S-4526.1

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**SUBSTITUTE SENATE BILL 5864**

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**State of Washington 68th Legislature 2024 Regular Session**

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

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

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

NEW SECTION. **Sec.**  (1) The department of social and health services and the health care authority shall 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 the programs, services, and resources offered by the department and authority. Both the department and the authority shall submit separate reports to the governor and the appropriate committees of the legislature with a preliminary report due by December 31, 2024, and a final report by June 30, 2025. The reports shall include any findings and recommendations from the feasibility and cost study and must include, but are not limited to:

(a) 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;

(b) 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;

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

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

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

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

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

(4) This section expires July 30, 2026.

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