

## Data Sources used in the CCS Needs Assessment 2010

### FHOP Web-based Surveys

With input from Stakeholders, FHOP designed four web-based surveys: FHOP Survey of CCS Families; FHOP Survey of Physicians; FHOP Survey of Hospitals, Health Plans, and County CCS Programs; and FHOP Survey of DME Providers. The family survey was available in Spanish and English and wording for most of the questions from this survey were taken from either the Family Voices Survey or the National Survey of Children with Special Health Care Needs. The survey links were distributed to Stakeholders to send through the relevant networks. Survey responses were collected in April 2010.

### 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
- Family-centeredness of child's health care
- Care coordination
- Impact of child's health on family activities, finances, and employment
- Adequacy of health insurance to cover needed services

In 2005/2006, there were several new topics and questions, such as: revised and improved care coordination questions; improved section on transition to adulthood; primary language spoken in the home; unmet need for interpreters during health care visits; number of ER visits; use of specific health care services; and reasons for difficulty using community-based 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 1,303 interviews were completed in California (up from 759 in 2001), the sample size 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 2005–2006*. Rockville, Maryland: U.S. Department of Health and Human Services, 2008.)

Data on selected indicators is presented from California and comparing California with the nation. (Source: Child and Adolescent Health Measurement Initiative. 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. [www.cshcndata.org](http://www.cshcndata.org))

### 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).

CMS Net was used for:

- Active Cases by Diagnosis through 4/12/2010
- Deaths among CCS clients 2008 and 2009
- Maps of CCS Cases and Payer types
- % of children who require Special Care Center (SCC) services that are authorized to SCC by county for the following diagnoses: Acute Lymphoid Leukemia (ALL), Brain Cancer, Cleft Lip & Palate, Congenital Heart Disease, Cystic Fibrosis, Hearing Loss, Hemophilia
- Primary Care Physician Address Data by County
- Time from Referral to CCS (new client) until Case is Opened
- Time from receipt of referral to CCS until entered into system
- Times from referral to CCS to first authorization for CCS services
- Time from service authorization request until services are authorized
- Time from service authorization request for wheel chair until authorized
- Time from service authorization request for hematology/oncology services until authorized
- Time from service authorization request for home health agency services until authorized

Los Angeles was in the process of migrating to CMS Net during the needs assessment process. Other than the data on active cases by diagnosis and primary care physician data, the Los Angeles data that was available was obtained from LA Automated Case Management System.

### Claims Paid Data

- CCS Expenditures 1998-2009 Charts
- CCS Highest Cost Condition Charts

### 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.

### **California Title V Application 2010**

- Newborn Metabolic Screening Data
- Newborn Hearing Screening Data

Prior to 2005 all newborns were screened for Phenylketonurea, Congenital hypothyroidism, galactosemia and sickle Cell disease. In 2005, congenital adrenal hyperplasia, and non-PKU inborn errors of metabolism tested by tandem mass spectrometry were added. In July 2007, cystic fibrosis and biotinidase deficiency were added.

#### Other Sources of Information:

#### **California Health Care Foundation. 2009. *Assessing the California Children's Services Program. Issue Brief.***

This issue brief was prepared by the California Health Care Foundation to assist the state of California as it considers restructuring the CCS program. The brief provides an overview of the CCS program, including policy regarding eligibility and coverage, program administration and financing, the service delivery system, the number of children enrolled and the characteristics of these children, and the cost and expenditure trends.

**Children's Specialty Care Coalition's Survey** of 14 medical groups based at the regional pediatric tertiary centers and are members of the Coalition. Survey focused on specialist shortages and the number open positions and time those positions have been open as well as average wait time for non-urgent specialty care. Data were made available from the Children's Specialty Care Coalition.

Health Management and Associates. 2009. *Considerations for Redesign of the California Children's Services (CCS) Program.* Report prepared for the State of California.

This paper was developed to provide the state of California with technical assistance as it considers options for redesigning the CCS program as part of the renewal of the State's Medicaid 1115 Hospital/Uninsured Waiver. The paper is based on interviews with 60 CCS stakeholders from around the state. It discusses the challenges facing the CCS program, and explores 4 options for redesign: 1) have CCS conditions covered by Medi-Cal managed care and Healthy Families health plans; 2) continue to include children with CCS-eligible time-limited conditions in the CCS program, but for CCS children who are Medi-Cal or Healthy Families eligible, enroll these children into Medi-Cal managed care or Healthy Families health plans and have the plans responsible for treating these conditions; 3) dis-enroll CCS children with complex, chronic conditions from existing Medi-Cal managed care health plans and Healthy Families health plans (so that there is an opportunity to structure a specialty health plan or medical home/special care center for these children that covers the whole child); and 4) Dis-enroll (carve out) all CCS children (including children with time-limited conditions) from existing Medi-Cal managed care and Healthy Families health plans.

Inkelas M, Samson K. *Specialty Health Care for Children in the Los Angeles California Children's Services Program (CCS) Report*. UCLA Center for Healthier Children, Families and Communities. 2005.

This report presents results from the 2005 Los Angeles CCS Survey. The survey addresses health care needs and access to health care for children in the LA CCS program. The indicators of health care access in the survey include: access to specialty care, delayed and missed care, access to a medical home, family centered care, care coordination, health insurance, access to transition services for adolescents, and experiences with CCS. The questions were asked of a random sample of parents of 2,000 children in the LA CCS program and the questionnaires were translated into Spanish. The response rate was 71.9%. Subgroups are compared by type of insurance coverage, activities affected by condition, parent education, child's race/ethnicity, child's age, and usual source of care, and the LA CCS results are compared to the California NS-CSHCN 2001 results. Results are presented in tables, figures, and text, and comparisons are statistically significant ( $p < 0.05$ ) unless otherwise indicated.

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.

Additional data and information came from the following webinars that FHOP scheduled (see [http://fhop.ucsf.edu/fhop/htm/ca\\_mcah/title\\_v/cshcn\\_t5\\_new.htm](http://fhop.ucsf.edu/fhop/htm/ca_mcah/title_v/cshcn_t5_new.htm) of links to webinars) for the CCS Needs Assessment Stakeholders:

- Melissa Rowan from HMA on the report "Considerations for Redesign of the California Children's Services Program."
- Data Snapshots of the CCS Program: Status of Federal Core Performance Measures and Access to Durable Medical Equipment" with Laurie Soman and Mara McGrath.
- Kathy Smith, RN, MN, on "The State of Children with Special Health Care Needs in California."
- "Benefits of Care Coordination for Children with Complex Disease: A Pilot Medical Home Project in a Resident Teaching Clinic" with Tom Klitzner, MD.

- "Transition issues for youth with special health care needs" with Clarissa Kripke, MD.
- Paul Wise, MD "Critical Issues in Redesigning the Care for Children with Chronic Illness: New Evidence from California and Around the Nation."
- Treeby Brown from the Association of Maternal and Child Health Programs: "Models of Care for Children and Youth with Special Health Care Needs: Promising Models for Transforming California's System of Care."