

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,
Sacramento
Tulare Parenting Network
UC Davis Medical Ctr.
UCSF Benioff Children's Hospital
UCSF Benioff Children's Hospital
Oakland
WarmLine FRC
Yuba County FRN*

May 23, 2016

Karen Smith, MD
Director, Department of Public Health
714 P St Ste 1350
Sacramento, CA 95814

Jennifer Kent
Director, Department of Health Care Services
1600 – 9th Street, #460
Sacramento, CA 95814

Dear Directors Smith and Kent:

We are writing on behalf of the Children's Regional Integrated Service System (CRISS) to provide comments on the state's Title V Block Grant application for 2017. CRISS is a 27-county collaborative of family support organizations, children's hospitals, pediatric provider organizations, and county CCS programs dedicated to supporting a more effective, efficient, and family-centered CCS program for children with special health care needs. Our comments are attached.

We would like to note that the timeframe for responding with comments was exceptionally short (we received the draft on May 18) and request that in the future the public comment period be longer to allow for a more thorough review of draft documents.

Please feel free to contact us if you have questions about our comments.

CRISS Steering Committee

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

cc: Patricia McClelland, Systems of Care Division, DHCS

**Children’s Regional Integrated Service System (CRISS)
Comments on Title V Block Grant Application 2017
May 23, 2016**

Page 23: Linkage of State Selected Priorities with National Performance and Outcome Measures

CRISS has specific comments regarding the following paragraph in this section:

“For the CSHCN domain, the first priority need is to provide a whole child approach to CSHCN services encompassing an organized system of care, medical home and transition. This priority is related to NPM 11, the percent of children with and without special health care needs having a medical home, and NPM 12, the percent of adolescents with and without special health care needs who received services necessary to make transitions to adult health care. The second CSHCN priority relates to improving access to medically necessary services. This relates most closely to NPM 11, having a medical home.”

CRISS comments: We think that, important as a medical home is for CSHCN, the truly critical element to measure is easy access to appropriate and timely pediatric subspecialty care. **We recommend that DHCS measure access to Special Care Centers and implement other indicators of access to subspecialty care.**

Page 33: Five Year State Action Plan

We have comments specific to the following sections of the State Action Plan:

Domain: CSHCN Health	
Priority 4: Provide high quality care to all CYSHCN within an organized care delivery system.	
<p>1. By June 30, 2020, increase the children enrolled in the California Children’s Services (CCS) who receive primary and specialty care through a single system of care by 20%.</p>	<p>1. Through the CCS Advisory Group stakeholder process, refine the selected whole child approach to optimize access to qualified providers. <u>CRISS comments:</u> As noted in comments below, the whole child model was chosen by DHCS, not the CCS Advisory Group. Many Advisory Group members continue to have concerns about the DHCS proposal.</p> <p>2. Develop a methodology to track the number of clients receiving whole child care through CMS Net and/or other DHCS data source. <u>CRISS comments:</u> We recommend that DHCS track the provision of whole child care through current and planned county CCS program oversight, care coordination, and authorization of primary care via CCS SARs.</p> <p>3. Conduct surveys of CCS families and providers to assess satisfaction with organized care delivery system. <u>CRISS comments:</u> Future surveys of CCS families and providers to assess satisfaction with systems changes should be compared to FHOP surveys conducted for the 2015 Title V Needs Assessment.</p>

<p>3. By June 30, 2020, increase by 20% the number of 20 year old CCS clients with selected conditions* who report having an identified adult subspecialist to assume specialty care.</p> <p>*congenital heart disease, cystic fibrosis, respiratory failure, T1 DM, hemophilia, ALL, sickle cell disease, cerebral palsy, s/p organ transplant.</p>	<p>1. Explore current CCS transition practices including transition fair, parent liaisons, and the Redesign State Advisory Board transition workgroup findings.</p> <p>2. Increase the number of family members providing input into state and local transition practices. <i>CRISS comments: We strongly support increased family involvement in state and local transition planning and initiatives, as well as in planning for their own children's transitions.</i></p> <p>3. With CCS Advisory Group, review options for CCS clients to have a visit with an adult physician through managed care. <i>CRISS comments: See our comments below on transition and recommendation that the state set and Medi-Cal managed care plans be required to meet network adequacy standards for transitioning youth, including increased opportunities for single case agreements if there are no specialists in plan networks appropriate to youths' medical conditions.</i></p>	<p>Percent of children with special health care needs (CSHCN) receiving care in a well-functioning system <i>CRISS comments: We would like to see details on how DHCS would define and measure this.</i></p>
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Domain: CSHCN Health		
Priority 5: Increase access to CCS-paneled providers such that each child has timely access to medically necessary care by a qualified provider		
<p>1. By June 30, 2020, increase the percent of CCS families reporting that their child always saw a specialist when needed from 72% to 90%, based on CCS/FHOP survey.</p>	<p>1. With CCS AG, explore strategies to increase access to CCS-paneled providers, with focus on rural areas, including streamlining process and developing reports of shortage areas. <i>CRISS comments: What process is DHCS proposing to streamline?</i></p> <p>2. Based on the findings of the Title V needs assessment, define issues associated with non-participation in CCS of durable medical equipment, pharmacy, home health and behavioral health providers, and explore methods to increase their participation in CCS.</p> <p>3. Review the criteria for providers to be CCS-paneled with the goal of increasing numbers of paneled providers while maintaining quality standards. <i>CRISS comments: What leads DHCS to think that provider paneling criteria present a major access barrier? Numerous research papers suggest the role of other barriers such as extremely low Medi-Cal rates and payment delays, compounded by geographic barriers in rural areas, as well as the general inadequacy of the pediatric subspecialty workforce for all children, regardless of insurance status. None of those papers suggests changing provider paneling criteria as a solution; in fact, some explicitly cite the importance of CCS program standards in creating and maintaining the state's pediatric system of care. We strongly recommend against any strategies that would reduce CCS quality standards and instead urge DHCS to look at other drivers in access barriers, including reimbursement rates.</i></p>	<p>NPM 11: Percent of children with and without special health care needs having a medical home <i>CRISS comments: We recommend that for purposes of this priority DHCS measure children's access to pediatric sub-specialists and Special Care Centers, not medical homes.</i></p>

Pages 63 and 67: Domain: Children with Special Health Care Needs - Annual Report (FY 2014-2015)

Goal 1: Provide high quality care to all CYSHCN within an organized delivery system

SMART OBJECTIVE: By June 30, 2020 increase the children in CCS who received primary and specialty care through a single system of care by 20%.

CRISS comments: We remain concerned that the Department continues to equate "organized delivery system" with Medi-Cal managed care and to assume that the only way for CSHCN to experience coordinated primary and specialty care is to receive both through managed care plans. In our view the CCS program is an "organized delivery system", one that is organized specifically for the needs of CSHCN. It contains essential elements of an organized delivery system, including a defined network of credentialed providers, utilization management and pre-authorization of services, and quality monitoring and improvement activities. It is true that primary care typically is delivered through a parallel system for these children, but we believe that coordination of primary and specialty care can be achieved while retaining the integrity of the CCS program. For most children enrolled in CCS, the most important medical relationships they have are with their pediatric subspecialists, and that is the arena in which the CCS program holds the expertise and experience. In addition, several county CCS programs in the state already have launched or are in the process of launching initiatives for better coordination with primary care and authorization of primary care providers for CCS-related care. In our view it will be simpler and safer to broaden the role of CCS in coordinating with primary care than to ask managed care plans to develop the expertise needed to oversee the treatment of children with complex medical conditions. **We recommend that DHCS support and promote county CCS programs' efforts to coordinate with and authorize primary care services for CCS children.**

We also have specific comments about the following sections on page 67 in this domain:

"DHCS has identified priority needs for this domain, in particular for CCS clients, including having standards and policies in place to facilitate the provision of high quality care within an organized care delivery system to all CYSHCN." ***CRISS comments: Please see our comments above regarding the importance of a broader definition of "organized care delivery system" for CSHCN.*** "This priority need was a key factor in developing models for the CSHCN portion of the 1115 Waiver of 2010–2015. The first 1115 waiver pilot was initiated in 2013 in San Mateo County through the County Organized Health System, Health Plan of San Mateo. The goal was to have all health care for the CCS child organized within one system. DHCS developed and is currently preparing to administer a family satisfaction phone survey to assess the families' knowledge and satisfaction with the demonstration project, knowledge and satisfaction with their care coordinator, access, and satisfaction with providers, satisfaction with the medical services provided, and to establish a baseline to compare against future surveys." ***CRISS comments: The CCS Advisory Group and others have questioned why DHCS did not require and facilitate evaluation of the HPSM model, including collection of baseline data. It is inaccurate to refer to what HPSM is implementing as a "pilot" if baseline data have not been collected and there have been no collection and analysis of comparison data using specific metrics.***

"In 2014, DHCS initiated another effort to improve the CCS program, CCS Redesign. For CCS Redesign, a stakeholder advisory board composed of individuals from various organizations and backgrounds with expertise in both the CCS Program and care for CYSHCN was created. The goals of this stakeholder process include maintaining a patient and family-centered approach, provide comprehensive treatment for the whole child, improve care coordination through an organized delivery system, improve quality, streamline care delivery, and maintain cost neutrality. Because of the success of the San Mateo Whole Child model, DHCS is proposing to expand this whole child model to other counties with a County Organized Health System, with advisory group

feedback.” **CRISS comments:** *It is disappointing to have to point this out, but there is no evidence that the HPSM project is a success. Without baseline data and an independent evaluation, there simply is no way for us to tell. In addition, the statement regarding the role of the CCS Advisory Group in promoting expanding the whole child model to COHS counties is misleading on two counts. Most importantly, the Advisory Group has not as a body agreed that the San Mateo model is the best model or even that it is an appropriate model for incorporating CCS into MCMC. In fact, the majority of Advisory Group members have expressed and continue to express concerns about the Department's direction in wanting to fold CCS program functions into MCMC plans. In addition, the DHCS whole child model proposal for COHS counties is not the same as the HPSM model; currently HPSM contracts back with San Mateo County CCS staff, who remain responsible for CCS utilization management, including care planning, case management, and service authorizations. The Department proposal would transfer these responsibilities to the COHS plans with no requirement for continued CCS staff involvement in CCS children's care.*

Page 64: Goal 2: Increase Access to Medical Homes for CYSHCN

SMART OBJECTIVE: By June 30, 2020, increase the number of CYSHCN who receive care within a medical home by 20% as measured by the medical home CCS performance measure.

CRISS comments: CRISS supports a clearer, more consistent definition of medical home for CSHCN as well as standardized methods to measure achievement of the goal. **As CRISS representatives have recommended at CCS Advisory Group meetings, we urge DHCS to build on earlier work on medical homes for CCS children begun several years ago under Dr. Marian Dalsey's leadership of state CMS.**

Page 64: Goal 3: Improve Transition Services in CYSHCN

SMART OBJECTIVE: By June 30, 2020, increase by 20% the number of 20 year old CCS clients with selected condition who report having an identified adult subspecialist to assume specialty care

CRISS comments: We appreciate the Department's commitment to achieving smoother, more effective transitions for youth aging out of CCS. CRISS family members talk about transition as one of their most difficult and emotionally fraught experiences as they and their children try to navigate the switch from the pediatric world to a colder, less family-friendly, and more complicated adult medical world. As you know, CRISS has been working to improve transition in our member counties for many years through the work of our Family-Centered Care and Medical Therapy Program work groups and we are proud of the improvements we have promoted and achieved over the years. We strongly support county activities to improve transition services and we look forward to working within the CCS Advisory Group and the technical work group looking at transition to promote these critically needed services.

While CCS programs continue to improve their services, it is vital that managed care plans make their own improvements. The biggest barrier we have observed to successful transition for CCS youth is the lack of adult-oriented primary and specialty care providers willing to take these youth. The best CCS-level transition services will be meaningless without an adequate adult-oriented primary and specialty care network for youth making the transition to adult care. **We recommend that the state set and Medi-Cal managed care plans be required to meet network adequacy standards for transitioning youth, including increased opportunities for single case agreements if there are no specialists in plan networks appropriate to youths' medical conditions.**

Page 64: Goal 4: Increase Access to High Quality Care

SMART OBJECTIVE: By June 30, 2020, increase the rate of CCS families reporting that their child always saw a specialist when needed from 72% to 90% based on the CCS/FHOP survey.

CRISS comments: As discussed in an earlier comment, we are concerned if DHCS believes that CCS provider paneling criteria present a major barrier in children’s access to appropriate specialty care. As we noted earlier, research papers concerning access to pediatric specialty care in California report the role of other barriers such as extremely low Medi-Cal rates and payment delays, compounded by geographic barriers in rural areas. Research also confirms the general inadequacy of the pediatric subspecialty workforce for all children, regardless of insurance status. None of the papers suggests changing provider paneling criteria as a solution; in fact, some explicitly cite the importance of CCS program standards in creating and maintaining the state’s pediatric system of care. **We strongly recommend against any strategies that would reduce CCS quality standards and instead urge DHCS to look at other drivers in access barriers, including reimbursement rates.**

Pages 64-65: Goal 5: Maintain and Support Regionalization of Care

SMART OBJECTIVE: By June 30, 2020, 99% of county CCS programs will report on use of telehealth services.

CRISS comments: CRISS has consistently supported the appropriate use of telehealth services to expand access to care for children with complex medical conditions, in both rural and non-rural areas, and we support the Department’s objective to achieve universal reporting by county CCS programs on use of telehealth. We think the Department also should have specific strategies to address the preservation and strengthening of our regionalized system of pediatric care for CSHCN, which is the linchpin of health care for all children in the state. **We urge DHCS to work with stakeholders to select and implement specific measures to gauge the general health and stability of the regionalized pediatric system of care for CSHCN.**

Page 92: II.F.3. Family Consumer Partnership

CRISS comments: This section describes state and local activities to promote family consumer partnerships. We are proud that CRISS is cited as a partner with the state in involving families in policy planning and service development, and we appreciate the several earlier references in the application to the state’s interest in increased family involvement in state and local CCS planning and oversight. We do feel, however, that overall that there should be a great deal more attention to family engagement in the application and in the state’s approach to the CCS program, including plans for specific steps to increase family engagement at the state level. **To that end, we recommend that the state increase family representation on the CCS Advisory Group, the body charged with advising the state on its plans for CCS redesign and for improvements to the current program. (There currently are only two official family representatives on this body.) If DHCS moves ahead with its whole child model in COHS counties, we also recommend that the Department establish a statewide whole child model stakeholder advisory group with strong representation from family resource organizations.**

