

A-Engrossed Senate Bill 91

Ordered by the Senate April 11
Including Senate Amendments dated April 11

Printed pursuant to Senate Interim Rule 213.28 by order of the President of the Senate in conformance with pre-session filing rules, indicating neither advocacy nor opposition on the part of the President (at the request of Senate Interim Committee on Human Services, Mental Health and Recovery)

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.

Requires Department of Human Services to request from Centers for Medicare and Medicaid Services approval of waiver to obtain federal financial participation in costs of program to pay parents of minor children with disabilities to provide attendant care services to children. Specifies requirements for program and prohibits administration of program without Centers for Medicare and Medicaid Services approval of waiver or federal matching funds **unless federal funding is available under short-term program.**

Allows department to adopt rules to limit cost, size or growth rate of program to safeguard developmental disability services provided under state plan for medical assistance.

Requires department to provide annual reports to committees of Legislative Assembly related to human services on program and on adequacy of workforce to meet needs of children with disabilities for attendant care services.

Declares emergency, effective on passage.

A BILL FOR AN ACT

1
2 Relating to home-based care for children with disabilities; and declaring an emergency.

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

4 **SECTION 1. (1) As used in this section:**

5 (a) **"Agency" means an agency that hires, trains and supervises direct support profes-**
6 **sionals using state funds received from the Department of Human Services.**

7 (b) **"Attendant care services" means services provided directly to an individual with a**
8 **disability to assist with activities of daily living, instrumental activities of daily living and**
9 **health-related tasks.**

10 (c) **"Child" means an individual under 18 years of age who has a developmental or intel-**
11 **lectual disability.**

12 (d) **"Client" means an individual who receives attendant care services.**

13 (e) **"Client child" means a child who receives attendant care services from the child's**
14 **parent.**

15 (f) **"Developmental disability services" has the meaning given that term in ORS 427.101.**

16 (g) **"Direct support professional" means an individual who is hired, employed, trained,**
17 **paid and supervised by an agency to provide attendant care services to a client of the agency.**

18 (h) **"Nonparent caregiver" means a direct support professional, personal support worker**
19 **or similar provider who is paid to provide attendant care services to clients who are not the**
20 **provider's children.**

21 (i) **"Parent" includes a:**

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 (A) Natural or adoptive parent of a child;

2 (B) Stepparent of a child; and

3 (C) Legal guardian of a child.

4 (j)(A) "Parent provider" means a parent who is paid to provide attendant care services
5 to the parent's minor child.

6 (B) "Parent provider" does not include a parent who is paid to provide attendant care
7 services to a child who is 18 years of age or older.

8 (k)(A) "Personal support worker" means an individual who is employed by a client or the
9 client's representative and paid to provide attendant care services to the client.

10 (B) "Personal support worker" does not include a direct support professional.

11 (L) "State plan" means Oregon's state plan for medical assistance, described in 42 U.S.C.
12 1396a, approved by the Centers for Medicare and Medicaid Services.

13 (m) "Very high behavioral needs" means a minor child's extraordinary needs for support
14 due to the child's behavioral condition as indicated by a federally approved functional needs
15 assessment adopted by the department that assigns the child to the highest service level.

16 (n) "Very high medical needs" means a minor child's extraordinary needs for support due
17 to the child's medical condition as indicated by a federally approved functional needs as-
18 sessment adopted by the department that assigns the child to the highest service level.

19 (2) Subject to rules adopted under subsection (8) of this section, to section 2 of this 2023
20 Act and to available funding, the department shall administer a program to compensate
21 parents to provide attendant care services to the parents' children who have been assessed
22 by the department to have very high medical or very high behavioral needs.

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

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

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

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

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

33 (B) Shall pay parent providers overtime at the same rate and under the same circum-
34 stances as direct support professionals who are not parent providers;

35 (C) Except as authorized by the department by rule, may not pay providers of attendant
36 care services, including parent providers, to provide services to a minor child during school
37 hours unless the minor child is temporarily at home recovering from surgery or illness and
38 the temporary absence from school is recommended by the child's health care provider; and

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

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

45 (ii) Homeschool the client child; or

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

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

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

9 (a) May not be responsible for a vulnerable adult who requires physical care and moni-
10 toring;

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

14 (c) Unless they are included as a goal or service in the child's individual support plan and
15 related to the child's disability-related support needs, may not perform tasks that are not for
16 the primary benefit of the client child, including but not limited to:

17 (A) Grocery shopping for the household;

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

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

20 (D) Transporting individuals other than the client child to or from activities or appoint-
21 ments.

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

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

27 (b) Must clearly state that the assignment is limited to decisions regarding the develop-
28 ment and implementation of the child's individual support plan and does not limit the au-
29 thority of the parent provider to make decisions for the client child with respect to health
30 care, education or religious training.

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

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

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

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

42 (c) Training requirements for:

43 (A) Parent providers regarding federal and state administrative rules regulating home-
44 based and community-based services, including the impact of the rules on parent-child re-
45 lationships with respect to discipline, supervision, physical intervention and

1 self-determination of client children during the hours that the parent provider is being paid
2 to provide attendant care services;

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

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

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

11 (e) Procedures to ensure that the program described in this section is implemented con-
12 sistently and equitably throughout this state;

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

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

17 (9) The department may adopt rules necessary to manage the cost, size and growth rate
18 of the program described in this section that are necessary to protect the eligibility for and
19 levels of services under programs serving individuals receiving developmental disability ser-
20 vices provided for in the state plan, including the development of criteria to limit the number
21 of children eligible to participate in the program.

22 (10) Annually, the department shall report to the interim committees of the Legislative
23 Assembly related to human services or, if the Legislative Assembly is in session, to the
24 committees of the Legislative Assembly related to human services, in the manner provided
25 in ORS 192.245, updates on the program described in this section, including:

26 (a) The number of client children receiving attendant care services, the number of chil-
27 dren receiving the services from parent providers and the number of children receiving the
28 services from nonparent caregivers;

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

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

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

37 **SECTION 2.** (1) Except as provided in section 4 of this 2023 Act, the Department of Hu-
38 man Services may not administer the program described in section 1 of this 2023 Act without
39 the Centers for Medicare and Medicaid Services' approval of a new waiver or without other
40 arrangements with the Centers for Medicare and Medicaid Services to receive federal finan-
41 cial participation in the costs of the program during a state of emergency or a public health
42 emergency.

43 (2) The department may not administer a program that pays a parent to provide attend-
44 ant care or personal care services to the parent's minor child, including but not limited to
45 the program described in section 1 of this 2023 Act, using General Fund moneys that are not

1 matched by federal Medicaid funds.

2 **SECTION 3.** On or before the earlier of August 1, 2023, or 30 days after the effective date
3 of this 2023 Act, the Department of Human Services shall initiate the process, including
4 consulting with tribes and requesting public comments, to apply to the Centers for Medicare
5 and Medicaid Services for approval of a new waiver as described in section 4 of this 2023 Act.

6 **SECTION 4.** The Department of Human Services shall apply for any short-term program
7 that is made available by the Centers for Medicare and Medicaid Services that provides fed-
8 eral matching funds to continue paying parents who were paid parent providers as of March
9 1, 2023, to be paid parent providers until the program described in section 1 of this 2023 Act
10 can be implemented. The department shall submit an application for a short-term program
11 as provided in this section no later than January 1, 2024.

12 **SECTION 5.** (1) Section 3 of this 2023 Act is repealed on January 2, 2025.

13 (2) Section 4 of this 2023 Act is repealed on June 30, 2025.

14 **SECTION 6.** In addition to and not in lieu of any other appropriation, there is appropri-
15 ated to the Department of Human Services, for the biennium beginning July 1, 2023, out of
16 the General Fund, the amount of \$3,000,000, which may be expended for carrying out the
17 provisions of sections 1 and 4 of this 2023 Act.

18 **SECTION 7.** This 2023 Act being necessary for the immediate preservation of the public
19 peace, health and safety, an emergency is declared to exist, and this 2023 Act takes effect
20 on its passage.

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