



Hemophilia Council of California • 4629 Whitney Ave. Suite 1 • Sacramento, CA 95821



Western States Hemophilia Regional Network  
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July 1, 2015

Jennifer Kent, Director  
California Department of Health Care Services (DHCS)  
1501 Capitol Mall, 6<sup>th</sup> Floor  
Sacramento, CA 95814

Dear Director Kent:                    **Subject: Opposition to DHCS Proposal on Transitioning California Children’s Services (CCS) into Managed Medi-Cal Health Plans (CCS Whole Child Model)**

We respectfully write on behalf of the Hemophilia Council of California (HCC) and Western States Hemophilia Regional Network (WSHRN) to oppose the DHCS California Children’s Services (CCS) Redesign’s “Whole Child” Model. The “Whole Child” model proposes to move California’s most medically fragile children, those eligible for CCS, into Medi-Cal Managed Care by 2019.

The HCC represents the 4,000 Californians with hemophilia and over 360,000 living with von Willebrand Disease. The Western States Regional Network (WSHRN) represents the 11 federally supported Hemophilia Treatment Centers (HTCs) that are located in California – comprised of CCS Special Care Centers and CCS Panelled Providers. HTCs provide expert diagnosis and treatment using multi-disciplinary teams to improve health outcomes and reduce costs for Californians with rare, chronic, and costly genetic blood disorders.

**It is unrealistic to expect Medi-Cal Managed Health Plan clinicians to have sufficient knowledge and skill in rare disorder diagnosis, prevention, and treatment. Volume and centralization is essential to provide the quality of care which keeps persons with high-risk high cost rare chronic disorders healthy, and reduces resource utilization.** CCS Special Care Center requirements are structured to maintain this expertise. Furthermore, we are concerned that the Department’s CCS proposal:

1. Removes the authority to determine medical necessity for rare disorder care from CCS Special Care Centers and moves it to the Managed Medi-Cal Health Plans. There is no data to support the Department’s position that these medically fragile children would be better cared for under the managed care delivery system.
2. Does not ensure patient access to CCS rare disorder specialty teams. Hemophilia and von Willebrand Disease are, respectively, rare and under-recognized disorders with multiple co-morbidities. Not ensuring access to California’s network of eleven federally supported HTCs jeopardizes beneficiary health, productivity, and longevity. It increases risks of avoidable hospitalizations, crippling, and pain related to spontaneous and trauma induced internal bleeding.
3. Does not ensure a “carve out” of clotting factor, which we support, which is currently the policy under Medi-Cal Managed Care for both CCS and Genetically Handicapped Persons Program (GHPP) insured Californians hemophilia.

4. Does not ensure network adequacy and oversight. The California State Auditor's June 2015 Medi-Cal Audit found: A) network inadequacy for adults in Medi-Cal Managed Care, B) about 12,500 unanswered calls per month by the Medi-Cal Ombudsman, and C) DCHS did not perform required Medi-Cal managed care plans audits to determine if the beneficiaries' needs were being met.

Per the DHCS Goals: We too want to preserve high quality cost-effective care and quality of life for medically vulnerable Californians. We wish to achieve this by maintaining CCS beneficiary access to our proven HTC/CCS Special Care Center model. And we want to build on "lessons learned".

**Quality and Cost Effectiveness:** Internal bleeding can result in permanent deformity, neurological damage, unnecessary hospitalizations, and mortality. HTC care is designed to diminish these risks and bad outcomes and reduce costs for all Californians with complex, incurable, rare, and under-recognized blood disorders.

HTCs provide comprehensive expert care services per federal grant goals and National Hemophilia Foundation Standards. HTC care has chief elements of the Chronic Care Model and patient centered specialty home. HTCs conduct extensive education to parents and affected youngsters on how to identify and treat bleeding events rapidly at home using infusions of clotting factor concentrate that contain the missing protein needed for blood to clot. This medically supervised home therapy avoids hospitalization, reduces days lost from work and school. California HTCs care for thousands of affected individuals annually, and are uniquely positioned to advance evidence-based medicine, care delivery, and public health. We conduct CDC surveillance on hemophilia complications to better understand those highest risks that might be modified by interventions. HTCs train the next generation of hematologists, which bolsters statewide specialist capacity. HTCs conduct clinical trials and post-licensing monitoring of newly approved FDA medications. These include gene therapy – a potential cure – and longer acting products that could increase adherence. HTC clinicians have long partnered with Medi-Cal Policy Unit, GHPP and CCS leadership and have enacted procedures to avoid waste and reduce costs.

**Building on Lessons Learned:** In 2015, we had this case we wish to avoid. A child with hemophilia was enrolled in one of the Managed Medi-Cal health plans which contracts with the State under the Two Plan Model. This Managed Medi-Cal health plan did not get the child the prescribed dosage of clotting factor in the home setting as per Children's Hospital Los Angeles HTC protocol where the child historically received hemophilia care. As a result, the child had a severe internal bleed and was hospitalized for over a week. The child now has potential joint damage and may need surgical interventions. This could have been prevented if the health plan provided the clotting factor as prescribed by the HTC. This particular Managed Medi-Cal health plan was not experienced in authorizing care for pediatric hemophilia patients with an inhibitor. Their inexperience delayed timely delivery of the lifesaving/life sustaining clotting factor in the home. This is unacceptable. We fear this scenario will be repeated if this DHCS model for CCS is implemented.

We look forward to further discussions with you and your staff. We hope you will extend the CCS "Carve Out" via legislation in 2015. We hope you will allow the CCS Redesign process to discuss the "whole child" provisions of your proposal which we conceptually support. We cannot support mandating Medi-Cal Managed Health Plans for California's most medically vulnerable children under the current CCS Redesign Proposal at this time.

Respectfully,



Randall Curtis, MBA  
Board Chair  
Hemophilia Council of California



Diane J. Nugent, M.D.  
Regional Medical Director  
Western States Regional Hemophilia Network