Senate Fiscal Agency
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BILL ANALYSIS

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Senate Bill 641 (Substitute S-1)
Sponsor: Senator Jim Ananich
Committee: Health Policy and Human Services

Date Completed: 6-16-22

CONTENT

The bill would amend the Social Welfare Act to do the following:

- **Require the Department of Health and Human Services (DHHS) to ensure the availability of accessible, quality health care for individuals with sickle cell disease who were enrolled in certain Medicaid managed care organizations (MCOs).**
- **Require the DHHS to require, by the fiscal year (FY) 2024 contract year, comprehensive health care program Medicaid MCOs to implement a sickle cell disease quality strategy for children and adults with sickle cell disease.**
- **Require the DHHS to leverage the State sickle cell disease surveillance system to provide an annual report to the Legislature, and to post the report on its website.**
- **Require the DHHS, and in partnership with the comprehensive health care program Medicaid MCOs, to identify, document, and share, by January 1, 2025, best practices regarding sickle cell disease care management and care coordination with Medicaid-enrolled primary care and sickle cell disease specialty providers with a goal of improving services for members with sickle cell disease and their families.**
- **Require the DHHS to develop, by January 1, 2024, guidelines to incorporate sickle cell disease performance standards and measures into contract for the contract year 2025.**
- **Require the DHHS to develop, by January 1, 2025, a plan for improving the transition from pediatric care to adult care for adolescents with sickle cell disease who are aging out of the Medicaid program, and a plan for helping qualified beneficiaries maintain Medicaid coverage under another eligibility category, in order to maintain continuity of care.**
- **Require the DHHS to develop guidelines to incorporate sickle cell disease performance standards and measures into contracts for the contract year 2025.**

The bill would require the DHHS to ensure the availability of accessible, quality health care for individuals with sickle cell disease who were enrolled in Medicaid MCOs that had a contract with the DHHS to provide services to Medicaid members in the comprehensive health care program.

By the FY 2024 contract year, the DHHS would have to require comprehensive health care program Medicaid MCOs to implement a sickle cell disease quality strategy for children and adults with sickle cell disease that included the following components:

-- Measurable goals to improve the identification of members with sickle cell disease within 90 days after enrolling in the contracted health plan.

-- Care coordination strategies and supports to help members with sickle cell disease access sickle cell disease specialists and other related care supports.
-- A training curriculum to educate primary care providers on sickle cell disease, including information on emergency warning signs and complications, evidence-based practices and treatment guidelines, and when to make referrals to specialty sickle cell disease treatment providers.
-- Performance measures relative to access to care and available therapies, engagement in treatment, and outcomes for individuals with sickle cell disease, with the metrics to be reported annually by the comprehensive health care program Medicaid MCOs and with incentive payments attached to the measures.

The DHHS also would have to do the following:

-- Leverage the State sickle cell disease surveillance system[1] to provide an annual report to the Senate and House appropriations committees and the Senate and House Fiscal Agencies, the included identifying gaps and quality in services, access to care trends; uptake of disease modifying therapies, health outcomes, insurance enrollment figures of children and adults, and disparities; the DHHS would have to publish the report on its website.
-- By January 1, 2025, and in partnership with the comprehensive health care program Medicaid MCOs, identify, document, and share best practices regarding sickle cell disease care management and care coordination with Medicaid-enrolled primary care and sickle cell disease specialty providers with a goal of improving services for members with sickle cell disease and their families.
-- Leverage the DHHS Public Health Strategic Plan to Address Sickle Cell Disease Across the Lifespan 2015-2018 and the entities and its strategic planning participants, enter into a contract by January 1, 2022, with a publicly funded university to develop a sickle cell disease-focused comprehensive assessment tool or a supplement to an existing comprehensive assessment tool to screen members identified with sickle cell disease for comorbidities, medical history for the treatment of sickle cell disease including disease-modifying medications and pain management, psychosocial history, barriers to accessing or completing treatments, social supports, other care coordinators working with the member, community resources being used or needed, quality of life, and personal preferences for engagement with a care coordinator.
-- By January 1, 2025, develop a plan for improving the transition from pediatric care to adult care for adolescents with sickle cell disease who are aging out of the Medicaid program, and a plan for helping qualified beneficiaries maintain Medicaid coverage under another eligibility category, in order to maintain continuity of care.

By January 1, 2024, the DHHS would have to develop guidelines to incorporate sickle cell disease performance standards and measures into contracts for the contract year 2025. The guidelines would have to include a mechanism to incentivize plans to meet the included standards and measures. The DHHS would have to report publicly the included standards and performance measures annually.

Proposed MCL 400.106c

[1] In 2010, the Centers for Disease Control and Prevention implemented the Registry and Surveillance System for Hemoglobinopathies (RuSH) pilot program to collect state-specific, population-based data on people with sickle cell disease and thalassemia in order to provide accurate and up-to-date information to the public. The two-year pilot program was supported and conducted in collaboration with the National Institutes of Health's National Heart, Lung, and Blood Institute. Seven states were funded to participate in the data collection: California, Florida, Georgia, Michigan, New York, North Carolina, and Pennsylvania.

BACKGROUND

Sickle cell disease is a group of inherited red blood cell disorders that affect hemoglobin, the protein in red blood cells that carries oxygen. Red blood cells with healthy hemoglobin are smooth, disk-shaped, and flexible; however, red blood cells with sickle cell hemoglobin become hard, sticky, and are C-shaped. Health red blood cells live up to 120 days, but red blood cells affected by sickle cell disease live only for 10 to 20 days.

Symptoms and complications of sick cell disease include anemia, pain, acute chest syndrome, splenic sequestration, stroke, jaundice, and priapism.

According to the Centers for Disease Control and Prevention, sickle cell disease affects approximately 100,000 Americans and is more prevalent in African American births. Sickle cell disease is a genetic condition that is present at birth, and it is inherited when a child receives two genes, one from each parent, that code for abnormal hemoglobin. Individuals who inherit one sickle cell gene and one normal gene have sickle cell trait (SCT). Those with SCT generally do not have any symptoms of sickle cell disease but can pass the trait on to their children. In the United States, babies are screened for sickle cell disease as part of the newborn screening program.

Generally, sickle cell disease is a lifelong illness. Currently, the only cure for some patients who have sickle cell disease is a blood and bone marrow transplant. Physicians may recommend medicines or transfusions to manage compilations, reduce symptoms, and prolong life.

Management of sickle cell disease is focused on preventing and treating pain episodes and other complications. Along with lifestyle behaviors such as hydration, avoiding places with high altitudes or low-oxygen exposure, and temperature maintenance, prevention strategies include medical screenings and interventions. Individuals living with sickle cell disease are directed to pay special attention to prevention of infections, vision loss, stroke, and severe anemia.

Legislative Analyst: Stephen P. Jackson

FISCAL IMPACT

The bill would have an indeterminate negative fiscal impact on the DHHS and no fiscal impact on local units of government. The DHHS would incur increased administrative costs resulting from the development and documentation of best practices for sickle cell disease care management for primary care and sickle cell disease specialty providers. Additionally, the DHHS would incur costs related to the development of a comprehensive assessment tool for individuals with sickle cell disease. Costs would depend on if the contract the DHHS entered into required the development of a new assessment tool or if it would require the modification of an existing assessment tool.

The treatment of sickle cell disease is covered by the State's Medicaid and Healthy Michigan Program, as well as through the Children's Special Health Care Services (CSHCS) Program. The fiscal year 2021-22 enacted budget included $6.6 million to expand CSHCS medical care and treatment to the approximately 400 adults in Michigan diagnosed with sickle cell disease who are not covered by Medicaid or other health insurance coverage.

Fiscal Analyst: Ellyn Ackerman

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