiracial CSHCN are significantly less likely to report no unmet needs for health care than are Whites (84.8% for Whites vs. 77.3% for Blacks, 76.2% for Hispanics, and 74.2% for multiracial).** CA data reflects this same pattern, although the small sample size prevents these differences from achieving statistical significance. A larger CA sample would likely reveal that Blacks and Multi-racial CSHCN are significantly less likely to have no unmet needs.

* Difference between CA and Nation significant at $p < .05$
** Differences within the Nation significant at $p < .05$
^ Difference within the State significant at $p < .05$

Unmet Medical Needs by Medical Home

From the National Survey of CSHCN 2001

- Compared to CSHCN nationwide with medical homes, those without medical homes are significantly more likely to have unmet need for health care services (24.6% for those without medical homes vs. 10.5% for those with). CA data again reflects the same pattern, but differences fail to achieve statistical significance (26.6% for those without medical homes vs. 15.9% with).

Unmet Medical Needs by Insurance Status

From the National Survey of CSHCN 2001

- In both CA and nationwide, CSHCN without insurance are significantly more likely to report unmet medical needs than those with insurance.^,** There were no significant differences between CA and the nation.
- In CA, 21.6% of those currently insured report unmet needs compared to 57.2% without insurance^
- Nationwide, 16.1% of those currently insured report unmet needs compared to 46.2% of those not insured**

From the "Experiences with health care for California's children with special health care needs" 2003

- Nearly half of children in Medi-Cal (43%) were reported having at least one unmet need. Rates of unmet need among those children in Medi-Cal requiring a particular service were high for mental health (42%) and specialty care (10%). Among all CSHCN in California, the highest reported rates of unmet need were for respite care (35%), family counseling or mental health services (23%) and mental health services for the child (22%)

- Most health services needed by CSHCN in Medi-Cal are covered benefits of the federal Medicaid program. Unlike adult services, children's benefits in Medi-Cal come from the expansive federal Early and Periodic Screening Diagnosis and Treatment (EPSDT) requirements. The medical necessity definition in EPSDT requires the state Medicaid program to provide children with any federal Medicaid benefit that is needed to ameliorate a condition. Moreover, the CCS program covers specialty care for those children in Medi-Cal or Healthy Families with severe or disabling conditions. CCS also pays for some specialty services for commercially insured children whose health plans limit benefits:
    - Fewer parents of CSHCN in Medi-Cal (61%) compared to those with private insurance (86%) reported that their child's needs are met by insurance benefits.
    - Parents of 18% of CSHCN in Medi-Cal said that the benefits "never" meet their child's health care needs.

* Difference between CA and Nation significant at $p < .05$
** Differences within the Nation significant at $p < .05$
^ Difference within the State significant at $p < .05$

Unmet Need for Family Support Services

From the National Survey of CSHCN 2001

- 25.1% of CSHCN families in CA who needed respite care, genetic counseling and/or mental health services did not get all the support services that were needed (vs. 23.1% nationwide, difference not significant)
- Nationally, there were no statistically significant differences in unmet needs for family support services by race. In CA, the sample is too small to detect any significant differences.

Access

From the "Experiences with health care for California's children with special health care needs" 2003

- In general parents of CSHCN in Medi-Cal report experiencing more access problems than parents of CSHCN in other state Medicaid programs. (Nearly 80% of CCS children are Medi-Cal beneficiaries.)

Access to Specialty Care

From the "Experiences with health care for California's children with special health care needs" 2003

- Parents of CSHCN in Medi-Cal more frequently reported difficulty obtaining a referral (54%) if their child is significantly affected by their medical condition.
- Most children eventually got needed specialty care even when they had problems with referrals. Parents of 9% of the CSHCN who needed a specialist (about 44,000 children) said that the child did not receive the needed care, with no differences between children in Medi-Cal (10%) and children in private insurance (8%)

Problems Getting Referrals

From the National Survey of CSHCN 2001

Problems getting Referral for Specialty care

- In CA, 27.5% of CSHCN who needed specialty care had problems getting a referral (vs. 21.9% nationwide, difference not significant)

Problems getting Referral for Specialty Care by presence of a Medical Home

- CSHCN in CA and nationwide with a medical home were significantly more likely than those without a medical home to report no problems getting referrals for needed specialty care (100% with medical homes in CA and national vs. 54.6% of CSCHN in CA and 58.8% nationwide without a medical home)**,^^. CA rates did not differ significantly from national rates.

* Difference between CA and Nation significant at *p* < .05
** Differences within the Nation significant at *p* < .05
^ Difference within the State significant at *p* < .05

Problems getting Referral for Specialty care by Type of Health Problem

- Nationally, CSHCN managed by prescription drugs (Rx meds) who needed specialty care were significantly more likely to report no problems getting a referral (86.4%) than CSCHN who have functional limitations and need a referral (72.5%), or CSHCN who have above routine needs/use of services (72.6%), or CSHCN who are managed by Rx meds and have above routine needs/use of services (78.4%)** In CA, data reflect a similar pattern, however differences are not statistically significant due to small sample size.

Problems getting Referral for Specialty care by Insurance Adequacy

- In both CA and nationally, CSHCN not having adequate insurance were significantly less likely to report having no problems getting a referral for need specialty care (58.5% for CA and 66.9% nationally) than were CSCHN with adequate insurance (81.4% in CA, 85.2% nationally)

Waiting times from referral to first authorization for CCS services

From CMS Net

In 54 CA counties, average waiting times for referral to authorization vary from 55 to 227 days, with an average of 127 days.

- in 26% of counties, average waiting time was between 55 to 98 days
- in 41% of counties, average waiting time was between 99 to 141 days
- in 24% of counties, average waiting time was between 142 to 184 days
- in 9% of counties, average waiting time was between 185 to 227 days

Access to Ancillary Services

From CMS Net

Wait time between request for in-home support services and authorization

- Average Wait time between request for and authorization for in-home support services ranges from 0 to 1469 days, with average being 24 days, the mode (most frequent value) being 0 days and the median (middle value) being 5 days.

Access to Equipment

From CMS Net

Wait time between request for equipment (wheelchairs) and authorization

- Average Wait time between request for and authorization of equipment ranges from 0 to 1838 days, with average being 29 days, the mode (most frequent value) being 0 days and the median (middle value) being 12 days.

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* Difference between CA and Nation significant at $p < .05$
** Differences within the Nation significant at $p < .05$
^ Difference within the State significant at $p < .05$

Provider Certification

From CMS Branch

- The length of time between when a provider application is received and when it is approved for paneling is 5 to 7 weeks. This time frame is based on the assumption that the provider has an active Medi-Cal number in good standing along with all the required documentation to fully complete the provider's paneling application

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[i] National Survey of CSHCN, 2001

[ii] Inkelas M, Ahn P, Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

[iii] CMS Net

[iv] State performance measures

Children with Special Health Care Needs
Health Insurance Coverage

Research shows that for children generally, retention of coverage is important for health care continuity, quality of care, parent adherence to medical advice and parent self-management of children's conditions.

Current Insurance Coverage for CSHCN

From the National Survey of CSHCN, 2001[i]

	Private or employer- based insurance only	Medicaid, SCHIP, Title V, or other public insurance only	Combination of public and private insurance	Uninsured at time of survey
California %:	72.2*	16.6*	6.9	4.3
Nationwide %:	64.9	21.7	8.1	5.2

- CSHCN in CA are significantly more likely than CSCHN nationally to have private or employer based only and significantly less likely to have public insurance only

From the "Your Voice Counts!!" Survey[ii]:

- More than half (53%) of children were enrolled in Medi-Cal managed care, 26% were enrolled in private managed care plans, 20% were enrolled in Medi-Cal fee for service, and 1% in private fee for service plans.
- Although nearly half (46%) of the families did not know whether their child was in a managed care plan, most of the children (72%) were in a plan with at least one feature of managed care, such as having a network of doctors or requiring a primary care physician.

No Insurance Coverage during Past Year

From the National Survey of CSHCN, 2001

- 9.9% of CSHCN in CA and 11.6% nationally were without health insurance at some point during the year prior to the survey. Differences are not significant.

* Difference between CA and Nation significant at $p < .05$
** Differences within the Nation significant at $p < .05$
^ Difference within the State significant at $p < .05$

Current Insurance Inadequate

From the National Survey of CSHCN, 2001

- 36.5% of CSHCN in CA and 33.8% nationally report that their current insurance is not adequate. Differences are not significant.

Current Insurance inadequate by Race

	Hispanic	White	Black	Multiracial	Other
California %:	46.1**	33.2	21.6	45.6	37.2
Nationwide %:	46.7	31.5	34.2	35.5	36.6

- Nationally, Hispanics were more likely than all other groups to not have adequate insurance for their CSHCN
- CA data reflects a similar pattern, although small sample sizes result in Hispanics only differing significantly from Blacks, but not from Whites.

From the "Your Voice Counts!!" Survey:

- Of children needing home health care, 39% reported problems. Of those, half had insurance that wouldn't pay for home health care. Fifty one percent of families reporting problems had trouble getting payment for enough home health care hours.

- Of children needing therapies, 35% reported problems. The most common problem for children who needed some kind of therapy was that they did not get the therapy they needed. Lack of coverage for occupational therapy and speech therapy was the second most common problem followed by difficulty getting a referral and an adequate number of visits to meet their child's needs.

Current Insurance by Specific Types of Special Health Needs

From the National Survey of CSHCN, 2001

- Nationally, CSHCN managed by prescription drugs are significantly more likely to have adequate insurance (73.7%) than CSHCN who have functional limitations (57.3%), above routine needs/use of services (59.7%) or both above routine needs/use of services and use of prescription drugs (66.9%)

- CA data reflect similar patterns, but only CSHCN who are managed by prescriptions drugs are significantly more likely to have adequate insurance than CSHCN who have above routine need/use of services (76.2% vs. 47.2%). With a larger sample size, other differences would likely be significant.

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* Difference between CA and Nation significant at $p < .05$

** Differences within the Nation significant at $p < .05$

^ Difference within the State significant at $p < .05$

Reasonableness of Costs Not Covered by Insurance

From the National Survey of CSHCN, 2001

- In CA, 30.7% of CSHCN have costs that are not covered by insurance that are never or sometimes reasonable, 28.8% have costs that are usually reasonable and 40.5% have costs that are always reasonable. National data reflect a similar pattern and did not differ significantly from CA.

From the "Experiences with health care for California's children with special health care needs", 2003**:**

- Recent expansions of Medi-Cal and the Healthy Families program have improved children's financial access to health care. However, having insurance coverage does not guarantee that CSHCN are covered for all the services that they need.
- In 2001, the rate of uninsurance for CSHCN (4%) was similar to the uninsurance rate among all children 0-17 years in California (55)
- However, a larger proportion of CSHCN (10%) was currently uninsured or experienced a gap in coverage. Although gaps in insurance may be temporary, changes in coverage disrupt services.
- Most health services needed by CSHCN in Medi-Cal are covered benefits of the federal Medicaid program. Unlike adult services, children's benefits in Medi-Cal come from the expansive federal Early and Periodic Screening Diagnosis and Treatment (EPSDT) requirements. The medical necessity definition in EPSDT requires the state Medicaid program to provide children with any federal Medicaid benefit that is needed to ameliorate a condition. Moreover, the CCS program covers specialty care for those children in Medi-Cal or Healthy Families with severe or disabling conditions. CCS also pays for some specialty services for commercially insured children whose health plans limit benefits:
    - Fewer parents of CSHCN in Medi-Cal (61%) compared to those with private insurance (86%) reported that their child's needs are met by insurance benefits.
    - Parents of 18% of CSHCN in Medi-Cal said that the benefits "never" meet their child's health care needs.

Needs Met By Insurance

From the "Experiences with health care for California's children with special health care needs", 2003

Access to Care for Children with Special Health Care Needs Ages 0-17, California 2001

	All CSHCN (%)	CSHCN in Medi-Cal(%)
Insurance benefits usually meet child's needs.	81.4	60.9
Have enough information about how health plan works.	88.0	72.4
Non-covered costs reasonable.	69.4	57.5
Insurance usually allows child to see needed providers.	80.1	60.5
Would switch health plan if could.	33.4	44.9
Health plan is good for CSHCN.	80.3	80.1

Note: All differences are statistically significant

- Fewer parents of CSHCN in Medi-Cal (61%) compared to those with private insurance (86%) reported that their child's needs are met by insurance benefits. Parents of 18% of CSHCN in Medi-Cal said that the benefits "never" meet their child's health care needs. The report says "The NS-CSHCN shows that although medical benefits in Medi-Cal are generally more comprehensive than benefits in private insurance, this does not mean that children are always able to obtain these services. Parents of children in Medi-Cal more frequently perceived that the coverage does not meet their child's needs. Yet most health services needed by CSHCN in Medi-Cal are covered benefits of the federal Medicaid program.

Impact of Coverage System on Families

From the "Your Voice Counts!!" Survey**:**

- Over half of the parents reported spending some time each week providing health care at home. One-fifth spent 20 or more hours per week providing this care.

- One third of the parents reported that their child's health conditions caused financial problems; 28% said they stopped working; and 37% cut down the hours they worked.

- Almost half the parents reported spending between $500 and $3000 out of their own pocket for the special health care needs of their child in the past year. One-tenth said they spent $3000 or more.

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[i] National Survey of CSHCN, 2001

[ii] Wells, N., Doksum, T., Martin, L., Cooper, J. (2000) What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

Children with Special Health Care Needs Screening

Newborn Screening

From Title V Reports, 2001-2003[i]

In CA, all newborns are screened for 4 conditions: phenylketonuria, congenital hypothyroidism, galactosemia, and sickle cell disease. Nationwide, the number of screenings states mandate range from 4 to 36. California is in the process of mandating screening for an additional 26 conditions.

- CA has high rates of screening for the 4 conditions it mandates: 99.9% in 2001, 99.0% in 2002, and 98.5% in 2003

- In CA, very high percentages of those needing treatment for each of these conditions receive it, with 100% of those needing treatment for PKU, congenital hypothyroidism, and galactosemia in 2003 receiving. Rates for receiving needed treatment of sickle cell disease are slightly lower and have been increasing for the last three years: 2001 = 94%, 2002 – 95.9%, 2003 – 97.6%

- In CA in 2003, 709 infants had a presumptive positive screen for congenital hypothyroidism and there were 275 confirmed cases; 164 infants had a presumptive positive screen for PKU and there were 34 confirmed cases; 93 infants had a presumptive positive screen for galactosemia and there were 6 confirmed cases; and 86 infants had presumptive positive screens for sickle cell disease and there were 84 confirmed cases

California Newborn Hearing Screening

From Title V reports – Statewide data

	1999	2000	2001	2002	2003*
Annual Indicator	9.8%	13.7%	21.6%	52.2%	52.2%
Annual Performance Objective	10%	10%	15%	40%	60%

* Projected

From the State Newborn Hearing Screening Program (NHSP) Data[ii]

- In CA, all newborns born at CCS-approved hospitals are required to be offered hearing screening and all infants in CCS-approved NICUs must be screened. In

2003, approximately 74% of all newborns born in the state were born at a CCS approved hospital.

- In 2003, 90.7% of newborns at CCS-approved hospitals received hearing screening at birth, and 94.3% did so in 2004
- Screening rates in WBN in CCS approved hospitals that were certified to participate in the NHSP were 97.1% in 2004 and 97.2% in 2003
- Screening rates in CCS approved NICU that were certified to participate in the NHSP were 91% in 2004 and 86.3%in 2003
- In 2004, 0.9/1000 of those screened in WBN identified with hearing loss, and 5.5/1000 of those screened in NICU
- There were some regional variations in NICU screening rates, with Regions A and B reporting the lowest levels of screening (Region A: 2003 = 85.9%, 2004 = 87.9%; Region B: 2003 = 73.4%, 2004 = 86%, and Region D reporting the highest: 2003 = 99.3%, 2004 = 98%)
- Regional screening rates for WBN ranged from 96.4% to 98.1%

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[i] Data are from California's Title V Application 2005,

[ii] Data are from the California Newborn Hearing Screening Program, 2003 and 2004

Children with Special Health Care Needs
Organization of Services

Organization of Services

From the National Survey of CSHCN, 2001[i]

Community-Based Service Systems Organized for Easy Use

- In CA, the National MCHB outcome of having community-based service systems organized so families can use them easily was successfully achieved for 65.9% of CSHCN (vs. 74.3% nationally, difference is not significant)

Community-Based Service Systems Organized for Easy Use by Race

- Nationally, this outcome was more likely to be achieved for Whites (77.4%) than for Hispanics (66.4% and Blacks (65.3%), or other (59.2).
- In CA, the sample size is very small, but generally reflects the pattern of the national data

From **"**Experiences with health care for California's children with special health care needs" [ii]**:**

- In general, parents of CSHCN in Medi-Cal reported more difficulty in navigating the system of services and obtaining the health care benefits needed by the child than did parents of CSHCN in other state Medicaid programs.

From the "Your Voice Counts!!" Survey:

- Most parents were dissatisfied with the lack of "family-centeredness" of their primary health plan. Parents were most dissatisfied with the lack of information or newsletters about issues of interest or resources outside of their plan. Many were dissatisfied with or did not know whether their plan offered parent support groups or gave parents an opportunity to give advice to the plan.

Care Coordination and Communication Among Providers

From the "Experiences with health care for California's children with special health care needs":

Care coordination involves sharing of medical information between providers as well as helping parents navigate service systems. Parents of children with complex conditions often need help coordinating multiple appointments and services. The health needs of many CSHCN are also relevant to their ability to attend school or child care as well as their need for referral to public programs such as early intervention, CCS, and Regional Centers.

- Most parents who received professional care coordination said they were generally satisfied with it, suggesting that professional care coordination based at public programs, health plans and even provider offices is helping children access needed care.

Coordination and consistency of care for children in foster care

<u>From the UCLA Health Services Assessment for Children in Foster Care</u>**:**[iii]

- Fewer than one third of agencies report that judges review a child's health plan when making decisions about a child's placement.

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[i] National Survey of CSHCN, 2001

[ii] Inkelas M, Ahn P, Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

[iii] Halfon N, Inkelas M, Flint R, Shoaf K, Zepeda A, Franke T. 2002. Assessment of factors influencing the adequacy of health care services to children in foster care. UCLA Center for Healthier Children, Families and Communities.

Children with Special Health Care Needs
Family-Centered Care, Participation, and Satisfaction

Family partnership in decision-making

From the National Survey of CSHCN 2001[i]:

- The MCHB core outcome: Families of CSHCN will partner in decision-making and will be satisfied with the services they receive, was successfully achieved for 57.5% of CSHCN nationwide, and by 47.6% in CA. This difference is almost statistically significant.

Family partnership in decision-making by race

- Nationally, for 55.8% of Hispanic CSHCN, 51.6% of Black CSHCN, and 56.5% of other CSHCN, the MCHB outcome of families partnering in decision-making and being satisfied with the services they received was NOT successfully achieved. Compared to Whites (37% did not achieve this outcome), Hispanic, Black, and other CSHCN are significantly less likely to achieve this outcome. In CA, the data reflect a similar pattern with even large percentages of Hispanic, Black and other CSHCN for whom this outcome was not achieved. However, there are very small numbers in the CA sample for this item and only Hispanic CSHCN differ significantly from White CSHCN.

Family Participation

From State Performance Measures[ii]

This summary performance measure is designed to assess the degree to which the CMS program demonstrates family participation. The measure combines responses to 6 questions regarding family member participation on advisory committees or task forces, offering of financial support for parent activities or groups, providing opportunities for family members to provide feedback regarding their satisfaction with services received through CCS program, involving family members in in-service trainings of CCS staff and providers, hiring family advocates for their expertise as paid staff or consultants to the CCS program, and involving family members of diverse cultures in all the above activities.

In 51 CA counties, the percentage of points counties received on this measure ranged from 0 to 100% with an average of 41% of possible points.

- 6% of counties scored 80% or more of possible points
- 18% of counties scored between 60 to 79% of possible points
- 22% of counties scored between 40 to 59% of possible points
- 29% of counties scored between 20 to 39% of possible points
- 26 of counties scored less than 20% of possible points

Understanding How Health Plans Work

From the "Experiences with health care for California's children with special health care needs"[iii]

- About ¾ (73%) of parents of CSHCN in Medi-Cal said that they have enough information about how their child's health insurance plan works, compared to 92% of parents of privately insured children.

- Among parents of the children most severely affected by their condition, 56% of those in Medi-Cal reported having enough information about their health insurance plan compared to 92% of privately insured children.

From the "Your Voice Counts!!" Survey[iv]:

- Nearly half (46%) of families surveyed did not know whether their child was in a managed care plan, though most (72%) were in fact in a plan with at least one managed care feature, such as a network of doctors or required primary care doctor.

Satisfaction with Services/Care

From the "Your Voice Counts!!" Survey

- 44% of families said they were "very satisfied" with their child's primary plan; 42% were "somewhat satisfied", 12% were "somewhat dissatisfied" and 2% were "very dissatisfied.
- Parents of children in Medi-Cal managed care plans were most satisfied with their doctor's overall quality of care than those in private managed care plans.

Quality of the Provider-Parent Relationship

From the "Experiences with health care for California's children with special health care needs"

Research generally shows that a good interpersonal relationship between the provider and parent/child improves adherence to medical advice, patient satisfaction, self-rated access to care, fewer unmet needs and fewer emergency department visits.

- Fewer children in Medi-Cal (62%) than with private insurance (82%) were reported to have enough time with their providers.
- Most indicators show lower parent ratings of how well the child's provider understand the child's unique needs and provides the information needed by the family about the child's condition

Access to Care for Children with Special Health Care Needs, Ages 0-17, California 2001

	All CSHCN (%)	CSHCN in Medi-Cal(%)
Child has a personal doctor or nurse.	86.8	72.2
Doctors communicate well (among children receiving professional care coordination).	66.2	82.0
Provider communicates well with school, early intervention, programs, provider.	52.6	56.1
Provider is sensitive to family values and customs.	84.5	75.0
Provider spends enough time with child.	77.8	62.3
Provider gives specific information needed.	72.3	61.1

Note: All differences are statistically significant

From the "Your Voice Counts!!" Survey:

- Parents who responded in Spanish were less satisfied in terms of overall quality of care from their doctors, their doctor's overall communication with the family, and their waiting times. Spanish respondents were more satisfied with their doctor's respect for their child and the family than those responding in English

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[i] National survey of CSHCN 2001

[ii] State performance measures

[iii] Inkelas M, Ahn P, Larson K. 2003. "Experiences with health care for California's children with special health care needs." Los Angeles, CA: UCLA Center for Healthier Children, Families and Communities

[iv] Wells, N., Doksum, T., Martin, L., Cooper, J. (2000) What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs.

Children with Special Health Care Needs
Transition to Adulthood

From CMS Net

Number of CCS Clients Age 20 with Insurance

- Out of the CCS cases active as of 3/15/05, there were a total of 2746 clients 20 years of age. Within 52 CA counties, the percentages of these clients with insurance range from 1 to 100% with an average of 22% having insurance.

Expenditure data for CCS program
By Selected Diagnosis
FY 2003-2004

ICD-9 Codes	Medi-Cal	HF	CCS-only	Total
Congenital Heart Disease (754-747)	$48,200,000	$4,000,000	$1,800,000	**$54,000,000**
Cleft Lip/Palate (749)	$3,900,000	$539,000	$727,000	**$5,166,000**
Cerebral Palsy (343)	$32,190,000	$363,000	$4,583,000	**$37,136,000**
Hearing Loss (389)	$4,700,000	$496,000	$945,000	**$6,141,000**
Hemophilia (286)	$80,200,000	$8,279,000	$5,510,000	**$93,989,000**
Acute Lymphocytic Leukemia (204)	$15,800,000	$2,220,000	$981,000	**$19,001,000**
Brain Cancer (191)	$8,722,000	$1,158,000	$586,000	**$10,466,000**
Cystic Fibrosis (277)	$8,245,000	$372,000	$532,000	**$9,149,000**
Total	**$201,957,000**	**$17,427,000**	**$15,664,000**	**$235,048,000**

Expenditure and Beneficiary data for CCS program
By Selected Service Provided
FY 2003-2004

Procedure Codes	Medi-Cal	# M/C	HF	# HF	CCS-only	# CCS	Total	Total #
Developmental Screening	**$67,700**		**$1,700**		**$5,900**		**$75,300**	
96110	$30,400		$920		$3,600		$34,920	
96111	$37,300		$780		$2,300		$40,380	
Hearing Aids	**$2,024,000**	**1,635**	**$249,000**	**187**	**$507,000**	**405**	**$2,781,822**	**2,227**
Z5946	$832,000		$135,000		$230,000		$1,197,000	
V5030-V5255	$1,192,000		$114,000		$277,000		$1,583,000	
Equipment (Wheelchairs)	**$6,693,000**		**$132,000**		**$554,000**		**$7,379,000**	
E0950-1030	$295,000		$7,700		$28,000		$330,700	
E1050-E1298	$793,000	2,574	$23,000	160	$78,000	284	$897,018	**3,018**
E1399	$5,900,000		$109,000		$476,000		$6,485,000	
Home Health Services	**$1,600,000**		**$109,000**		**$114,000**		**$1,823,000**	
Z6900-Z6916	$1,600,000		$109,000		$114,000		$1,823,000	
Inpatient Services	**$581,264,000**	**27,441**	**$40,492,000**	**2,031**	**$14,839,000**	**976**	**$636,624,472**	**30,448**
099-219	$581,000,000		$40,400,000		$14,800,000		$636,200,000	
250-949	$264,000		$92,000		$39,000		$395,000	
NICU	**$187,000,000**		**$580,000**		**$1,300,000**		**$188,880,000**	
170-175	$187,000,000		$580,000		$1,300,000		$188,880,000	
ICU	**$120,000,000**		**$12,000,000**		**$3,800,000**		**$135,800,000**	
PICU	**$80,700,000**		**$7,200,000**		**$2,000,000**		**$89,900,000**	
Factor	**$79,000,000**	**382**	**$8,500,000**	**50**	**$5,331,000**	**64**	**$92,831,496**	**496**
J7190-J7195 & Z5230	$79,000,000		$8,500,000		$5,331,000		$92,831,000	

Appendix H

Tables of County Level CCS Data

	Page
Table of CCS Cases by County	2
Table of Percent of Children receiving CCS Services with a Medical Home by County	3
Table of CCS-Paneled Pediatricians by County and Number of Pediatricians per 100 Children Served by CCS	4
Table of CCS-Paneled Specialists by County and Number of Pediatricians per 100 Children Served by CCS	5
Table of Average Number of Days between Referral to CCS and Eligibility Determination by County	6
Table of Average Number of Days between Referral to CCS and Authorization for services by County	7
Table of Number of Chilren Age 20 Served by CCS and Number and % with Insurance	8
Table of Diagnosis Data for Los Angeles County CCS	9

Appendix I

Maps of County Level CCS Data

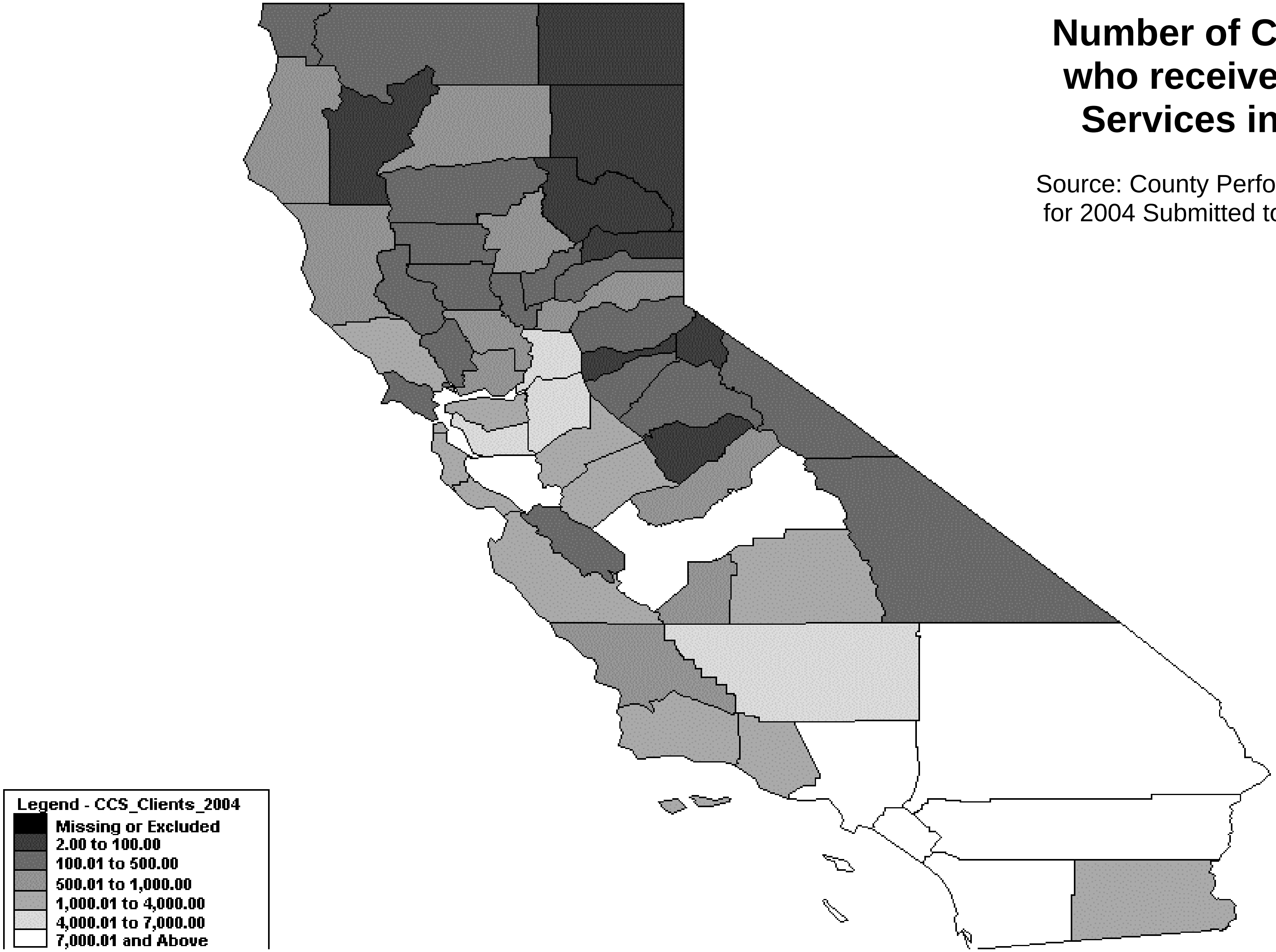
	Page
Number of Children who received CCS Services in 2004 – Color Map	2
Number of Children who received CCS Services in 2004 – Black and White Map	3
Percent of Children Served by CCS in 2004 with a Medical Home – Color Map	4
Percent of Children Served by CCS in 2004 with a Medical Home – Black and White Map	5
CCS-Paneled Pediatricians by CCS Cases for 2004 – Black and White Map	6
Key CCS-Paneled Specialists by CCS Cases for – Black and White Map	7
CCS-Approved Facilities by Number of Children Receiving CCS Services in 2004 – Color Map	8

Number of Children who received CCS Services in 2004

Source: County Performance Data for 2004 Submitted to State CMS

Number of Children who received CCS Services in 2004

Source: County Performance Data for 2004 Submitted to State CMS

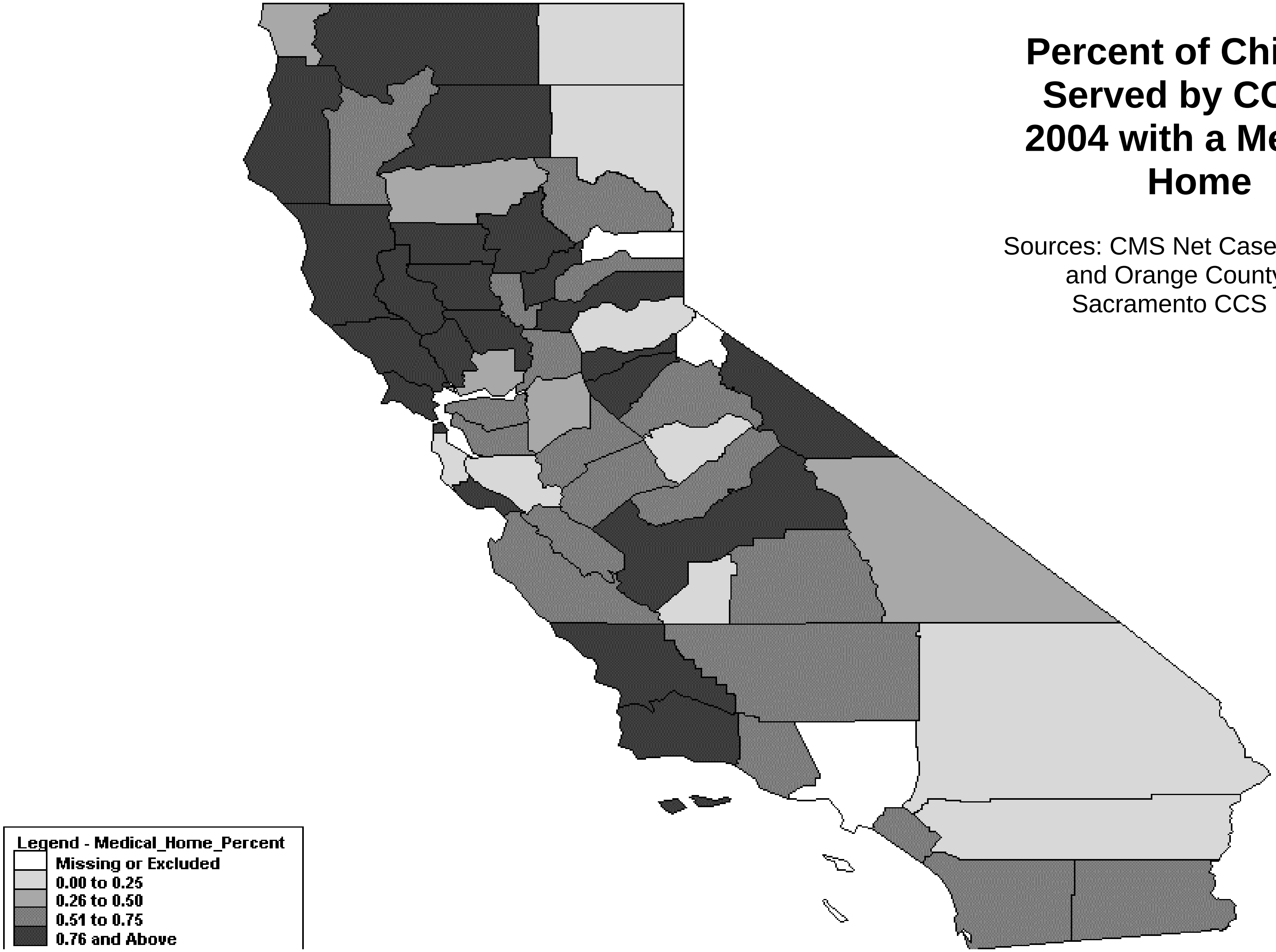


Percentage of Children Served by CCS in 2004 with a Medical Home

Sources: CMS Net Cases for 2004, and Orange County and Sacramento CCS Data

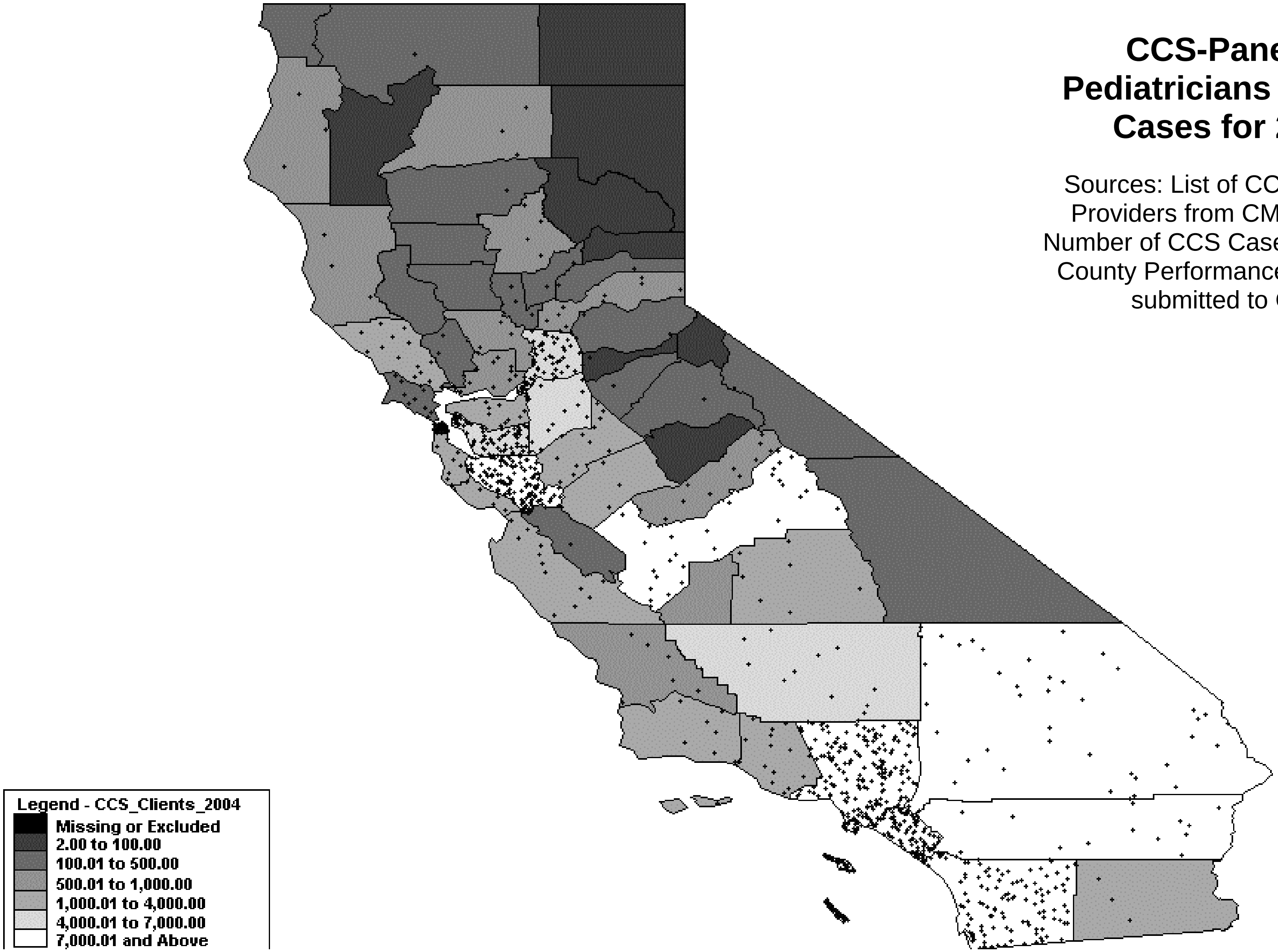
Percent of Children Served by CCS in 2004 with a Medical Home

Sources: CMS Net Cases for 2004,
and Orange County and
Sacramento CCS Data



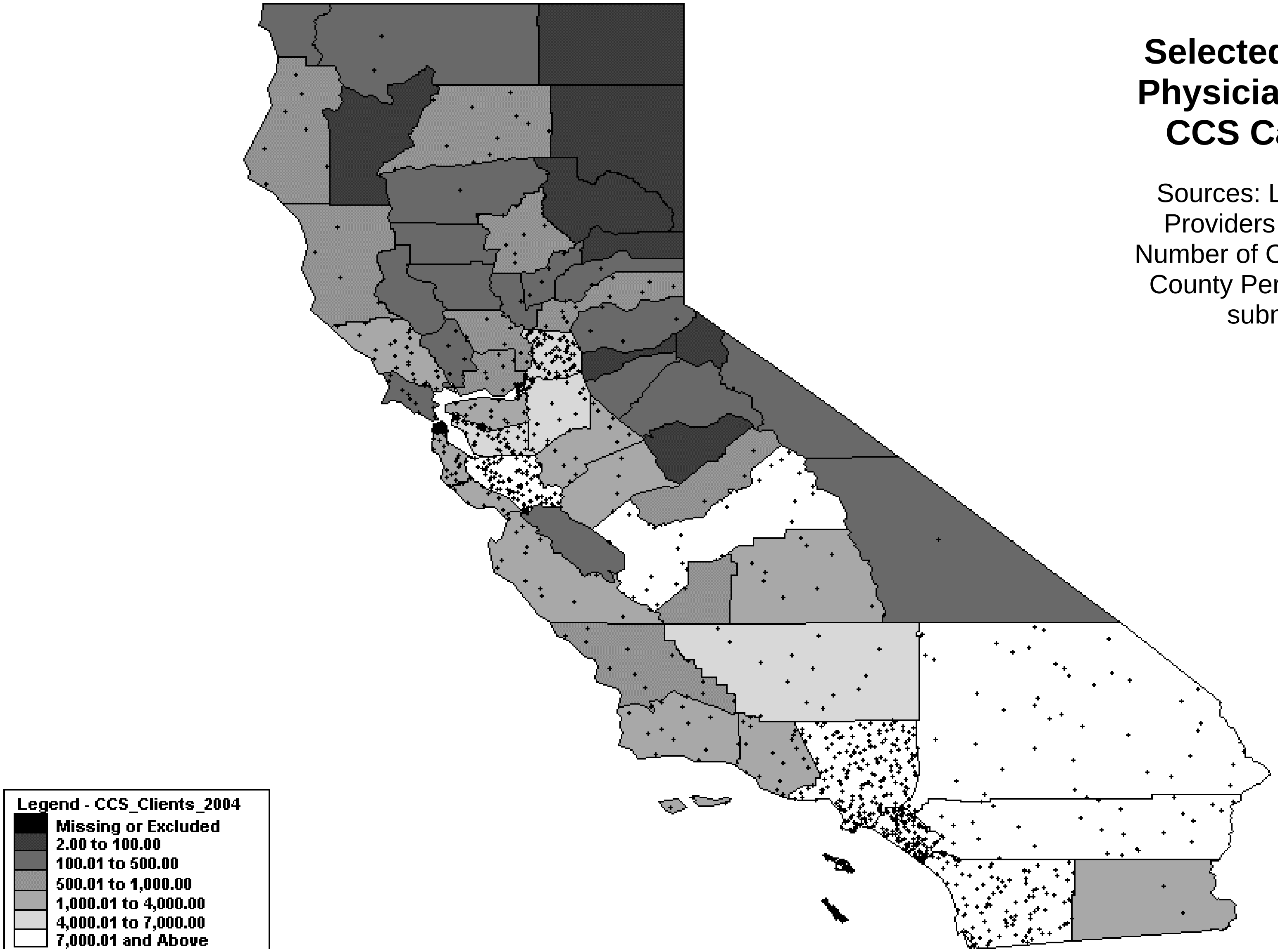
CCS-Paneled Pediatricians by CCS Cases for 2004

Sources: List of CCS-Paneled Providers from CMS Branch; Number of CCS Cases from 2004 County Performance Measures submitted to CMS



Selected CCS-Paneled Physician Specialist by CCS Cases for 2004

Sources: List of CCS-Paneled Providers from CMS Branch; Number of CCS Cases from 2004 County Performance Measures submitted to CMS



Legend for Specialists

1 Dot = 5 Specialists (Includes: CHILD NEUROLOGY, NEONATAL PERINATAL MEDICINE, NEUROLOGY, NEUROSURGERY, OPHTHALMOLOGY, ORTHODONTIC, ORTHOPEDIC SURGERY, OTOLARYNGOLOGY, OTOLARYNGOLOGY MAXILLOFACIAL SURGERY, PEDIATRIC ALLERGY IMMUNOLOGY, PEDIATRIC CARDIOLOGY, PEDIATRIC CRITICAL CARE, PEDIATRIC ENDOCRINOLOGY, PEDIATRIC GASTROENTEROLOGY, PEDIATRIC HEMATOLOGY ONCOLOGY,

CCS-Approved Facilities by Number of Children Receiving CCS Services in 2004

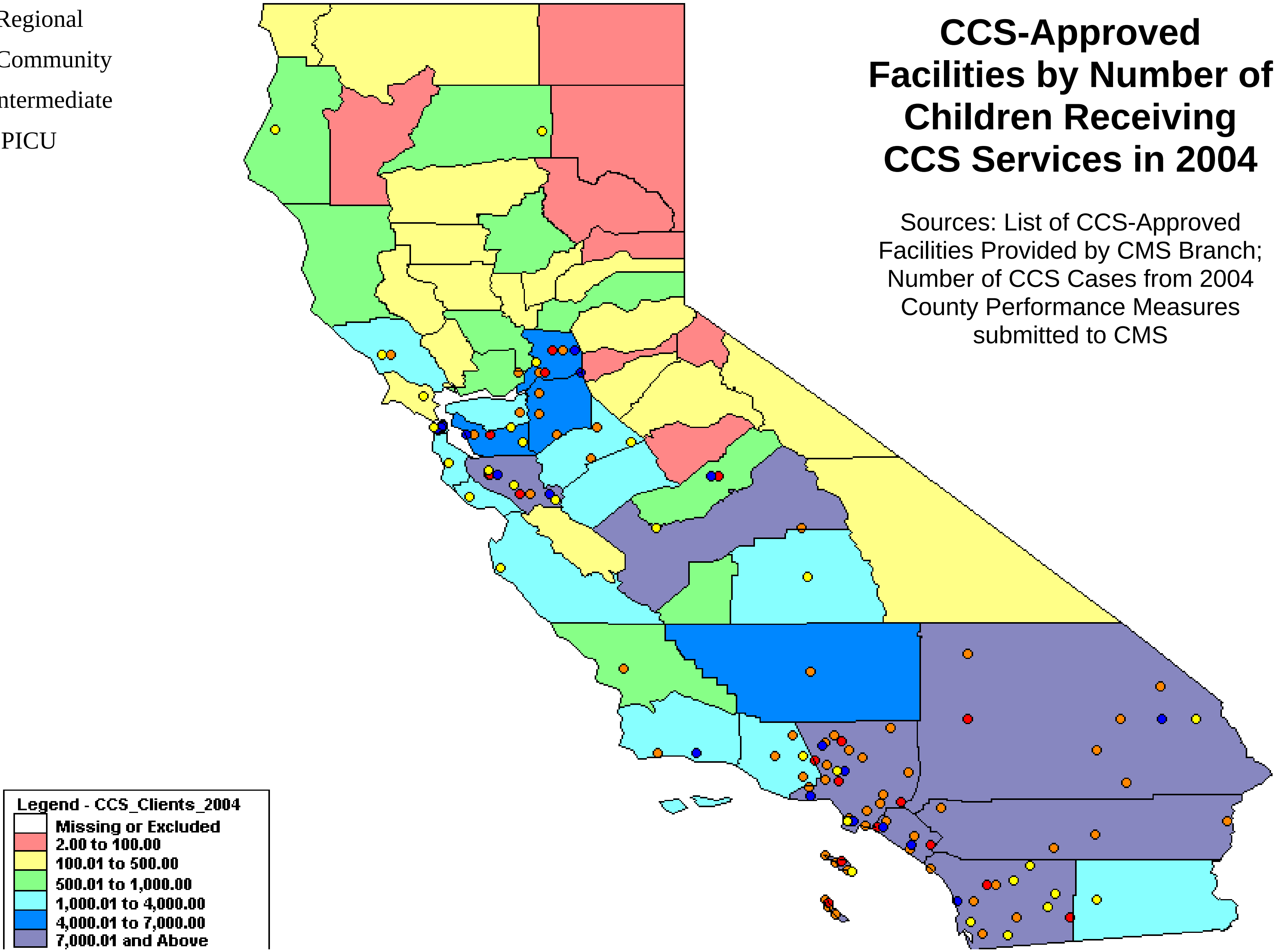
Sources: List of CCS-Approved Facilities Provided by CMS Branch; Number of CCS Cases from 2004 County Performance Measures submitted to CMS

🔴 = Regional

🟠 = Community

🟡 = Intermediate

🔵 = PICU



Appendix J

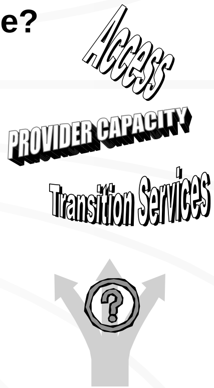
Slide Show Presentation, April 28, 2005
CCS Title V CSHCN Stakeholder Meeting

Setting CCS Action Priorities for California's Title V 5-Year Plan

Family Health Outcomes Project (FHOP)

April 28, 2005

Why Are We Here?



To identify 3 priority areas that will:

1. Be incorporated into the Title V MCAH block grant application
2. Be used by CCS to focus program efforts for the next 5 years

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How will we do it?

- We will follow a formal, rational and inclusive process
- This will involve using predefined criteria to prioritize issue areas identified by the stakeholders group and CCS

Review of Process to Date

- Stakeholders met (1/05)
  1. Reviewed objectives and process
  2. Selected criteria for setting priorities
  3. Weighted criteria
  4. Reviewed how data will be presented
  5. Met in groups to identify issues/data sources

Review of Process to Date

- Between meetings
  1. Break-out group members reviewed summaries / gave additional input
  2. Data requests / Data collection / Data review and analysis
  3. Criteria rating scales developed
  4. Materials sent to Stakeholders for review
  5. Issue areas / objectives identified

Today's Objectives

- Stakeholders will use criteria to prioritize among identified issues / objectives
- FHOP will facilitate identification of data development agenda
- All stakeholders will have an understanding of and accept the prioritized areas
- Meeting will lay ground work for next steps in the planning process

Purposes of the Process Today

- **Assure that each stakeholder has equal input to final selection of priorities**
- **Provide a systematic, rational decision-making process that can be communicated to others**
- **Provide a way for stakeholders to incorporate both knowledge and values**
- **Provide stakeholders the same decision-making tools and information**
- **Assist in selecting a manageable number of priorities**

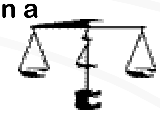
Today's Prioritization Process

April 28, 2005

1. Review priority-setting criteria
2. Presentation of data and issue / objective list
3. Review Data and agree on final objective list
4. Review rating method
5. Rate problems
6. Tally scores to produce a group ranking
7. Discuss and confirm results
8. Brainstorm / discuss data development

Review of Criteria

- Criteria: the values or standards the group selected and will use to make decisions about priorities
- Each criterion was given a weight, for example:

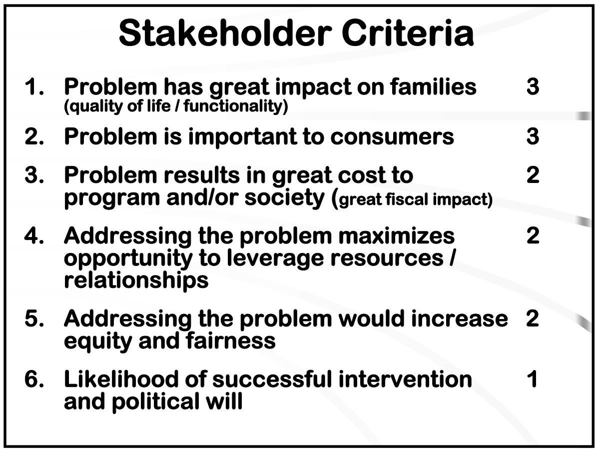


1 = important

2 = more important

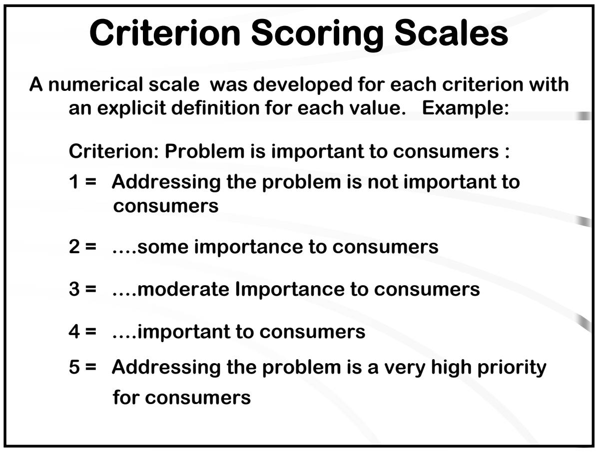
OR

3 = extremely important



Stakeholder Criteria

1.	Problem has great impact on families (quality of life / functionality)	3
2.	Problem is important to consumers	3
3.	Problem results in great cost to program and/or society (great fiscal impact)	2
4.	Addressing the problem maximizes opportunity to leverage resources / relationships	2
5.	Addressing the problem would increase equity and fairness	2
6.	Likelihood of successful intervention and political will	1



Criterion Scoring Scales

A numerical scale was developed for each criterion with an explicit definition for each value. Example:

Criterion: Problem is important to consumers :

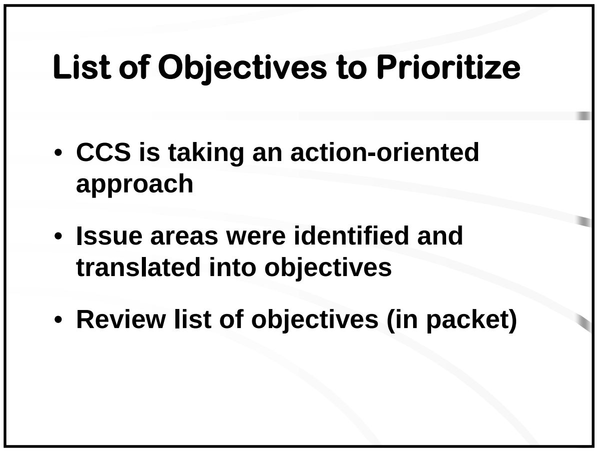
1 = Addressing the problem is not important to consumers

2 = ….some importance to consumers

3 = ….moderate Importance to consumers

4 = ….important to consumers

5 = Addressing the problem is a very high priority for consumers



List of Objectives to Prioritize

- CCS is taking an action-oriented approach
- Issue areas were identified and translated into objectives
- Review list of objectives (in packet)

Indicators

How selected

- Interviews
- Breakout groups
- Availability of data

Most frequently mentioned:

- Access to medical specialists
- Coordination and communication between providers
- Family access to information

Identified CCS Issues / Objectives

Definitions

- CSHCN – children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally
- Title V CSHCN program in CA is CCS
- CCS children - CCS enrolled children are children who have an eligible medical conditions and whose families meet financial eligibility requirements

Data Request

- Requested data from State CMS and from Los Angeles, Orange, and Sacramento counties

Sources of Data

- The National Survey of Children with Special Health Care Needs (NS-CSHCN), 2001
- CMSNet Data
- State Performance Measures Data
- California's Title V Application 2005
- California Newborn Hearing Screening Program, 2003 and 2004
- Data from Los Angeles, Sacramento, and Orange County

Data Sources (cont.)

- Inkelas M., Ahn P., Larson K. 2003. *Experiences with health care for California's children with special health care needs*. Los Angeles, CA: UCLA Center for Healthier Children.
- Wells, N., Doksum, T., Martin, L., Cooper, J. 2000 *What Do Families Say About Health Care for Children with Special Health Care Needs in California? Your Voice Counts!! Family Survey Report to California Participants.*
- Halfon N., Inkelas M., Flint R., Shoaf K., Zepeda A., Franke T. 2002. *Assessment of factors influencing the adequacy of health care services to children in foster care. UCLA Center for Healthier Children, Families and Communities*.

Prevalence Information

- 10.3% of CA children are identified as having special health care needs (vs. 12.8% nationally, p <.05*
- About 15% of CA's CSHCN receive specialty care through the CCS program (approx.150,000 annually)**
- 80% of CCS children are covered by Medi-Cal**
- Most children were affected by more than one condition:
  - 37% had 2 or 3 conditions
  - More than 50% had 4 or more conditions

Source: *National Survey of CSHCN 2001, ** **** Experiences with Health Care for California's CSHCN**, **Your Voice Counts!! Survey,

Prevalence Information

Total 2004 CCS Cases = 170,880*

Active CCS Cases and percent by diagnosis:**

- Accidents, poisoning, violence, and immunization reactions: 10160; 13.5%
- Perinatal morbidity and congenital anomalies: 10,088 (13.4% and 11.9%)
- Undiagnosed condition: 10289 (13.7%)

Source: *State Performance Measures, **CMS Net as of 3/15/05

Prevalence Information

- Compared to the nation, fewer CA children ages 0 to 3, 4 to 7, and 8-11 are identified as CSHCN
- Significantly more of CA CSHCN are Hispanic and fewer are black or white than nationally
- The poorest children in CA (below199% FPL) are significantly less likely than the poorest children in the nation to be identified as CSHCN

Source: National Survey of CSHCN, 2001

CSHCN in CA by Race

	Hispanic	White	Black	Multiracial	Other
California %:	7.6	13.7	15.7	10.2	6.9
Sample Size:	339	472	75	30	47
Est. Pop.:	313,648	462,157	95,424	29,636	66,118
Nationwide %:	8.5	14.2	13	15.1	7.8
Sample Size:	4,320	35,950	5,036	1,581	1,658
Est. Pop.:	1,077,970	6,401,832	1,133,566	275,998	239,361

Source: National Survey of CSHCN, 2001

Prevalence Information

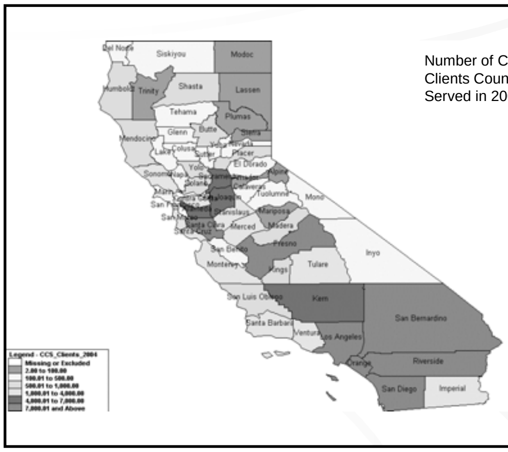
- 97% of CA CSHCN needed prescription medications
- 85% needed therapy services
- 43% needed durable medical equipment
- 21% needed home health services
- 11% needed mental health services

Source: Your Voice Counts!! Survey

Prevalence Information

- 24% of CA CSHCN have their daily activities consistently limited or affected by their condition, 40% are moderately affected, 39% are never limited by their condition
- 50% of CA CSHCN missed 0-3 days of school due to illness. 20% missed 4-6 days, 15% 7-10 days, and 16% missed 11 or more days

Source: National CSHCN Survey, 2001



Number of CCS
Clients Counties
Served in 2004

Medical Home

<u>American Academy of Pediatrics definition:</u>

Medical care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, culturally effective, and delivered or directed by a well-trained primary care or specialty physician who helps to manage and facilitate essentially all aspects of care for the child.

Medical Home

Objective: Increase number of family-centered medical homes for CSCHN and the number/% of CCS children who have a designated medical home

- **55% of CSHCN children in CA lack a medical home; significantly more than national rate of 47.3%**
- **Significantly more <u>insured</u> CSHCN in CA lack a medical home (54.3%) compared to national rates for insured CSHCN (46.5%)**

Source: National CSHCN Survey, 2001

Medical Home

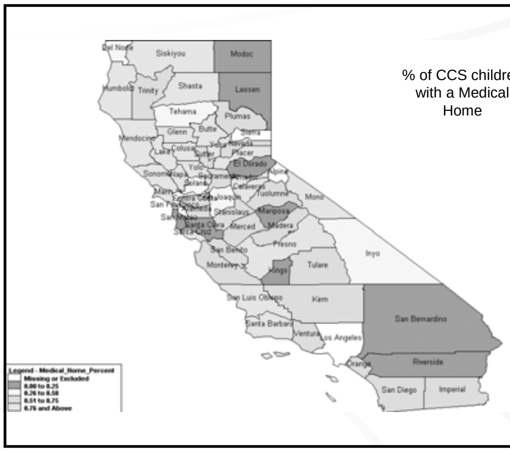
- 73.5% of uninsured CSCHN in CA lack a medical home
- In CA, CSHCN without medical homes are significantly more likely to have unmet need for health care services (26.6%) than those without a medical home (15.9%)

Source: National CSHCN Survey, 2001

In CMS Net, medical home is defined as having a primary care provider.

CA Counties vary widely in their percentages of CCS children with a medical home (range 0-100%, average 61%)

- **in 33% of counties, 80% had a medical home**
- **in 25% of counties, between 60 to 79% had a medical home**
- **in 23% of counties, between 40 to 59% had a medical home**
- **in 5% of counties, between 20 and 39% had a medical home**
- **in 14% of Counties have fewer than 20% had a medical home**



% of CCS children with a Medical Home

Family Involvement and Satisfaction Goal

Objective 2: Increase family access to educational information and information about accessing CCS services, including availability of and access to services offered by health plans

MCHB Core Outcome: Community-Based Service Systems Organized for Easy Use

- **In CA, this outcome was successfully achieved for 65.9% of CSHCN (vs. 74.3% nationally, difference is not significant**
- **Nationally by race, Hispanic, Black and other were significantly less likely to achieve the outcome. CA follows the pattern, but only statistically significant for Hispanic**

Source: National CSHCN Survey, 2001

- **By race Nationally, Hispanic, Black and other are significantly less likely to achieve the outcome. CA follows the pattern, but SS only for Hispanic***
- **Parents of CSHCN in Medi-Cal reported more difficulty navigating system of services and obtaining health care benefits for child than did parents of CSHCN in other state Medicaid programs****
- **46% of Family Voices survey respondents did not know whether their child was in a managed care plan, while 72% were in a plan with at least one feature of managed care (i.e., such as having a network of doctors or requiring a primary care physician)****

***Source: National CSHCN Survey, 2001, ** Experiences with Health Care for California's CSHCN, *** From the "Your Voice Counts!!" Survey**

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3. Increase family partnership in decision making and satisfaction with services

- **Most parents dissatisfied with lack of "family centeredness" of their primary health plan***
- **CA had significant more CSHCN without family center care – MCHB core outcome** (43.7% vs. 33.2 nationally)**
- **Parents were most dissatisfied with the lack of information or newsletters about issues of interest or resources outside of their plan***
- **Many were dissatisfied with or did not know whether their plan offered parent support groups or gave parents an opportunity to give advice to the plan***

Source: *Family Voices, **National CSHCN Survey, 2001

- **Fewer children in Medi-cal (62%) than with private insurance (82%) report enough time with provider***

CMS Performance Data Family Participation Measure (advisory committees, task forces, evaluation)

- **Involving family members: Statewide average - 41% of total possible points**
- **Slightly more than half (55 %) of Counties had less than 40% of possible points**

Source: *Experiences with Health Care for CA CSHCN, **HRSA

Screening

Objective 4: Increase the % of infants born in CA who receive newborn hearing screening services.

- **74% of newborns in the state were born at CCS approved hospitals**
- **In 2003, 90.7% of newborns at CCS-approved hospitals received hearing screening at birth, and 94.3% did so in 2004**

Screening Data

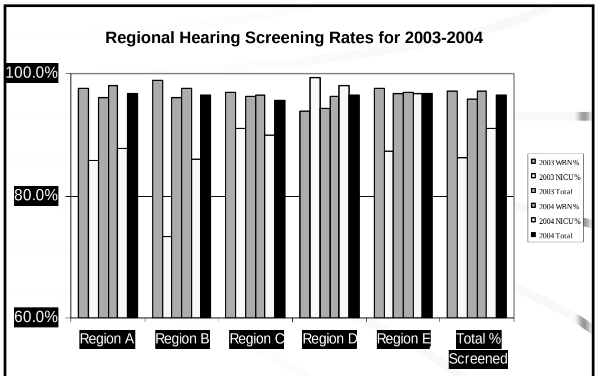
• % of total newborns screened has increased every year since 1999. Title V estimated 52% were screened in 2003

	1999	2000	2001	2002	2003*
Annual Indicator	9.80%	13.70%	21.60%	52.20%	52.20%
Annual Performance Objective	10%	10%	15%	40%	60%

Source: From Title V reports – Statewide data

Screening

- Screening rates in CCS NICU certified to participate in NHSP were 86% in 2003 and 91% in 2004.
- There were variations in rates, with Region A (Bay Area and coastal CA) reporting 88%, Region B 86% (northwestern and central CA) and Region C 98% (south eastern CA)



Regional Hearing Screening Rates for 2003-2004

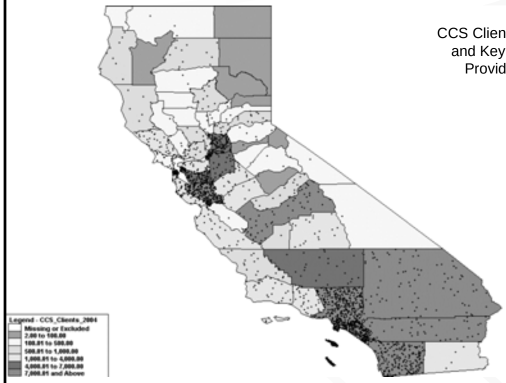
Insurance Coverage and Access to Care

Objective 5. Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists

Number of Key CCS-Paneled Medical Providers

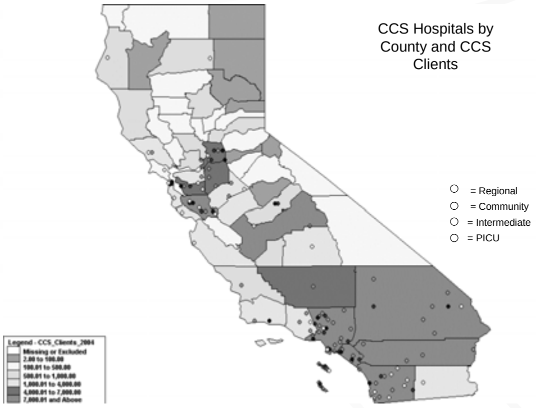
	# Approved Providers
CHILD NEUROLOGY	57
NEONATAL PERINATAL MEDICINE	16
NEUROLOGY	464
NEUROSURGERY	409
OPHTHALMOLOGY	1484
ORTHODONTIC	733
ORTHOPEDIC SURGERY	1663
OTOLARYNGOLOGY	839
OTOLARYNGOLOGY MAXILLOFACIAL SURGERY	13
PEDIATRIC	6005
PEDIATRIC ALLERGY IMMUNOLOGY	44
PEDIATRIC CARDIOLOGY	96
PEDIATRIC CRITICAL CARE	6
PEDIATRIC ENDOCRINOLOGY	43
PEDIATRIC GASTROENTEROLOGY	2
PEDIATRIC HEMATOLOGY ONCOLOGY	93
PEDIATRIC INFECTIOU DISEASE	2
PEDIATRIC NEONATOLOGY	286
PEDIATRIC NEPHROLOGY	37
PEDIATRIC NEUROLOGY	5
PEDIATRIC NEUROSURGERY	1
PEDIATRIC PULMONOLOGY	1
PEDIATRIC SURGERY	28
PSYCHIATRY & NEUROLOGY	67
Total	12394

- Number of key providers per 100 CCS clients varies widely, with a low of 0 in Sierra and a high of 32 in San Francisco
- Average of 8 providers per 100 CCS children
- Uncertain which of these approved providers is currently accepting CCS clients
- Problems with CCS provider list



CCS Clients 2004
and Key CCS
Providers

CCS Hospitals by County and CCS Clients



Objective 6. Increase access of CCS children to preventive health care services (primary care, well child care, immunizations, screening) as recommended by the AAP

- **Currently, CCS does not collect this data**

Objective 7. Increase access to CCS services by increasing the financial eligibility limit ($40,000 limit)

Recent expansions of Medi-Cal and the Healthy Families program have improved children's financial access to health care. However, having insurance coverage does not guarantee that CSHCN are covered for all the services that they need.

Source: *Experiences with Health Care for CA CSHCN

•CSHCN in CA are significantly more likely than CSHCN nationally to lack adequate public or private insurance – MCHB core outcome(40.7% vs. 59.3%)

	Private or employer-based	Medicaid, SCHIP, Title V, or other	Combination of public and private	Uninsured at time of survey
California %:	72.2*	16.6*	6.9	4.3
Nationwide %:	64.9	21.7	8.1	5.2

- CSHCN in CA are significantly more likely than CSCHN nationally to have private or employer based only and significantly less likely to have public insurance only

Source: National CSHCN Survey, 2001

Objective 8: Increase access to services for CCS youth, 17 – 21 years

- Currently no data available

Organization of Services

Objectives 9: Facilitate the timely referral of foster care children with CCS eligible medical conditions to CCS services

- Fewer than 1/3 of local agencies report that judges review a child's health plan when making decisions about that child's foster care placement.

Source: UCLA Health Services Assessment for Children in Foster Care

Organization of Services

Objective 10: Decrease the time between referral to CCS and receipt of CCS Services

- **In 53 counties, the average waiting times from referral to eligibility vary from 2 to 107 days, with an average of 50 days:**
  - **14% less than 25 days**
  - **39% between 26 and 50 days**
  - **8% between 51 and 75 days**
  - **17% between 76 or more**

Source: CMS Net

- **Many 'negative' time periods between 1st referral and eligibility determination**

- **In 54 counties, the average waiting times from referral to authorization vary from 55 to 227 days, with an average of 127 days:**
  - **26% between 55 and 98 days**
  - **41% between 99 and 141 days**
  - **24% between 142 and 184 days**
  - **9% between 185 and 227 days**

Objective 11. Decrease the time between referral to the Medical Therapy Program and receipt of MTP services

- Data not currently collected

Objective 12. Improve the uniform application of CCS authorization and referral policies across the state

Objective 13. Implement a system of standards of service delivery for all children with CCS medically eligible conditions regardless of payor source, including sharing of data.

Objective 14: Coordinate to develop and implement a system of timely referral between mental health and CCS systems for CCS eligible children.

- Children with CCS problems accessing mental health service
  Children who are CSS enrollees and MediCal beneficiaries are covered for specialty mental health services under terms of specialty mental health carve-out.
- Children with mental health problems in need of CCS services
  All county Mental Health Plans have MOU with a health plan. If child is eligible for CSS services, child should have a medical home, and mental health plan should be able to exchange information and share care with the health plan.

Transition to Adulthood

Objective 15: Increase capacity of local CCS programs to develop and implement transition plans for adolescents transitioning to adult services

- Over 90% of children with special health care needs now live to adulthood, but are less likely than their non-disabled peers to complete high school, attend college, or be employed.
- Health and health care are two of the major barriers to making successful transitions

Source: HRSA

- Out of the CCS cases active as of 3/15/05, there were a total of 2,746 clients 20 years of age. Within 52 CA counties, the percentages of these clients with insurance range from 1 to 100%, with an average of 24% having insurance

- The transition of youth to adulthood has become a priority issue nationwide, as evidenced by the President's 2002 "New Freedom Initiative"**

Source: *CCS Data, **HRSA

Rating the Issues / Objectives

Individuals Rate Objective Areas

Apply the criteria using the agreed upon scoring and weighting values.

Apply the criteria to the objective by:

- Determining the numeric “score” (1 to 5) for the criterion
- Multiplying the numeric score by the “weight” for that criterion, that is:

1 = Important
2 = Very important
3 = Extremely important

Example of individual scoring:

Issue / Objective	**CRITERIA** (Weight)		**TOTAL**
	Great impact on families (2)	**Addressing would increase equity** (3)	
Children have medical home	4 x 2 = 8	4 x 3 = 12	20
Family access to information	5 x 2 = 10	2 x 3 = 6	16

Scores are Summed to Produce a Group Ranking

Issue / Objective	PARTICIPANTS				TOTAL
	1	2	3	4	
Medical homes	16	12	9	6	**43**
Family access to information	10	10	6	12	**38**
Family partnership / satisfaction	4	6	12	8	**30**
Universal new-born hearing screening	20	15	12	15	**62**

Rank Objective Areas & Confirm Agreement

Highest Score = Top Ranked Problem

From previous example:

Universal new-born hearing screening	**62**
Medical homes	**38**
Family partnership / satisfaction	**36**
Universal new-born hearing screening	**30**

Appendix K

Family Health Outcomes Project

Proposed CCS Program Objectives for Priority Consideration at the Stakeholder Meeting, April 28, 2005

These objectives have been developed to address the problems identified through data, interviews, the Stakeholder breakout workgroups, and CCS staff.

Overarching Principle: Address disparity issues when developing strategies and tracking priority objective outcomes.

Medical Home

1. Increase number of family-centered medical homes for CSCHN and the number/% of CCS children who have a designated medical home.

Family Involvement and Satisfaction

2. Increase family access to educational information and information about accessing CCS services, including availability of and access to services offered by health plans

3. Increase family partnership in decision making and satisfaction with services

Screening

4. Increase the % of infants born in California who receive newborn hearing screening services

Insurance Coverage and Access to Care

5. Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists

6. Increase access of CCS children to preventive health care services (primary care, well child care, immunizations, screening) as recommended by the AAP

7. Increase access to CCS services by increasing the financial eligibility limit ($40,000 limit)

8. Increase access to services for CCS youth, 17-21 years of age

Organization of Services

9. Facilitate the timely referral of foster care children with CCS eligible medical conditions to CCS services

10. Decrease the time between referral to CCS and receipt of CCS services.

11. Decrease the time between referral to the Medical Therapy Program and receipt of MTP services

12. Improve the uniform application of CCS authorization and referral policies across the state

13. Implement a system of standards of service delivery for all children with CCS medically eligible conditions regardless of payor source, including sharing of data.

14. Coordinate to develop and implement a system of timely referral between mental health and CCS systems for CCS eligible children.

Transition to Adulthood

15. Increase capacity of local CCS programs to develop and implement transition plans for adolescents transitioning to adult services

CCS Stakeholder Criteria, Definitions and Rating Scales for prioritizing among identified CSHCN issues/objectives

(April 28, 2005)

1. **Criterion Name: Problem has great impact on families (quality of life, functionality)**
   Weight: **3**
   Definition/Concepts: This means that the child and the family's quality of life and functionality are affected by the problem. Examples are a parent cannot work; a child cannot go to school.
   Rating Scale: 3
   1= Problem is not affecting the quality of life or functionality of the family
   2= Problem is minimally or occasionally affecting the quality of life or functionality of the family
   3= Problem is moderately and/or frequently affecting the quality of life or functionality of the family
   4= Problem is negatively impacting the family's quality of life and functionality most of the time.
   5= Problem is severely negatively impacting the family's quality of life and functionality most or all of the time

2. **Criterion Name: Addressing the problem is important to consumers**
   Weight: 3
   Definition/Concepts: Addressing the problem is important to the recipients or potential recipients of services: child, siblings, parents, extended family
   Rating Scale:
   1= Addressing the problem is not important to consumers
   2= Addressing the problem is of some importance to consumers
   3= Addressing the problem is of moderate Importance to consumers
   4= Addressing the problem is important to consumers
   5= Addressing the problem is a very high priority for consumers

3. **Criterion Name: Problem results in great cost to program and/or society, there is a significant fiscal impact of not addressing it**
   Weight: 2
   Definition/Concepts: If problem is not addressed the result will be increased monetary costs, e.g., health care and/or social services costs to the CCS program or to society and loss of education and productivity of individuals because of chronic illness, disability or premature death.
   Rating Scale:
   1= Economic / societal cost is minimal
   2= There is some potential increased costs
   3= There is likely to be moderate increased costs
   4= There is likely to be substantial increased costs
   5= There will be great economic and societal cost

4. **Criterion Name: Addressing the problem maximizes opportunity to leverage resources and relationships for effective system change.**
   Weight: 2
   Definition/Concepts: There is opportunity for Agencies or Collaborative Partners to plan together or pool resources to address the problem and/or there is opportunity to build new relationships. Allows us to take advantage of opportunities to leverage resources and relationships to affect systems change
   Rating Scale:
   1= No known opportunity to collaborate
   2= There may be opportunities to collaborate
   3= There are opportunities to collaborate
   4= There are opportunities to collaborate and some collaboration is already occurring
   5= Major collaborative efforts are already underway

5. **Criterion Name: Addressing the problem would increase equity and fairness**
   Weight: 2
   Definition/Concepts: Definition/Concepts: This means that one or more population subgroups as defined by race/ethnicity, income, insurance status, gender or geography, diagnosis are more impacted than the general group. Addressing the problem or issues would promote equity and reduce disparities.
   Rating Scale:
   1= No group is disproportionately affected by the problem
   2= It appears that one or more groups is disproportionately affected by the problem, but differences are not statistically significant
   3= Statistically significant differences exist in one group
   4= Statistically significant differences exist in more than one group
   5= Very large statistically significant differences exist in one or more groups

6. **Criterion Name: There is likelihood of success. Problem is amenable to prevention or intervention, and/or there is political will to address it**
   Weight: 1
   Definition/Concepts: This means that there is a good chance that the strategies used to intervene in the identified problem will result in an improvement in outcomes. The intervention strategies are shown in research literature, by experts or by National, State or program experience to be effective or promising. The group also indicated this criterion would incorporate political will, e.g., the problem is a national or regional priority
   1= No known intervention available
   2= Promising intervention with limited impact (not effecting a wider array of problems), little political will
   3= Proven intervention with limited impact, moderate political will
   4= Promising or proven intervention with broad impact and moderate political will
   5= Proven intervention with broad impact and strong political will

CCS Stakeholder Issue/Objective Prioritization Rating Tool

Appendix M

CRITERION #1: PROBLEM HAS GREAT IMPACT ON FAMILIES (QUALITY OF LIFE, FUNCTIONALITY)	**CRITERION #5: ADDRESSING THE PROBLEM WILL INCREASE EQUITY AND FAIRNESS**
CRITERION #2: ADDRESSING PROBLEM IS IMPORTANT TO CONSUMERS	**CRITERION #6: LIKELIHOOD OF SUCCESS / AMMENABLE TO INTERVENTION AND POLITICAL WILL**
CRITERION #3: PROBLEM RESULTS IN GREAT COST TO PROGRAM AND/OR SOCIETY (FISCAL IMPACT)	
CRITERION #4: ADDRESSING PROBLEM MAXIMIZES OPPORTUNITY TO LEVERAGE RESOURCES	

Issue/Objective	**In the line below each criterion number (e.g. C1), the assigned weight is Then, For each issue area score each criterion (1 through 5) and multiply the score by the assigned weight. Add weighted criterion scores to obtain Total Score for Issue/objective.**								**Total Score For Issue / Objective**
	C1	**C2**	**C3**	**C4**	**C5**	**C6**			
	3	**3**	**2**	**2**	**2**	**1**			
1. Children have medical homes									
2. Families have educational and access to services information									
3. Family partnership in decision-making and satisfaction with services									
4. Newborns receive hearing screening services									
5. Access to qualified providers (#)									
6. Access to preventive health services (primary care, screening)									
7. Higher financial eligibility limit									
8. Access to services for youth ages 17-21									
9. Timely referral of foster care children to CCS									
10. Time between referral to and receipt of CCS services									

CCS Stakeholder Issue/Objective Prioritization Rating Tool

CRITERION #1: PROBLEM HAS GREAT IMPACT ON FAMILIES (QUALITY OF LIFE, FUNCTIONALITY)	**CRITERION #5: ADDRESSING THE PROBLEM WILL INCREASE EQUITY AND FAIRNESS**
CRITERION #2: ADDRESSING PROBLEM IS IMPORTANT TO CONSUMERS	**CRITERION #6: LIKELIHOOD OF SUCCESS / AMMENABLE TO INTERVENTION AND POLITICAL WILL**
CRITERION #3: PROBLEM RESULTS IN GREAT COST TO PROGRAM AND/OR SOCIETY (FISCAL IMPACT)	
CRITERION #4: ADDRESSING PROBLEM MAXIMIZES OPPORTUNITY TO LEVERAGE RESOURCES	

Issue / Objective	**In the line below each criterion number (e.g. C1), the assigned weight is Then, For each issue area, score each criterion (1 through 5) and multiply the score by the assigned weight. Add weighted criterion scores to obtain Total Score for Problem.**								**Total Score For Issue / Objective**
	C1	**C2**	**C3**	**C4**	**C5**	**C6**			
	3	**3**	**2**	**2**	**2**	**1**			
11. Time between referral to & receipt of Medical Therapy Program services									
12. Uniform application of CCS authorization and referral policies									
13. System of standards of service delivery (all payors and share data)									
14. Timely referral between mental health and CCS									
15. Local CCS program capacity to transition adolescents to adult services									
16.									
17.									
18.									
19.									
20.									
21.									

Appendix N

CCS Stakeholder's Priority Issue / Objective Rating Scores

Initials	Medical homes	Family access to information	Family partner-ship/ satisfaction	Newborn screening	Access to providers (#)	Acess to preventive health	Higher financial eligibility	Acess to services (17-21)	Referral of Foster Care children	Time between referral and receipt of services	Time between referral & receipt of MTP	Uniform application of auth & policies	System of standards of service	Coord. system of referrals to/from	Capacity to transition adol to adult services
ek	44	58	55	28	51	40	37	33	28	35	34	33	53	60	39
tk	59	39	39	24	61	40	28	43	26	37	29	47	39	40	44
	44	49	59	61	61	57	35	53	40	44	33	35	33	43	49
ct	50	50	51	46	54	53	50	47	48	49	46	37	37	45	45
mu	30	29	38	35	46	41	35	34	44	58	51	61	63	64	33
tb	54	51	50	48	61	62	47	54	46	50	46	50	49	49	51
da	43	54	38	39	58	58	40	70	48	55	54	49	36	46	53
hh	29	43	38	40	55	56	52	51	44	37	43	48	30	48	48
sr	58	51	45	59	40	51	42	46	45	45	42	35	45	55	35
ps	48	34	26	50	63	29	48	56	61	36	39	56	54	49	56
	53	41	36	36	50	52	37	42	48	45	45	38	60	55	44
	33	38	48	37	56	31	37	35	36	40	27	37	28	46	43
	50	59	40	31	62	41	39	36	42	43	36	58	49	44	34
ml	49	47	37	52	53	43	39	41	47	50	37	41	48	53	34
fm	45	37	36	31	41	35	36	35	29	34	34	31	38	39	32
ks	41	40	32	36	53	36	33	51	35	39	34	29	33	50	47
jd	63	63	63	17	63	63	14	64	64	64	63	63	63	65	65
	45	40	36	57	62	62	34	46	45	59	50	31	29	55	45
	51	39	40	39	42	33	31	35	33	32	34	36	35	31	28
	41	46	52	49	60	39	36	51	47	36	38	36	55	45	45
ew	53	51	53	36	55	44	53	46	47	51	49	29	43	54	46
las	50	58	56	33	53	52	37	46	58	52	37	54	60	52	56
Totals	1033	1017	968	884	1200	1018	840	1015	961	991	901	934	980	1088	972

California Children's Services (CCS) Title V Stakeholders Meeting
Priority Objectives (Ranked Scores)
April 28, 2005

Overarching Principles:

- CCS will address disparity issues when developing strategies and tracking priority objective outcomes.

- The CCS program shall ensure that children with CCS eligible health care needs have access to and receive services from appropriately trained pediatric providers and shall develop and apply standards of care intended to lower morbidity and mortality rates among eligible children.

Rank	Score	Proposed Objective
1	1200	Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists, and nutritionists
2	1088	Coordinate to develop and implement a system of timely referral between mental health, developmental services, social services, special education services and CCS
3	1033	Increase number of family-centered medical homes for CSCHN and the number / % of CCS children who have a designated medical home
4	1018	Increase access of CCS children to preventive health care services (primary care providers, well child care, immunizations, screening) as recommended by the AAP
4	1017	Increase family access to educational information and information about accessing CCS services, including availability of and access to services offered by health plans
4	1015	Increase access to services for CCS youth, 17-21 years of age
5	991	Decrease the time between referral to CCS and receipt of CCS services
6	980	Implement a system of standards of service delivery for all children with CCS medically eligible conditions regardless of payor source, including sharing of data
7	972	Increase capacity of local CCS programs to develop and implement transition plans for adolescents transitioning to adult services
8	968	Increase family partnership in decision-making and satisfaction with services
9	961	Facilitate the timely referral of foster care children with CCS eligible medical conditions to CCS services
10	934	Improve the uniform application of CCS authorization and referral policies across the state
11	901	Decrease the time between referral to the Medical Therapy Program and receipt of MTP services
12	884	Increase the % of infants born in California who receive newborn hearing screening services
13	840	Increase access to CCS services by increasing the financial eligibility limit ($40,000 limit)

Data Development Notes from
CCS Title V Needs Assessment Stakeholder Meeting
April 28, 2005

Stakeholders were asked to identify data issues and data development recommendations relevant to the priority objectives identified during the priority-setting portion of the meeting. At the conclusion of this discussion, ***it was agreed that the first CCS data development step will be to develop a matrix of data available for children covered by CMS/CCS*** *(Troy Jacobs offered to assist with this process)*.

The three priority objectives identified by the group were:

- Expand the number of qualified providers participating in the CCS program, e.g., medical specialists, audiologists, occupational and physical therapists and nutritionists
- Coordinate to develop and implement a system of timely referral between mental health, developmental services, social services, special education services and CCS
- Increase the number of family-centered medical homes for CSHCN and the number/% of CCS children who have a designated medical home

The group's input on data development issues and recommendations relevant to these priorities is documented below. Other comments (made verbally and in written notes) were collected during the meeting and have also been included in the data issues/development sections below.

Assessing Access to Providers

- Availability of providers (paneled and non-paneled) by county and by region (use health care region) broken down by sub-specialties and how many paneled providers are accepting CCS enrolled children
- Assess need vs. availability of providers (paneled and non-paneled, by county and by health care region): number of CCS children, diagnostic breakdown, number of providers by pediatric specialty, number of orthodontists, etc.
- Clean up the provider list so the data becomes meaningful – eliminate dead, moved, retired providers from the list; identify the providers that are taking new patients
- Send approved providers copies of their CCS applications annually to have them review and update their information (e.g., address, specialties, accepting patients)
- Restructure CCS-paneled provider data base (Counties in rows, types of providers in columns – use standardized provider types across all counties)
- Collect/enable analysis of event vs. person data

- In progress – Business Objects to help access data. Need user friendly access, by county
- Assess waiting times between referral, eligibility determination, authorization and services received
- Map flow patterns of where children go to receive care (can get from OSHPD data set for hospitalizations, claims paid data (*Tom Klitzner* offered to help with methods)
- Track barriers to provider access. Can local programs identify problem areas with access? Can CMS keep track of these?
- Collect complaints data
- Implement survey to assess CCS clients' satisfaction with providers, such as the CAHPS survey questions for CSHCN
- Quality of care data, mortality statistics need to be looked at when considering lowering standards to increase provider participation

Developing a Coordinated System of Timely Referrals Among Programs Serving CCS Children

- Develop a MATRIX of available data across existing CSHCN programs (*Troy Jacobs*, offered to help with developing the method/matrix for obtaining this information)
- Link data across programs, i.e., track CCS children across systems. Work towards establishing common program fields across state programs – *Juno Duenas* may be helpful. Use identifying information. Consider using a uniform confidentiality form across programs.
- Look at other states and see what they do to collect data across programs

Assessing Access and Function of a Medical Home

- Need to define medical home; who decides; levels; types of medical home, services medical home provides. Use and compare continuity of care scores for children in medical homes – and those not in medical homes
- Agree upon and institute a consistent definition of medical home, consistent recording of information across counties
- Important once definition is established to get baseline data on "medical home" in order to monitor progress towards accomplishment of the medical home objective
- How many CCS children/adolescents have an AAP medical home?
- Make sure that those who are authorized as medical home providers know what they are supposed to be doing
- How are counties completing the "medical home" field? Make it a required field
- Every system should be required to identify the patient's medical home
- Use connections with other state groups to work on establishing medical homes
- Monitor whether/when children get comprehensive assessments

- Medical Home: roundtables to do case management across medical homes – collect data via roundtables
- Medical Home index
- Continuity of care scores
- Problem of tracking patients as they change medical homes
- Collect / Analyze data regarding medical homes and related outcomes: school attendance, lost days of work by parents, hospitalizations and re-hospitalization; need *baseline data* first
- Consider using the national medical home survey questions to gather California data – may help guide counties to ask appropriate questions

<u>Data on Children with Special Health Care Needs (CSHCN)</u>

- Explore possibility of Increasing California sample size for National CSHCN SURVEY
- Get data support (data, demonstration funds) from federal MCH – look across CSHCN diagnostic and eligibility criteria

<u>Overarching and Other Data Development Concerns and Recommendations</u>

- CMS Net data should be collected and analyzed by age and race
- Assess accuracy of diagnostic codes / how to increase accuracy
- Need accurate numbers of pediatric specialists (total vs. paneled)
- Assess duplication of patient data
- Need data on CSHCN from health plans—can we get it?
- Need to document other types of service-related data available, e.g., various audits to document care and provider surveys
- Need data regarding provision of non-CCS services by providers
- Clarify encounter data in both fee-for-service and capitated delivery systems – look at encounter data in Medi-Cal Managed Care (MCMC)
- Look to “outside” agencies for assistance in collecting data (e.g., MCMC, Specialists, AAP, Children’s Hospitals)
- Look at what/how data is collected across programs in other States
- Collect and analyze all data by counties / jurisdictions to extent possible
- What % of children in Healthy Families has CCS vs. what % of children in Medi-Cal has CCS coverage? Is the Healthy Families population underrepresented in CCS? Are providers making referrals to CCS?