

# Senate Bill 91

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## 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**.

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:**

**(A) With a developmental or intellectual disability; or**

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

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

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

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

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

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

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

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

**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 (B) Stepparent of a child; and

2 (C) Legal guardian of a child.

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

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

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

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

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

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

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

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

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

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

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, child or any family member or for which the  
28 parent or other family member serves in any administrative or leadership capacity, including  
29 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 schedule the parent provider for shifts that are already covered by a quali-  
33 fied direct support professional who is not a member of the child's household except to sub-  
34 stitute for the direct support professional during brief periods of absence of the direct  
35 support professional due to sickness or leave;

36 (B) May not reassign a direct support professional who is providing attendant care ser-  
37 vices to a client child or reduce the hours of the direct support professional for the purpose  
38 of allowing the parent provider to provide the services;

39 (C) May not knowingly schedule a parent provider in a manner that would result in a  
40 reduction in hours of a personal support worker providing attendant care services to a client  
41 child for the purpose of allowing the parent provider to provide the services, except to sub-  
42 stitute for the personal support worker during brief periods of absence of the personal sup-  
43 port worker due to sickness or leave;

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

45 (E) Must offer a parent provider the same wages and benefits offered to direct support

1 professionals who are not parent providers;

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

5 (G) May pay parent providers in one household to provide a total of no more than 60  
 6 hours per week of attendant care services, regardless of the number of client children or  
 7 parent providers in the household;

8 (H) Subject to subparagraph (G) of this paragraph, shall pay parent providers overtime  
 9 at the same rate and under the same circumstances as direct support professionals who are  
 10 not parent providers;

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

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

19 (i) Have the child attend school less than the number of school hours attended by stu-  
 20 dents without disabilities who are in the same grade and the same school district as the cli-  
 21 ent child;

22 (ii) Homeschool the client child; or

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

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

28 (5) A parent provider, during the hours that the parent provider is paid to provide at-  
 29 tendant care services to the client child:

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

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

35 (c) May not perform tasks that are not for the primary benefit of the client child, in-  
 36 cluding but not limited to:

37 (A) Grocery shopping for the household;

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

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

40 (D) Transporting individuals other than the client child to or from activities or appoint-  
 41 ments;

42 (E) Attending outside activities, performances or athletic events of children in the  
 43 household other than the client child except for the primary purpose of supporting the client  
 44 child's participation in a community activity of the client child's choosing; or

45 (F) Travel with the client child, if the travel includes an overnight stay away from the

1 child's home, unless the travel is for the primary purpose of supporting the client child to  
 2 travel as part of a team or community activity.

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

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

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

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

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

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

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

22 (c) Training requirements for:

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

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

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

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

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

38 (f) A requirement that any appeal related to the implementation of the Medically Fragile  
 39 Model Waiver or the Medically Involved Children's Waiver granted by the Centers for Medi-  
 40 care and Medicaid Services is the sole responsibility of the central office staff of the de-  
 41 partment; and

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

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

1 levels of services under 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 committees of the Legislative  
4 Assembly related to human services or, if the Legislative Assembly is in session, to the  
5 committees of the Legislative Assembly related to human services, in the manner provided  
6 in ORS 192.245, updates on the program described in this section, including:

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

9 (b) The number of hours of attendant care services provided by parent providers;

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

13 (d) A report on the adequacy of the direct care workforce of nonparent caregivers in this  
14 state to provide services to all children with developmental disability services who are eligi-  
15 ble for attendant care services.

16 **SECTION 2.** (1) The Department of Human Services may not administer the program  
17 described in section 1 of this 2023 Act without the Centers for Medicare and Medicaid  
18 Services' approval of the Medically Fragile Model Waiver or a Medically Involved Children's  
19 Waiver under 42 U.S.C. 1396n(c), described in section 1 of this 2023 Act, or without other  
20 arrangements with the Centers for Medicare and Medicaid Services to receive federal finan-  
21 cial participation in the costs of the program during a state of emergency or a public health  
22 emergency.

23 (2) The department may not administer a program that pays a parent to provide attend-  
24 ant care or personal care services to the parent's minor child, including but not limited to  
25 the program described in section 1 of this 2023 Act, using General Fund moneys that are not  
26 matched by federal Medicaid funds.

27 **SECTION 3.** On or before the earlier of August 1, 2023, or 30 days after the effective date  
28 of this 2023 Act, the Department of Human Services shall initiate the process, including the  
29 required Tribal Consultation and request for public comments, to apply to the Centers for  
30 Medicare and Medicaid Services for approval of a Medically Fragile Model Waiver or a Med-  
31 ically Involved Children's Waiver under 42 U.S.C. 1396n(c) described in section 1 of this 2023  
32 Act.

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

34 **SECTION 5.** This 2023 Act being necessary for the immediate preservation of the public  
35 peace, health and safety, an emergency is declared to exist, and this 2023 Act takes effect  
36 on its passage.

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