

Senate Bill 1565

Sponsored by Senator HAYDEN (Presession 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 the DHS to pay for a certain number of hours of in-home care for minor children with disabilities. The Act requires DHS to seek out all means to get federal matching funds from the Centers for Medicare and Medicaid Services to pay for the care. (Flesch Readability Score: 62.6).

Requires the Department of Human Services to pay for attendant care services for children with developmental disabilities who have very high behavioral health needs or very high medical needs. Requires the department, for children in each category, to pay for no less hours of attendant care services for a child than for the average attendant care hours utilized by the children in the same category and to supplement underutilized hours by paying the child's parent to provide the services. Directs the department to seek any federal funding available for attendant care services no later than April 1, 2024.

Declares an emergency, effective on passage.

A BILL FOR AN ACT

1
2 Relating to developmental disability services; amending ORS 427.191 and section 2, chapter 367,
3 Oregon Laws 2023; and declaring an emergency.

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

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

6 427.191. (1) As used in this section:

7 (a) "Agency" means an agency that hires, trains and supervises direct support professionals us-
8 ing state funds received 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) "**Average utilization**" means the average monthly hours of attendant care services
13 utilized in a month by a service group.

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 (g) "**Deficit number of hours**" means the difference between the average utilization for
23 a service group in a month and the number of hours of attendant care services that are
24 utilized by a child in that service group in a month.

25 [(f)] (h) "Developmental disability services" has the meaning given that term in ORS 427.101.

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

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

6 [(i)] (k) “Parent” includes a:

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

8 (B) Stepparent of a child; and

9 (C) Legal guardian of a child.

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

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

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

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

17 (n) **“Service group” means the cohort of children receiving attendant care services under
18 this section as either children with very high behavioral needs or as children with very high
19 medical needs.**

20 [(L)] (o) “State plan” means Oregon’s state plan for medical assistance, described in 42 U.S.C.
21 1396a, approved by the Centers for Medicare and Medicaid Services.

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

25 [(n)] (q) “Very high medical needs” means a minor child’s extraordinary needs for support due
26 to the child’s medical condition as indicated by a federally approved functional needs assessment
27 adopted by the department that assigns the child to the highest service level.

28 (2) Subject to rules adopted under subsection (8) of this section, to section 2, chapter 367,
29 Oregon Laws 2023, and to available funding, the department shall administer a program to compen-
30 sate parents to provide attendant care services to the parents’ children who have been assessed by
31 the department to have very high medical or very high behavioral needs.

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

33 (a) A parent provider must be employed by an agency and not by the child or the other parent
34 of the child;

35 (b) The parent provider may not be paid to provide attendant care services to the client child
36 by an agency that is owned by the parent, the child or any family member or for which the parent
37 or other family member serves in any administrative or leadership capacity, including as a member
38 of a board of directors; and

39 (c) The agency employing the parent provider to provide attendant care services to the client
40 child:

41 (A) May not employ a parent provider as an independent contractor;

42 (B) Shall pay parent providers overtime at the same rate and under the same circumstances as
43 direct support professionals who are not parent providers;

44 (C) Except as authorized by the department by rule, may not pay providers of attendant care
45 services, including parent providers, to provide services to a minor child during school hours unless

1 the minor child is temporarily at home recovering from surgery or illness and the temporary absence
2 from school is recommended by the child's health care provider; and

3 (D) May not pay providers of attendant care services, including parent providers, to provide
4 services to a minor child during school hours due to the determination of a school district or due
5 to the choice of a parent of the client child to:

6 (i) Have the child regularly attend school less than the number of school hours attended by
7 students without disabilities who are in the same grade and the same school district as the client
8 child;

9 (ii) Homeschool the client child; or

10 (iii) Enroll the client child in a private school that offers fewer school hours than the school
11 hours offered by the local public school to the majority of students in the same grade as the client
12 child.

13 (4) Subsection (3)(c)(D) of this section does not prohibit a school district or other entity from
14 compensating parents of students with disabilities for providing support for educational activities
15 that would otherwise be the responsibility of the school district.

16 (5) A parent provider, during the hours that the parent provider is paid to provide one-on-one
17 attendant care services to the client child:

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

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

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

25 (A) Grocery shopping for the household;

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

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

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

29 (6) If required by the Centers for Medicare and Medicaid Services, the department may require
30 a parent provider to assign an alternative legal representative for the client child to make decisions
31 about or manage the development and implementation of the client child's individual support plan.
32 The assignment:

33 (a) Must be on a form prescribed by the department; and

34 (b) Must clearly state that the assignment is limited to decisions regarding the development and
35 implementation of the child's individual support plan and does not limit the authority of the parent
36 provider to make decisions for the client child with respect to health care, education or religious
37 training.

38 (7) A parent provider is subject to the requirements of mandatory reporting of abuse under ORS
39 124.060 and 419B.010, 24 hours per day, seven days per week.

40 (8) The department shall adopt rules for the program described in this section using an advisory
41 committee appointed under ORS 183.333 that represents the interests of parents, children with de-
42 velopmental or intellectual disabilities, adults with disabilities, agencies, organizations of direct
43 support professionals and personal support workers and organizations that advocate for persons with
44 disabilities. The rules must include all of the following:

45 (a) Strategies to safeguard nonparent caregivers and avoid the displacement of nonparent

1 caregivers by parent providers;

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

4 (c) Training requirements for:

5 (A) Parent providers regarding federal and state administrative rules regulating home-based and
6 community-based services, including the impact of the rules on parent-child relationships with re-
7 spect to discipline, supervision, physical intervention and self-determination of client children during
8 the hours that the parent provider is being paid to provide attendant care services;

9 (B) Client children to learn to advocate for themselves with respect to choosing and managing
10 direct support professionals before and after reaching 18 years of age; and

11 (C) Community developmental disability programs related to the employment of parent providers,
12 including on how to support families to manage issues concerning conflicts of interest, provider
13 recruitment and retention and the empowerment of the client child to have a meaningful voice in
14 the selection of the client child's direct support professionals;

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

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

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

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

23 (9) **Subject to subsection (10) of this section**, the department may adopt rules necessary to
24 manage the cost, size and growth rate of the program described in this section that are necessary
25 to protect the eligibility for and levels of services under programs serving individuals receiving de-
26 velopmental disability services provided for in the state plan, *[including the development of]* **except**
27 **by developing** criteria to limit the number of children eligible to participate in the program.

28 (10)(a) **Each biennium, the total number of hours of attendant care services paid for by**
29 **the department under this section for each service group may not be less than the average**
30 **utilization paid for the service group in the previous biennium.**

31 (b) **The department shall ensure that every child in a service group is able to receive**
32 **attendant care services for the number of hours of average utilization for the child's service**
33 **group by compensating parent providers to provide attendant care services for the deficit**
34 **number of hours.**

35 [(10)] (11) Annually, the department shall report to the interim committees of the Legislative
36 Assembly related to human services or, if the Legislative Assembly is in session, to the committees
37 of the Legislative Assembly related to human services, in the manner provided in ORS 192.245, up-
38 dates on the program described in this section, including:

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

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

44 (c) A comparison of the cost per child of providing attendant care services by parent providers
45 under the program with the cost per child of providing attendant care services by nonparent

1 caregivers; and

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

4 **(12) Any moneys appropriated to the department by the Legislative Assembly for the**
 5 **purpose of compensating parent providers or for the staffing necessary for compensating**
 6 **parent providers under this section may not be used by the department for any other pur-**
 7 **pose.**

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

9 **Sec. 2.** (1) Except as provided in section 4 [*of this 2023 Act*], **chapter 367, Oregon Laws 2023,**
 10 the Department of Human Services may not administer the program described in [*section 1 of this*
 11 *2023 Act*] **ORS 427.191** without the Centers for Medicare and Medicaid Services' approval of a
 12 [*new*] waiver **or amendments to an existing waiver** or without other arrangements with the Cen-
 13 ters for Medicare and Medicaid Services to receive federal financial participation in the costs of the
 14 program during a state of emergency or a public health emergency. **No later than April 1, 2024,**
 15 **the department shall pursue federal financial participation by means of any available federal**
 16 **authority, including but not limited to a waiver or an amendment to a waiver under section**
 17 **1915(c) of the Social Security Act or a waiver under section 1115 of the Social Security Act.**

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

22 **SECTION 3.** **This 2024 Act being necessary for the immediate preservation of the public**
 23 **peace, health and safety, an emergency is declared to exist, and this 2024 Act takes effect**
 24 **on its passage.**