

Multiple Agency Fiscal Note Summary

Bill Number: 5864 S SB	Title: Rare disease supports
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Estimated Cash Receipts

Agency Name	2023-25			2025-27			2027-29		
	GF-State	NGF-Outlook	Total	GF-State	NGF-Outlook	Total	GF-State	NGF-Outlook	Total
Washington State Health Care Authority	Non-zero but indeterminate cost and/or savings. Please see discussion.								
Department of Social and Health Services	0	0	125,000	0	0	0	0	0	0
Total \$	0	0	125,000	0	0	0	0	0	0

Estimated Operating Expenditures

Agency Name	2023-25				2025-27				2027-29			
	FTEs	GF-State	NGF-Outlook	Total	FTEs	GF-State	NGF-Outlook	Total	FTEs	GF-State	NGF-Outlook	Total
Washington State Health Care Authority	Non-zero but indeterminate cost and/or savings. Please see discussion.											
Department of Social and Health Services	.0	125,000	125,000	250,000	.0	0	0	0	.0	0	0	0
Total \$	0.0	125,000	125,000	250,000	0.0	0	0	0	0.0	0	0	0

Estimated Capital Budget Expenditures

Agency Name	2023-25			2025-27			2027-29		
	FTEs	Bonds	Total	FTEs	Bonds	Total	FTEs	Bonds	Total
Washington State Health Care Authority	.0	0	0	.0	0	0	.0	0	0
Department of Social and Health Services	.0	0	0	.0	0	0	.0	0	0
Total \$	0.0	0	0	0.0	0	0	0.0	0	0

Estimated Capital Budget Breakout

NONE

Prepared by: Jason Brown, OFM	Phone: (360) 742-7277	Date Published: Final 2/ 6/2024
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Individual State Agency Fiscal Note

Bill Number: 5864 S SB	Title: Rare disease supports	Agency: 107-Washington State Health Care Authority
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Part I: Estimates

☐ No Fiscal Impact

Estimated Cash Receipts to:

Non-zero but indeterminate cost and/or savings. Please see discussion.

Estimated Operating Expenditures from:

Non-zero but indeterminate cost and/or savings. Please see discussion.

Estimated Capital Budget Impact:

NONE

The cash receipts and expenditure estimates on this page represent the most likely fiscal impact. Factors impacting the precision of these estimates, and alternate ranges (if appropriate), are explained in Part II.

Check applicable boxes and follow corresponding instructions:

- ☒ If fiscal impact is greater than \$50,000 per fiscal year in the current biennium or in subsequent biennia, complete entire fiscal note form Parts I-V.
- ☐ If fiscal impact is less than \$50,000 per fiscal year in the current biennium or in subsequent biennia, complete this page only (Part I).
- ☐ Capital budget impact, complete Part IV.
- ☐ Requires new rule making, complete Part V.

Legislative Contact: Sandy Stith	Phone: 786-7710	Date: 01/31/2024
Agency Preparation: Lena Johnson	Phone: 360-725-5295	Date: 02/06/2024
Agency Approval: Cliff Hicks	Phone: 360-725-0875	Date: 02/06/2024
OFM Review: Jason Brown	Phone: (360) 742-7277	Date: 02/06/2024

Part II: Narrative Explanation

II. A - Brief Description Of What The Measure Does That Has Fiscal Impact

Significant provisions of the bill and any related workload or policy assumptions that have revenue or expenditure impact on the responding agency by section number.

Please see attached.

II. B - Cash receipts Impact

Cash receipts impact of the legislation on the responding agency with the cash receipts provisions identified by section number and when appropriate, the detail of the revenue sources. Description of the factual basis of the assumptions and the method by which the cash receipts impact is derived. Explanation of how workload assumptions translate into estimates. Distinguished between one time and ongoing functions.

II. C - Expenditures

Agency expenditures necessary to implement this legislation (or savings resulting from this legislation), with the provisions of the legislation that result in the expenditures (or savings) identified by section number. Description of the factual basis of the assumptions and the method by which the expenditure impact is derived. Explanation of how workload assumptions translate into cost estimates. Distinguished between one time and ongoing functions.

Part III: Expenditure Detail

III. A - Operating Budget Expenditures

Non-zero but indeterminate cost and/or savings. Please see discussion.

III. B - Expenditures by Object Or Purpose

Non-zero but indeterminate cost and/or savings. Please see discussion.

III. C - Operating FTE Detail: FTEs listed by classification and corresponding annual compensation. Totals agree with total FTEs in Part I and Part IIIA.

NONE

III. D - Expenditures By Program (optional)

NONE

Part IV: Capital Budget Impact

IV. A - Capital Budget Expenditures

NONE

IV. B - Expenditures by Object Or Purpose

NONE

IV. C - Capital Budget Breakout

Acquisition and construction costs not reflected elsewhere on the fiscal note and description of potential financing methods.

NONE

IV. D - Capital FTE Detail: FTEs listed by classification and corresponding annual compensation. Totals agree with total FTEs in Part IVB.

NONE

Part V: New Rule Making Required

Provisions of the bill that require the agency to adopt new administrative rules or repeal/revise existing rules.

HCA Fiscal Note

Bill Number: **5864 SSB**

HCA Request #: 24-120

Title: **Rare Disease Contact**

Part I: Estimates

☐ No Fiscal Impact

Estimated Cash Receipts to:

NONE

Estimated Operating Expenditures from:

NONE

Estimated Capital Budget Impact:

NONE

The cash receipts and expenditure estimates on this page represent the most likely fiscal impact. Factors impacting the precision of these estimates, and alternate ranges (if appropriate), are explained in Part II.

Check applicable boxes and follow corresponding instructions:

- ☒ If fiscal impact is greater than \$50,000 per fiscal year in the current biennium or in subsequent biennia, complete entire fiscal note form Parts I-V.
- ☐ If fiscal impact is less than \$50,000 per fiscal year in the current biennium or in subsequent biennia, complete this page only (Part I).
- ☐ Capital budget impact, complete Part IV.
- ☐ Requires new rule making, complete Part V.

HCA Fiscal Note

Bill Number: **5864 SSB**

HCA Request #: 24-120

Title: **Rare Disease Contact**

Part II: Narrative Explanation

II. A – Brief Description Of What The Measure Does That Has Fiscal Impact

Significant provisions of the bill and any related workload or policy assumptions that have revenue or expenditure impact on the responding agency by section number.

AN ACT Relating to establishing a point of contact for any person diagnosed with a rare disease; and adding a new section to chapter 41.05 RCW.

Sec 1 (New)

(1) Department of Social Health and Services (DSHS) and the Health Care Authority (HCA) must complete a feasibility and cost study for a point of contact for an individual diagnosed with a rare disease. Each will submit a separate preliminary report of the findings and recommendations by December 31, 2024 and a final report by June 30, 2025. The report must include, but is not limited to:

- a) how DSHS and HCA staff that interface with clients and the public may increase their understanding about the special conditions and symptoms of rare diseases;
- b) possible educational materials, trainings, or other resources on rare diseases, both across programs and for internal staff members;
- c) an assessment of current program delivery and address barriers that those 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) 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.

(3) Rare disease means a disease that affects fewer than 200000 people in the US.

(4) This section expires July 30, 2026

II. B – Cash Receipts Impact

Cash receipts impact of the legislation on the responding agency with the cash receipts provisions identified by section number and when appropriate, the detail of the revenue sources. Description of the factual basis of the assumptions and the method by which the cash receipts impact is derived. Explanation of how workload assumptions translate into estimates. Distinguish between one time and ongoing functions.

NONE

II. C – Expenditures

Agency expenditures necessary to implement this legislation (or savings resulting from this legislation), with the provisions of the legislation that result in the expenditures (or savings) identified by section number. Description of the factual basis of the assumptions and the method by which the expenditure impact is derived. Explanation of how workload assumptions translate into cost estimates. Distinguish between one time and ongoing functions.

HCA Fiscal Note

Bill Number: **5864 SSB**

HCA Request #: 24-120

Title: **Rare Disease Contact**

Indeterminate fiscal impact.

This bill relates to providing a single point of contact for patients with a rare disease. The substitute bill requires DSHS and HCA to study associated feasibility and costs and to submit separate preliminary reports of the findings and recommendations by December 31, 2024 and a final report by June 30, 2025.

Apple Health Managed Care:

- A full-time equivalent (FTE) position will be needed to collect the data and to potentially develop an advisory group. For this feasibility study multiple entities will need to work together including HCA, DSHS (ALTSA and DDA), private insurance and other.
- The best solution would be potentially to contract this work out to third party contract agencies instead of adding FTEs. The project management team will be needed to support this work.

Apple Health Fee-for-Service (FFS):

- Due to the amount of work in the feasibility and cost study, Apple FFS would request this be contracted out. This bill will require multi-departmental and multi-agency participation in work groups and unsure on which division will lead. This may also require a potential review of current contracts with all agency carriers.
- Assuming this will take significant project management. Assuming a knowledge base for completing reports with existing staff; however, requires multi-departmental and multi-agency participation as noted above. Cost estimate for completion of feasibility and cost study will require procurement of third party contracting for project management and actuarial services or an increase in FTE to support work.
- Time frame is too aggressive for amount of work. Assumed it will be difficult to determine the number of clients that have rare diseases which will require significant research.
- **Estimate \$500,000 for the work above for HCA using a contracted project management team.**

Employee and Retiree Benefits (ERB):

- If ERB staff are to participate in the feasibility and cost report, it is likely this work will be absorbed by existing staff.

Part III: Expenditure Detail

III. A - Operating Budget Expenditure

NONE

HCA Fiscal Note

Bill Number: **5864 SSB**

HCA Request #: 24-120

Title: **Rare Disease Contact**

III. B - Expenditures by Object Or Purpose

NONE

III. C - Operating FTE Detail: FTEs listed by classification and corresponding annual compensation. Totals agree with total FTEs in Part I and Part IIIA.

NONE

III. D - Expenditures By Program (optional)

NONE

Part IV: Capital Budget Impact

IV. A - Capital Budget Expenditures

NONE

IV. B - Expenditures by Object Or Purpose

NONE

IV. C - Capital Budget Breakout: Acquisition and construction costs not reflected elsewhere on the fiscal note and description of potential financing methods.

NONE

IV. D - Capital FTE Detail: FTEs listed by classification and corresponding annual compensation. Totals agree with total FTEs in Part IVB.

NONE

Part V: New Rule Making Required

Provisions of the bill that require the agency to adopt new administrative rules or repeal/revise existing rules.

NONE

Individual State Agency Fiscal Note

Bill Number: 5864 S SB	Title: Rare disease supports	Agency: 300-Department of Social and Health Services
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Part I: Estimates

☐ No Fiscal Impact

Estimated Cash Receipts to:

ACCOUNT	FY 2024	FY 2025	2023-25	2025-27	2027-29
General Fund-Federal 001-2		125,000	125,000		
Total \$		125,000	125,000		

Estimated Operating Expenditures from:

	FY 2024	FY 2025	2023-25	2025-27	2027-29
Account					
General Fund-State 001-1	0	125,000	125,000	0	0
General Fund-Federal 001-2	0	125,000	125,000	0	0
Total \$	0	250,000	250,000	0	0

Estimated Capital Budget Impact:

NONE

The cash receipts and expenditure estimates on this page represent the most likely fiscal impact. Factors impacting the precision of these estimates, and alternate ranges (if appropriate), are explained in Part II.

Check applicable boxes and follow corresponding instructions:

- ☒ If fiscal impact is greater than \$50,000 per fiscal year in the current biennium or in subsequent biennia, complete entire fiscal note form Parts I-V.
- ☐ If fiscal impact is less than \$50,000 per fiscal year in the current biennium or in subsequent biennia, complete this page only (Part I).
- ☐ Capital budget impact, complete Part IV.
- ☐ Requires new rule making, complete Part V.

Legislative Contact: Sandy Stith	Phone: 786-7710	Date: 01/31/2024
Agency Preparation: Cassi Postma	Phone: 3609999999	Date: 02/05/2024
Agency Approval: Dan Winkley	Phone: 360-902-8236	Date: 02/05/2024
OFM Review: Jason Brown	Phone: (360) 742-7277	Date: 02/05/2024

Part II: Narrative Explanation

II. A - Brief Description Of What The Measure Does That Has Fiscal Impact

Significant provisions of the bill and any related workload or policy assumptions that have revenue or expenditure impact on the responding agency by section number.

Substitute Senate Bill 5864 directs the Department of Social and Health Services (DSHS) to conduct a study to determine the feasibility and cost of implementing a point of contact for individuals diagnosed with rare diseases to increase access and reduce barriers in navigating the programs, services and resources available. DSHS must submit a preliminary report of the findings and recommendations from the study by December 31, 2024, and a final report by June 30, 2025, to the governor and legislature.

II. B - Cash receipts Impact

Cash receipts impact of the legislation on the responding agency with the cash receipts provisions identified by section number and when appropriate, the detail of the revenue sources. Description of the factual basis of the assumptions and the method by which the cash receipts impact is derived. Explanation of how workload assumptions translate into estimates. Distinguished between one time and ongoing functions.

A portion of the costs incurred to implement this legislation will be funded with federal Title XIX - Medicaid funds.

II. C - Expenditures

Agency expenditures necessary to implement this legislation (or savings resulting from this legislation), with the provisions of the legislation that result in the expenditures (or savings) identified by section number. Description of the factual basis of the assumptions and the method by which the expenditure impact is derived. Explanation of how workload assumptions translate into cost estimates. Distinguished between one time and ongoing functions.

Section 1(1) of this bill directs DSHS 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, and to submit a report of the findings to the governor and legislature.

To meet the directive of this bill, DSHS Aging and Long-Term Support (ALTSA) and Developmental Disabilities (DDA) administrations will engage a contractor to conduct the feasibility study, then create and submit a preliminary report of the findings and recommendations from the study by December 31, 2024, and a final report by June 30, 2025.

The report will include, but will not be limited to:

- 1) How the appropriate staff that interface with clients and the public may increase their understanding about the special conditions and symptoms of rare diseases.
- 2) 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.
- 3) An assessment of how the programs deliver services and address barriers that individuals diagnosed with rare diseases may have when navigating the delivery system.
- 4) An implementation plan to reduce barriers for individuals diagnosed with rare diseases who are trying to connect with existing supports and services.
- 5) The development of a plan to increase awareness for individuals and clients regarding the available resources for individuals diagnosed with a rare disease.

Additionally, DSHS (ALTSA and DDA) will evaluate the Comprehensive Assessment Reporting Evaluation (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 will be included in the report.

Based on prior studies, DSHS estimates the total fiscal impact of the related work to be approximately \$250,000 and to occur in fiscal year 2025. The outcomes of the feasibility study could result in additional fiscal impacts to DSHS and partner agencies.

Part III: Expenditure Detail

III. A - Operating Budget Expenditures

Account	Account Title	Type	FY 2024	FY 2025	2023-25	2025-27	2027-29
001-1	General Fund	State	0	125,000	125,000	0	0
001-2	General Fund	Federal	0	125,000	125,000	0	0
Total \$			0	250,000	250,000	0	0

III. B - Expenditures by Object Or Purpose

	FY 2024	FY 2025	2023-25	2025-27	2027-29
FTE Staff Years					
A-Salaries and Wages					
B-Employee Benefits					
C-Professional Service Contracts		250,000	250,000		
E-Goods and Other Services					
G-Travel					
J-Capital Outlays					
M-Inter Agency/Fund Transfers					
N-Grants, Benefits & Client Services					
P-Debt Service					
S-Interagency Reimbursements					
T-Intra-Agency Reimbursements					
9-					
Total \$	0	250,000	250,000	0	0

III. C - Operating FTE Detail: FTEs listed by classification and corresponding annual compensation. Totals agree with total FTEs in Part I and Part IIIA.

NONE

III. D - Expenditures By Program (optional)

Program	FY 2024	FY 2025	2023-25	2025-27	2027-29
Developmental Disabilities Administration (040)		125,000	125,000		
Aging and Long-Term Support Administration (050)		125,000	125,000		
Total \$		250,000	250,000		

Part IV: Capital Budget Impact

IV. A - Capital Budget Expenditures

NONE

IV. B - Expenditures by Object Or Purpose

NONE

IV. C - Capital Budget Breakout

Acquisition and construction costs not reflected elsewhere on the fiscal note and description of potential financing methods.

NONE

IV. D - Capital FTE Detail: FTEs listed by classification and corresponding annual compensation. Totals agree with total FTEs in Part IVB.

NONE

Part V: New Rule Making Required

Provisions of the bill that require the agency to adopt new administrative rules or repeal/revise existing rules.