

SENATE BILL REPORT

SB 6486

As of February 8, 2020

Title: An act relating to expanding medicaid coverage for individuals with a rare disease.

Brief Description: Expanding medicaid coverage for individuals with a rare disease.

Sponsors: Senators Rivers, Short, Brown and Becker.

Brief History:

Committee Activity: Health & Long Term Care: 1/31/20, 2/03/20 [DPS-WM].
Ways & Means: 2/06/20.

Brief Summary of First Substitute Bill

- Establishes a state health coverage program for persons diagnosed with a rare disease.

SENATE COMMITTEE ON HEALTH & LONG TERM CARE

Majority Report: That Substitute Senate Bill No. 6486 be substituted therefor, and the substitute bill do pass and be referred to Committee on Ways & Means.

Signed by Senators Cleveland, Chair; Randall, Vice Chair; O'Ban, Ranking Member; Becker, Dhingra, Frockt, Muzzall, Rivers and Van De Wege.

Staff: Evan Klein (786-7483)

SENATE COMMITTEE ON WAYS & MEANS

Staff: Sandy Stith (786-7710)

Background: Medicaid is a program administered jointly by the federal and state governments to provide health coverage to low-income individuals. Washington's Medicaid program is known as Apple Health. A United States citizen is eligible for the Medicaid program if they are between ages 19 and 64, has a modified adjusted gross income of 133 percent of the federal poverty level or less, and is ineligible for Medicare.

This analysis was prepared by non-partisan legislative staff for the use of legislative members in their deliberations. This analysis is not a part of the legislation nor does it constitute a statement of legislative intent.

Congress, in the Orphan Drug Act of 1983, defined a rare disease as any condition that affects fewer than 200,000 people in the nation. Rare diseases include genetic conditions, infections, some rare cancers, and autoimmune diseases. The National Institutes of Health estimates there may be as many as 7000 rare diseases, and that 25 to 30 million Americans may be living with a rare disease.

Summary of Bill (First Substitute): Beginning January 1, 2021, the Health Care Authority (Authority) must provide health coverage to individuals who have been diagnosed with a rare disease and are not eligible for categorically needy medical assistance (Medicaid). Rare disease means any disease or condition affecting less than 200,000 persons in the United States. The amount, scope, and duration of health care services provided must be the same as that provided to individuals eligible for Medicaid.

The Authority must:

- manage application and renewal procedures to maximize enrollment of eligible individuals;
- seek federal funding to defray state costs associated with providing coverage to eligible persons;
- submit a waiver request to the federal Centers for Medicare and Medicaid Services to allow the state to receive federal match funding; and
- pursue a state plan amendment under the Tax Equity and Fiscal Responsibility Act to receive matching funds.

Coverage must be provided to eligible persons regardless of approval of the waiver request. The Authority must report the status of the waiver to the Legislature by December 1, 2020, and inform the Legislature of any statutory changes needed to allow the state to receive federal match funds.

EFFECT OF CHANGES MADE BY HEALTH & LONG TERM CARE COMMITTEE (First Substitute):

- Requires HCA to pursue a state plan amendment under the Tax Equity and Fiscal Responsibility Act, to receive federal matching funds.

Appropriation: None.

Fiscal Note: Available.

Creates Committee/Commission/Task Force that includes Legislative members: No.

Effective Date: Ninety days after adjournment of session in which bill is passed.

Staff Summary of Public Testimony on Original Bill (Health & Long Term Care): *The committee recommended a different version of the bill than what was heard.* PRO: This is a growing problem in the United States. Families with a double income may be doing fine, but when tragedy strikes, these families suffer. Often, one parent must leave their job and families are sometimes driven to bankruptcy because they cannot afford increased health care costs. There is work being done to narrow the scope of the legislation so that the fiscal note

is not overwhelming. Parents who have children with a rare disease are privileged if they are able to still work. Out of pocket costs for families with a family member with a rare disease are tens of thousands of dollars or more. One in ten people in the United States have a rare disease. Twenty-two percent of children have rare diseases. Removing the financial burden of health insurance will allow parents to spend more time as caregivers. Under the Tax Equity and Fiscal Responsibility Act, instead of having to apply to CMS for a federal waiver, the state could incorporate this coverage as part of the Medicaid state plan.

Persons Testifying (Health & Long Term Care): PRO: Senator Ann Rivers, Prime Sponsor; Mary McDirmid, citizen; Diana Stadden, The Arc of Washington State; Adrienne Stuart, Washington State Developmental Disabilities Council.

Persons Signed In To Testify But Not Testifying (Health & Long Term Care): No one.

Staff Summary of Public Testimony (Ways & Means): PRO: This bill is a work in progress. We have been untangling it as we go along. Community advocates for developmental disabilities are confused by the fiscal note for this bill. There are 21 states that already have this in place. Most states say that the cost for treating a child with a rare disorder at home cannot exceed what it would be in a hospital or institution. Some have a fee or sliding scale. With this many states that have done this, we do not understand why the Health Care Authority cannot scope the costs.

Persons Testifying (Ways & Means): PRO: Senator Ann Rivers, Prime Sponsor; Diana Stadden, The Arc of Washington State.

Persons Signed In To Testify But Not Testifying (Ways & Means): No one.