



SB 424 (Durazo) California Children's Services (CCS) Modernization Act

Ensuring that children with complex and life-threatening medical conditions receive the care they need.

Summary

SB 424 (Durazo), the California Children's Services (CCS) Modernization Act seeks to strengthen the current CCS program by making a number of modifications including updating eligibility to align with the Affordable Care Act, ensuring that CCS conditions currently listed only in regulation are captured in law, covering lifesaving drugs the same regardless of whether they are administered on an in-patient or outpatient basis, ensuring that providers, hospitals and specialty care clinics receive the support needed to ensure patients can continue to access care, and preserving the expert case management and support that is a hallmark of the program's success.

Background

The California Children's Services (CCS) Program provides diagnosis, treatment, and medical case management to approximately 200,000 children under the age of 21 who have complex and/or lifethreatening health care conditions and who (1) are enrolled in Medi-Cal, (2) are low-income, or (3) have catastrophic medical care costs that would exceed 20 percent of their family's adjusted gross income. The program, established in 1927, serves the state's most medically fragile pediatric population, including children with conditions like cancer, sickle cell disease, cystic fibrosis, severe burns, and congenital heart disease. The program also sets quality standards for pediatric specialty care in California, including standards for children's hospitals, pediatric units in other hospitals, and pediatric subspecialists. These standards serve to benefit all children in California. Finally, the program provides access to knowledgeable nurse case managers who ensure that families receive appropriate medical care and support services.

Problem

The statute governing the operation of the CCS program needs updating to protect access to care and to modernize eligibility to align with recent changes in federal and state health insurance coverage rules. Eligibility for the CCS program has not been updated since the 1990s and does not reflect the health insurance coverage reforms that have been enacted over the past several decades, including implementation of the Affordable Care Act. In addition, many of the life-threatening medical conditions covered by the CCS program are authorized in regulation, rather than in statute, making access to specialized care for these children vulnerable to administrative changes without legislative oversight. Provider reimbursement is woefully inadequate and is having a consequential impact on access to care. Despite rampant inflation, CCS physician rates have been frozen since 2002 and hospital rates have not been increased since 2012 which is impeding the ability to maintain a sufficient workforce to meet the needs of children with medical complexity. Relatedly, state policy forces hospitals to absorb a portion of the costs of new breakthrough drug therapies for some of the most complex, life-threatening diseases. Finally, the CCS program provides families with expert and intensive case management support that is provided by public health nurses trained to understand the unique needs of CCS patients. This specialized expertise is being eroded by the implementation of the Department of Health Care Services "Whole Child Model" program, which carves CCS into Medi-Cal managed care.

CCS Modernization Fact Sheet February 14, 2023 Page 2

Solution

CCS is a unique, regionalized program that provides critical medical and support services to children and families. The program must be updated if it is to be preserved. SB 424 seeks to preserve the program by:

- Codifying in statute the CCS medical conditions that are now only in regulation;
- Modernizing financial eligibility of the program to better align with the Affordable Care Act;
- Making reimbursement more sustainable for the physicians, special care centers and hospitals providing CCS care by adjusting physician rates for inflation, and providing grants to hospitals and special care centers to the offset costs of providing care;
- Requiring high-cost, breakthrough drugs for CCS patients to be reimbursed the same way whether the drug is administered on an in-patient or outpatient basis;
- Maintains the status quo regarding Whole Child Model, with no further expansion;

SB 424 also includes a trigger to enable the Governor to suspend physician rate increases and grants to hospitals and clinics if the state is in a deficit.

Support

California Children's Hospital Association (co-sponsor) Children's Specialty Care Coalition (co-sponsor)