

HOUSE BILL REPORT

HB 2184

As Reported by House Committee On:
Human Services, Youth, & Early Learning

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, Rude, Senn, Leavitt, Simmons, Reed, Graham, Callan, Macri, Chopp, Barkis, Fosse, Couture, Goodman, Nance, Springer, Riccelli, Farivar, Reeves and Davis.

Brief History:

Committee Activity:

Human Services, Youth, & Early Learning: 1/10/24, 1/19/24 [DPS].

Brief Summary of Substitute Bill

- Requires the Department of Social and Health Services Developmental Disabilities Administration (DDA) to apply to the federal government for amendments to relevant DDA Medicaid waivers to allow parent caregivers of minor children with developmental disabilities to receive payment.
- Provides that if the DDA's amendment requests are unsuccessful and cannot be cured, within 30 days of the denial the DDA must apply for a demonstration waiver to allow caregiver parents to receive payment.
- Requires the DDA to commence payments immediately upon receiving approval.

HOUSE COMMITTEE ON HUMAN SERVICES, YOUTH, & EARLY LEARNING

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.

Majority Report: The substitute bill be substituted therefor and the substitute bill do pass. Signed by 10 members: Representatives Senn, Chair; Cortes, Vice Chair; Rule, Vice Chair; Couture, Assistant Ranking Minority Member; Callan, Dent, Goodman, Ortiz-Self, Taylor and Walsh.

Staff: Omeara Harrington (786-7136).

Background:

Personal Care Services for Persons with Developmental Disabilities.

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, 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 or through one of five DDA home and community-based services waivers. 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.

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.

Summary of Substitute Bill:

By January 31, 2025, the DDA must submit a request to the CMS for amendments to applicable DDA home and community-based services waivers that would allow natural, adoptive, and stepparents who provide personal care services to their minor children with

developmental disabilities to receive payment for providing those services to the greatest extent allowable under federal law.

If the amendment requests are not accepted and cannot be cured, within 30 days of receiving notice of the denial the DDA must apply to the CMS for a demonstration waiver for parental payment under the same circumstances.

The DDA must commence payments immediately upon receiving approval from the CMS.

Substitute Bill Compared to Original Bill:

The substitute bill delays the date by which the DDA must submit amendment requests to the CMS is delayed from October 1, 2024, to January 31, 2025.

The DDA is only directed to request amendments to applicable home and community-based services waivers, rather than requiring the DDA to also request amendments to the Community First Choice program.

Appropriation: None.

Fiscal Note: Requested on January 5, 2024.

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) This bill provides an opportunity for Washington to be an innovator, solves a workforce challenge, and eases the burden on families in difficult situations. Managing care needs is a full-time job and not all parents have access to service providers, particularly in rural environments. Currently, children with disabilities qualify for care hours that their families cannot use. One family that was approved for 185 hours a month of in home personal care, looked for a caregiver for 6 months, and there were no applicants. If a caregiver can be found, parents spend a lot of time training them, as most of the training they have received pertains to care of adults. The majority of BIPOC families struggle to find caregivers who are multi-cultural and multilingual. Parents deserve to be supported for the role they play in filling this gap and expanding the workforce in areas of the most need.

Caregiving goes far beyond parenting, and involves tasks like bathing, toileting, and repositioning. Doctors have observed parents having to perform caregiving in medically complex situations without formal medical training due to the unavailability of home nurses. Some parents are replacing a 40-person paid medical team when their child leaves a hospital setting.

Parents with children who are disabled face myriad severe challenges, including missed work or inability to work, frequent pharmacy visits and medical appointments, the requirement to manage life-sustaining equipment, and the degradation of their own mental health. This situation has created a women's rights issue, as it is often women who end up leaving the workforce to provide care. Some people may feel that parents should not be paid for caring for their own children, but parents of disabled children serve as nurse, therapist, teacher, and nutritionist. Not every child can go to school and give parents a break and allow them to work. In some situations parents must make a choice between having custody of children or having a place to live, not being able to afford both. It is time for the state to acknowledge the work of unpaid caregivers with a paycheck. Parents are not asking to become rich, rather, they need relief from financial burdens. Parent caregivers need an income to live on, and if the state has to pay someone, it should pay parents.

(Opposed) None.

Persons Testifying: Representative Jamila Taylor, prime sponsor; Adana Protonentis, Kindred Leaders; Adrienne Stuart; Moses Perez, Open Doors for Multicultural Families; Deborah Ritter; Jill Brown; Lindsey Topping-Schuetz; Heidi Fredericks; Stephanie Raghubeer, Mary Bridge Children's Multicare; Kristina Smith, Kindred Joy Coaching; Hodan Mohammad, Washington Multicultural Services Link; Katie Scheid, Parents Empowering Parents; Tonya Cloud; Seth Davidson; Jamie Thompson; and Lelach Rave, Washington Chapter of the American Academy of Pediatrics.

Persons Signed In To Testify But Not Testifying: Kayla Scott; Brittany Huerta; Nakul Jinsi; Eva Dellis; Savanna Brown; and Courtney Hansen.