

SENATE BILL REPORT

SB 6486

As of January 31, 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.

Brief Summary of Bill

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

SENATE COMMITTEE ON HEALTH & LONG TERM CARE

Staff: Evan Klein (786-7483)

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.

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: 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,

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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; and
- submit a waiver request to the federal Centers for Medicare and Medicaid Services to allow the state to receive federal match funding.

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.

Appropriation: None.

Fiscal Note: Requested on January 20, 2020.

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: 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: 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: No one.