December 12, 2023

Initiative 23-0029A1

Hon. Rob Bonta
Attorney General
1300 I Street, 17th Floor
Sacramento, California 95814

Attention: Ms. Anabel Renteria
Initiative Coordinator

Dear Attorney General Bonta:

Pursuant to Elections Code Section 9005, we have reviewed the proposed measure (A.G. File No. 23-0029, Amendment #1) related to the California Children's Services (CCS) program.

BACKGROUND

Californians Have Health Care Coverage Through Public Programs or Private Insurance. Nearly one half of Californians have health care coverage through a publicly funded program. These programs include Medi-Cal, which covers services for low-income people, and Medicare, which covers health care services for the elderly and disabled. Most Californians who are not enrolled in these public programs have private health insurance, either from their job or from purchasing coverage in a state-run health insurance marketplace called "Covered California."

CCS Covers Specialty Health Care for Children With Serious Diseases. Created in 1927, CCS is a state program that provides health care services for people under the age of 21 with serious and chronic diseases, such as hemophilia, cystic fibrosis, and cancer. The program covers the cost of services related to the treatment of the disease, such as visits with medical specialists, stays at the hospital, prescription drugs, and medical equipment. In addition, the program provides medical case management services, and, for some children, physical and occupational therapy at K-12 schools. Generally, the California Department of Health Care Services (DHCS) and county governments run this program and oversee the delivery of services. For some children, health insurance plans that contract with the state oversee the delivery of CCS services. The program serves around 200,000 children each year.

Legislative Analyst's Office
California Legislature
Gabriel Petek, Legislative Analyst
925 L Street, Suite 1000, Sacramento, CA 95814
(916) 445-4656

To Qualify for CCS, Children Must Have Specific Diseases or Health Conditions… Under state law, a child must first be diagnosed with a specific disease to qualify for the CCS program. Laws adopted by the California Legislature specify only a few of the diseases that qualify for CCS services. The rest of the qualifying diseases are determined by formal rules and guidance adopted by DHCS. State law also requires DHCS to keep abreast of advances in medical sciences and consider whether to add qualifying diseases or services. Before changing its formal rules and guidance, DHCS must undertake a process to notify stakeholders.

…And Come From Families Meeting Certain Income-Based Requirements. In addition to meeting the program's medical requirements, children must come from families that meet certain income-based requirements. More than 90 percent of CCS children qualify because they are enrolled in Medi-Cal. Children who are not enrolled in Medi-Cal can still qualify for CCS in limited circumstances. For example, children can qualify when the cost of health care related to their disease is anticipated to be greater than 20 percent of their families' income levels. Also, there are no income-based requirements to qualify for physical and occupational therapy at K-12 schools.

CCS Program Has Different Ways of Paying Providers. There are various kinds of providers that participate in the CCS program, each with a different way of being paid. For example, physicians generally are paid for each service provided to a CCS child. As another example, most hospitals are paid each time a child is admitted to the hospital for inpatient services—that is, services provided when the child stays one or more nights. This payment is intended to support the hospital's costs to treat a child during their stay, with some exceptions. Hospitals also generally are paid for services provided during outpatient visits—that is, when the child returns home the same day.

CCS Is Supported by Federal, State, and County Funds. For children enrolled in Medi-Cal, the federal government pays for a share of the cost of CCS services. When the state seeks to make changes to the CCS program in Medi-Cal, it must get approval from the federal government to receive federal funds. The state is responsible for paying the remaining share of cost. To cover this share, the state generally uses money from the General Fund, the state's primary budget account. In some cases, money from other sources is used, such as funds from counties for services required to be funded by counties under state law. For children not enrolled in Medi-Cal, CCS services mostly are supported using money from the General Fund and county funds. California spends around $2 billion each year on the CCS program across all fund sources.

PROPOSAL

Formally Specifies Which Diseases Qualify for CCS Program. The measure formally defines in state law which diseases currently qualify children for the CCS program. Specifically, the measure adopts DHCS's formal rules and guidance as written on January 1, 2022. The department also would be required every five years to work with stakeholders to determine whether to add more qualifying diseases to the program. If this process results in the department adding more qualifying diseases, the state would be required to pay counties for their costs associated with the increase in CCS children.

Creates New Financial Assistance Program for Families. The measure directs DHCS to provide financial assistance to families with children who have a qualifying disease but do not meet the income-based requirements of the CCS program. The financial assistance would cover medically necessary items and services to treat the qualifying disease, above a minimum amount paid for by families. This minimum amount would be connected to the threshold for out-of-pocket expenses of certain health insurance plans in the Covered California marketplace—for most families, $9,100 in 2024. The measure requires many other parts of this financial assistance program to be determined by DHCS. For example, DHCS would determine how much of the cost of health care above the family's minimum amount to cover.

Increases Payments for CCS Providers in Three Ways. The measure increases payments to providers for existing CCS services in three ways, described below:

- ***New Hospital Grant Program.*** The measure requires DHCS to provide an annual grant to each hospital that is approved by the state to provide CCS services. The grant would be $200 times a hospital's (1) total number of days CCS children stayed for inpatient services and (2) total number of outpatient visits provided to CCS children. The grant would support inpatient and outpatient services related to treating CCS-qualifying diseases.

- ***Payment Increases for Physicians.*** The measure requires DHCS to review payments to physicians for CCS services. If these payments are below what the federal Medicare program pays for the same or similar services, the state would need to increase them to at least the Medicare level.

- ***Direct Payment for Certain Specialty Drugs.*** Most hospitals generally do not receive direct payment for drugs provided to CCS children during inpatient services. Instead, most hospitals are expected to cover these costs as part of their payments for inpatient services. As an exception, the federal government has approved DHCS to directly pay hospitals for a specific list of high-cost drugs. The measure formally adopts this list as it was approved by the federal government prior to January 1, 2024. In addition, the measure adds to this list drugs and other treatments designated by the federal Food and Drug Administration—the federal department that regulates drugs—as a "breakthrough therapy." These therapies, which are considered to have promising benefits for patients, are reviewed and approved on a faster timeline than other drugs. This latter requirement would only apply to breakthrough therapies approved for use by the Food and Drug Administration on or after July 1, 2021.

Restricts Which Funds Can Support Measure's Costs. The measure prohibits the state from using certain fund sources to support its associated costs. For example, the state could not use county funds to support the financial assistance program or the increased payments to providers. The state also could not support the measure's costs using money from a state tax on health insurance plans known as the managed care organization tax. Moreover, the measure prohibits the state from counting the new hospital grant program as a Medi-Cal payment—meaning that the

state could not seek federal approval to use federal funds to help cover the cost. (The state would be allowed to seek such approval for the physician rate increases and the payments for specialty drugs, but payments are not contingent on federal approval.)

FISCAL EFFECTS

Two Key Components Would Increase State General Fund Spending. The measure would increase state General Fund spending in two key ways, each subject to uncertainty.

- ***Financial Assistance Program.*** The measure would increase state General Fund spending to provide financial assistance to families with children who meet the medical, but not income-based, requirements of the CCS program. The cost of this financial assistance program is uncertain. For example, the number of families who would qualify and choose to participate in this program is unknown. In addition, the measure tasks DHCS with determining how much financial assistance to provide participating families, and these future decisions are not known.

- ***Increased Payments to CCS Providers.*** The measure would increase General Fund spending to provide grants to hospitals, increase physician payments, and directly pay hospitals for specialty drugs and therapies. There also is uncertainty with these costs. For example, it is uncertain how CCS payments to physicians compare to payments in the Medicare program. Also, data on the use and cost of specialty drugs in inpatient settings are limited, making it difficult to estimate the cost to directly pay hospitals for these drugs. Moreover, because the state already directly pays hospitals for a list of relatively high-cost drugs, it is possible that it would choose to add to this list certain specialty drugs that are approved in future years by the Food and Drug Administration even absent the measure.

Keeping in mind these uncertainties, it is likely that the two components would increase state General Fund spending, with the overall cost potentially ranging in the hundreds of millions of dollars to around a billion dollars each year.

Other Potential Impacts. The measure could have additional potential impacts on state spending. For example, the measure requires DHCS to periodically consider whether to add more diseases that qualify for CCS services. To the extent this requirement results in more diseases qualifying for the program than in the measure's absence, there would be more children enrolled in CCS and higher costs to the state General Fund associated with paying for all medically necessary services. Also, higher levels of payments to CCS providers as a result of the measure could impact the use of CCS services and the health outcomes of CCS children, with corresponding impacts to spending. The net fiscal effect of these various other potential impacts is unknown.

Summary of Fiscal Effects. We estimate the measure would have the following major fiscal effects.

- State General Fund cost potentially ranging in the hundreds of millions of dollars to around a billion dollars each year to assist families with the cost of health care for children with qualifying serious and chronic diseases, as well as to increase payments to providers in the California Children's Services program.

Sincerely,

Gabriel Petek
Legislative Analyst

for Joe Stephenshaw
Director of Finance