

Washington State Department of Social and Health Services

# Transforming Lives

## REPORT TO THE LEGISLATURE

### Engrossed 2nd Substitute House Bill 1694 Sec 11

Addressing Home Care Workforce Shortages:  
Exploring Paying Parents of Minors to Provide Personal Care

December 31, 2023

DSHS Developmental Disabilities Administration  
Office of the Assistant Secretary  
PO Box 45310  
Olympia, WA 98504-5310  
(360) 407-1500  
[www.dshs.wa.gov/dda](http://www.dshs.wa.gov/dda)



# Table of Contents

Executive Summary.....	3
Recommendations .....	3
Background .....	5
Practices in Other States.....	6
Extraordinary Care .....	8
Safeguards.....	12
Target Population, Cost and Budget Estimates .....	13
Employer Type .....	16
Provider Training.....	16
Technical Systems Implications .....	17
Medicaid Financial Eligibility Implications .....	17
Positive Impacts of Implementation.....	18
Risks and Barriers to Implementation .....	19
Timeline for Implementation.....	20
Next Steps and Follow Up Items when Funded .....	21
Collaborator Impact and Engagement.....	21
Conclusion.....	21
Appendices.....	23
Appendix A – Collaborator Impact and Engagement.....	24
Appendix B -Tribal Forum document.....	31

## Executive Summary

In the 2023 legislative session, the Washington State Legislature passed Engrossed 2<sup>nd</sup> Substitute House Bill 1694 which included several changes and additions to address shortages in the home care workforce. Section 11 directs the Department of Social and Health Services to study the feasibility and cost of paying parents of children under 18 years old when the child is medically complex or has complex support needs related to behaviors. For purposes of this report, parents are defined as biological, step, adoptive or foster, and referenced hereafter as “parent” or “parent of a minor.”

The business driver behind this feasibility study is to help bridge the gap between demand for caregivers and the availability of caregivers. The state of Washington, and the rest of the nation, is facing a shortage of paid caregivers which is anticipated to increase as the population ages. The program changes envisioned in this report may mitigate the shortage by paying parents to provide care to their children who have extraordinary, complex care needs.

This report offers:

- Recommendations to fund this new provider type.
- Options to define medically complex, behaviorally complex, and children who have extraordinary personal care needs.
- Estimates of the number of children expected to be served and anticipated annual cost to the state, both if federal matching funds are approved and if they are not approved.
- Recommendations on training for parents to support their children’s care needs.
- Necessary statutory or regulatory changes.
- Elements needed to prepare federal waiver or state plan amendments to request approval for the use of federal matching funds through a Medicaid program.
- Information technology changes for the agency and associated costs.
- Benefits and risks of implementing the change.
- A proposed timeline for implementation.
- The results of an impact assessment performed related to this change.
- Readiness considerations.

## Recommendations

The Department of Social and Health Services’ Developmental Disabilities Administration is excited and honored to be given the opportunity to study and report on a change to our service delivery system that may truly transform the lives of the families we support.

There are potentially two options to obtain federal matching funds for personal care. There are

pros and cons to both options as detailed throughout this report.

The first is to request approval from the Centers for Medicare and Medicaid Services to pay parents of minors through the current Community First Choice program. Most individuals receive their personal care benefit in Washington state through this program. The federal regulation that governs the Community First Choice program does not expressly prohibit nor does it specifically allow paying legally responsible parties; it is unknown if CMS would approve this.

Entitlement programs under a Medicaid State Plan, like Community First Choice, are unable to be limited; therefore, DDA would need to allow the parents of all children to be paid as a provider. This would expand the scope of legislative direction to pay parent providers for children with medically or behaviorally complex care needs. As a result, families' Medicaid eligibility may be impacted based on household income. This may have a revolving effect in that when the child loses access to Medicaid and access to personal care, the parent can no longer be paid to do personal care until family income is low enough to reenroll the child in Medicaid. These children would need to enroll on one of DDA's 1915(c) Home and Community Based Services (HCBS) waivers to maintain Medicaid eligibility to continue access to their personal care services. HCBS Waiver eligibility excludes the parental income and only counts the child's income.

The second option is to provide personal care services through a Home and Community Based Services or other type of waiver allowable by CMS. The federal match for waivers is 6% less than Community First Choice. This loss in match could be countered by parents earning more income for the family, having access to private insurance and reducing reliance on Medicaid for themselves or others in their household. The DDA eligible children would also retain Medicaid eligibility as waivers only look at the child's income for Medicaid benefits. To operationalize this option, DDA will need to seek federal approval to restore personal care as a service in our already existing HCBS waivers or add another waiver. DDA will need to consult with CMS to determine the best option, but DDA would prefer to add the service to existing waivers rather than add a new waiver. The legislature has directed DDA to complete a report, due December 2024, that explores opportunities to restructure services offered under the waivers and feedback from stakeholders is that there is an interest in consolidating and reducing the number of waivers DDA operates. Adding another waiver conflicts with that feedback. Given the timeframe to complete this report, DDA was unable to receive technical assistance from CMS on whether there are other options to allow parents to be paid to care for their children or whether one of the options identified by DDA staff would be approved. However, information provided by other states that we connected with indicated they are all paying parents through personal care services in their waivers or seeking to do so. One state, Arizona, operates their entire program under an 1115 waiver, rather than using any 1915(c) options.

DSHS' Developmental Disabilities Administration recommends that the Legislature appropriate funding to request approval from CMS to restore personal care to the Core, Individual and Family Services, Basic Plus and Children's Intensive In-home Behavioral Supports waivers to pay parents of minors. This will allow DDA to gain valuable information about the utilization of this provider type and possible impacts to families, clients, case management functions, and systems changes that could be used to determine whether it is feasible to include in the Community First Choice program.

It is further recommended that the Legislature codify the presumption of parental responsibility as currently identified in department rule in [WAC 388-106-0130](#). This will allow DDA to continue to assess a client's benefit with the understanding that parents will meet the needs of their children some portion of the time without being paid.

DDA consulted with several interested parties and heard from them a recommendation that complex or extraordinary needs include as many children as possible because children deemed eligible for assistance with their personal care have support needs that are beyond typically developing children. Options are outlined later in [Target Population, Cost and Budget Estimates](#).

Additionally, it is assumed and recommended that parents of minor children who are paid to provide care be deemed long-term care workers as defined in [RCW 74.39A.009](#). This is in alignment with parent providers of adult children. Interested parties voiced their agreement with this proposal.

Finally, to help meet the intent of the legislation and expand the long-term care provider pool, DDA recommends that the legal guardians and foster parents of children also be allowed to be paid providers for the children for whom they provide care. Legal guardians and foster parents have the same legal responsibilities as well as the same costs and challenges as parents do to care for the minor children with disabilities. They are also currently prohibited from being paid to provide personal care services to children in their care. DDA would put policies in place to ensure there is no duplication of services that foster parents are already compensated to do.

## **Background**

The Department of Social and Health Services has offered personal care services to individuals eligible for Medicaid since 1989. The original Medicaid Personal Care program was implemented under an optional benefit that states could elect in their Medicaid state plan under federal rules. The federal rules that govern the Medicaid Personal Care program ([42 CFR §440.167](#)) prohibit states from receiving federal matching funds if payments are made to individuals who are legally responsible for the Medicaid beneficiary. The statute defines legally

responsible individuals as both parents of minors and spouses. To receive 50% matching funds from the federal government, DSHS wrote program rules in WAC chapters 388-106 and 388-825 that prohibit biological, step, adoptive and foster parents from being paid to provide personal care services to their own minor children.

In 2014, the Washington State Legislature passed Engrossed Substitute House Bill 2746 directing DSHS to implement a Community First Choice option available under section 1915(k) of the Social Security Act. Doing so allowed the state to expand the types of services available beyond hourly personal care and has an additional 6% in federal matching funds. The state reinvested savings to establish the Individual and Family Services Waiver and expand capacity on the Basic Plus waiver. The Community First Choice program was implemented July 1, 2015, and serves nearly all DDA's approximately 16,500 clients eligible for personal care services today. Less than 75 individuals receive services under the original Medicaid Personal Care program. There are approximately 5,000 children currently eligible to receive personal care services through DDA.

## Practices in Other States

Understanding other states' experiences and solutions will help Washington develop a program that best serves these new parent providers while ensuring the health, safety and well-being of the children served, so we connected with other states to learn from their experience.

Expansion of the direct care workforce to include parents or others legally responsible to care for minors has garnered widespread interest because longstanding shortages of caregivers were exacerbated during the COVID-19 pandemic. Several states, including California and Colorado, allow parents to be paid to deliver personal care services to their minor children under certain circumstances. However, of the states who currently pay parents of minors, most did so under the flexibilities CMS provided states during the COVID-19 Public Health Emergency<sup>1</sup>. DDA learned from a few states, including Oregon, that they are working with their legislatures to modify the policies put in place during the pandemic to pay parents to ensure budget appropriations are sufficient to meet the increase in service utilization they saw with the new pandemic era policies. A recent bill passed in Oregon (Senate Bill 91 passed in 2023) directs that paying parents be done through a 1915c waiver and reduces the budget expenditures dramatically so far fewer children will be able to use their parents as providers.

In Spring 2023, the National Association of State Directors of Developmental Disabilities Services, or NASDDDS, surveyed all state and territory members regarding paying legally

---

<sup>1</sup> Burns, Alice; Mohamed, Maiss; O'Malley Watts, Molly, "Pandemic-Era Changes to Medicaid Home-and Community-Based Services (HCBS): A Closer Look at Family Caregiver Policies", *KFF.ORG*, September 19, 2023, <https://www.kff.org/medicaid/issue-brief/pandemic-era-changes-to-medicaid-home-and-community-based-services-hcbs-a-closer-look-at-family-caregiver-policies/>

responsible individuals, including parents of minors. Of the 27 states or territories responding, 12 pay legally responsible individuals to provide personal care. Washington is one of at least three states actively exploring this option.

DDA in turn asked fellow NASDDDS members for information on their experiences with payment to parents for personal care. Five states responded to the inquiry (Oklahoma, Vermont, Louisiana, New Mexico, and Minnesota). Four of the five states are currently paying legally responsible individuals, including parents, to provide personal care with the fifth state also exploring this option. Oklahoma provided written information from five additional states based on their research or located in publicly available periodicals or legislative sites. Louisiana and Vermont engaged in conversation with us.

All states who responded to DDA as currently paying parents are doing so under a 1915(c) Home and Community Based Services waiver. Minnesota and New Mexico are using a self-directed option. Minnesota is also in the process of applying to use 1915(i) and 1915(k) authorities to expand their programs and plans on allowing for payment to parents of minors.

States reported challenges with separating regular parental responsibilities from the personal care tasks parents are paid to provide. Louisiana implemented the requirement of a signed affidavit from parents indicating that they understood what tasks they could be paid to do. A specific example of a challenge experienced by Louisiana was the administration of medication. In the Louisiana policy, parents cannot be paid to give their child medication unless qualified to do so under nurse delegation. This concern was also acknowledged in recent legislation from the state of Oregon. Oregon's new legislation includes the following limitations and reads, in part:

*A parent provider, during the hours that the parent provider is paid to provide attendant care services to the child:*

- 1. May not be responsible for a vulnerable adult who requires physical care and monitoring.*
- 2. May not be responsible for the care of a child, other than the client child, who is under 10 years of age and shall have another caregiver immediately available at all times to attend to the needs of the child.*
- 3. May not perform tasks that are not for the primary benefit of the client child, including but not limited to:*
  - a. Grocery shopping for the household*
  - b. Housekeeping not required for the care of the client child*
  - c. Remote work or operation of a home business*

Another similarity among states is that the parents are employed through an agency, rather than being directly contracted with the state. Virginia did not require employment by an agency

during the Public Health Emergency but will be requiring it moving forward<sup>2</sup>. Oregon will also require employment by an agency moving forward and identified specific limits on what the agency could allow. Examples of limits include not reassigning hours currently assigned to a non-parent provider and not assigning more than 30% of the annually allocated hours to a parent provider.

Extraordinary care, a requirement under the 1915(c) waiver and discussed further below, is uniquely defined by each state but includes having needed assistance in at least one Activity of Daily Living outside of typical developmental milestones. Colorado and Wyoming limit this to address solely the healthcare needs of the child. They also require physician attestation of need and parental ability to provide care and/or the parent meeting state certification requirements.

All states have some limitations on how many hours a parent can be paid (usually 40 hours per week, or in the case of Wyoming, four hours per day). Louisiana and Minnesota are in the process of expanding this to 60 hours per week including two-parent paid provider households. Oregon has a 60 hours per week limit regardless of the number of parent providers or child clients served in the household.

Louisiana and Vermont were the only states that provided information on the training that parent providers are required to complete. The training requirements for parents in those states is the same as for other individual providers.

As a mitigation strategy for the perceived risk of increases in instances of abuse or neglect, virtual visits by case managers were not allowed by the state of Louisiana.

Finally, the state of Louisiana reported that interested party engagement was an integral part of designing the parameters for the waiver amendment. And Arizona, which is just beginning to explore this option, is initiating public engagement conversations. DDA sought external input in the development of this report and will provide many more opportunities for feedback if an appropriation is provided to design state plan or waiver amendments. Effectively engaging with interested parties and potential beneficiaries will ensure that we design a program that will meet their needs. Communicating the program requirements and limitations to current and prospective participants through a variety of channels will increase the likelihood of their success in navigating it. Communication and engagement tactics can be found in [Appendix A](#).

## **Extraordinary Care**

Federal rules prohibit payment of legally responsible individuals under the Medicaid State Plan

---

<sup>2</sup> McIntyre, Meghan, "'Godsend' caregiver program for Virginians with disabilities set to end this fall", Virginia Mercury, May 8, 2023, <https://www.virginiamercury.com/2023/05/08/godsend-caregiver-program-for-virginians-with-disabilities-set-to-end-this-fall/>



optional benefit and are silent on this under the rules that govern Community First Choice. However, under a Home and Community Based Services waiver, the payment to a legally responsible individual is permissible “when such services are deemed extraordinary care.”<sup>3</sup> CMS defines extraordinary as “care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization.” Guidance from CMS indicates that criteria for extraordinary care “must include how the state will distinguish extraordinary from ordinary care.”

Additional guidance from CMS says:

“State policies should include additional safeguards such as:

- Determining that the provision of personal care or similar services by a legally responsible individual is in the best interests of the waiver participant. A state should consider establishing safeguards when the legally responsible individual has decision-making authority over the selection of providers of waiver services to guard against self-referral.
- Limiting the amount of service that a legally responsible individual may furnish. For example, a state may decide to limit the amount to no more than 40 hours in a week and thereby take into account the amount of care that a legally responsible individual ordinarily would provide.
- Implementing payment review procedures to ensure that the services for which payment is made have been rendered in accordance with the service plan and the conditions that the state has placed on the provision of such services.
- Addressing other foreseeable risks that might attend the provision of services by legally responsible individuals.”<sup>4</sup>

A recent webinar hosted by NASDDDS included information about how other states have determined whether care is extraordinary.

- Minnesota defines extraordinary care as an activity a spouse or parent of a minor would not ordinarily be responsible to perform, e.g., bathing assistance for a 15-year-old child or clean tracheostomy suctioning.
- Pennsylvania defines extraordinary care as support that goes beyond what would be expected to be performed in the usual course of parenting, and when needed support exceeds what is typically required for a child of the same age.
- Louisiana uses the federal definition, but further breaks it down into age groups.

---

<sup>3</sup> CMS Instructions, Technical Guide and Review Criteria, January 2019, [https://wms-mmdl.cms.gov/WMS/help/35/Instructions\\_TechnicalGuide\\_V3.6.pdf](https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf)

<sup>4</sup> CMS Instructions, Technical Guide and Review Criteria, January 2019, [https://wms-mmdl.cms.gov/WMS/help/35/Instructions\\_TechnicalGuide\\_V3.6.pdf](https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf)

Children under the age of 5 must have significant medical, nursing, or behavioral support needs because children of that age typically need a lot of support with ADLs. Children ages 5-12 may only have their parents as their paid provider if their care or support is outside what can be provided in traditional school, day care or after care systems. Parents of children ages 13-18 may be paid if the child's level of support results in their inability to be left alone (e.g., after school) or the person is placed on home-bound education and qualified direct support workers cannot be found.

- Wyoming's definition of extraordinary care is defined as meeting the following criteria:
  1. The participant's Adaptive Behavior Quotient is 0.35 or lower on the Inventory for Client and Agency Planning assessment; and
  2. The participant needs assistance with Activities of Daily Living or Instrumental Activities of Daily Living exceeding the range of expected activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant, and which will avoid institutionalization. (Example: a 12-year-old needing assistance with dressing and bathing, whereas the average 12-year-old does not.); or
  3. The participant requires care from a person with specialized medical skills relating to the participant's diagnosis or medical condition as determined appropriate by the participant's medical professional and the Division.

Defining extraordinary care can be done in a variety of ways to meet both the federal requirements and legislative direction. DDA recommends the use of the current assessment tool and the algorithms already built into it that generate acuity levels.

To qualify for services from DDA a person must meet three types of eligibility criteria: statutory eligibility as a person with developmental or intellectual disability, functional eligibility criteria for each service as defined in DDA rules, and financial eligibility criteria to receive Medicaid. To determine functional eligibility and service amount for personal care services, DDA uses the Comprehensive Assessment Reporting and Evaluation tool to evaluate and assign clients into classification groups as defined in [WAC 388-106-0125](#). These classification groups assess the functional acuity of individuals, considering their cognitive performance, clinical complexity, mood/behaviors symptoms, and needs for assistance with activities of daily living. Each classification includes scores of activities of daily living as defined in [WAC 388-106-0105](#), a behavior score as defined in [WAC 388-106-0100](#), and a cognitive performance score as defined in [WAC 388-106-0090](#). Additionally, the CARE tool defines exceptional care needs (E group) in [WAC 388-106-0110](#).

Summary of classification groups:

- E-Group: Individuals in this group meet criteria for Exceptional Care meaning that they are often immobile with very high ADL assistance needs, need turning and repositioning, have a bowel program and catheter, and need their caregiver to range of motion on their limbs. There are two subgroups in the E classification group, E-Medium and E-High.
- D-Group: Individuals in this group meet criteria for clinical complexity (see C-group below) and have a moderate cognitive impairment or they have a more severe cognitive impairment without being clinically complex. Membership in this group is usually evidenced by poor decision-making, short-term memory loss and lack of ability to make themselves understood to their providers. There are 4 sub-groups within D, D-Low, D-Medium, D-Medium High, and D High.
- C-Group: Individuals in this group meet criteria for clinical complexity. This means they have a qualifying condition, diagnosis or indicator coupled with particular needs related to their activities of daily living. These people are generally more medically complex than those in lower groups and may or may not also have moderate cognitive impairment. There are 4 sub-groups within C, C-Low, C-Med, C-Med-High, C-High.
- B-Group: The intent of this category is to identify individuals who do not meet criteria for any of the groups above, but who exhibit behavioral symptoms that cause them distress or are distressing or disruptive to others with whom the individual comes in contact. There are 4 sub-groups for this group, B-Low, B-Med, B-Med-High, and B-High.
- A-Group: Individuals in this group require assistance with ADLs but do not meet the criteria to be placed in any higher group above because they do not have any behavioral symptoms and are not clinically complex. There are 3 sub-groups, A-Low, A-Med and A-High.

To determine classification levels the CARE tool also considers developmental milestones for children as defined in [WAC 388-106-0130](#). The CARE tool does not generate hours of support for tasks that a parent or other legally responsible adult would ordinarily perform on behalf of a child of the same age who does not have a disability or chronic illness. The services the department provides are solely related to the child's disability. Additionally, a presumption of parental responsibility is incorporated into the workflow of the CARE assessment when determining a child's needs. The department's rules presume that when a child is living with their legally responsible parent the child's needs are met at least  $\frac{3}{4}$  of the time by that parent unpaid.

Given the flexibility from CMS for states to define what extraordinary care of a child is, it is reasonable to suggest all children eligible for personal care have extraordinary needs because personal care hours are not generated unless the child's needs are beyond what is typical of children of the same age. However, HB 1694 asked DDA to "study the feasibility and cost of paying the parents of children under 18 years old who are medically complex or have complex support needs related to their behaviors." Using one or more of the classification groups listed

above or any number of combinations of data gathered from clients during their annual assessment could be used to define extraordinary care more narrowly to meet legislative direction.

The E classification group includes children with significant medical care needs. The CARE assessment includes questions about any behaviors that an individual may exhibit, regardless of classification group, and assigns a behavior point score, if warranted. A behavior point score of 12 or above is predictive of an individual having complex support needs related to their behaviors. Alternative ways to define extraordinary care could include using other information captured in the CARE assessment such as classifications groups, types and amount of support needed for activities of daily living, behavior point scores, specific behaviors and/or medical diagnoses, or a combination of the above. To meet the intent of legislation, DDA recommends allowing parents of children in the E classification group as well as children with a behavior point score of 12 or higher in any classification group to be paid.

DDA sought feedback from parents and other interested parties who would be affected by this change. They shared that limiting the population of people eligible for this new provider type will lead to frustration among parents who want, but are not eligible, to participate. DDA also heard from interested parties that there are children not receiving services or not receiving their full benefit because their parent is their preferred caregiver. Personal care includes tasks that are intimate, and many clients would prefer their parents to perform them. With the addition of parents as caregivers the number of children accessing personal care will increase and budget appropriations will be needed. Additionally, children currently eligible for personal care will utilize more of their assessed benefit, which will also result in increased costs. Other states reported both occurred when they began paying parents of children.

## **Safeguards**

CMS rules require that if a state chooses to pay legally responsible relatives to provide personal care services, the state must have additional state policies and procedures in place beyond what they already require. Some of the additional requirements include how the state ensures that the provision of services by a legally responsible individual is in the best interest of the participant and that there are controls to ensure that payments are made only for services rendered as compared to support provided because the provider is the parent. DDA will need additional resources for a successful implementation and ongoing program support and monitoring.

DDA is recommending a client to case manager ratio of 35:1 to implement these additional requirements. DDA will also need additional staff for training, quality assurance, and change management necessary to support effective awareness, engagement, and adoption of this change by all impacted groups. The department submitted a [decision package](#) for the 2024

legislative session to meet this need.

## Target Population, Cost and Budget Estimates

Of the 4,700 children currently eligible to receive personal care services, 65% (3,100) had providers paid by DDA in the past year. Those who received paid services utilized 74% of their authorized hours. If children have the option to have their parents paid to complete their personal care tasks, DDA presumes all authorized hours would be claimed and those who did not have a paid provider would now access one.

### Costs to allow all children to have their parent(s) as their paid provider:

The chart below shows the costs to add personal care to waivers and serve all children, which was the preference of the interested parties DDA met with. This estimate assumes that all DDA eligible children eligible for personal care would have their parent(s) be paid to deliver personal care tasks and all their assessed hours would be claimed. This model assumes a 50% federal match with waiver, which is a reduction of 6% from the CFC matching rate. It also includes the number of children in each classification group currently, the number of unused authorized personal care hours and the additional cost per year if the unused hours are claimed. The cost estimates illustrate the outside range of new costs that might occur.

Classification Group	Number of Children in Group	Unused Hours Per year	Total Costs Per Year
E High	275	303,710	\$ 10,897,000
E Medium	26	22,182	\$ 796,000
D High	101	60,369	\$ 2,166,000
D Medium	295	167,676	\$6,016,000
D High			
D Medium	370	146,012	\$ 5,239,000
D Low	83	26,813	\$962,000
C High	177	44,830	\$1,609,000
C Medium	534	162,141	\$5,818,000
C High			
C Medium	892	165,429	\$5,935,000
C Low	7	324	\$ 12,000
B High	703	176,287	\$ 2,970,000
B Medium	173	32,665	\$ 717,000
B High			

Classification Group	Number of Children in Group	Unused Hours Per year	Total Costs Per Year
<b>B Medium</b>	838	96,630	\$ 2,057,000
<b>B Low</b>	65	7,427	\$ 201,000
<b>A High</b>	92	7,624	\$ 274,000
<b>A Medium</b>	82	6,436	\$ 230,000
<b>A Low</b>	19	101	\$ 4,000
<b>Total</b>	4,732	1,426,656	\$51,189,000
			<b>General Fund State</b>
			\$25,594,000
			<b>Federal</b>
			\$25,595,000

Paying parents to complete the personal care tasks for their minor children will increase state general fund annual expenditures for personal care services by up to \$25.6 million. Based on information learned during DDA’s outreach to the No Paid Services Caseload over the past few years, it is further assumed that in addition to the historical caseload growth, the caseload could increase by approximately 200 children whose parents reported they wanted personal care for their children immediately or within the next year. The cost for those children would be included in the personal care forecast, at an estimated annual cost of \$3.2 million general fund.

DDA serves about 1,000 children receiving personal care services that are not currently enrolled on a waiver. Those children would need to be on a waiver and doing so will allow them access to other waiver services. Adding these children would increase the general fund costs by approximately \$1.8 million per year.

Finally, CMS will likely require new assurances to ensure safeguards are in place for children receiving paid care from a legally responsible adult. To meet these requirements, DDA would need to decrease the caseload size for these children from 75:1 to 35:1 at an annual general fund cost of \$8.6 million. Additionally, some interested parties and other states we spoke with expressed a concern about increased isolation or abuse or neglect. Parents may experience increased burnout due to being both the informal and paid provider to their child. A way to mitigate this is increasing home visits to quarterly per [RCW 71A.12.320](#), instead of annually.

This will require reduced caseloads.

Annual Costs	
<b>Unused hours per year state GF</b>	\$25,594,000
<b>200 additional to personal care, State GF</b>	\$3,253,000
<b>Adding existing children to waiver, State GF</b>	\$1,800,000
<b>Staff, equipment, etc. State GF</b>	\$8,631,000 112 FTE
<b>Grand Total</b>	<b>\$39,278,000</b>

Costs for medically or behaviorally complex children to have their parent(s) as their paid provider.

The chart below shows the cost of paying parents when the child is medically complex or has complex support needs related to behaviors. This model also assumes the provision of the service through a 1915(c) waiver. This estimate assumes that only children who are assessed in the E classification group or have a behavior point score of 12 or above eligible for personal care would have their parent(s) be paid to deliver personal care tasks. It includes the number of children who currently meet that criterion, the number of unused authorized personal care hours and the additional cost per year if the unused hours are claimed. There are also other ways to define complex support needs.

Classification Group	Number of Children in Group	Unused Hours Per Year	Annual Cost Per Year
E High	275	303,710	\$10,897,000
E Med	26	22,182	\$796,000
D High	35	20,920	\$751,000
D Med High	202	114,815	\$4,119,000
D Med	233	91,948	\$3,300,000
D Low	36	11,629	\$417,000
C High	27	6,838	\$245,000
C Med High	232	70,443	\$2,528,000
C Med	413	76,594	\$2,748,000
C Low	2	92	\$3,400
B High	552	138,421	\$4,966,000
B Med	221	25,484	\$914,000
B Low	14	1,600	\$57,500

Total	2268	884,676	\$31,741,900
			<b>General Fund State</b>
			\$15,870,950
			<b>Federal</b>
			\$15,870,950

Paying parents to complete the personal care tasks for their minor children will increase state general fund annual expenditures for personal care services by up to \$15.9 million, which is approximately 40% less than paying for all children.

Annual Costs	
<b>Unused hours per year state GF</b>	\$15,870,950
<b>Staff, equipment, etc. State GF</b>	\$4,300,000 56 FTE
<b>Grand Total</b>	\$20,170,950

## Employer Type

[RCW 74.39A.326](#) prohibits family members of clients from working for home care agencies unless “the family member providing care is older than the client.” This means parents of children could work both as Individual Providers employed by the Consumer Directed Employer and as employees of DSHS contracted home care agencies. According to [RCW 74.39A.074](#), any parents hired through an agency would need to complete standard training and certification requirements, which includes 75 hours of training, certification as Home Care Aide by the Department of Health and annual continuing education. Parent providers who are IPs are exempted from being certified and taking continuing education by [RCW 18.88B.041](#). They are only required to take 12 hours of training. These statutes create a disparity in provider qualifications between long-term care workers who do the same work but choose different employers. This may need to be addressed before seeking approval from CMS.

DDA sought feedback from various interested parties who shared that they would prefer parent providers to be hired as IPs through the Consumer Directed Employer. Given this feedback, and due to the need for a modification to RCW, DDA recommends this group of providers be hired and paid as IPs as defined in [RCW 74.39A.240](#). If directed to allow parents to be hired by either the Consumer Directed Employer or a home care agency, statute should be modified to remove disparities in certification and training requirements.

## Provider Training



Training requirements for long-term care workers are in statute and state rule. Providers who are hired by the Consumer Directed Employer as IPs are trained exclusively through the SEIU 775 Training Partnership. Home care agency employees have the same training requirements, and the agencies are responsible for ensuring their employees are trained. DDA met with several interested parties, including parents, training facilitators, the SEIU 775 Benefits Group and others to discuss training options for these providers. DDA learned from these interested parties that they would like to have the required training remain aligned with the requirements for parent providers of adult children.

The parents DDA met with also report there is a need to have additional paid training for parents of children with exceptional needs available when requested. While a wide variety of training topics already exist as part of Continuing Education requirements for some providers, there may be unmet needs for these parents that will require curriculum development with input from parents.

A high-level summary of the training feedback received from parents and other interested parties is available in [Appendix A](#).

## **Technical Systems Implications**

The technical and system changes needed to create this new provider type are minimal and can be completed within existing resources. System changes needed include system configurations to identify the parents being paid for care of their minor child. Changes to the Consumer Directed Employer system are small and can be made within their existing budget. System changes are built into the administration payment DSHS makes to the Consumer Directed Employer. The time needed for development and testing of systems changes would need to be scheduled and prioritized using the existing governance and management processes making changes to impacted systems.

## **Medicaid Financial Eligibility Implications**

To be financially eligible for Medicaid, earned income of an individual is counted toward basic food, cash and other social programs. If parents are being paid, this may affect their household members' eligibility for these programs, including Medicaid benefits.

Clients eligible for Community First Choice, without being on a waiver, may lose eligibility when the parents' income increases. Children enrolled on a waiver would not lose eligibility when parental income increases because parental income is not considered for waiver coverage groups. To be enrolled on a waiver there must also be a monthly waiver service needed. This

could be an existing waiver service or if personal care were to be added to the waiver the need for personal care would satisfy this requirement.

**In summary:**

- If parents of minors are added as a provider type to the current Community First Choice program instead of an HCBS Waiver:
  - Parental income may affect the child’s eligibility for Medicaid.
  - Other family members including other children in the household could lose Medicaid eligibility as parent income increases.
- If personal care is added to HCBS waivers with parents of minors as a provider type:
  - Limits parent providers to only clients enrolled on a DDA waiver.
  - Increases in parent income will not affect the child’s eligibility for Medicaid.
  - To be enrolled on a waiver children will need to go through the disability determination process if they are not already receiving SSI. This determination may take up to 90 days.

## **Positive Impacts of Implementation**

Families raising children with an intellectual or developmental disability are more likely to experience poverty. These families have additional direct and indirect costs not experienced by other families. Families have lower rates of employment especially among mothers<sup>5</sup>. DDA met with interested parties, including families with young children, who told us stories of caring for their children and how their households would benefit from being paid to provide for care needs. A summary of their input can be found in [Appendix A](#). All attending parents reported they would utilize this option, if available.

DDA also met with other interested parties, including nursing staff from Seattle Children’s Hospital, who reported that nursing care is exceptionally more costly than paying an individual provider rate. They shared that children with exceptional medical care needs are often unable to discharge home because their parents must work outside of the home to financially support their family and maintain health insurance. These families also cannot find paid or unpaid caregivers to help. This has contributed to children having hospital stays beyond the need for medically necessary treatment.

DDA has identified the following additional positive impacts of paying parents of minors:

- Improvement to the workforce shortage by increasing the provider pool across the system. If parents can provide all or part of the care for a child, this may allow an already assigned paid provider to take on other clients.

---

<sup>5</sup> Emerson, Eric, “Poverty and People with Intellectual Disabilities”, Mental Retardation and Developmental Disabilities Research Reviews, 2007 pp 107-113, <https://onlinelibrary.wiley.com/doi/10.1002/mrdd.20144>

- Enhancement to continuity of care. Parents are already familiar with the child’s needs. Clients are more at ease with having parents care for them – less disruption of routines, no stranger coming into the home, etc.
- Clients will receive increased culturally and linguistically appropriate care.
- Hospital and nursing costs may reduce as children will have less reliance on skilled care for their child to discharge home.
- Burden on parents may be reduced as they do not need to train caregivers on their child’s individual care needs.
- Provider turnover will reduce.
- Honors the family and person’s choice of worker.
- This is a progressive solution keeping Washington as a leader in long-term care.
- Provides an income and access to health insurance and other benefits to parents who are unable to work or must work fewer hours due to the significant care needs of their child(ren).
  - This would bring additional income into homes.
  - Would give parents employment history that could be used in future job endeavors.
  - Provides additional training and resources to parents.
- Paying parents when providers are unable to meet care needs would likely reduce the need for children to be placed or remain in a hospital or institutional settings.

## **Risks and Barriers to Implementation**

While there are many benefits that would result from this change, DDA recognizes that there are also challenges to be addressed. The following barriers have been identified:

- Families have expressed concern if the scope of extraordinary care is narrow and limits access.
- Constituents may have concern that parents are being paid to take care of their own children using taxpayer dollars.
- DDA’s tribal partners expressed concern that in rural communities traveling to training is often challenging. Limited access to transportation may prevent parents from accessing in-person training that is needed.
- A lack of infrastructure or technology, such as high-speed internet access, may impact the ability of providers in rural communities to be paid to provide support, as employers may require online submission of timesheets.
- In addition, lack of high-speed internet access may prevent providers from easily attending online trainings. This concern was also shared by our tribal partners.
- DDA’s tribal partners have long been concerned about required background checks disqualifying people from becoming a paid provider.
  - Parents will need to be informed that in 2020 the Washington State Legislature

passed HB 1645, which allows people to request a Certificate of Parental Improvement by the Secretary when that person has a founded finding of negligent treatment or maltreatment or physical abuse, or when that person's child was found by a court to be dependent because of a finding that the person abused or neglected their child.

- DDA met with tribal partners who shared feedback about barriers particular to their communities in addition to the above identified barriers (see [Appendix B](#)).
- Some interested parties expressed a concern about increased isolation or abuse or neglect.
  - A way to mitigate this is increasing home visits to quarterly per [RCW 71A.12.320](#), instead of annually. This will require reduced caseloads.
- Interested parties stated that one reason why there are opponents to this plan is the assumption some parents would use this for financial gain.
- For families receiving HUD housing or other income-based benefits, the earnings may negatively affect their benefit.
- Parents may experience increased burnout due to being both the informal and paid provider to their child.
- If parents become paid providers, it will be vital for the employer of this new category of providers to share the information, knowledge, tools, and skills they will need to successfully navigate the resources, bargained benefits, and laws/rules that apply to them. For example, they will need to be informed, educated and skilled in navigating the hiring process and using the timekeeping and payment systems through the employer. This will require communication and engagement tactics that meet people where they are and bring them along in the change. Specific tactics for addressing this risk are included in [Appendix A](#).

## Timeline for Implementation

The implementation cannot be phased in because once a waiver or State Plan Amendment has been approved CMS requires that the program is available statewide to those who are eligible.

If done through a State Plan Amendment, then the projected timeline for implementation, if approved, would be approximately one year.

A waiver amendment to restore personal care back into waivers and allow payments to parents of minor children cannot be submitted to CMS prior to approval of current amendment requests. CMS's system does not accommodate simultaneous amendments that have significant substantive changes. DDA will submit five waiver amendments for CMS approval of

changes related to HB 1188 passed in the 2023 Legislative session on Jan. 2, 2024. The hope is that CMS will approve the amendments for HB 1188 by Dec. 31, 2024, but this is not a certainty due to the complex nature of the changes. After finalization of the HB 1188 amendments, DDA can then start another amendment process, which takes approximately six months to do before sending to CMS for approval. The exact date of implementation depends on how quickly CMS approves the amendments. It is currently taking CMS a minimum of six months for approval, and often longer, as they are experiencing a staff shortage. Given this timeline, the earliest date parents of minor children could be paid through a DDA waiver is Jan. 1, 2026.

## **Next Steps and Follow Up Items when Funded**

To successfully design and execute the implementation plan, the following additional considerations are required:

- Obtain consultation from our tribal partners.
- Secure organizational change management resources to:
  - Gather additional input from interested parties (re: implementation, how will we define this process, design what the program looks like, parameters).
  - Manage the transition during and after implementation. This will require a structured process and data that allow DDA to monitor the readiness plan of impacted groups. Tactics that support these outcomes are included in [Appendix A](#).
- Gather additional input from the identified employers.
- Collaborate with the SEIU 775 Benefits Group regarding training requirements and any curriculum changes needed.

## **Collaborator Impact and Engagement**

DDA engaged the services of Vivid Company to perform a change impact analysis, risk assessment, and collaborator (interested party) analysis and engagement related to implementing the changes described in this report. Certified Change Management Professionals met with DDA leaders and subject matter experts to perform an initial assessment of the change envisioned by this feasibility study. Prosci tools, professional experience and a deep historical knowledge of the DDA-impacted Collaborator Groups were used to conduct the assessment and develop findings and recommendations. See [Appendix A](#) for the full report from Vivid Company.

## **Conclusion**

DDA has been honored to be given the opportunity to study and report on paying parents to provide personal care to their children. DDA is prepared to engage with staff from CMS, our tribal partners, our fellow state agencies, advocacy organizations and families that will be

impacted by this change to ensure the program is designed to meet the needs of the families we serve in the most fiscally responsible way possible.

DDA asks that the Legislature appropriate funding to allow DDA to pay parents of minors. DDA suggests adding personal care services with a provider type of Parents of Minor Children into our already existing waivers, with the recommendation of paying parents through the CDE. DDA has partnered with many interested parties throughout the state and has an overwhelming amount of support for this endeavor. This change would truly transform the lives of the families we support.

# Appendices

## Appendix A – Collaborator Impact and Engagement

### Collaborator Engagement Summary Analysis

An important best practice for any change being considered is to gather input from internal and external collaborator (interested party) groups who will be impacted by that change. This feedback is then used to inform implementation planning efforts in ways such that the impacts to these collaborator groups is mitigated to the extent possible. For this Feasibility Study, DDA received input from 314 internal collaborators and 21 external collaborator group representatives. A summary of each is provided here.

- Internal Collaborator Engagement:** DDA surveyed four internal collaborator groups in September 2023 – Case Resource Managers; Headquarters Staff; Field Services Supervisor/Managers; and DDA Support Staff – to invite their feedback regarding the potential benefits and challenges of being a paid parent provider. 314 individuals responded to the survey. Respondents were asked to consider the questions from the perspective of a Client, a Parent, and a Case Resource Manager. The table below illustrates the most highly selected responses regarding potential benefits and barriers of implementing this program from each perspective.

	Client Perspective	Parent Perspective	CRM Perspective
<b>Potential Benefits</b>	My parent will provide my care and they know me already; I trust them.	Parents will receive pay for providing authorized care to their loved one.	Consumer Directed Employer will have the ability to identify potential providers more quickly.
<b>Potential Challenges</b>	My parent will not get a respite break as often.	Parent will need to distinguish between parent-care and provider-care activities.	There will be increased complexity in managing a case if there are concerns with the quality of care.

In addition to the potential benefits and barriers described above, the internal engagement survey contained one open-ended question asking respondents to tell DDA what else they wanted us to know about this program. The pie chart below represents the themes that emerged from the 148 responses DDA received.



### Internal Engagement Survey: Open-Ended Response Themes

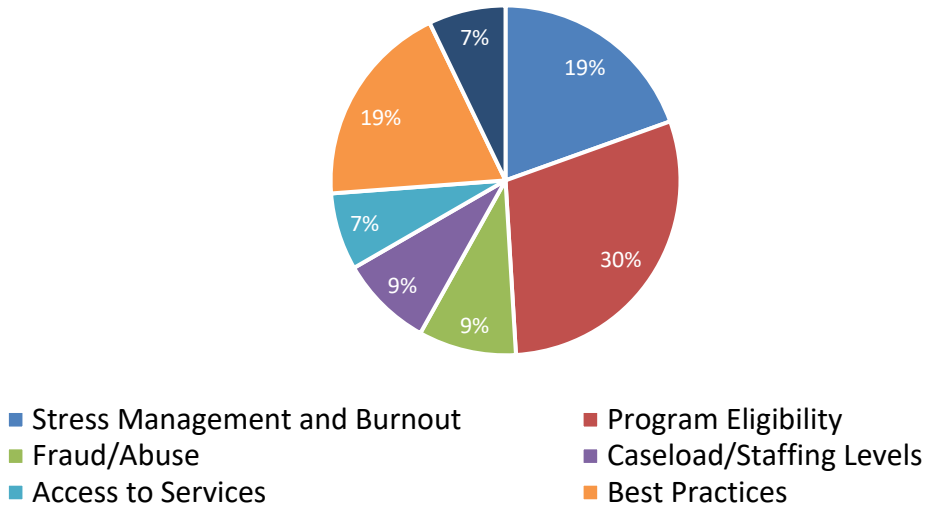


Figure 4 Internal Engagement Survey Theme Analysis

The table below illustrates examples of the specific feedback DDA received for each of the themes that were highlighted in the Collaborator Engagement Summary Analysis section of this document.

Theme	Collaborator Feedback
Program Eligibility	<ul style="list-style-type: none"> <li>“...It will be important that [eligibility is] clear so that families are not left feeling they were not included because of a local case management decision...”</li> <li>“Comprehensive evaluation will be needed to determine a parent’s capacity/ability to offer proper [care], as well as delineate and demonstrate clear boundaries between the role of parenting vs. paid caregiving.”</li> </ul>
Stress Management / Burnout	<ul style="list-style-type: none"> <li>“...it would benefit the clients by allowing the parent to stay in the home and not have to seek outside work, causing more stress to an already fragile family dynamic.”</li> <li>“...it is essential to have a respite system set up for clients’ enrollment in a parent paid model as well as a robust support system for the client and parent paid provider.”</li> </ul>
Best Practices	<ul style="list-style-type: none"> <li>“...There will be issues with parents understanding the scope of what it means to be a parent vs. a paid caregiver... We should also look at societal obstacles that make it difficult to provide adequate care...including insufficient inclusion in after-school/extracurricular activities and behavioral supports.”</li> <li>“...there will need to be...someone to guide the parents on WACs and policies and help navigate Consumer Directed Employer.”</li> </ul>

Theme	Collaborator Feedback
Fraud / Abuse	<ul style="list-style-type: none"> <li>• ...families could use it as a second income and may misrepresent things during the annual assessment to try to get more hours.</li> <li>• ...If the parent is the paid caregiver, DDA will need to follow good oversight practices...</li> </ul>
Caseload / Staffing Levels	<ul style="list-style-type: none"> <li>• It would be good to have designated people who can assist parents who are working on getting hired by Consumer Directed Employer, so it doesn't take time away from the case management work.</li> <li>• Having to complete an ECMP referral for most clients will mean more work for the CRM.</li> </ul>
Caregiver Shortage	<ul style="list-style-type: none"> <li>• We have a serious caregiver shortage and need as many options for caregiving supports as possible to ensure the health and safety of our clients.</li> <li>• This could help families where parents are unable to work because they cannot find a daycare that will take their child who has behavioral or medical challenges.</li> </ul>
Access to Services	<ul style="list-style-type: none"> <li>• Families who are not native English speakers can experience challenges in navigating the hiring process and using the Consumer Directed Employer systems.</li> <li>• Parents will need supports beyond CRM to assist with the Consumer Directed Employer hiring process; CRMs cannot take time away from case management to facilitate solving complex problems between the IP and the Consumer Directed Employer.</li> </ul>

These responses underscore the importance of the need for clear program eligibility requirements and parameters that are rooted in established best practices, and communicated in ways that are easily understood.

- **External Collaborator Engagement:** DDA engaged with 21 representatives of its external collaborator groups in August 2023 to seek their input with regard to training considerations and other potential benefits and barriers to being a paid parent provider. The table below provides a synopsis of the feedback provided by these collaborators.

	Training	Being a Paid Provider
<b>Potential Benefits</b>	Conducting classes online will reduce travel needs and increase the likelihood of receiving training in a timely fashion.	<ul style="list-style-type: none"> <li>• Both parents can be providers.</li> <li>• Parents will experience less financial stress.</li> <li>• Parents are able to gain employment after leaving their profession.</li> <li>• Parents will no longer be working two jobs.</li> </ul>

	Training	Being a Paid Provider
<b>Potential Barriers</b>	Parents of newborns who are medically complex must take training <i>in addition</i> to the hospital-provided training.	
<b>Additional Considerations</b>		This role needs to be recognized as a job.

Overall, the Collaborator Group participants expressed their gratitude for the opportunity to provide input to this Feasibility Study and are eager to do what is necessary to support this program’s implementation.

### Impact assessment and analysis

The purpose of an impact assessment and analysis is to tell the story, at a high level, about the degree to which DDA Collaborator Groups would experience impacts across ten different areas – called “aspects” – were the program to be implemented. The list of aspects includes: Process, Systems, Tools, Job Roles, Critical Behaviors, Mindset, Reporting Structure, and Compensation.

The information produced from this impact assessment will inform the Legislature and DDA about the considerations and effort required to prepare for, and implement, the change described in the feasibility study. The summary results of the impact assessment are shown in the table below.

	Parents of Children	Tribal Governments	Case Resource Manager (CRM) Staff	Self-Advocates	SEIU	CDE	SEIU 775 Benefits Group	DDA HQ Program Managers	HCA	DDA Core Collaborator Groups	DOH	CMS	MSD CARE Team
# of Collaborators	2000	29	400	200	10	50	100	7	15	50	25	10	20
Aspects Impacted	8	8	5	6	3	3	3	5	3	6	3	3	3
Degree of Impact	4.5	3.5	3.4	3.3	2.0	2.0	2.0	1.8	1.3	1.0	1.0	1.0	1.0

Figure 1 Impact Assessment Summary

Overall, the impact assessment showed that parents of children, self-advocates, DDA Case Resource Managers and tribal governments will be most highly impacted by this change. These groups will need to understand and utilize new processes, update systems, and develop and use new tools related to parents as paid providers who are employed by the Consumer Directed Employer. Additionally, parent providers may also need to develop new mindsets, such as becoming an employee and being covered by a collective bargaining agreement. Their household income may change if they choose to leave their current jobs to be paid to care for their child.

The table below provides additional detail as to the degree of impact across all aspects for each Collaborator Group. The data indicate the importance of relevant training on new or updated processes, systems, and tools so that impacted Collaborator Groups can operate successfully when the new provider group and supporting program is in operation. Additionally, the data reflect the importance of successfully communicating the benefits of this new program so that Collaborator Groups can be effective champions of it through their behaviors and mindset.

**Impact scoring legend:**  
**0 = No Impact, 1 = Extremely Low Impact, 2 = Low Impact,**  
**3 = Moderate Impact, 4 = High Impact, 5 = Extremely High Impact**

Collaborator Group	Processes	Systems	Tools	Job Roles	Critical Behaviors	Mindset, Attitudes, Beliefs	Reporting Structure	Compensation
Parents of Children	5	5	4	4	5	4	4	5
Tribal Governments	4	4	3	3	4	3	3	4
Self-Advocates	3	3	3	4	3	4		
Case Resource Manager Staff	3	4	4		3	3		
DDA HQ Program Managers	1	1	2		3	2		
SEIU	2	2	2					
SEIU 775 Benefits Group	2	2	2					
CDE	2	2	2					
HCA	2	1			1			
DDA Core Collaborator Groups	1	1	1	1	1	1		
CMS	1	1	1					
DOH	1	1	1					
MSD CARE Team	1	1	1					

Figure 2 Aspects Impacted Grid

### Risk Assessment Summary Analysis

The Organizational Change Management Risk Assessment evaluates 14 characteristics of the change envisioned by this feasibility study and 14 attributes of DDA as an organization. For example:

- **Change Characteristics:** the scope and scale of the change, the degree of impact on reporting structure or compensation, the complexity of the change, and the number of individuals impacted.
- **Organizational Attributes:** historical responsiveness to change, leadership mindset about change, and overall change saturation.

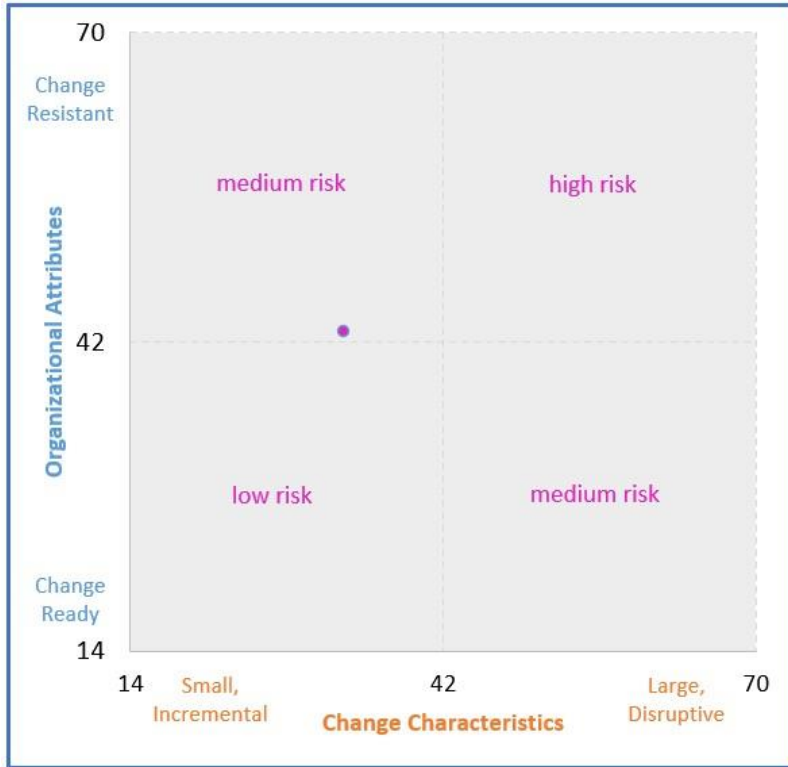


Figure 3 Risk Analysis Grid

The Change Characteristics and Organizational Attributes are considered together to determine the overall risk. This enables the project to distinguish between OCM-related areas needing significant focus and risk management, versus those areas that need basic risk awareness and monitoring.

For this Feasibility Study, the Change Characteristics score was 33 out of a possible 70 points. The Organizational Attributes score was 43 out of 70 possible points. This results in an overall rating of **medium risk** for OCM purposes. The OCM plan and execution tactics for this implementation, when it occurs, will need to be scaled accordingly.

**Readiness Findings and Recommendations**

Given the result of this initial impact and risk assessment, DDA should anticipate some resistance to the changes envisioned in the feasibility study recommendations, were they to be implemented. DDA will need to apply change management best practices to help mitigate these impacts so the organization can minimize resistance and increase the likelihood of a smooth transition among the impacted Collaborator groups. Our recommended change management tactics are outlined in the paragraphs below.

First, we recommend DDA use more intensive face-to-face engagement tactics, including

regular town hall-style meetings, focus groups, and 1:1 meetings for the highly impacted Collaborator Groups. These forums would supplement scheduled written communications and would be held either virtually or in-person. They would serve to open a two-way feedback loop that allows individuals to understand what is happening with their previous feedback so they can better see themselves in the change.

Next, DDA will need to perform a deep assessment of tools and processes, including WAC and policy and procedure manuals, and updating them as appropriate. Staff training and system readiness will also be required. Further, we recommend performing periodic assessments to measure results of these change management tactics and adapting them as necessary. Together, these tactics will prepare these highly impacted groups to be successful when the program is launched and is operational.

Finally, we recommend DDA use assessment tools, such as pulse surveys and periodic readiness assessments to measure readiness among all collaborator groups. The survey and assessment data will help DDA understand and monitor the trajectory of readiness for the new program. If the data show gaps in readiness, we recommend employing additional communication tactics (i.e.; newsletter, pre-recorded video modules, or additional targeted messaging) to address those gaps.

#### **Collaborator Impact and Engagement Summary**

The data outlined in the impact and risk assessments, input regarding best practices from other states and the collaborator engagement feedback clearly underscore the importance of including the voices of those impacted by this change and helping them to become adequately prepared when the new program is planned and implemented. An organizational change management resource who is well equipped to partner with DDA leaders to execute the recommended tactics provided in the previous paragraph will be vital for DDA to realize the benefits of this proposed program.

## Appendix B -Tribal Forum document

### ***(Information gathered from tribes at the tribal forums July 2023 – August 2023)***

The Washington Department of Social and Health Services Aging and Long-Term Support Administration, and Developmental of Disabilities Administration collaborated to hold open forums between July 20, 2023 - August 18, 2023. The objective was to hear from tribes and Urban Indian Health Organizations to discuss barriers to the implementation of HB 1694 within Indian Country.

In all forums, tribes stressed the need to honor, acknowledge and respect tribal sovereignty and self-determination, recognizing tribes are self-governed nations and that what would work for one government may not work for another. Tribes stressed the importance of not doing something like this fast but doing it right, as well as considering what works for communities AND tribes themselves. Tribes stated that often, appropriate governance structures to support implementation are not considered or not put in place. For example, tribes in this forum spoke that they feel they are an afterthought after the implementation.

Tribes requested that the department understand the traditional values that are held when providing care for their elder or a loved one. Tribes stated that although other communities may feel an institution is an option for their loved ones, it is not an option for them. Tribes care for their elders and loved ones with respect and give back to them as they gave to the community. Tribes want their elders and loved ones to be in their home and want them to have dignity and honor. It is important that tribal members, especially elders, be honored in having their own self-directed care; having someone they are familiar and comfortable with in providing the care, and not opening their home to a stranger. During the discussion, DSHS and tribes strategized together to identify some barriers to implementation of such a pilot.

The first identified characteristics of a barrier was the use of an outside agency for individual providers that involves SEIU 775. Tribes stated, while they understand that SEIU 775 works to recognize and treat everyone equally, they fail to recognize tribes are self-governed nations and should be treated as such. Tribes prefer to have their own autonomy of membership and be treated through an equitable lens. One tribe mentioned that because of SEIU 775 and the agency it works with for individual providers, they have opted to provide their own HCA for paid providers.

Other barriers include:

- Training, in geographically rural tribal communities, it may be challenging to travel to locations that offer training. In addition, there may be a lack of public transportation or gaining access to transportation that may prevent tribes from accessing the training that is needed to become an individual provider.
- During the discussion of training, tribes spoke of the how the training is provided and that trainings like the one provided for individual providers, often fails to look at:
  - Individual learning styles.
  - The literacy level of provider as compared to the written test.
  - The eligibility requirements to be a provider and what they must do.

- The relevance of the written test.
  - What is being lectured and what caretakers are having to go through.
- A lack of infrastructure or technology, such as broadband, may impact the ability of rural communities to support receiving access to long-term services and supports. In addition, access to any trainings that may be virtual.
- Lack of awareness of the program should this be implemented.
  - How would tribes know this program exist or the policy has changed to support spouse and/or parent to be a paid caretaker?
- Background checks for crimes that may disqualify them from being a caretaker. Individuals can be disqualified because of a crime that was committed 10-20 years ago and the tribal member may have not committed any crimes since.
- Policies and requirements that make it hard for tribes to engage with services and resources for providers.
- Completing an assessment to identify support needs has been a barrier to access services. It can be almost a month long wait to schedule the assessment
  - It was suggested to explore options for tribes to perform the assessment themselves.
- There was an inquiry that tribes would like to consider for the feasibility and cost of paying the parents of children under 18 years old who are medically complex or have complex support needs related to their behaviors; tribes are interested in knowing if this would apply to some of the placements caring for children who fit the criteria.

In conclusion, one tribe concluded stating lack of clarity, existing policies that will remain and lack of political will, is ultimately the barrier to implementation.