

Senate Bill 538

Sponsored by Senator PATTERSON, Representatives NERON, NOSSE, Senator HAYDEN; Senators FREDERICK, WEBER, WOODS, Representatives GRAYBER, MCLAIN, NELSON, PHAM H (Pre-session filed.)

SUMMARY

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure **as introduced**. The statement includes a measure digest written in compliance with applicable readability standards.

Digest: The Act requires ODHS to pay parents to provide in-home care for minor children with disabilities. The Act requires ODHS to seek out all means to get federal matching funds from CMS to pay for the care. (Flesch Readability Score: 71.4).

Requires the Department of Human Services to pay parents to provide attendant care services for children with developmental disabilities who have very high behavioral health or medical needs. Directs the department to seek any federal funding available for attendant care services no later than January 1, 2026.

Declares an emergency, effective on passage.

A BILL FOR AN ACT

1
2 Relating to in-home care for minor children with disabilities; amending ORS 427.191 and section 2,
3 chapter 367, Oregon Laws 2023; and declaring an emergency.

4 Whereas Oregon has promised to fund home- and community-based supports to ensure that
5 children with disabilities grow up as fully included members of their families and communities; and

6 Whereas the Department of Human Services has allocated hours to children on the basis of need
7 but has historically budgeted based only on utilization, despite the workforce crisis and children's
8 unique needs for stable and familiar caregivers; and

9 Whereas long term in-home care services are a less costly alternative to institutional care,
10 saving Oregon taxpayers significant amounts through lower reimbursement rates; and

11 Whereas efforts to improve the in-home care workforce have never produced full employment
12 and approximately one-third of authorized hours system-wide go unused; and

13 Whereas the Centers for Medicare and Medicaid Services has recently announced the Access
14 Rule requiring states to take steps to ensure that home- and community-based supports are in fact
15 available; and

16 Whereas the Centers for Medicare and Medicaid Services has encouraged states to allow legally
17 responsible individuals to be paid for their caregiving after seeing the positive effects of doing so
18 during the COVID-19 public health emergency; and

19 Whereas research in states like Colorado has shown that paid family caregiving leads to better
20 outcomes for medically fragile children and lower costs to taxpayers in the form of fewer
21 hospitalizations; and

22 Whereas nationwide research has shown that families of children with disabilities often have to
23 forgo income opportunities due to the care needs of their children and that a lack of income has
24 lasting impacts on those children; and

25 Whereas the child care crisis for all Oregon families is particularly acute for families of children
26 with disabilities who often cannot find highly trained providers to meet their children's needs; and

27 Whereas the State of Oregon is committed to supporting children with disabilities and their

NOTE: Matter in **boldfaced** type in an amended section is new; matter *[italic and bracketed]* is existing law to be omitted. New sections are in **boldfaced** type.

1 family caregivers through legislative actions that promote fair labor practices, equitable compen-
 2 sation and comprehensive support systems; now, therefore,

3 **Be It Enacted by the People of the State of Oregon:**

4 **SECTION 1.** ORS 427.191 is amended to read:

5 427.191. (1) As used in this section:

6 (a) “Agency” means an agency **or provider of agency with choice services, as defined in**
 7 **ORS 427.181**, that hires, trains and supervises direct support professionals using state funds re-
 8 ceived from the Department of Human Services.

9 (b) “Attendant care services” means services provided directly to an individual with a disability
 10 to assist with activities of daily living, instrumental activities of daily living and health-related
 11 tasks.

12 (c) **“Authorized hours” means the number of hours approved in an individualized service**
 13 **plan, as defined in ORS 427.101, for attendant care services.**

14 [(c)] (d) “Child” means an individual under 18 years of age who:

15 (A) Has a developmental or intellectual disability; or

16 (B) Meets the eligibility criteria to receive services under the Medically Fragile (Hospital)
 17 Model Waiver or the Medically Involved Children’s Waiver approved by the Centers for Medicare
 18 and Medicaid Services under 42 U.S.C. 1396n(c).

19 [(d)] (e) “Client” means an individual who receives attendant care services.

20 [(e)] (f) “Client child” means a child who receives attendant care services from the child’s par-
 21 ent.

22 [(f)] (g) “Developmental disability services” has the meaning given that term in ORS 427.101.

23 [(g)] (h) “Direct support professional” means an individual who is hired, employed, trained, paid
 24 and supervised by an agency to provide attendant care services to a client of the agency.

25 [(h)] (i) “Nonparent caregiver” means a direct support professional, personal support worker or
 26 similar provider who is paid to provide attendant care services to clients who are not the provider’s
 27 children.

28 [(i)] (j) “Parent” includes a:

29 (A) Natural or adoptive parent of a child;

30 (B) Stepparent of a child; and

31 (C) Legal guardian of a child.

32 [(j)(A)] (k)(A) “Parent provider” means a parent who is paid to provide attendant care services
 33 to the parent’s minor child.

34 (B) “Parent provider” does not include a parent who is paid to provide attendant care services
 35 to [a child] **an individual, related to the parent**, who is 18 years of age or older.

36 [(k)(A)] (L)(A) “Personal support worker” means an individual who is employed by a client or
 37 the client’s representative and paid to provide attendant care services to the client.

38 (B) “Personal support worker” does not include a direct support professional.

39 [(L)] (m) “State plan” means Oregon’s state plan for medical assistance, described in 42 U.S.C.
 40 1396a, approved by the Centers for Medicare and Medicaid Services.

41 [(m)] (n) “Very high behavioral needs” means a minor child’s extraordinary needs for support
 42 due to the child’s behavioral condition as indicated by a federally approved functional needs as-
 43 sessment adopted by the department that assigns the child to the highest service level.

44 [(n)] (o) “Very high medical needs” means a minor child’s extraordinary needs for support due
 45 to the child’s medical condition as indicated by a federally approved functional needs assessment

1 adopted by the department that assigns the child to the highest service level.

2 (2) Subject to rules adopted under subsection [(8)] (11) of this section[,] **and** to section 2, chapter
 3 367, Oregon Laws 2023, [*and to available funding,*] the department shall administer a program to
 4 compensate parents to provide attendant care services to the parents' children who have been as-
 5 sessed by the department to have very high medical or very high behavioral needs.

6 (3) To be eligible for the program described in this section:

7 (a)(A) A parent provider must be employed by an agency [*and not by the child or the other parent*
 8 *of the child*]; **and**

9 [(b)] (B) The parent provider may not be paid to provide attendant care services to the client
 10 child by an agency that is owned by the parent, the child or any family member or for which the
 11 parent or other family member serves in any administrative or leadership capacity, including as a
 12 member of a board of directors; [*and*] **or**

13 (b)(A) **Another parent, and not the parent provider, must be the employer of record for**
 14 **the client child; or**

15 (B) **The parent provider must assign an alternative legal representative for the client**
 16 **child to make decisions about or manage the development and implementation of the client**
 17 **child's individual support plan. The assignment must:**

18 (i) **Be on a form prescribed by the department; and**

19 (ii) **Clearly state that the assignment is limited to decisions regarding the development**
 20 **and implementation of the client child's individual support plan and does not limit the au-**
 21 **thority of the parent provider to make decisions for the client child with respect to health**
 22 **care, education or religious training.**

23 [(c)] (4) [*The*] **An** agency employing [*the*] **a** parent provider to provide attendant care services
 24 to [*the*] **a** client child:

25 [(A)] (a) May not employ a parent provider as an independent contractor; **and**

26 [(B)] (b) Shall pay parent providers overtime at the same rate and under the same circumstances
 27 as direct support professionals who are not parent providers[;].

28 [(C)] (5) Except as authorized by the department by rule, [*may not pay providers of attendant care*
 29 *services, including parent providers,*] **a parent provider may not be paid:**

30 (a) To provide services to a minor child during school hours unless the minor child is tempo-
 31 rarily at home recovering from surgery or illness and the temporary absence from school is recom-
 32 mended by the child's health care provider; [*and*] **or**

33 [(D)] (b) [*May not pay providers of attendant care services, including parent providers,*] To provide
 34 services to a minor child during school hours due to the determination of a school district or due
 35 to the choice of a parent of the client child to:

36 [(i)] (A) Have the child regularly attend school less than the number of school hours attended
 37 by students without disabilities who are in the same grade and the same school district as the client
 38 child;

39 [(ii)] (B) Homeschool the client child; or

40 [(iii)] (C) Enroll the client child in a private school that offers fewer school hours than the
 41 school hours offered by the local public school to the majority of students in the same grade as the
 42 client child.

43 [(4)] (6) Subsection [(3)(c)(D)] (5)(b) of this section does not prohibit a school district or other
 44 entity from compensating parents of students with disabilities for providing support for educational
 45 activities that would otherwise be the responsibility of the school district.

1 [(5)] (7) A parent provider, during the hours that the parent provider is paid to provide one-on-
2 one attendant care services to the client child:

3 (a) May not be responsible for a vulnerable adult who requires physical care and monitoring;

4 (b) May not be responsible for the care of a child, other than the client child, who is under 10
5 years of age and shall have another caregiver immediately available at all times to attend to the
6 needs of the child; and

7 (c) Unless they are included as a goal or service in the child's individual support plan and re-
8 lated to the child's disability-related support needs, may not perform tasks that are not for the pri-
9 mary benefit of the client child, including but not limited to:

10 (A) Grocery shopping for the household;

11 (B) Housekeeping not required for the disability-related support needs of the client child;

12 (C) Remote work or operation of a home business; or

13 (D) Transporting individuals other than the client child to or from activities or appointments.

14 [(6) *If required by the Centers for Medicare and Medicaid Services, the department may require a*
15 *parent provider to assign an alternative legal representative for the client child to make decisions about*
16 *or manage the development and implementation of the client child's individual support plan. The as-*
17 *assignment:]*

18 [(a) *Must be on a form prescribed by the department; and]*

19 [(b) *Must clearly state that the assignment is limited to decisions regarding the development and*
20 *implementation of the child's individual support plan and does not limit the authority of the parent*
21 *provider to make decisions for the client child with respect to health care, education or religious*
22 *training.]*

23 **(8) The number of authorized hours that a parent provider may be paid to provide at-**
24 **tendant care services under the program described in this section may not be limited except**
25 **by:**

26 (a) **The choice of the parent provider or the parent provider's inability to provide the**
27 **care;**

28 (b) **An agency that employs the parent provider;**

29 (c) **Any applicable collective bargaining agreement; or**

30 (d) **The client child.**

31 **(9) A nonparent caregiver may be paid using funding available through the state's Com-**
32 **munity First Choice Option under 42 U.S.C. 1396n(k).**

33 [(7)] (10) A parent provider is subject to the requirements of mandatory reporting of abuse under
34 ORS 124.060 and 419B.010, 24 hours per day, seven days per week.

35 [(8)] (11) The department shall adopt rules for the program described in this section using an
36 advisory committee appointed under ORS 183.333 that represents the interests of parents, children
37 with developmental or intellectual disabilities, adults with disabilities, agencies, organizations of
38 direct support professionals and personal support workers and organizations that advocate for per-
39 sons with disabilities. The rules must include all of the following:

40 (a) Strategies to safeguard nonparent caregivers and avoid the displacement of nonparent
41 caregivers by parent providers;

42 (b) Requirements for agencies to demonstrate consistent efforts to recruit, train and retain
43 nonparent caregivers;

44 (c) Training requirements for:

45 (A) Parent providers regarding federal and state administrative rules regulating home-based and

1 community-based services, including the impact of the rules on parent-child relationships with re-
 2 spect to discipline, supervision, physical intervention and self-determination of client children during
 3 the hours that the parent provider is being paid to provide attendant care services;

4 (B) Client children to learn to advocate for themselves with respect to choosing and managing
 5 direct support professionals **or personal support workers** before and after reaching 18 years of
 6 age; and

7 (C) Community developmental disability programs related to the employment of parent providers,
 8 including on how to support families to manage issues concerning conflicts of interest, provider
 9 recruitment and retention and the empowerment of the client child to have a meaningful voice in
 10 the selection of the client child's direct support professionals **or personal support workers**;

11 (d) A process for a client child to object to the hiring of any caregiver, including the child's
 12 parent, or to raise concerns about a provider's caregiving;

13 (e) Procedures to ensure that the program described in this section is implemented consistently
 14 and equitably throughout this state;

15 (f) A requirement that any appeal related to the requirements of or benefits under the program
 16 is the sole responsibility of the central office staff of the department; and

17 (g) Other requirements that the department deems necessary to carry out the provisions of this
 18 section.

19 [(9)] **(12)** The department may adopt rules necessary to manage the cost, size and growth rate
 20 of the program described in this section that are necessary to protect the eligibility for and levels
 21 of services under programs serving individuals receiving developmental disability services provided
 22 for in the state plan, [including the development of] **except by developing** criteria to limit the num-
 23 ber of children eligible to participate in the program.

24 [(10)] **(13)** Annually, the department shall report to the interim committees of the Legislative
 25 Assembly related to human services or, if the Legislative Assembly is in session, to the committees
 26 of the Legislative Assembly related to human services, in the manner provided in ORS 192.245, up-
 27 dates on the program described in this section, including:

28 (a) The number of client children receiving attendant care services, the number of children re-
 29 ceiving the services from parent providers and the number of children receiving the services from
 30 nonparent caregivers;

31 (b) The number of hours of attendant care services provided by parent providers and number
 32 of hours of attendant care services provided by nonparent caregivers;

33 (c) A comparison of the cost per child of providing attendant care services by parent providers
 34 under the program with the cost per child of providing attendant care services by nonparent
 35 caregivers; and

36 (d) A report on the adequacy of the direct care workforce in this state to provide services to
 37 all children with developmental disability services who are eligible for attendant care services.

38 **(14) Any moneys appropriated to the department by the Legislative Assembly for the**
 39 **purpose of compensating parent providers or for the staffing necessary for compensating**
 40 **parent providers under this section may not be used by the department for any other pur-**
 41 **pose.**

42 **SECTION 2.** Section 2, chapter 367, Oregon Laws 2023, is amended to read:

43 **Sec. 2.** (1) Except as provided in section 4 [of this 2023 Act], **chapter 367, Oregon Laws 2023,**
 44 the Department of Human Services may not administer the program described in [section 1 of this
 45 2023 Act] **ORS 427.191** without the Centers for Medicare and Medicaid Services' approval of a

1 [new] waiver **or amendments to an existing waiver** or without other arrangements with the Cen-
2 ters for Medicare and Medicaid Services to receive federal financial participation in the costs of the
3 program during a state of emergency or a public health emergency. **No later than January 1, 2026,**
4 **the department shall pursue federal financial participation by means of any available federal**
5 **authority, including but not limited to a waiver or an amendment to a waiver under section**
6 **1915(c) of the Social Security Act or a waiver under section 1115 of the Social Security Act.**

7 (2) The department may not administer a program that pays a parent to provide attendant care
8 or personal care services to the parent's minor child, including but not limited to the program de-
9 scribed in [section 1 of this 2023 Act] **ORS 427.191**, using General Fund moneys that are not matched
10 by federal Medicaid funds.

11 **SECTION 3. This 2025 Act being necessary for the immediate preservation of the public**
12 **peace, health and safety, an emergency is declared to exist, and this 2025 Act takes effect**
13 **on its passage.**

14 _____