

LEGISLATURE OF NEBRASKA  
ONE HUNDRED EIGHTH LEGISLATURE  
SECOND SESSION

**LEGISLATIVE BILL 1261**

Introduced by Walz, 15.

Read first time January 16, 2024

Committee: Health and Human Services

- 1 A BILL FOR AN ACT relating to public health and welfare; to adopt the
- 2 Amyotrophic Lateral Sclerosis Respite Services Act.
- 3 Be it enacted by the people of the State of Nebraska,

1           Section 1. Sections 1 to 8 of this act shall be known and may be  
2 cited as the Amyotrophic Lateral Sclerosis Respite Services Act.

3           Sec. 2. The Legislature finds that:

4           (1) Supporting the efforts of families and caregivers that care for  
5 individuals with amyotrophic lateral sclerosis is efficient, cost  
6 effective, and humane;

7           (2) Respite services reduce family and caregiver stress, enhance  
8 family and caregiver coping ability, and strengthen the ability of family  
9 and caregivers to meet the challenging demands of caring for family  
10 members with amyotrophic lateral sclerosis; and

11           (3) Coordinated respite services must be available to provide  
12 reliable services when needed by families and caregivers in Nebraska.

13           Sec. 3. For purposes of the Amyotrophic Lateral Sclerosis Respite  
14 Services Act:

15           (1) Caregiver means an individual providing ongoing care for an  
16 individual diagnosed with amyotrophic lateral sclerosis;

17           (2) Department means the Department of Health and Human Services;

18           (3) Provider means an individual or agency selected by a family or  
19 caregiver to provide respite services to an individual with amyotrophic  
20 lateral sclerosis;

21           (4) Respite care means the provision of short-term relief to primary  
22 caregivers from the demands of ongoing care for an individual with  
23 amyotrophic lateral sclerosis and includes: (a) Identifying local  
24 training resources and organizing training opportunities for respite care  
25 providers; (b) linking families and caregivers with payment resources;  
26 (c) quality assurance and evaluation; and (d) assisting families and  
27 caregivers to identify respite care needs and resources; and

28           (5) Respite services program means a program that: (a) Is operated  
29 by a private nonprofit organization or a public agency that provides  
30 respite services and comprehensive patient services and support to the  
31 amyotrophic lateral sclerosis community; (b) receives funding through the

1 Amyotrophic Lateral Sclerosis Respite Services Program established under  
2 the act; (c) acts as a local resource for respite services information  
3 and referral; and (d) facilitates access to local respite services.

4       Sec. 4. (1) The department shall establish the Amyotrophic Lateral  
5 Sclerosis Respite Services Program to develop and encourage statewide  
6 coordination of respite services and work with a community-based private  
7 nonprofit organization that (a) operates statewide, (b) is affiliated  
8 with a national organization, and (c) provides care to individuals with  
9 amyotrophic lateral sclerosis.

10       (2) The Amyotrophic Lateral Sclerosis Respite Services Program  
11 shall:

12       (a) Provide policy and program development support, including, but  
13 not limited to, data collection and outcome measures;

14       (b) Provide technical assistance to community respite services  
15 programs;

16       (c) Develop and distribute respite services information;

17       (d) Promote the exchange of information and coordination among state  
18 and local governments, community respite services programs, agencies  
19 serving individuals with amyotrophic lateral sclerosis, families, and  
20 respite care advocates to encourage efficient provision of respite  
21 services and reduce duplication of effort;

22       (5) Ensure statewide access to community respite services programs;  
23 and

24       (6) Monitor and evaluate implementation of community respite  
25 services programs.

26       Sec. 5. (1) The department shall coordinate the establishment of  
27 community respite services programs. The programs shall accept proposals  
28 submitted in the form and manner approved by the department from  
29 community-based private nonprofit organizations, as described in section  
30 4 of this act, to operate community respite services programs. Pursuant  
31 to criteria established by the department, the Amyotrophic Lateral

1 Sclerosis Respite Services Program shall designate and fund agencies  
2 described in the Amyotrophic Lateral Sclerosis Respite Services Act to  
3 operate community respite services programs.

4 (2)(a) The department shall award grants as provided in subdivision  
5 (b) of this subsection to any nonprofit organization that (i) is  
6 organized under section 501(c)(3) of the Internal Revenue Code of 1986,  
7 as amended, (ii) has the ability to operate statewide, (iii) is  
8 affiliated with a national organization, and (iv) has an agreement with  
9 providers of respite care that meets the requirements of the Amyotrophic  
10 Lateral Sclerosis Respite Services Act.

11 (b) The department shall award grants, up to the amount appropriated  
12 to the department for the program, each fiscal year as follows: (i) Up to  
13 five percent, but no more than five thousand dollars, may be used by the  
14 department for administration expenses; (ii) after administrative  
15 expenses, eighty percent or more of the remaining funds shall be applied  
16 to grants as described in this subsection; and (iii) any remaining funds  
17 shall be distributed by the department to a publicly owned school of  
18 medicine for the purpose of amyotrophic lateral sclerosis research in an  
19 amyotrophic lateral sclerosis designated clinic.

20 Sec. 6. Respite services made available through the Amyotrophic  
21 Lateral Sclerosis Respite Services Program shall:

22 (1) Include a flexible array of respite care options responsive to  
23 family and caregiver needs and be made available before families and  
24 caregivers are in crisis;

25 (2) Be sensitive to the unique needs, strengths, and cultural values  
26 of an individual, family, or caregiver;

27 (3) Offer the most efficient access to an array of coordinated  
28 respite services built on existing community support and services;

29 (4) Be driven by community strengths, needs, and resources; and

30 (5) Use a variety of funds and resources, including, but not limited  
31 to (a) family or caregiver funds, (b) private and volunteer resources,

1 (c) public funds, and (d) exchange of care among families or caregivers.

2 Sec. 7. The department may adopt and promulgate rules and  
3 regulations for the operation and administration of the Amyotrophic  
4 Lateral Sclerosis Respite Services Act, including, but not limited to:

5 (1) Criteria, procedures, and timelines for designation of the  
6 community-based private nonprofit and public agencies that receive  
7 funding to provide respite services through community respite services  
8 programs;

9 (2) A requirement that each community respite services program  
10 publicize the telephone number, website, and address where families and  
11 caregivers may contact the Amyotrophic Lateral Sclerosis Respite Services  
12 Program; and

13 (3) Procedures and guidelines for determining priorities,  
14 eligibility standards, and eligibility criteria for the selection of  
15 caregivers to participate in programs funded under the Amyotrophic  
16 Lateral Sclerosis Respite Services Act.

17 Sec. 8. (1) It is the intent of the Legislature to appropriate one  
18 hundred thousand dollars in fiscal year 2024-25 and each year thereafter  
19 to the department for the Amyotrophic Lateral Sclerosis Respite Services  
20 Program.

21 (2) The department may use the funds appropriated for the program  
22 for (a) the purposes described in section 4 of this act, except that no  
23 less than eighty percent of the appropriated funds shall be used to  
24 provide community respite care services, (b) costs related to developing  
25 provider recruitment and training, information and referral, outreach,  
26 and other components for the provision of respite services, (c) startup  
27 costs related to the establishment of community respite services  
28 programs, and (d) minimum administrative costs for operating the  
29 Amyotrophic Lateral Sclerosis Respite Services Program.