

Children's Regional Integrated Service System

American Academy of Pediatrics, CA Dist.
California Children's Hospital Association
CARE Parent Network
CCS Programs: Alameda, Butte, Colusa, Contra Costa, El Dorado, Glenn, Humboldt, Marin, Mendocino, Napa, Placer, Sacramento, San Francisco, San Joaquin, San Mateo, Santa Clara, Santa Cruz, Shasta, Solano, Sonoma, Stanislaus, Sutter, Tehama, Yolo and Yuba
Children's Hospital Oakland
Children's Specialty Care Coalition
Colusa County FRC
Community Gatepath Family Resource Network of Alameda County
Family Resource Network of San Joaquin County
Family Voices of California
Lucile Packard Children's Hospital Matrix Parent Network and Resource Center
Parents Helping Parents
Peaks and Valleys
Rowell Family Empowerment of No CA
Safe Passage FRC
Santa Clara Valley Health and Hospital System
Support for Families of Children with Disabilities
Sutter County Parent Network
Sutter Medical Center
UC Davis Medical Ctr.
UCSF Children's Hospital
WarmLine FRC
Yuba County FRN

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David Maxwell-Jolly, PhD, Director
California Department of Health Care Services

Melissa Rowan, Senior Consultant
Health Management Associates

RE: CCS Stakeholder Discussion Guide

Dear Dr. Maxwell-Jolly and Ms. Rowan:

We are writing on behalf of the Children's Regional Integrated Service System (CRISS) to convey our comments regarding the CCS stakeholder process. CRISS is a collaborative of family support organizations, pediatric hospitals and provider groups, and county CCS programs in a 25-county region in Northern California. A number of our members are participating in the stakeholder interview process, but as a coalition with membership from the three major constituent groups (families, pediatric providers and county CCS programs), we feel that our collective comments also should be part of the process.

For more than a decade CRISS has worked to identify the ways in which the CCS program works effectively and to strengthen those characteristics, as well as to identify the ways in which the program does not function effectively and to develop workable solutions to address those problems. We have a successful track record in both regards and have been cited as an effective organization in a number of reports looking at the organization of services for children with special health care needs (CSHCN) and the CCS program specifically.¹ Most recently we were pleased to see Valerie Lewis's presentation on her interviews with CCS stakeholders recognize that the CRISS region (the greater Bay Area) is more effective at reducing problems with CCS such as inter-county variation in eligibility and authorizations. We believe this is in great part because CRISS functions as an ongoing stakeholder process for the CCS program that includes the three groups of people with the greatest knowledge about these children and families and the services they need.

We have looked at the Discussion Guide, bringing to it our many years of experience with systems of health care delivery for children with complex medical conditions, and have the following comments and recommendations.

Process Assumptions: Basic Principles of Care for Children with Special Health Care Needs

We believe that it is helpful to structure the discussion on basic principles, i.e. the underlying principles that should guide the development and implementation of any system designed for children with complex, potentially disabling and/or life-threatening conditions. The basic principles we support for children with CCS conditions include:

- All health care delivery to children, particularly children with special health care needs (CSHCN), should be based on and flow from their medical and related needs. The medical necessity definition and standards of care for all children, including CSHCN, should reflect sound pediatric principles and address children's health, developmental, social and behavioral needs. This medical necessity definition should be based on the EPSDT standard: Children shall receive all diagnostic or treatment

¹ See, for example, Hansel and Reifman, California's Broken System for Caring for Children with Special Health Care Needs, Senate Office of Research, 2000.

services to correct or ameliorate defects and physical and mental illness and conditions. Services must be covered if they correct, compensate for, or improve a condition, or prevent a condition from worsening, even if the condition cannot be prevented or cured. These services shall include all those listed in federal Medicaid statute, whether or not they are covered under California's state plan. The determination that a service is medically necessary shall lie primarily with the child's treating physician or other health care provider.

- Children should have access to medically and developmentally appropriate care regardless of their geographic region. The literature is clear that regionalized pediatric care is efficient and cost-effective.² County-based systems of care that limit access to pediatric or other appropriate providers are not acceptable for CSHCN. Children should retain access to regionalized pediatric health care systems for CCS-approved neonatal, pediatric intensive care, and other pediatric specialty care.
- CSHCN should have clearly identified medical homes including primary care providers, pediatric sub-specialists and care coordination. Families should have the ability to exercise choice in selecting providers, contingent on providers' meeting pediatric credentialing standards.
- Provider networks should include all pediatric sub-specialties, pediatric hospitals, child-appropriate DME and other supply vendors, and other pediatric-appropriate services. Providers should meet clearly established standards for credentialing that reflect pediatric training and experience.
- The benefit package for children should be broad and representative of children's needs, including appropriate medical, dental, developmental, behavioral, and rehabilitative services; pharmaceuticals; DME and medical supplies; and ancillary services. Care coordination should be a recognized component of service delivery to CSHCN.
- Managed care plans seeking to enroll CSHCN should be designed specifically for this population. There is no evidence that traditional managed care plans, designed for a routine, healthy population, are equipped to serve children with complex, chronic, multi-system, and expensive needs. Managed care expansion should not take place until specific evidence is available regarding the impact of managed care on children with special health care needs in terms of quality and access.
- Financing of health care delivery to CSHCN should recognize their special needs:
 - Children's access to health care should not be hindered by inadequate reimbursement to providers. Fee-for-service systems should reimburse at rates that reflect actual costs of care. Fee-for-service reimbursement should include the capacity to cover pediatric services beyond typical medical care (e.g. office visits) such as care coordination.
 - Capitated systems should have capitation rates that are risk-adjusted to reflect actual costs of care. Rates should include additional services such as care coordination. Capitated systems should not include risk to providers (thus removing financial disincentives to provision of necessary care) and should avoid full risk to plans through strategies such as reinsurance or risk-sharing with the state (such as the current CCS carve-out).

For all its flaws, the CCS program aligns with these principles and does result in children with complex conditions reaching the pediatric sub-specialty care they need in a timely manner. Any redesign of CCS should be based on adherence to these basic principles.

² See, for example, Tilford et al, Pediatrics Vol. 106, No. 2, August 2000, pp. 289-294; Richardson et al, Pediatrics Vol. 96, No. 3, September 1995, pp. 417-423; Chang and Klitzner, Pediatrics Vol. 109, No. 2, Feb 2002, pp.173-181

Carve-Out Options: Questions 1-3

Of the four options offered in the Discussion Guide, Option 3 makes the most sense to us, as it would draw on the strengths of the existing CCS program. Many people in the field have noted that there are children whose time-limited conditions may not require the most important elements of the CCS program-- treatment planning for complex conditions, care coordination among potentially multiple providers, and medical case management. It's likely that these children would do fine outside of the CCS program, assuming, of course, that they have insurance coverage that ensures that they receive appropriate and timely pediatric specialty care. This is an important assumption, but beyond the scope of the CCS program or this stakeholder discussion. We also like the idea of a "whole child" carve-out for children with complex conditions, as we believe it makes more sense for the child to be served in a single system. Given that by definition this population of children has complicated medical conditions, it is vital that the single system in this case be one that is driven by care of special health care needs, rather than by access to primary care, as in traditional managed care.

Options 1 and 4 make no sense to us at all. Option 1 turns the concept of the CCS program on its head (limiting CCS to treatment of children with time-limited conditions who, as discussed above, probably won't make use of CCS's most effective and specialized elements) and creating a new "specialty" health plan or network, something the CCS program already has in place to a great extent. Option 4 is simply untenable for children with complex medical conditions. As we have noted many times, and as the literature supports, there is no evidence that traditional managed care plans can do a better job than a program like CCS that has the focus and expertise to address children's special needs.³ California has not conducted any in-depth evaluations of the impact of carved-in CCS services in the five counties that currently have that arrangement. Experience with a managed care CCS carve-in is variable; problems with timely authorization of health care and provider payment are prevalent in some systems, while others work well without significant problems in either client services or provider payment. These exceptions notwithstanding, in our view, CSHCN are simply too small a population to get the special attention they need in a traditional plan, while at the same time, their unpredictability and high expense upset traditional risk arrangements. For these reasons, we oppose the idea of moving children with CCS conditions into traditional ("regular") managed care plans for their whole-child care.

Comprehensive Changes to the CCS Program: Questions 4-19

We agree that it makes sense to look at the CCS program as a whole and to consider fundamental ways in which it can be restructured so that it is more effective for children and families and easier to use for providers. We believe that ideas for comprehensive changes should recognize and build on what works well in the CCS program now:

- statewide quality standards for CSHCN that set the standards for all pediatric specialty care in the state;
- creation of a network of paneled providers and approved facilities and programs;
- efficient identification and referral of children with CCS conditions;
- identification of appropriate treatment options and development of an individual treatment plan;
- authorization of specialty services by approved providers, according to the treatment plan, based on the most appropriate care, and regardless of the geographic location of the service;
- monitoring of children's receipt of authorized services;
- attention to provision of family-centered care, including, at least in some counties, contracts with local family support organizations for parent health liaisons and other family-centered activities;
- risk arrangements that protect children's access to care (i.e. no fiscal disincentive to access);

³ See, for example, Aizer et al, Working Paper 10429, National Bureau of Economic Research, Cambridge, MA, April 2004; Report on the Family Voices Managed Care Survey in Atlanta, Denver, Des Moines and Seattle, Family Voices, Federation for Children with Special Needs, 1998; Doksum et al, California Survey of Health Care Experiences of Families of Children with Special Health Care Needs: Final Report, Abt Associates Inc., March 8, 2000

- enhanced Medi-Cal reimbursement rates; and
- low overall administrative costs (under 8% system-wide).

Based on our underlying principles and recognition of what we believe works in the current CCS program, we recommend that the discussion of comprehensive change incorporate the following elements:

- Children with complex medical conditions benefit from a specialized managed care arrangement, such as CCS, that has clear quality standards specific to CSHCN; a credentialed statewide pediatric network with easy access to regionalized care; and individual medical case management.
- The program must include a focus on the provision of family-centered care, with clear attention to the MCHB core performance measures for such care.
- Risk arrangement must be approached very carefully, as CCS-type conditions are unpredictable and often very expensive, two qualities that make them particularly unsuited to traditional full- or even partial-risk arrangements.
- There should be statewide implementation of major changes to CCS, as these children often require access to regionalized facilities, programs and specialists, although the actual operations of the program, including case management, could be regionalized or local. We support the idea of testing proposals for significant redesign in regional pilots with external evaluation and reporting of results.
- Comprehensive changes to the program should be based on the child's condition, not the payer source (Medi-Cal, Healthy Families, straight CCS).
- There must be a focus on the medical home concept, particularly one designed specifically for children with complex medical conditions, such as the chronic care model for child health or a disease management program specifically designed for children. Adult-oriented approaches will not work for children and youth.
- Quality assurance and improvement must be built into the program, with clear quality measures specific to CCS standards, clinical outcome measures specific to CSHCN, outcome reporting, and an ongoing quality improvement program

Final Recommendations

- We urge you to remember the core mission of the CCS program-- to ensure that CSHCN are identified and steered to the most appropriate pediatric subspecialty care in order to achieve the best possible health outcomes-- and to assure that any changes made to the program maintain and if possible improve upon achievement of that core mission.
- We strongly urge you to ensure that all comprehensive changes selected reflect the underlying principles of care for CSHCN detailed above and reject any proposals to fold treatment of CCS conditions into traditional managed care plans ("carve-in").
- We believe that the strategies implemented in other states are worth studying, although we caution that California is a huge and diverse state compared to states such as Florida, Colorado, Rhode Island and Arizona. We don't think it's practical to assume that our state could adopt even a desirable model from one of those states without substantial adaptation. To that end, we strongly urge the state to resist making quick decisions about adopting a single new model or strategies for the complete redesign of the CCS program without a more thoughtful process involving the constituents concerned with CSHCN, including family organizations.
- We strongly recommend that there be a time-limited, quick-turnaround process to develop the desired model for California's Medicaid waiver that would include:
 1. release of the final document summarizing the stakeholder interviews and written comments;
 2. conference call with the stakeholder group for presentation of and comments on the report and its concrete recommendations for comprehensive changes to the CCS program;

3. convening of a work group of the major constituent groups, including families, to consult with the state on design of the restructured program for preparation of the concept paper to federal CMS; and
4. use of the work group to assist the state in fleshing out the program design over the course of the year prior to submission of the waiver.

Thank you for this opportunity to include our input in the state's CCS stakeholder process. We look forward to working with you on this critically important project to improve health care delivery for children with special health care needs.

Sincerely,

CRISS Steering Committee

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