

# Children's Regional Integrated Service System

*American Academy of Pediatrics,  
CA District  
California Children's Hospital  
Association  
CARE Parent Network  
CCS Programs: Alameda,  
Butte, Colusa, Contra  
Costa, El Dorado, Fresno,  
Glenn, Humboldt, Marin,  
Mendocino, Napa, Placer,  
Sacramento, San Francisco,  
San Joaquin, San Mateo,  
Santa Clara, Santa Cruz,  
Shasta, Solano, Sonoma,  
Stanislaus, Sutter, Tehama,  
Tulare, Yolo and Yuba  
Children's Specialty Care  
Coalition  
Colusa County FRC  
Community Gatepath  
Exceptional Parents Unlimited  
Family Resource Network  
of Alameda County  
Family Resource Network  
of San Joaquin County  
Family Voices of California  
Kaiser Permanente, Northern CA  
Lucile Packard Children's Hospital  
Matrix Parent Network and  
Resource Center  
Parenting Network: Visalia Family  
Resource Center  
Parents Helping Parents  
Rowell Family Empowerment of  
Northern California  
Safe Passage FRC  
Santa Clara Valley Health and  
Hospital System  
Support for Families of Children  
with Disabilities  
Sutter County Parent Network  
Sutter Medical Center  
Tulare Parenting Network  
UC Davis Medical Ctr.  
UCSF Benioff Children's Hospital  
UCSF Benioff Children's Hospital  
Oakland  
WarmLine FRC  
Yuba County FRN*

July 2, 2015

Jennifer Kent, Director  
Anastasia Dodson, Associate Director for Policy  
California Department of Health Care Services  
1501 Capitol Avenue  
Sacramento, CA 95814

Dear Director Kent and Ms. Dodson,

We are writing on behalf of the Children's Regional Integrated Service System (CRISS) regarding the DHCS CCS Redesign "Whole-Child Model", as presented in the document released June 11, 2015. The model proposes the elimination of most of the core services of the CCS program, with the transfer of those core services—including care planning, case management, and service authorizations—to existing traditional Medi-Cal managed care plans that assume full financial risk. We understand that the Department is seeking legislative authority this year in order to begin implementation in 21 counties with County Organized Health Systems (COHS) and up to four counties with a two-plan model by 2017. CRISS has many concerns about this proposal and its potential impact on timely and coordinated access to appropriate care for CCS children as well as on the state's entire regionalized system of care for all children with special health care needs. In addition, the proposal also would dismantle the population-based, public health functions of the CCS program. These concerns are reviewed below.

## Why This Proposal Now?

We are disappointed in the redesign process, since clearly the goals of the Department regarding redesign have changed significantly over the course of the meetings. At the first RSAB meeting in December, 2014, statements were made by DHCS staff that the Department was not predisposed to mandate that treatment of CCS health conditions for CCS-enrolled children be transferred to managed care organizations, that numerous models would be under consideration, and that the intent was for the Redesign Stakeholder Advisory Board (RSAB) to drive the redesign process. The core concept of the proposal calls for mandatory enrollment of CCS children in Medi-Cal managed care for treatment of their CCS conditions and does not reflect the discussions about potential redesign models at RSAB. This disconnect prompts us to pose the following questions to the Department:

1. Given what was said about the redesign process and what has been discussed at RSAB since December, what changed between then and now to prompt this proposal from the Department?

2. The Department proposes to eliminate CCS program management of eligible conditions for more than 31,000 children currently enrolled in County Organized Health Systems, approximately 20% of total CCS enrollment. We understand that Riverside and San Bernardino counties have been proposed for inclusion as two-plan model counties; their inclusion would add more than 25,000 children to this proposal and increase the total number of children included to a third of total CCS enrollment. On what data is the Department basing this proposal? What evidence does it have to indicate that transferring responsibility for core CCS services to Medi-Cal managed care plans with full financial risk would improve care to children with CCS conditions? Why does the Department want this model for these very vulnerable children? And has the Department planned a fallback if local CCS case management infrastructure has been dismantled and access or other problems arise with one or more Medi-Cal managed care plans?
3. Why does DHCS feel that the proposed "Whole-Child Model" would reduce the fragmentation of care inherent in the current health care system for CCS-eligible children? We feel that moving responsibilities for case management and utilization review into many disparate managed care plans will actually increase the fragmentation of subspecialty care for CCS-eligible children, compared to the current system in which one set of CCS policies governs benefits and access. Disparities in breadth of benefits, case management practices, and provider networks among managed care plans would likely create barriers to access and confusion for both providers and patients, especially when patients move or require out-of-network services.
4. The federally mandated Title V Needs Assessment surveys last November indicated high, sometimes extraordinarily high, satisfaction among families with CCS services, including access to pediatric subspecialty care and CCS case management. For example, 89% of parents reported being very satisfied or satisfied with CCS case management services, and 82% of parents rated overall CCS services as scoring between 8 and 10 on a scale of 1 to 10. In what ways does the Department believe that the transfer of CCS functions to Medi-Cal managed care plans could improve family satisfaction with their children's care?
5. Last month the California Budget and Policy Center issued a report on child health services that reported that between Fiscal Years 2007-08 and 2012-13 State General Fund spending for CCS dropped by 17%, after adjusting for inflation, while CCS enrollment rose by 3.5% in the same time period. Given the evident cost-effectiveness and high satisfaction with current program, what problem is the Department trying to fix with this proposal for radical change in the health care system for CCS children?

We have attached a list of additional questions about the proposal. **We request that the Department provide detailed answers to all these questions at the July 17 RSAB meeting.**

### **CRISS Principles for Analyzing Redesign Proposals**

In order to approach the RSAB process, CRISS developed "Principles of Health Care Delivery to Children and Youth with Special Health Care Needs" (<http://criss-ca.org/CRISS%20PrinciplesofHealthCareDeliveryfor%20CSHCN%200415.pdf>) that lay out critical components that we believe must be included in any redesigned CCS system of care. The core concept of the Department's CCS redesign model violates the CRISS Principles in these critical ways:

- The model would put CCS services into traditional Medi-Cal managed care plans and these plans are not designed specifically for CCS children or their conditions. In contrast, the CCS program is a managed care approach that was designed specifically for children with complex medical conditions from its establishment in 1927 as a response to the impact of the polio epidemic on children and their families. CCS is now a nationally respected health care delivery program for children with special health care needs.

- The model does not ensure fiscally disinterested decisions about access to medical necessary services. The CCS program's separation of medical decision-making and financial risk ensures that its case management and authorization decisions are made solely on the basis of the child's medical conditions and other relevant child and family needs.
- The model does not ensure access to the entire CCS statewide provider network as children's needs dictate. There is no clear definition of an "adequate" provider network, no requirement for pediatric specialty expertise in the plan utilization management structure, and no evidence that timely access to appropriate providers can be ensured.
- The model does not assure that acuity-based (risk-based) care is provided to high risk children. The CCS Special Care Center standards are based on a fee-for-service reimbursement system and vague as to the periodicity of care. Currently the pediatric subspecialist physician and team will determine the allocation of resources, with, at minimum, annual case conferencing for most Centers. For a child with a diagnosis such as cystic fibrosis, for example, providing just a minimum of an annual case conference is clearly inadequate. Health plans will never have the medical expertise across the subspecialty spectrum to allocate appropriate resources across the continuum of care; certainly there will be no incentive to do so. This is precisely why CCS requires paneling of appropriate subspecialists according to the diagnosis. The allocation of resources should be determined by the Special Care Center, not the plan.
- No thorough evaluation of the Medi-Cal managed care model has been conducted prior to the Department's proposal to implement major system-wide changes. For example, there has been no evaluation of the one CCS pilot currently in operation. We believe it is dangerous to make the major changes in CCS proposed by the Department without solid evidence that access to appropriate care and quality outcomes would be preserved under the new structure.

**In addition, we are extremely concerned that any proposal that may weaken the CCS statewide provider network threatens the entire regionalized pediatric system of care that serves all children in California, not just those eligible for CCS. This is potentially catastrophic.**

### **Alternate Approaches to Redesign**

**For these reasons, CRISS cannot support the proposed model and urges the Department to reconsider its approach.** Given what we already know about the medical complexity and vulnerability of CCS children, as well as the quality and cost-effectiveness of the CCS program, there is no urgency to make the radical changes proposed by the Department and every reason to make any changes in a slow and deliberative way. **Instead, we urge the Department to extend the CCS carve-out and to focus on ways to improve the CCS program, building on its strengths and the recommendations from the 2014/2015 Title V Needs Assessment specific to children with special health care needs** (California Title V Block Grant Program, <http://www.cdph.ca.gov/programs/mcah/Documents/Title%20V%20DRAFT%202014%20Report%202016%20Application%20Public%20Document.pdf>; see especially pp. 50-55), including such approaches as:

- addressing the whole child by extending CCS authorizations to include the whole child via close coordination with CCS-paneled primary care providers and child- and family-centered medical homes;
- implementing acuity assessments of enrolled children, development of individual care plans, and intensive care coordination for high-need children and families;
- improving care coordination across the multiple systems used by many CCS children, including behavioral health, special education, and Regional Centers;

- mandating family and youth participation at every level in design, implementation, evaluation and decision-making concerning the system of care, with financial support to enhance participation;
- focusing attention on quality improvement of the system, including the use of standardized quality measures appropriate to children and youth with special health care needs and attention to family satisfaction and participation;
- collecting and analyzing program data regarding process and outcome measures and releasing the information in periodic public reports.

Many of these new activities and approaches already are being implemented with considerable success in the CRISS region and elsewhere in the state.

We would like to underscore CRISS's continued commitment to working with the Department and with other stakeholders to develop and implement new approaches to the CCS program that will enhance its services for children with complex medical conditions and protect the regional pediatric system of care.

Sincerely,

### **CRISS Steering Committee**

Bernardette Arellano, Director, Government Relations, California Children's Hospital Association  
Katy Carlsen, MD, Medical Director, Placer County CCS  
Arlene Cullum, Director, Women's and Children's Ambulatory Services, Sutter Medical Center  
Greg Cutcher, Administrator, San Francisco County CCS  
Chris Dybdahl, Administrator, Santa Cruz County CCS  
Louis Girling, MD, Medical Director, Alameda County CCS  
Kausha King, Parent Health Liaison, CARE Parent Network  
Wendy Longwell, Parent Consultant, Rowell Family Empowerment of Northern California  
Pip Marks, Manager, Family Voices of California  
Terri Cowger Hill, Health Care Advocate, UCSF Benioff Children's Hospital Oakland  
Laurie A. Soman, CRISS Director, Lucile Packard Children's Hospital  
Meredith Wolfe, Administrator, Humboldt County CCS

**Children's Regional Integrated Service System (CRISS)  
Questions re: DHCS "Whole-Child Model" for CCS Redesign**

1. How does the Department believe the proposal will protect timely access to appropriate providers if vital CCS components like treatment plans, service authorizations and case management are transferred to entities that are at full financial risk and have little or no experience managing the needs of this population? What evidence does DHCS have that medically appropriate decisions, including appropriate care plans and timely authorizations, can be made by an entity at financial risk? Who at the plan level would be responsible for case management, care planning and authorizations? What expertise would they be required to have, specifically pediatric expertise in children and youth with special health care needs?
2. What is the definition of "adequate network"? Will the Department require that plans contract with a broad array of CCS-approved providers and facilities, including CCS-certified tertiary and quaternary facilities? Because CCS conditions may be both severe and rare, many CCS children, even in relatively urban areas, require access to providers throughout the state and sometimes to services in other areas of the country. How would the Department ensure that children are able to access needed services out-of-network or out-of-state? What expertise would the plans have in order to know when and where children need to be sent for care?
3. What protections will be in place to ensure that children with Special Care Center-eligible conditions in fact are required to be referred to and seen in the Centers on at least an annual basis? How will the Department know if this standard is being met?
4. What evidence does DHCS have regarding the current performance and quality of the County Organized Health Systems proposed for initial implementation, particularly with children and adults with disabilities? Can we see the studies?
5. Why doesn't the Department proposal include an evaluation of current pilots before making major changes like what is proposed? Why does the proposal not include an evaluation of the proposed initial implementation in a sample of COHS counties before moving forward elsewhere in the state?
6. Monitoring, oversight, and enforcement of standards and policies would be critical and there is little evidence right now that the state is prepared to do that. We note that the State Auditor report released in June criticized the Department's current performance in monitoring and ensuring access and quality in the plans for the populations already enrolled in managed care. (Partnership Health Plan, a COHS proposed to assume responsibility for case management and utilization management for 14 primarily rural counties, was one of the plans cited for inaccurate information on network providers.) How would the Department improve its monitoring, oversight and enforcement if it moves forward with the CCS redesign proposal? Does the Department plan to require plans to adhere to performance measures specific to children and youth with special health care needs? What kind of performance monitoring would the Department enforce? How often and would there be timely public reports? How will the Department know if something is going wrong with these children in time to avoid potential disaster?
7. Does DHCS acknowledge the key public health functions of the CCS program, including population-based approaches to promote health equity by establishing and maintaining high quality standards for the regionalized pediatric subspecialty health care system; identifying service gaps in the system; addressing the social determinants of health, including food and housing stability, access to transportation, and health literacy and family education; and promoting multi-agency efforts to

evaluate and improve the quality and effectiveness of health services for eligible children and youth? How does DHCS envision that these key public health functions would be accomplished if the CCS program were eliminated?

8. Why did DHCS settle on initial implementation of this radical change in care for CCS children in primarily small rural counties? Almost all CCS children in these counties are referred at some point to CCS-approved specialty care and hospitals located outside their county, sometimes hundreds of miles away. Why start with the most vulnerable children in regions with the least robust provider networks?
9. CCS ensures access not only to pediatric-appropriate providers and hospitals but also to medications, durable medical equipment and supplies beyond what Medi-Cal covers. Would the plans be required to cover those items? What expertise will plan staff have to know which items CCS children need and where to obtain them?
10. Maintenance and transportation services for families, such as travel, food and lodging, often are critical to ensuring that children, particularly those from rural areas, are able to reach the services they need. The CCS program currently supports the maintenance and transportation benefit. Would managed care plans be required to cover these services?

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