

# HOUSE BILL REPORT

## HB 1200

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### As Reported by House Committee On:

Early Learning & Human Services

**Title:** An act relating to authorizing payment for parental caregivers of minor children with developmental disabilities.

**Brief Description:** Authorizing payment for parental caregivers of minor children with developmental disabilities.

**Sponsors:** Representatives Taylor, Low, Jacobsen, Alvarado, Ryu, Berry, Mena, Macri, Callan, Obras, Doglio, Fosse, Gregerson, Simmons, Peterson, Goodman, Wylie, Couture, Street, Pollet, Penner, Kloba, Cortes, Nance, Springer, Davis, Leavitt, Scott, Salahuddin, Stonier and Hill.

### Brief History:

#### Committee Activity:

Early Learning & Human Services: 1/29/25, 2/14/25 [DPS].

#### Brief Summary of Substitute Bill

- Requires the Department of Social and Health Services Developmental Disabilities Administration to submit a request to amend applicable home and community-based services waivers to allow parents to receive payment for providing extraordinary personal care services.

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### HOUSE COMMITTEE ON EARLY LEARNING & HUMAN SERVICES

**Majority Report:** The substitute bill be substituted therefor and the substitute bill do pass. Signed by 9 members: Representatives Bergquist, Chair; Cortes, Vice Chair; Burnett, Assistant Ranking Minority Member; Bernbaum, Goodman, Hill, Ortiz-Self, Penner and Taylor.

**Minority Report:** Without recommendation. Signed by 1 member: Representative Dent.

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

**Staff:** Omeara Harrington (786-7136).

**Background:**

The Department of Social and Health Services Developmental Disabilities Administration (DDA) assists individuals with developmental disabilities and their families to obtain services and support based on individual preferences, capabilities, and needs. While some DDA clients live in residential habilitation centers or an institutional setting, most clients live in the community. Clients of the DDA may receive services through the Community First Choice program under the Medicaid State Plan, through one of five DDA home and community-based services waivers, or both. In general, DDA clients who receive personal care services receive those services under the Community First Choice program. Personal care services provide assistance with everyday tasks like bathing, dressing, and managing medication.

The Comprehensive Assessment Reporting Evaluation system (CARE) is an assessment tool used to assess abilities and needs for long-term care services. The base number of in-home personal care hours for which a DDA client is authorized is determined by using the CARE assessment to place them into one of five groups and seventeen sub-classifications. The number of hours for each sub-classification varies depending on the client's group and activities of daily living (ADL) score. Those meeting criteria for exceptional care needs are placed in Group E and are given 393 base hours or 327 base hours, depending on their ADL score. Those meeting criteria for the mood and behavior qualification, but who do not meet the classification for another group, are classified into Group B, and are given 129 base hours if their ADL score is high enough to place them in the Group B High category. The DDA adjusts the base hours to account for informal supports and age-appropriate functioning and other paid services that meet some of an individual's need for personal care services.

Medicaid payments are generally not authorized for personal care services provided by legally responsible individuals, such as spouses or parents of minor children. However, states may seek a waiver from the Centers for Medicare and Medicaid Services (CMS) to allow legally responsible persons to receive payment for the provision of extraordinary care. Extraordinary care is described by the CMS as care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person of the same age without a disability or chronic illness, and which is necessary to assure the person's health and welfare and avoid their institutionalization.

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**Summary of Substitute Bill:**

The Developmental Disabilities Administration (DDA) must submit a request to the Centers for Medicare and Medicaid Services (CMS) by January 31, 2026, to amend applicable DDA home and community-based services waivers to allow parents who provide personal care

services to their minor children with developmental disabilities to receive payment for providing extraordinary care. "Extraordinary care" means care provided to a minor child who is assessed in an E classification category or the B High classification category, that exceeds the range of activities that a legally responsible individual, such as a parent, would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and is necessary to assure the health and welfare of the minor child and avoid their institutionalization. Parents include natural parents, adoptive parents, stepparents, and legal guardians.

The DDA may adopt rules for assessing and authorizing personal care hours for minors with compensated parental caregivers and other rules as necessary to comply with CMS requirements related to authorizing payments to legally responsible individuals, such as parents. In implementing the authorization, the DDA must allow parental caregivers the option to be employed as individual providers subject to the same training and oversight requirements as other individual providers who are parents of the person for whom they are providing care. Only personal care services hours served by parent providers may be offered as a waiver service, and all other assessed personal care services hours served by other providers must remain on the Community First Choice program.

**Substitute Bill Compared to Original Bill:**

The substitute bill removes the expansion that would, as of July 1, 2031, authorize payment to a parent caregiver for providing extraordinary care to their minor child who is a client of the Developmental Disabilities Administration regardless of the child's assessed classification category.

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**Appropriation:** None.

**Fiscal Note:** Available.

**Effective Date of Substitute Bill:** The bill takes effect 90 days after adjournment of the session in which the bill is passed.

**Staff Summary of Public Testimony:**

(In support) At one point, institutional care was standard, now community-based services are the norm. There are 38 states that employ parent caregivers. Washington should offer parity for parent caregivers providing extraordinary personal care services. The state recognizes this is a job and will pay anyone other than the parents of minors to perform this work. The type of care at issue goes far beyond what average parents do, and these parents need resources to ease the burdens they face every day. Examples of the types of care provided by parents include navigating full body bracing, breathing issues, feeding assistance, round the clock monitoring, seizures, and multiple hospitalizations. Many

children prefer to have their parents as caregivers to preserve their dignity when it comes to bathroom needs, as well as meeting linguistic needs and honoring cultural differences. Parents know their children best and can see subtle signs that something is wrong.

The workforce shortage makes it impossible for people to access the services they already have been assessed. The request is not to pay parents for being parents, it is to provide compensation for work that cannot be hired out. The budget is based on utilization, and continues to be reduced due to unused hours. However, the hours are unused not because services are not needed; they cannot be accessed. Available caregivers are often not qualified to handle the level of medical complexity at issue, as much of caregiver training is aimed at elder care. One parent was able to be paid under skilled nursing hours only because she was trained as a registered nurse, and was paid for care for her child for the last months of the child's life. Paying parent caregivers would free some of the qualified workers to help families that cannot provide parental care. This will provide the community a tangible tool to provide support and get more medically complex kids transitioned home to their families.

Parents should not have to choose between caring for a child and providing for their family. Parents of children with disabilities have gone through multiple jobs, only to be unable to gain or maintain employment due to disability care needs. Others have sacrificed dream careers and had their lives upended to stay home and provide care. Parents of children with complex medical needs face unique and overwhelming challenges that are so consuming that they constitute a full-time job. It is also extremely expensive to care for a disabled child and provide special clothing, shoes, diapers, and mobility-assistance devices, particularly when a parent is not able to work. Many are at a crisis point where they cannot continue to provide care without financial help. The only other option is institutionalization. In-home care is less expensive than institutional care; moreover, if parents can be employed as caregivers that income may allow them to move off of other support programs. Passage of this bill would allow parents to return to the workforce, and the state would receive federal match. None of this is factored into fiscal estimates for the bill. The bill provides plenty of time for the state to plan and budget for full implementation.

(Opposed) None.

**Persons Testifying:** Representative Jamila Taylor, prime sponsor; Kelsey Stanczyk; Kimie Nova, Impacted parent & PEPWa; Katie Scheid, Impacted Parent and PEPWa; Melissa Kerson; Michele Hagerstrom, Mary Bridge Children's Hospital; Bevan Martin; Anna Miller; Courtney Criss, The Arc of Snohomish County; Jennifer Heinlein Jennifer Heinlein; Carolyn Ringo, Sacred Heart Children's Hospital; Michele Hagerstrom, BSN, RN, Mary Bridge Children's Palliative Care; Jessica Morrow, Impacted parent and PEPWa; Mike Pugsley, Ashley House; Lindsey Topping-schuetz; Brittany Huerta; Leonardo Salas Ramos, Open Doors; and Sonia Ramos Marentos, Open Doors.

**Persons Signed In To Testify But Not Testifying:** Catherine Young, Tacoma Special education PTA; Teena Curry, On behalf of my Mother, Pat Curry; Amanda Harpell-Franz; Laura Blankenship; Amber Nilles; Deb Ritter; Sai Samineni; Lori Helmy; Ayan Elmi, Washington Multicultural Services Link; Dominique Nkamicaniye, Seattle; Whitney Stohr; Sonora Standafer; Leah Wright; Amber Nilles; Amanda Harpell-Franz ; Audrianna Kinnard; Brianna Johnson; Celeste Nearing; Erin krempasky; Melissa Wren, Parent, Caregiver, Homeschooling Parent of a Disabled, Additional Needs Child; Rebecca Sumner; Savannah O'Malley; Stuart Reed; Emani Donaldson; Leonardo Salas; and Andrea Graham.