
SUBSTITUTE SENATE BILL 5864

State of Washington

68th Legislature

2024 Regular Session

By Senate Health & Long Term Care (originally sponsored by Senator Fortunato)

READ FIRST TIME 01/31/24.

1 AN ACT Relating to assisting individuals diagnosed with a rare
2 disease with accessing existing support services and programs;
3 creating a new section; and providing an expiration date.

4 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:

5 NEW SECTION. **Sec. 1.** (1) The department of social and health
6 services and the health care authority shall study the feasibility
7 and cost of implementing a point of contact for an individual
8 diagnosed with a rare disease to increase access and reduce barriers
9 in navigating the programs, services, and resources offered by the
10 department and authority. Both the department and the authority shall
11 submit separate reports to the governor and the appropriate
12 committees of the legislature with a preliminary report due by
13 December 31, 2024, and a final report by June 30, 2025. The reports
14 shall include any findings and recommendations from the feasibility
15 and cost study and must include, but are not limited to:

16 (a) How the appropriate department and authority staff that
17 interface with clients and the public may increase their
18 understanding about the special conditions and symptoms of rare
19 diseases;

1 (b) Considerations of possible educational materials, trainings,
2 or other resources that allow for an increased understanding of rare
3 diseases, both across programs and for internal staff members;

4 (c) An assessment of how the programs deliver services and
5 address barriers that individuals diagnosed with rare diseases may
6 have when navigating the delivery system;

7 (d) An implementation plan to reduce barriers for individuals
8 diagnosed with a rare disease who are trying to connect with existing
9 supports and services; and

10 (e) The development of a plan to increase awareness for
11 individuals and clients regarding the available resources for
12 individuals diagnosed with a rare disease.

13 (2) In addition to the work outlined in subsection (1) of this
14 section, the department of social and health services shall evaluate
15 the comprehensive assessment reporting evaluation assessment and
16 authorization process and consider how they factor in rare diseases
17 and the symptoms of rare diseases. The report submitted by the
18 department as outlined in subsection (1) of this section must also
19 include a summary of the work outlined in this subsection and an
20 implementation plan to incorporate the rare disease symptoms into the
21 assessment process and ensure symptoms of rare diseases are being
22 considered in the assessment.

23 (3) For the purpose of this section, "rare disease" means a
24 disease that affects fewer than 200,000 people in the United States.

25 (4) This section expires July 30, 2026.

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