



Rep. Camille Y. Lilly

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1 AMENDMENT TO HOUSE BILL 2535

2 AMENDMENT NO. _____. Amend House Bill 2535 by replacing
3 everything after the enacting clause with the following:

4 "Section 1. Short title. This Act may be cited as the
5 Recognize, Assist, Include, Support, and Engage (RAISE) Family
6 Caregivers Act.

7 Section 5. Definitions. As used in this Act:

8 (1) "Advisory Council" means the Family Caregiving
9 Advisory Council.

10 (2) "Family caregiver" means an adult family member or
11 other individual who has a significant relationship with, and
12 who provides a broad range of assistance to, an individual
13 with a chronic or other health condition, disability, or
14 functional limitation.

15 (3) "Director" means the Director of Aging.

16 (4) "Strategy" means the Family Caregiving Strategy.

1 Section 10. Family Caregiving Strategy.

2 (a) In general. The Director, in consultation with the
3 heads of other appropriate State agencies, shall develop
4 jointly with the Advisory Council and other State agencies
5 responsible for carrying out family caregiver programs, and
6 make publicly available on the website of the Department on
7 Aging, a Family Caregiving Strategy.

8 (b) Contents. The Strategy shall identify recommended
9 actions that State agencies, units of local government,
10 communities, health care providers, long-term services and
11 supports providers, and others are taking, or may take, to
12 recognize and support family caregivers in a manner that
13 reflects their diverse needs, including with respect to the
14 following:

15 (1) Promoting greater adoption of person-centered and
16 family-centered care in all health and long-term services
17 and supports settings, with the person receiving services
18 and supports and the family caregiver (as appropriate) at
19 the center of care teams.

20 (2) Assessment and service planning (including care
21 transitions and coordination) involving family caregivers
22 and care recipients.

23 (3) Information, education and training supports,
24 referral, and care coordination, including with respect to
25 hospice care, palliative care, and advance planning

1 services.

2 (4) Respite options.

3 (5) Financial security and workplace issues.

4 (6) Delivering services based on the performance,
5 mission, and purpose of a program while eliminating
6 redundancies.

7 (c) Duties of the Director. The Director, in carrying out
8 subsection (a), shall oversee the following:

9 (1) Collecting and making publicly available
10 information submitted by the Advisory Council under
11 subsection (d) of Section 15 to the Governor and the
12 General Assembly, including evidence-based or promising
13 practices and innovative models (both domestic and
14 foreign) regarding the provision of care by family
15 caregivers or support for family caregivers.

16 (2) Coordinating and assessing existing State programs
17 and activities to recognize and support family caregivers
18 while ensuring maximum effectiveness and avoiding
19 unnecessary duplication.

20 (3) Providing technical assistance, as appropriate,
21 such as disseminating identified best practices and
22 information sharing based on reports provided under
23 subsection (d) of Section 15, to State or local efforts to
24 support family caregivers.

25 (d) Initial strategy; updates. The Director shall:

26 (1) not later than 18 months after the effective date

1 of this Act, develop, publish, and submit to the Governor
2 and the General Assembly, an initial Strategy
3 incorporating the items addressed in the Advisory
4 Council's initial report under subsection (d) of Section
5 15 and other relevant information, including best
6 practices, for recognizing and supporting family
7 caregivers; and

8 (2) biennially update, republish, and submit to the
9 Governor and the General Assembly, taking into account the
10 most recent annual report submitted under paragraph (1) of
11 subsection (d) of Section 15:

12 (A) to reflect new developments, challenges,
13 opportunities, and solutions; and

14 (B) to review progress based on recommendations
15 for recognizing and supporting family caregivers in
16 the Strategy and, based on the results of such review,
17 recommend priority actions for improving the
18 implementation of such recommendations, as
19 appropriate.

20 (e) Process for public input. The Director shall establish
21 a process for public input to inform the development of, and
22 updates to, the Strategy, including a process for the public
23 to submit recommendations to the Advisory Council and an
24 opportunity for public comment on the proposed Strategy.

25 Section 15. Family Caregiving Advisory Council.

1 (a) Convening. The Director shall convene a Family
2 Caregiving Advisory Council to advise and provide
3 recommendations, including identified best practices, to the
4 Director on recognizing and supporting family caregivers.

5 (b) Membership.

6 (1) In general. The members of the Advisory Council
7 shall consist of:

8 (A) the appointed members under paragraph (2); and

9 (B) the State members under paragraph (3).

10 (2) Appointed members. In addition to the State
11 members under paragraph (3), the Director shall appoint
12 not more than 20 voting members of the Advisory Council
13 who are not representatives of State departments or
14 agencies and who shall include at least one representative
15 of each of the following:

16 (A) Family caregivers.

17 (B) Older adults with needs for long-term services
18 and supports.

19 (C) Individuals with disabilities.

20 (D) Health care and social service providers.

21 (E) Long-term services and supports providers.

22 (F) Employers.

23 (G) Paraprofessional workers.

24 (H) State and local officials.

25 (I) Accreditation bodies.

26 (J) Veterans.

1 (K) Area Agencies on Aging.

2 (L) Non-profit organizations representing adults
3 50 years of age and older.

4 (M) Care Coordination Units.

5 (N) State Long-Term Care Ombudsman.

6 (O) As appropriate, other experts and advocacy
7 organizations engaged in family caregiving.

8 (3) State members. The State members of the Advisory
9 Council, who shall be nonvoting members, shall consist of
10 the following:

11 (A) The Director of Healthcare and Family Services
12 or his or her designee.

13 (B) The Secretary of Human Services or his or her
14 designee who has experience in both aging and
15 disability.

16 (C) The Director of Veterans' Affairs or his or
17 her designee.

18 (D) The heads of other State departments or
19 agencies (or their designees), including relevant
20 departments or agencies that oversee labor and
21 workforce, economic, government financial policies,
22 community service, and other impacted populations, as
23 appointed by the Director.

24 (4) Diverse representation. The Director shall ensure
25 that the membership of the Advisory Council reflects the
26 diversity of family caregivers and individuals receiving

1 services and supports.

2 (c) Meetings. The Advisory Council shall meet quarterly in
3 person or virtually during the one-year period beginning on
4 the effective date of this Act and at least 3 times during each
5 year thereafter. Meetings of the Advisory Council shall be
6 open to the public.

7 (d) Advisory Council annual reports.

8 (1) In general. Not later than 12 months after the
9 effective date of this Act, and annually thereafter, the
10 Advisory Council shall submit to the Governor and the
11 General Assembly, and make publicly available on the
12 website of the Department on Aging, a report concerning
13 the development, maintenance, and updating of the
14 Strategy, including a description of the outcomes of the
15 recommendations and any priorities included in the initial
16 report in accordance with paragraph (2), as appropriate.

17 (2) Initial report. The Advisory Council's initial
18 report under paragraph (1) shall include:

19 (A) an inventory and assessment of all
20 State-funded efforts to recognize and support family
21 caregivers and the outcomes of such efforts, including
22 analyses of the extent to which State-funded efforts
23 are reaching family caregivers and gaps in such
24 efforts;

25 (B) recommendations:

26 (i) to improve and better coordinate State

1 programs and activities to recognize and support
2 family caregivers, as well as opportunities to
3 improve the coordination of such State programs
4 and activities with programs administered by units
5 of local government; and

6 (ii) to effectively deliver services based on
7 the performance, mission, and purpose of a program
8 while eliminating redundancies, avoiding
9 unnecessary duplication and overlap, and ensuring
10 the needs of family caregivers are met;

11 (C) the identification of challenges faced by
12 family caregivers, including financial, health, and
13 other challenges, and existing approaches to address
14 such challenges;

15 (D) an evaluation of how family caregiving impacts
16 the Medicare program, the Medical Assistance program
17 under Article V of the Illinois Public Aid Code, and
18 other State programs.

19 (e) All requirements of this Act shall be met as part of
20 the Department on Aging's overall strategic multi-agency State
21 plan, including reporting requirements.

22 Section 20. Funding. No additional funds are authorized to
23 be appropriated to carry out this Act. This Act shall be
24 carried out using funds otherwise authorized.

1 Section 25. Termination. The authority and obligations
2 established by this Act shall terminate on the date that is 3
3 years after the effective date of this Act.

4 Section 30. Repealer. This Act is repealed 3 years after
5 the effective date of this Act."