CCS Advocates Memo to DHCS

April 2016

The purpose of the memo is to highlight select CCS Advocates’ feedback and recommendations on key topics related to the proposed CCS redesign.

- On November 30, 2015, a group of CCS advocates (LPFCH, Alameda County and San Mateo CCS Programs, Children’s Specialty Care Coalition, CCHA, AAP-CA, Support for Families) met to discuss and develop an outline of key issues in preparation for a face-to-face meeting with DHCS to discuss these issues. The outline was sent to DHCS in advance.

- The CCS advocates highlighted several recommendations for the CCS redesign related to (1) clinical quality, practice and utilization management standards; (2) access and continuity of care; (3) family participation; (4) monitoring; and (5) CCS rates.

- Many of these issues were discussed with DHCS Director, Jennifer Kent, on December 5, 2015, and the original memo was revised subsequent to that discussion.

- Some of these recommendation address circumstances in which the care of CCS-enrolled children and youth is contracted to health plans, while others address opportunities to improve the care of those enrollees regardless of the system of care and financing.

Program Standards:

Participants recommended that the CCS redesign include the development and implementation of uniform clinical quality, utilization review and other program standards that all participating health plans are subject to, rather than allow individual health plans to institute unique practices and standards. Specifically, this included:

a. Existing statewide CCS practice standards and clinical policies and procedures that govern utilization decisions (i.e., CCS Program regulations, CCS Program Numbered Letters, CCS Program Information Notices, the CCS Program’s This Computes! announcements, and any legislative policy changes as applicable) would guide plan authorization decisions. Health plans shall use CCS Guidelines where they exist. These Guidelines shall take precedence even when they are more general and permissive than the evidence-based clinical guidelines used by health plans. In the absence of relevant CCS guidelines, protocols and clinical policies from national pediatric and pediatric subspecialty organizations and other evidence-based clinical guidelines shall be used to guide care coordination and utilization management policies. Federal Medicaid definitions of medical necessity shall apply.

b. Ensure access to the most appropriate and efficacious medically necessary drugs, including compounded medications, specialized pediatric (liquid) formulations, and over-the-counter products for management of the CCS-eligible condition. Provide a minimum of one year continuity of drug therapy for CCS children transitioning into health plans. Changes in
medications should be made only on the recommendation of the child’s personal physicians. Notwithstanding provisions for continuity, provide families with at least 90 days’ notice of intended changes of medication use or formulation.

c. Maintain a standardized and separate CCS drug formulary and related process.

d. Automatic state/local CCS program review of any plan denials of CCS services for medical necessity

e. Minimum professional qualifications for CCS care coordinators/case managers to which all health plans must adhere; care coordination/case management teams should include licensed RNs or PHNs and medical social workers.

f. Require that all health plans employ or contract with a pediatric physician who is certified by the American Board of Pediatrics and CCS empaneled to review all denials of service prior to issuing that decision, and who will meet regularly with the local and/or state CCS medical director to review cases and programmatic issues in order to ensure health plan compliance with CCS standards and policies.

g. Contract with county/state CCS staff to perform utilization review and care management functions during the initial phase of the whole child model.

h. Assure that CCS enrollees and their families are aware of their rights of appeal in terms of eligibility and denials of service when they are informed of their transition to health plans, and they are informed a minimum of 6 months in advance of transition.

Provider Network and Continuity of Care:

Advocates highlighted CCS-specific requirements to ensure adequate provider networks, access to care and continuity of care, including:

a. Ensure that access standards for pediatric specialty care are enforced.

b. Payment rates must be adequate to recruit and retain qualified providers with appropriate expertise.

c. Develop specific access, timeliness, and accountability standards around DME to ensure that CCS children are able to function maximally.

d. Assign each CCS beneficiary to a medical home that includes a developmental pediatrician. Encourage or otherwise provide incentives to plans to augment rates to CCS providers who provide a certified PCMH.

e. Require health plans to provide CCS members with provider and medication continuity for the duration of the CCS condition. A CCS provider who does not contract with the health plan but who is treating a CCS child pursuant to continuity of care will be paid at a minimum the existing CCS provider payment rate.

f. Support and train families to do care coordination for their child, as evidence shows that self-management supports for chronic health conditions are likely to be cost saving.

g. Include coordination with community services providers and programs outside of medical care providers as part of care coordination system.
h. Maintain a separate actuarially-sound health plan rate for CCS children, rather than employing a blended plan rate.

i. Health plans shall cover second opinions requested by patients or their families.

**Family Partnership:**

Participants emphasized the importance of ongoing family participation in the CCS program at the state, local and health plan levels. Key recommendations included the following:

a. There should be a “system” of family input. This includes families getting information, education and support at the local level to assist them in working with professionals in the care of their child, as well as building their capacity to partner at the local level and state level, (such as being on a local plan advisory group). CA is a big state and the state should support a network of informed, educated and supported families to give input at local and state level.

b. Require health plans to contract with local FRCs to provide family liaisons/navigators in all counties, such as programs in Alameda County and Rhode Island.

c. Require health plans to contract with local FRCs to provide information and education and ongoing support to families who can serve on the family advisory committee, whose meeting intervals and responsibilities will be outlined with input from family agencies and advocates.

d. In addition to or in place of the current CCS Advisory Group, create a new statewide advisory committee consisting of health plan family advisory committee members, advocates and family member agencies to interface with DHCS staff who have authority to address state issues.

e. Annually survey families about their experiences with each health plan, using instruments designed to assess circumstances unique to families with children with chronic health problems, including access to care, quality of care, the receipt of family-centered care, transition planning and care coordination in addition to CAHPS.

**Monitoring:**

Participants also proposed several specific monitoring activities to ensure adherence to CCS program requirements, including:

a. Develop a new CCS monitoring tool to assess health plan compliance with CCS standards, including Special Care Center Access, network adequacy, medical home access and participation, completion of a CCS care plan for all children and transition plans for children older than 14, convening family advisory committees, selected clinical outcomes and appeal rates.

b. Develop or adopt quality of care measurements specific to the needs of CSHCN and their families with input from advocates and family agencies.

c. Make DHCS audits and monitoring results as well as corrective action plans available online within a reasonable period of time after audits are complete.

d. Quality oversight processes for Special Care Centers should be comparable in terms of content specificity and frequency to those used for NICU/PICU.