

CCS: The Nation's First Program for Children with Special Health Care Needs

Laurie A. Soman
Lucile Packard Children's Hospital
CRISS

Birth of CCS Program

- CCS Program Established in 1927 for “Orthopedically Handicapping Conditions”
- “CCS” Originally “Crippled Children’s Services”
- Response to Polio Epidemic of 1900-1960
- Designed to Protect Middle Class Families from Financial Catastrophe from Medical Costs
- Federal Social Security Act Title V Established in 1935
- Program Name Changed to “California Children’s Services” in 1982
- Until 1982 CCS Income Ceiling Was **\$100,000/year**

What Is CCS?

- Addresses Acute or Chronic Medical Conditions, e.g.
 - Cancer
 - Congenital Heart Disease
 - Hemophilia
 - Sickle Cell Disease
 - Infectious Diseases
 - Cerebral Palsy
 - Spina Bifida
 - Cystic Fibrosis
- Conditions Added Over Years Since 1927, Often by Legislation or Regulation
- Does Not Cover Typical Primary Care
- Does Not Cover Developmental Delay/Disability
- Will Cover Mental Health Services as They Relate to Eligible Medical Condition

What Is CCS?

- CCS Provides Children and Families with:
 - ✓ Diagnostic and Treatment Services for Eligible Conditions
 - ✓ Medical Case Management
 - ✓ Physical and Occupational Therapy
- Two Wings of Program
 - ✓ Treatment Program: Diagnostic and Treatment Services for Medically Eligible Condition
 - ✓ Medical Therapy Program: Physical and Occupational Therapy for Eligible Conditions, including at School Sites

Why CCS Case Management?

- Assures that CCS Children and Families Get “Right Care at the Right Place at the Right Time”
- Built on Statewide Network of Approved Pediatric Providers, Hospitals, and Special Care Centers
- Authorizes and Pays for Health Care for Treatment of Medically Eligible Condition or Complications of Condition
- Tailors Authorizations to Specific Needs of Child and Family
- Coordinates with Special Education, Regional Centers, Medi-Cal Managed Care Plans, and Others

Who Are CCS Children?

- Program Caseload
 - ✓ ~175,000 Children/Youth Aged 0-21
- Income/Insurance Status
 - ✓ ~90%: Medi-Cal (including former Healthy Families-eligible children)
 - ✓ ~10% No insurance or underinsured

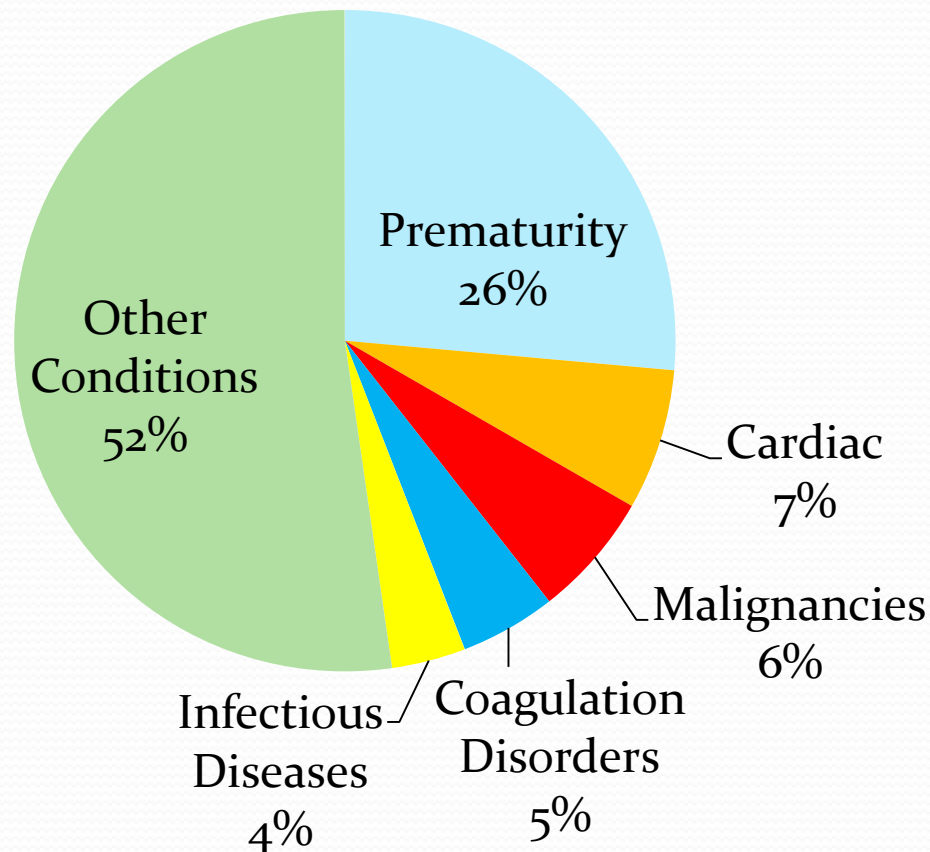
Who Are CCS Children?

- Top 5 Medical Conditions (2010*):
 - ✓ Congenital Heart Disease (16,750 cases)
 - ✓ Hearing Loss (14,093)
 - ✓ Cerebral Palsy (13,772)
 - ✓ Diabetes (6,700)
 - ✓ Malignancy (6,165)
 - ✓ Top conditions = 1/3 of total caseload for 2010
- Age Spread (2010*)
 - ✓ Largest Single Age Group 0-1 Year Olds
 - ✓ After 3 Years of Age, Numbers Fairly Stable Across Ages

* Data from presentation by Dr. Marian Dalsey, Children's Medical Services, 2/9/10

Percentage of CCS Medi-Cal Expenditures by Medical Condition

Total Expenditures \$1.69 Billion -- FY 2008-09



* Data from presentation by Dr. Marian Dalsey, Children's Medical Services, 2/9/10

Who Are CCS Children?

- Program Costs: \$1.8 Billion/Year (2010*)
 - ✓ Some children very expensive: 10% of CCS enrollees = 72% of CCS patient care expenditures^
 - ✓ Most children are not: 50% of CCS enrollees= 2% of CCS patient care expenditures^
- Overlap with Other Systems (e.g. Mental Health, Regional Center, Special Education, Foster Care)
 - ✓ We know many CCS children are served by other systems, but numbers are hard to find

* Data from presentation by Dr. Marian Dalsey, Children's Medical Services, 2/9/10

^ Data from Center for Policy, Outcomes and Prevention, Stanford, 11/13

CCS Sets State Pediatric Standards

- CCS Standards Drive California's Statewide Pediatric System of Care
- State CCS Develops State Standards for Pediatric Providers, Hospitals, and Special Care Centers
 - ✓ Panels Individual Providers
 - ✓ Approves Special Care Centers
 - ✓ Approves NICUs, PICUs, and Hospitals
- Quality Data Collected on NICUs
- Quality Data Now Being Collected on PICUs

Why Are Statewide Pediatric Standards Important?

- Children with serious and/or rare medical conditions have better outcomes when treated by providers and hospitals with pediatric expertise.
- High volume of cases treated leads to better outcomes. Only specialized pediatric centers see the number of many children's conditions needed to reach volume thresholds for quality.
- Children are not short adults; they and their families need access to physically, developmentally, and socially appropriate services and facilities.
- State CCS standards help to enforce and maintain the statewide system of care that ensures access to pediatric expertise, quality outcomes, and child- and family-centered care.

CCS and Medi-Cal Managed Care

- State Medi-Cal Managed Care Roll-Out Began 1994
- CCS Carved Out from Medi-Cal Managed Care via Specific Legislation: SB 1371 (Bergeson), 1994
- CCS Carve-in Counties
 - ✓ Permitted under SB 1371 or added shortly after
 - ✓ Marin, Napa, San Mateo, Santa Barbara, Solano, and Yolo
- CCS Carve-out Counties
 - ✓ Rest of State Has CCS Carve-Out from Managed Care
 - ✓ Includes Counties New to Medi-Cal Managed Care
- Current CCS Carve-Out
 - ✓ Ends December 31, 2015
 - ✓ More to come.....



In 1952 the Social Security Administrator for the United States wrote (with 1952 terminology):

“One of the best tests of a civilization is its concern for its handicapped members, and particularly for its handicapped children.”

This is still true.

For More Information

- CCS Program, Department of Health Care Services:
<http://www.dhcs.ca.gov/services/ccs/Pages/default.aspx>
- Center for Policy, Outcomes and Prevention at Stanford:
<http://pediatrics.stanford.edu/cpop/>
- Lucile Packard Foundation for Children's Health Program
for Children with Special Health Care Needs:
<http://lpfch-cshcn.org/advocacy/>