

SENATE BILL REPORT

SB 5864

As Reported by Senate Committee On:
Health & Long Term Care, January 30, 2024

Title: An act relating to establishing a point of contact for any person diagnosed with a rare disease.

Brief Description: Establishing a point of contact for any person diagnosed with a rare disease.

[Revised for 1st Substitute: Assisting individuals diagnosed with a rare disease with accessing existing support services and programs.]

Sponsors: Senator Fortunato.

Brief History:

Committee Activity: Health & Long Term Care: 1/12/24, 1/30/24 [DPS-WM].

Brief Summary of First Substitute Bill

- Directs the Department of Social and Health Services and the Health Care Authority to study the feasibility and cost of implementing a point of contact for an individual diagnosed with a rare disease to increase access and reduce barriers in navigating programs, services, and resources offered by both agencies.

SENATE COMMITTEE ON HEALTH & LONG TERM CARE

Majority Report: That Substitute Senate Bill No. 5864 be substituted therefor, and the substitute bill do pass and be referred to Committee on Ways & Means.

Signed by Senators Cleveland, Chair; Robinson, Vice Chair; Rivers, Ranking Member; Muzzall, Assistant Ranking Member; Conway, Dhingra, Holy, Padden, Randall and Van De Wege.

Staff: Julie Tran (786-7283)

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

Background: Rare Diseases. The United States Congress, in the Orphan Drug Act of 1983, defines a rare disease as a disease that affects fewer than 200,000 people in the United States. Rare diseases include genetic conditions, infections, some rare cancers, and autoimmune diseases. The National Institutes of Health estimates there are over 10,000 known rare diseases and, in the United States, rare diseases affect about 25 to 30 million Americans.

Comprehensive Assessment Reporting Evaluation. The Comprehensive Assessment Reporting Evaluation (CARE) is the tool used by the Department of Social and Health Services' (DSHS) case managers to document a client's functional ability, determine eligibility for long-term care services, evaluate what and how much assistance a client will receive, and develop a plan of care.

Summary of Bill (First Substitute): DSHS and Washington State Health Care Authority (HCA) must study the feasibility and cost of implementing a point of contact for an individual diagnosed with a rare disease to increase access and reduce barriers in navigating programs, services, and resources offered by both agencies. DSHS and HCA must submit a preliminary report of the findings and recommendations by December 31, 2024 and a final report by June 30, 2025.

The reports must include, but are not limited to:

- how the appropriate department and authority staff that interface with clients and the public may increase their understanding about the special conditions and symptoms of rare diseases;
- considerations of possible educational materials, trainings, or other resources that allow for an increased understanding of rare diseases, both across programs and for internal staff members;
- an assessment of how the programs deliver services and address barriers that individuals diagnosed with rare diseases may have when navigating the delivery system;
- an implementation plan to reduce barriers for individuals diagnosed with a rare disease who are trying to connect with existing supports and services; and
- the development of a plan to increase awareness for individuals and clients regarding the available resources for individuals diagnosed with a rare disease.

DSHS must evaluate the CARE assessment and authorization process and consider how they factor in rare diseases and the symptoms of rare diseases. The CARE assessment evaluation and implementation plan to incorporate the rare disease symptoms into the assessment process and ensure symptoms of rare diseases are being considered in the assessment must be included in the report.

DSHS and HCA must submit a preliminary report of the findings and recommendations by December 31, 2024 and a final report by June 30, 2025 to the Governor and the appropriate committees of the Legislature.

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

- Removes the provisions of the underlying bill and directs DSHS and HCA to study the feasibility and cost of implementing a point of contact for an individual diagnosed with a rare disease to increase access and reduce barriers in navigating programs, services, and resources offered by both agencies.
- Directs DSHS to evaluate the comprehensive assessment reporting evaluation assessment and authorization process and consider how they factor in rare diseases and the symptoms of rare diseases.
- Requires both agencies to submit a preliminary report of the findings and recommendations by December 31, 2024 and a final report by June 30, 2025.
- Changes the bill title.

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: *The committee recommended a different version of the bill than what was heard.* PRO: This is a good little bill inspired by my grandson, who has a rare disease. There is a lack of understanding about the special conditions that rare diseases may have. Families and individuals with rare diseases have trouble navigating the programs, services, and resources that are available. The purpose of the bill is to have somebody that understands rare diseases and has some experience to assist these individuals. This also connects to issues with caregiver hours and the need for more hours as rare diseases is not something that is typically dealt with.

Persons Testifying: PRO: Senator Phil Fortunato, Prime Sponsor.

Persons Signed In To Testify But Not Testifying: No one.