

SENATE BILL REPORT

SB 5211

As of January 27, 2025

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: Senators Frame, Harris, Bateman, Christian, Cortes, Dhingra, Hasegawa, Krishnadasan, Lovelett, Nobles, Orwall, Saldaña, Salomon, Shewmake, Slatter, Trudeau, Valdez, Wagoner and Wilson, C..

Brief History:

Committee Activity: Human Services: 1/27/25.

Brief Summary of Bill

- Directs the Developmental Disability Administration (DDA) of the Department of Social and Health Services to submit requests to the Centers for Medicare and Medicaid Services for amendments to 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 personal care services that qualify as extraordinary care no later than January 1, 2026, and as necessary thereafter.
- Provides that parental caregivers have the option to be employed as individual providers, subject to the same training and oversight as other individual providers.
- Defines child, parent, and extraordinary care.

SENATE COMMITTEE ON HUMAN SERVICES

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: Alison Mendiola (786-7488)

Background: Personal Care Services for Persons with Developmental Disabilities. The Department of Social and Health Services (DSHS) 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, most clients live in the community. Clients of DDA may receive services through the Community First Choice Program under the Medicaid State Plan or through one of five DDA Home and Community Based Services (HCBS) waivers. 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.

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 to allow legally responsible persons to receive payment for the provision of extraordinary care. Extraordinary care is described by the Centers for Medicare and Medicaid Services (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 are necessary to assure the person's health and welfare and avoid their institutionalization.

Federal Demonstration Waivers. Under section 1115 of the Social Security Act, the secretary of Health and Human Services has authority to grant waivers from certain Medicaid requirements to allow states to demonstrate innovative approaches in their Medicaid programs. The purpose of section 1115 demonstration projects is to demonstrate and evaluate policy approaches such as expanding eligibility, providing services not typically covered, and using innovative service delivery systems.

DDA offers five HCBS waivers:

- Basic Plus;
- Children's Intensive In-Home Behavioral Supports;
- Community Protection;
- Core; and
- Individual and Family Services.

Individual Providers. Individual providers (IPs) means a person, including a personal aide, who, under an individual provider contract with DSHS or as an employee of a consumer directed employer, provides personal care or respite care services to persons who are functionally disabled or otherwise eligible under programs authorized and funded by the Medicaid State Plan, Medicaid waiver programs, or similar state-funded in-home care programs. IPs provide personal care to older adults and people with disabilities. This includes helping clients with their daily living tasks such as bathing, dressing, using the

toilet, personal hygiene, transferring, walking, meal preparation, light housework, grocery shopping, and trips to medical appointments. To be a paid caregiver, a person must pass an in-state and Federal Bureau of Immigration criminal conviction background check, provide picture identification, be authorized to work in the United States and successfully complete all caregiver training requirements. IPs may begin providing direct care after completing the five-hour orientation and safety trainings.

Comprehensive Assessment and Reporting Evaluation. The Comprehensive Assessment Reporting Evaluation (CARE) is the tool used by DDA case managers to document a client's functional ability, determine eligibility for long-term care services, evaluate what and how much assistance a client will receive, and develop a plan of care. CARE classification is determined first by meeting criteria to be placed into a group, then a client is further classified based on activities of daily living (ADL) score or behavior point score into a classification sub-group following a classification path of highest possible base hours to lowest qualifying base hours. Each classification group is assigned a number of base hours based upon the level of funding provided by the Legislature for personal care services, and upon the relative level of functional disability of persons in each classification group compared to persons in other classification groups.

If a client meets the criteria for exceptional care, they will be placed in Group E CARE then further classified into:

- Group E High with 393 base hours if a person has an ADL score of 26 to 28; or
- Group E Medium with 327 base hours if a person has an ADL score of 22 to 25.

If a client meets the criteria for mood and behavior qualification and does not meet the classification for C, D, or E groups, then they are classified into Group B CARE and further classified into Group B High with 129 base hours if the client has an ADL score of 15 to 28.

Summary of Bill: No later than January 1, 2026, and as necessary thereafter, DDA is to submit requests to CMS for amendments to applicable DDA HCBS waivers to allow parents who provide personal care services to their minor children with developmental disabilities to receive payment for providing personal care services that qualify as extraordinary care.

When implementing the authorization to pay parents for providing extraordinary care to their minor children, DDA:

- may adopt rules for assessing and authorizing personal care hours for minors with compensated parental caregivers and other rules necessary to comply with CMS requirements related to payments to legally responsible individuals, such as parents;
- must allow parental caregivers the option to be employed as individual providers, subject to the same training and oversight as other individual providers; and
- may only offer personal care services hours served by parent providers as a waiver service.

All other assessed personal care services hours served by providers who are not parents must remain on the Community First Choice option.

"Minor child" means a person who is under the age of 18 and who is a client of DDA.

"Parent" means a natural parent, an adoptive parent, a stepparent, or a legal guardian.

Until July 1, 2031, "extraordinary care" means care provided to a minor child who is assessed in an E classification category or the B High classification category by CARE, 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.

Starting on July 1, 2031, "extraordinary care" means care provided to a minor child 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.

Appropriation: None.

Fiscal Note: Available.

Creates Committee/Commission/Task Force that includes Legislative members: No.

Effective Date: The bill contains several effective dates. Please refer to the bill.

Staff Summary of Public Testimony: PRO: What is happening to families with minor children with developmental disabilities is wrong. Families have been allotted personal care service hours but we simply don't have the workforce to provide these services. Instead, families provide these services without compensation requiring them to quit paid work, lose income, and lose housing. Forty-one percent of allotted hours go unused. Current law does not allow a parent to be compensated for providing these services although parents with adult children can be compensated. Promises made should be promises kept. Often a stranger can not be trusted to care for a child with developmental disabilities. The average caregiver simply does not have the required training to provide the services needed.

A baby can have a care team of 40 professionals while at the hospital and then goes home with the parents who now replace that team of 40 people. Providers simply do not have the medical training needed to provide the care needed. Additionally, there is even a greater shortage of finding providers that speak the same language as the family needing care. Many kids can become dysregulated when their routine is disrupted which happens with unreliable caregiving. When parents provide this care, the child is in better hands. A parent

caring for their child is cheaper and better for the child than institutionalizing them.

Some kids may have IEPs at school but the school does not have the ability to meet the child's needs. Or, you drop off your kid and find out there is no para available that day, or the nurse is running late so you have to stay to provide meds or take your kid back home. A lack of routine is harmful for many children. So many more families would testify on this bill but they simply do not have the bandwidth to take time from caregiving to try and further advocate for their family. Caregiving is an immense physical and emotional toll. It is not about replacing caregivers, it is acknowledging caregiving. Parents love their children, know how to address their complex needs, and already work as their child's caregiver so there is no reason why they should not be compensated for this caregiving.

Persons Testifying: PRO: Senator Noel Frame, Prime Sponsor; Jessica Morrow; Alexander Toole; Amanda Harpell-Franz; Jessica Morrow; Kimie Nova, Impacted parent; Angela Jovel, Open Doors; Jessica Morrow, Impacted parent; Demas Nesterenko, SEIU 775; Mike Pugsley, Ashley House NW; Carolyn Ringo, Sacred Heart Children's Hospital; Bevan Martin, Impacted parent; Alexander Toole, Self advocate; Melissa Kansan, Impacted parent; Courtney Criss, Arc of Snohomish and Impacted Parent; Savannah O'Malley, Impacted parent; Katie Scheid, Impacted parent and PEPWa; Stephanie Raghubeer, MD, Mary Bridge Children's Palliative Care; Lindsey Topping-Schuetz, Impacted parent and Rare Disease Coalition; Amanda Harpell-Franz, Impacted parent; Jennifer Heinlein, Impacted parent; Amber Nilles; Liv Taylor; Charlene Wilson; Sai Samineni, Parents Empowering Parents.

Persons Signed In To Testify But Not Testifying: No one.