

DRAFT

SUMMARY

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.

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

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

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

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

(a) **“Agency” means an agency that hires, trains and supervises direct support professionals using state funds received from the Department of Human Services.**

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

(c) **“Child” means an individual under 18 years of age:**

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) With a developmental or intellectual disability; or

2 (B) Who meets the eligibility requirements for services under the
3 Medically Fragile Model Waiver or the Medically Involved Children's
4 Waiver granted by the Centers for Medicare and Medicaid Services.

5 (d) "Client" means an individual who receives attendant care ser-
6 vices.

7 (e) "Client child" means a child who receives attendant care ser-
8 vices from the child's parent.

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

11 (g) "Direct support professional" means an individual who is hired,
12 employed, trained, paid and supervised by an agency to provide at-
13 tendant care services to a client of the agency.

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

17 (i) "Parent" includes a:

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

19 (B) Stepparent of a child; and

20 (C) Legal guardian of a child.

21 (j)(A) "Parent provider" means a parent who is paid to provide at-
22 tendant care services to the parent's minor child.

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

26 (k)(A) "Personal support worker" means an individual who is em-
27 ployed by a client or the client's representative and paid to provide
28 attendant care services to the client.

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

31 (L) "State plan" means Oregon's state plan for medical assistance,

1 described in 42 U.S.C. 1396a, approved by the Centers for Medicare and
2 Medicaid Services.

3 (m) “Very high behavioral needs” means a minor child’s extraor-
4 dinary needs for support due to the child’s behavioral condition as
5 indicated by a federally approved functional needs assessment adopted
6 by the department that assigns the child to the highest service level.

7 (n) “Very high medical needs” means a minor child’s extraordinary
8 needs for support due to the child’s medical condition as indicated by
9 a federally approved functional needs assessment adopted by the de-
10 partment that assigns the child to the highest service level.

11 (2) Subject to subsection (8) of this section and section 2 of this 2023
12 Act, the department shall administer a program to compensate par-
13 ents to provide attendant care services to the parents’ children who
14 have been assessed by the department to have very high medical or
15 very high behavioral needs.

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

17 (a) A parent provider must be employed by an agency and not by
18 the child or the other parent of the child unless the parent provider
19 was paid as a personal support worker for the child on or before July
20 1, 2022;

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

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

28 (A) May not schedule the parent provider for shifts that are already
29 covered by a qualified direct support professional who is not a member
30 of the child’s household except to substitute for the direct support
31 professional during brief periods of absence of the direct support pro-

1 fessional due to sickness or leave;

2 (B) May not reassign a direct support professional who is providing
3 attendant care services to a client child or reduce the hours of the
4 direct support professional for the purpose of allowing the parent
5 provider to provide the services;

6 (C) May not knowingly schedule a parent provider in a manner that
7 would result in a reduction in hours of a personal support worker
8 providing attendant care services to a client child for the purpose of
9 allowing the parent provider to provide the services, except to substi-
10 tute for the personal support worker during brief periods of absence
11 of the personal support worker due to sickness or leave;

12 (D) May not employ a parent provider as an independent contractor;

13 (E) Must offer a parent provider the same wages and benefits of-
14 fered to direct support professionals who are not parent providers;

15 (F) May not allocate to parent providers more than 30 percent of
16 the attendant care services hours that it contracts with the depart-
17 ment to provide during a 12-month period, except during a public
18 health emergency declared under ORS 433.441;

19 (G) May pay parent providers in one household to provide a total
20 of no more than 60 hours per week of attendant care services, re-
21 gardless of the number of client children or parent providers in the
22 household;

23 (H) Subject to subparagraph (G) of this paragraph, shall pay parent
24 providers overtime at the same rate and under the same circum-
25 stances as direct support professionals who are not parent providers;

26 (I) Except as authorized by the department by rule, may not pay
27 providers of attendant care services, including parent providers, to
28 provide services to a minor child during school hours unless the minor
29 child is temporarily at home recovering from surgery or illness and
30 the temporary absence from school is recommended by the child's
31 health care provider; and

(J) Except as provided by the department by rule, may not pay providers of attendant care services, including parent providers, to provide services to a minor child during school hours due to the termination of a school district or due to the choice of a parent of the client child to:

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

(ii) Homeschool the client child; or

(iii) Enroll the client child in a private school with school hours that are different than the school hours of the local public school.

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

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

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

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

(c) May not perform tasks that are not for the primary benefit of the client child, including but not limited to:

(A) Grocery shopping for the household;

(B) Housekeeping not required for the care of the client child;

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

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

(E) Attending outside activities, performances or athletic events of

1 children in the household other than the client child except for the
2 primary purpose of supporting the client child's participation in a
3 community activity of the client child's choosing; or

4 (F) Travel with the client child, if the travel includes an overnight
5 stay away from the child's home, unless the travel is for the primary
6 purpose of supporting the client child to travel as part of a team or
7 community activity.

8 (6) If required by the Centers for Medicare and Medicaid Services,
9 the department may require a parent provider to assign an alternative
10 legal representative for the client child to make decisions about or
11 manage the client child's attendant care services. The assignment:

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

13 (b) Must clearly state that the assignment is limited to decisions
14 regarding the development and implementation of the child's individ-
15 ual support plan and does not limit the authority of the parent pro-
16 vider to make decisions for the client child with respect to health care,
17 education or religious training.

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

21 (8) The department shall adopt rules for the program described in
22 this section using an advisory committee appointed under ORS 183.333
23 that represents the interests of parents, children with developmental
24 or intellectual disabilities, adults with disabilities, agencies, organiza-
25 tions of direct support professionals and personal support workers and
26 organizations that advocate for persons with disabilities. The rules
27 must include all of the following:

28 (a) Strategies to safeguard nonparent caregivers and avoid the dis-
29 placement of nonparent caregivers by parent providers;

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

(c) Training requirements for:

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

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

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

(d) A process for a client child to object to the hiring of the child's parent as a parent provider or to raise concerns about a parent provider's caregiving;

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

(f) A requirement that any appeal related to the implementation of the Medically Fragile Model Waiver or the Medically Involved Children's Waiver granted by the Centers for Medicare and Medicaid Services is the sole responsibility of the central office staff of the department; and

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

(9) The department may adopt rules necessary to manage the cost, size and growth rate of the program described in this section that are necessary to protect the eligibility for and levels of services under

1 **programs serving individuals receiving developmental disability ser-**
 2 **vices provided for in the state plan.**

3 **(10) Annually, the department shall report to the interim commit-**
 4 **tees of the Legislative Assembly related to human services or, if the**
 5 **Legislative Assembly is in session, to the committees of the Legislative**
 6 **Assembly related to human services, in the manner provided in ORS**
 7 **192.245, updates on the program described in this section, including:**

8 **(a) The number of client children receiving attendant care services**
 9 **from parent providers under the program;**

10 **(b) The number of hours of attendant care services provided by**
 11 **parent providers;**

12 **(c) A comparison of the cost per child of providing attendant care**
 13 **services by parent providers under the program with the cost per child**
 14 **providing attendant care services by nonparent caregivers; and**

15 **(d) A report on the adequacy of the direct care workforce of non-**
 16 **parent caregivers in this state to provide services to all children with**
 17 **developmental disability services who are eligible for attendant care**
 18 **services.**

19 **SECTION 2. (1) The Department of Human Services may not ad-**
 20 **minister the program described in section 1 of this 2023 Act without**
 21 **the Centers for Medicare and Medicaid Services' approval of the Med-**
 22 **ically Fragile Model Waiver or a Medically Involved Children's Waiver**
 23 **under 42 U.S.C. 1396n(c), described in section 1 of this 2023 Act, or**
 24 **without other arrangements with the Centers for Medicare and**
 25 **Medicaid Services to receive federal financial participation in the costs**
 26 **of the program during a state of emergency or a public health emer-**
 27 **gency.**

28 **(2) The department may not administer a program that pays a**
 29 **parent to provide attendant care or personal care services to the**
 30 **parent's minor child, including but not limited to the program de-**
 31 **scribed in section 1 of this 2023 Act, using General Fund moneys that**

1 are not matched by federal Medicaid funds.

2 **SECTION 3.** On or before the earlier of August 1, 2023, or 30 days
3 after the effective date of this 2023 Act, the Department of Human
4 Services shall initiate the process, including the required Tribal Con-
5 sultation and request for public comments, to apply to the Centers for
6 Medicare and Medicaid Services for approval of a Medically Fragile
7 Model Waiver or a Medically Involved Children’s Waiver under 42
8 U.S.C. 1396n(c) described in section 1 of this 2023 Act.

9 **SECTION 4.** Section 3 of this 2023 Act is repealed on January 2,
10 2025.

11 **SECTION 5.** This 2023 Act being necessary for the immediate pres-
12 ervation of the public peace, health and safety, an emergency is de-
13 clared to exist, and this 2023 Act takes effect on its passage.