

118TH CONGRESS
2D SESSION

S. 4280

To amend titles XVIII and XIX of the Social Security Act to require skilled nursing facilities, nursing facilities, intermediate care facilities for the intellectually disabled, and inpatient rehabilitation facilities to permit essential caregivers access during any period in which regular visitation is restricted.

IN THE SENATE OF THE UNITED STATES

MAY 8, 2024

Mr. BLUMENTHAL (for himself and Mr. CORNYN) introduced the following bill;
which was read twice and referred to the Committee on Finance

A BILL

To amend titles XVIII and XIX of the Social Security Act to require skilled nursing facilities, nursing facilities, intermediate care facilities for the intellectually disabled, and inpatient rehabilitation facilities to permit essential caregivers access during any period in which regular visitation is restricted.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Essential Caregivers
5 Act of 2024”.

1 **SEC. 2. FINDINGS.**

2 Congress finds the following:

3 (1) According to the National Center for Health
4 Statistics of the Centers for Disease Control and
5 Prevention, an estimated 1,300,000 individuals re-
6 sided in nursing homes in 2020 at the onset of the
7 COVID–19 pandemic and nearly half of all nursing
8 home residents were living with a diagnosis of Alz-
9 heimer’s or other related dementia.

10 (2) Regulations issued pursuant to the Nursing
11 Home Reform Act of 1987 established basic rights
12 and services for residents of nursing homes, includ-
13 ing “the right to a dignified existence, self-deter-
14 mination, and communication with and access to
15 persons and services inside and outside the facility”.

16 (3) In March of 2020, the Centers for Medicare
17 & Medicaid Services instructed nursing facilities to
18 restrict visitation for all visitors and non-essential
19 healthcare personnel and cancel communal dining
20 and group activities. Long-term care ombudsman
21 program representatives and State surveyors were
22 among those whose access to long-term care facilities
23 was prohibited or extremely restricted despite re-
24 opening guidance released by the Centers for Medi-
25 care & Medicaid Services in May of 2020.

1 (4) Many long-term care residents declined dra-
2 matically or died prematurely from “failure to
3 thrive” in isolation.

4 (5) According to the National Consumer Voice
5 for Quality Long-Term Care, in the first year of the
6 COVID–19 pandemic, 1 in 5 healthcare workers re-
7 signed, retired, or were fired. This exacerbated the
8 longstanding problem of staff shortages that already
9 existed. Lack of staff, combined with the forced ab-
10 sence of families, many of whom provided informal
11 care and support to residents, resulted in a signifi-
12 cant decline in residents’ health and well-being. Dur-
13 ing the pandemic, pressure ulcers in nursing home
14 residents rose by 31 percent, the number of resi-
15 dents experiencing significant weight loss rose by 49
16 percent, the number of residents reporting feeling
17 down, depressed, or hopeless rose by 40 percent, and
18 the number of residents prescribed antipsychotic
19 medications rose by 77.5 percent.

20 (6) According to the Department of Health and
21 Human Services, loneliness and isolation, such as
22 that experienced by long-term care residents during
23 the COVID–19 pandemic, represent profound
24 threats to an individual’s health and well-being.

1 (7) Essential Caregivers provide supplemental
 2 care for their loved one, regardless of staff short-
 3 ages, staff turnover, or emergencies. Essential Care-
 4 givers support residents and advocate on their be-
 5 half.

6 **SEC. 3. RIGHT TO ESSENTIAL CAREGIVERS; ACCESS TO ES-**
 7 **SENTIAL CAREGIVERS DURING PERIODS**
 8 **WHEN VISITATION IS OTHERWISE RE-**
 9 **STRICTED.**

10 (a) MEDICARE SKILLED NURSING FACILITIES.—Sec-
 11 tion 1819(c)(3) of the Social Security Act (42 U.S.C.
 12 1395i–3(c)(3)) is amended—

13 (1) by redesignating subparagraphs (A) through
 14 (E) as clauses (i) through (v), respectively;

15 (2) by striking “A skilled nursing facility
 16 must—” and inserting the following:

17 “(A) IN GENERAL.—A skilled nursing fa-
 18 cility shall—”; and

19 (3) by adding at the end the following new sub-
 20 paragraph:

21 “(B) ACCESS TO ESSENTIAL CAREGIVERS
 22 DURING EMERGENCY PERIODS WHEN VISITA-
 23 TION IS OTHERWISE RESTRICTED.—

24 “(i) DESIGNATION OF ESSENTIAL
 25 CAREGIVER.—Each skilled nursing facility

1 shall recognize the right of each resident of
2 such facility to—

3 “(I) designate and have access to
4 essential caregivers for such resident
5 at all times, including during any pe-
6 riod of emergency in which regular
7 visitation is restricted by order of a
8 Federal, State, or local authority or
9 by other operation of law; and

10 “(II) amend such designation at
11 any time.

12 “(ii) PRESUMPTION OF DESIGNA-
13 TION.—For purposes of clause (i), in the
14 case of a resident who is unable, by reason
15 of cognitive or mental disability, to make
16 an election described in such clause, the
17 resident representative (as defined in sec-
18 tion 483.5 of title 42, Code of Federal
19 Regulations) of such resident shall be per-
20 mitted to make such designation for such
21 resident.

22 “(iii) ACCESS TO ESSENTIAL CARE-
23 GIVERS DURING EMERGENCY PERIODS
24 WHEN VISITATION IS OTHERWISE RE-
25 STRICTED.—During a period of emergency

1 in which regular visitation is restricted by
 2 order of a Federal, State, or local author-
 3 ity or by other operation of law, including
 4 any period in which a waiver or modifica-
 5 tion of requirements pursuant to section
 6 1135 is in effect, a skilled nursing facility
 7 shall—

8 “(I) not deny in-person access to
 9 a resident by an essential caregiver of
 10 the resident except as provided in this
 11 subparagraph;

12 “(II) allow at least 1 essential
 13 caregiver to have access to and pro-
 14 vide assistance to such resident at
 15 such facility every day and at any
 16 time; and

17 “(III) enforce the agreement de-
 18 scribed in clause (vii)(III) with respect
 19 to an essential caregiver.

20 “(iv) RESTRICTIONS ON ACCESS.—

21 “(I) IN GENERAL.—During a pe-
 22 riod of emergency in which regular
 23 visitation is restricted by order of a
 24 Federal, State, or local authority or
 25 by other operation of law, including

1 any period in which a waiver or modi-
2 fication of requirements pursuant to
3 section 1135 is in effect, a skilled
4 nursing facility may deny access to a
5 resident by an essential caregiver of
6 the resident for—

7 “(aa) an initial period of not
8 longer than 7 days; and

9 “(bb) one additional period
10 of not longer than 7 days (in ad-
11 dition to the initial period de-
12 scribed in item (aa)) if the de-
13 partment of health of the State
14 in which the facility is located
15 approves the denial of access for
16 such additional period.

17 “(II) RULE OF APPLICATION.—

18 For purposes of subclause (I), a pe-
19 riod of emergency in which regular
20 visitation is restricted by order of a
21 Federal, State, or local authority or
22 by other operation of law shall begin
23 on the date that such order or other
24 operation of law takes effect and shall
25 end on the date that such order or

1 other operation of law expires or is
 2 otherwise terminated. During any
 3 such period, the maximum number of
 4 days for which a skilled nursing facil-
 5 ity may deny access to a resident by
 6 an essential caregiver of the resident
 7 is 7 total days (or, subject to the ap-
 8 proval of the department of health of
 9 the State in which the facility is lo-
 10 cated, 14 total days).

11 “(v) COMPLIANCE AND NOTIFICA-
 12 TION.—

13 “(I) AUTHORITY.—No essential
 14 caregiver who upholds the agreement
 15 described in clause (vii)(III) shall be
 16 denied access to the skilled nursing
 17 facility of the resident involved.

18 “(II) NOTIFICATION.— If an es-
 19 sential caregiver fails to comply with
 20 an agreement with a skilled nursing
 21 facility described in clause (vii)(III),
 22 the facility must first provide a warn-
 23 ing to the essential caregiver and resi-
 24 dent in writing citing specific issues of

1 non-compliance and providing clear
2 guidance for corrective measures.

3 “(III) ENFORCEMENT.—If an es-
4 sential caregiver or resident, after re-
5 ceiving a notification of noncompli-
6 ance described in subclause (II), fails
7 to take corrective action, the essential
8 caregiver may subsequently be denied
9 access to the resident. In such cases,
10 the facility shall provide to such care-
11 giver and such resident (or health
12 care proxy of such resident), not later
13 than 24 hours after such denial of ac-
14 cess occurs, a written explanation as
15 to why such caregiver was denied ac-
16 cess to such resident. Such expla-
17 nation must include the resident’s and
18 caregiver’s options for appeal under
19 the processes established under clause
20 (vi).

21 “(vi) OPTIONS FOR RESIDENTS AND
22 CAREGIVERS TO APPEAL DENIALS OF AC-
23 CESS.—

24 “(I) IN GENERAL.—Not later
25 than 2 years after the date of enact-

1 ment of this subparagraph, the Sec-
 2 retary shall issue a final rule estab-
 3 lishing a process for residents and
 4 caregivers to appeal denials of access.

5 “(II) APPEALS PROCESS.—The
 6 agency responsible for overseeing the
 7 appeals process established under sub-
 8 clause (I) shall—

9 “(aa) receive appeals from
 10 residents and essential caregivers
 11 challenging a decision by a
 12 skilled nursing facility to deny
 13 access under clause (v); and

14 “(bb) investigate all such
 15 appeals within 48 hours of re-
 16 ceipt.

17 “(III) BURDEN OF PROOF.—
 18 During an appeal received under the
 19 appeals process established under sub-
 20 clause (I), if a skilled nursing facility
 21 defends a decision to deny access to
 22 an essential caregiver under clause (v)
 23 on the basis that the essential care-
 24 giver violated the agreement described
 25 in clause (vii)(III), the skilled nursing

1 facility shall have the burden of proof
2 in demonstrating that the essential
3 caregiver violated such agreement.

4 “(IV) RESOLUTION OF AP-
5 PEAL.—With respect to an appeal re-
6 ceived under the appeals process es-
7 tablished under subclause (I), the
8 agency responsible for overseeing the
9 appeal shall make a determination as
10 to whether a skilled nursing facility
11 violated a requirement or prohibition
12 of this subparagraph within 48 hours
13 of commencing its investigation. If the
14 agency determines that a facility has
15 violated such a requirement or prohi-
16 bition the agency shall—

17 “(aa) require the facility to
18 allow immediate access to the es-
19 sential caregiver in question;

20 “(bb) require the facility to
21 establish a corrective action plan
22 to prevent the recurrence of such
23 violation within a 7-day period of
24 receiving notice from the agency;
25 and

1 “(cc) impose a civil money
2 penalty in an amount to be deter-
3 mined by the agency (not to ex-
4 ceed \$5,000) if such facility fails
5 to implement the corrective ac-
6 tion plan with the 7-day period
7 specified in item (bb).

8 “(vii) DEFINITION OF ESSENTIAL
9 CAREGIVER.—For purposes of this sub-
10 paragraph, the term ‘essential caregiver’
11 means, with respect to a resident of a
12 skilled nursing facility, an individual
13 who—

14 “(I) is designated by or on behalf
15 of the resident pursuant to clause (i)
16 or clause (ii);

17 “(II) will provide assistance to
18 such resident, which may include as-
19 sistance with activities of daily living
20 or providing emotional support or
21 companionship to such resident; and

22 “(III) agrees to follow all safety
23 protocols established by such facility,
24 which shall be clearly specified in
25 writing and may be no more restric-

1 tive than the safety protocols (includ-
 2 ing safety standards and entry re-
 3 quirements) applicable to staff of such
 4 facility.”.

5 (b) MEDICAID NURSING FACILITIES.—Section
 6 1919(c)(3) of the Social Security Act (42 U.S.C.
 7 1396r(c)(3)) is amended—

8 (1) by redesignating subparagraphs (A) through
 9 (E) as clauses (i) through (v), respectively;

10 (2) by striking “A nursing facility must—” and
 11 inserting the following:

12 “(A) IN GENERAL.—A nursing facility
 13 shall—”; and

14 (3) by adding at the end the following new sub-
 15 paragraph:

16 “(B) ACCESS TO ESSENTIAL CAREGIVERS
 17 DURING EMERGENCY PERIODS WHEN VISITA-
 18 TION IS OTHERWISE RESTRICTED.—

19 “(i) DESIGNATION OF ESSENTIAL
 20 CAREGIVER.—Each nursing facility shall
 21 recognize the right of each resident of such
 22 facility to—

23 “(I) designate and have access to
 24 essential caregivers for such resident
 25 at all times, including during any pe-

1 riod of emergency in which regular
2 visitation is restricted by order of a
3 Federal, State, or local authority or
4 by other operation of law; and

5 “(II) amend such designation at
6 any time.

7 “(ii) PRESUMPTION OF DESIGNA-
8 TION.—For purposes of clause (i), in the
9 case of a resident who is unable, by reason
10 of cognitive or mental disability, to make
11 an election described in such clause, the
12 resident representative (as defined in sec-
13 tion 483.5 of title 42, Code of Federal
14 Regulations) of such resident shall be per-
15 mitted to make such designation for such
16 resident.

17 “(iii) ACCESS TO ESSENTIAL CARE-
18 GIVERS DURING EMERGENCY PERIODS
19 WHEN VISITATION IS OTHERWISE RE-
20 STRICTED.—During a period of emergency
21 in which regular visitation is restricted by
22 order of a Federal, State, or local author-
23 ity or by other operation of law, including
24 any period in which a waiver or modifica-

tion of requirements pursuant to section
1135 is in effect, a nursing facility shall—

“(I) not deny in-person access to
a resident by an essential caregiver of
the resident except as provided in this
subparagraph;

“(II) allow at least 1 essential
caregiver to have access to and pro-
vide assistance to such resident at
such facility every day and at any
time; and

“(III) enforce the agreement de-
scribed in clause (vii)(III) with respect
to an essential caregiver.

“(iv) RESTRICTIONS ON ACCESS.—

“(I) IN GENERAL.—During a pe-
riod of emergency in which regular
visitation is restricted by order of a
Federal, State, or local authority or
by other operation of law, including
any period in which a waiver or modi-
fication of requirements pursuant to
section 1135 is in effect, a nursing fa-
cility may deny access to a resident by

1 an essential caregiver of the resident
2 for—

3 “(aa) an initial period of not
4 longer than 7 days; and

5 “(bb) one additional period
6 of not longer than 7 days (in ad-
7 dition to the initial period de-
8 scribed in item (aa)) if the de-
9 partment of health of the State
10 in which the facility is located
11 approves the denial of access for
12 such additional period.

13 “(II) RULE OF APPLICATION.—

14 For purposes of subclause (I), a pe-
15 riod of emergency in which regular
16 visitation is restricted by order of a
17 Federal, State, or local authority or
18 by other operation of law shall begin
19 on the date that such order or other
20 operation of law takes effect and shall
21 end on the date that such order or
22 other operation of law expires or is
23 otherwise terminated. During any
24 such period, the maximum number of
25 days for which a nursing facility may

1 deny access to a resident by an essen-
 2 tial caregiver of the resident is 7 total
 3 days (or, subject to the approval of
 4 the department of health of the State
 5 in which the facility is located, 14
 6 total days).

7 “(v) COMPLIANCE AND NOTIFICA-
 8 TION.—

9 “(I) AUTHORITY.—No essential
 10 caregiver who upholds the agreement
 11 described in clause (vii)(III) shall be
 12 denied access to the nursing facility of
 13 the resident involved.

14 “(II) NOTIFICATION.— If an es-
 15 sential caregiver fails to comply with
 16 an agreement with a nursing facility
 17 described in clause (vii)(III), the facil-
 18 ity must first provide a warning to the
 19 essential caregiver and resident in
 20 writing citing specific issues of non-
 21 compliance and providing clear guid-
 22 ance for corrective measures.

23 “(III) ENFORCEMENT.—If an es-
 24 sential caregiver or resident, after re-
 25 ceiving a notification of noncompli-

1 ance described in subclause (II), fails
 2 to take corrective action, the essential
 3 caregiver may subsequently be denied
 4 access to the resident. In such cases,
 5 the facility shall provide to such care-
 6 giver and such resident (or health
 7 care proxy of such resident), not later
 8 than 24 hours after such denial of ac-
 9 cess occurs, a written explanation as
 10 to why such caregiver was denied ac-
 11 cess to such resident. Such expla-
 12 nation must include the resident's and
 13 caregiver's options for appeal under
 14 the processes established under clause
 15 (vi).

16 “(vi) OPTIONS FOR RESIDENTS AND
 17 CAREGIVERS TO APPEAL DENIALS OF AC-
 18 CESS.—

19 “(I) IN GENERAL.—Not later
 20 than 2 years after the date of enact-
 21 ment of this subparagraph, the Sec-
 22 retary shall issue a final rule estab-
 23 lishing a process for residents and
 24 caregivers to appeal denials of access.

1 “(II) APPEALS PROCESS.—The
2 agency responsible for overseeing the
3 appeals process established under sub-
4 clause (I) shall—

5 “(aa) receive appeals from
6 residents and essential caregivers
7 challenging a decision by a nurs-
8 ing facility to deny access under
9 clause (v); and

10 “(bb) investigate all such
11 appeals within 48 hours of re-
12 ceipt.

13 “(III) BURDEN OF PROOF.—
14 During an appeal received under the
15 appeals process established under sub-
16 clause (I), if a nursing facility defends
17 a decision to deny access to an essen-
18 tial caregiver under clause (v) on the
19 basis that the essential caregiver vio-
20 lated the agreement described in
21 clause (vii)(III), the nursing facility
22 shall have the burden of proof in dem-
23 onstrating that the essential caregiver
24 violated such agreement.

1 “(IV) RESOLUTION OF AP-
 2 PEAL.—With respect to an appeal re-
 3 ceived under the appeals process es-
 4 tablished under subclause (I), the
 5 agency responsible for overseeing the
 6 appeal shall make a determination as
 7 to whether a nursing facility violated
 8 a requirement or prohibition of this
 9 subparagraph within 48 hours of com-
 10 mencing its investigation. If the agen-
 11 cy determines that a facility has vio-
 12 lated such a requirement or prohibi-
 13 tion the agency shall—

14 “(aa) require the facility to
 15 allow immediate access to the es-
 16 sential caregiver in question;

17 “(bb) require the facility to
 18 establish a corrective action plan
 19 to prevent the recurrence of such
 20 violation within a 7-day period of
 21 receiving notice from the agency;
 22 and

23 “(cc) impose a civil money
 24 penalty in an amount to be deter-
 25 mined by the agency (not to ex-

ceed \$5,000) if such facility fails to implement the corrective action plan with the 7-day period specified in item (bb).

“(vii) DEFINITION OF ESSENTIAL CAREGIVER.—For purposes of this subparagraph, the term ‘essential caregiver’ means, with respect to a resident of a nursing facility, an individual who—

“(I) is designated by or on behalf of the resident pursuant to clause (i) or clause (ii);

“(II) will provide assistance to such resident, which may include assistance with of activities of daily living or providing emotional support or companionship to such resident; and

“(III) agrees to follow all safety protocols established by such facility, which shall be clearly specified in writing and may be no more restrictive than the safety protocols (including safety standards and entry requirements) applicable to staff of such facility.”.

1 (c) INTERMEDIATE CARE FACILITIES FOR THE IN-
2 TELLECTUALLY DISABLED.—Section 1905(d) of the So-
3 cial Security Act (42 U.S.C. 1396d(d)) is amended—

4 (1) in paragraph (2), by striking “and” at the
5 end;

6 (2) in paragraph (3), by striking the period and
7 inserting “; and”; and

8 (3) by adding at the end the following new
9 paragraph:

10 “(4) the institution complies with the require-
11 ments relating to the designation of, and access to
12 residents by, essential caregivers described in section
13 1919(c)(3)(B) in the same manner as if such insti-
14 tution were a nursing facility.”.

15 (d) INPATIENT REHABILITATION FACILITIES.—Sec-
16 tion 1866(a)(1) of the Social Security Act (42 U.S.C.
17 1395cc(a)(1)) is amended—

18 (1) in subparagraph (X), by striking “and” at
19 the end;

20 (2) in subparagraph (Y), by striking the period
21 at the end and inserting “, and”; and

22 (3) by inserting after subparagraph (Y) the fol-
23 lowing new subparagraph:

24 “(Z) in the case of an inpatient rehabilitation
25 facility that is located on the same campus (as de-

1 fined by the Secretary) as a skilled nursing facility,
 2 nursing facility (as defined in section 1919(a)), or
 3 intermediate care facility for the intellectually dis-
 4 abled (as described in section 1905(d)), to comply
 5 with the requirements relating to the designation of,
 6 and access to residents by, essential caregivers de-
 7 scribed in section 1819(c)(3)(B) in the same manner
 8 as if such institution were a skilled nursing facil-
 9 ity.”.

10 (e) REGULATIONS.—The Secretary of Health and
 11 Human Services shall, after consultation with stakeholders
 12 (including residents, family members, long-term care om-
 13 budsmen, other advocates of nursing home residents, and
 14 nursing home providers), promulgate regulations to carry
 15 out this Act and the amendments made by this Act.

16 (f) RULES OF CONSTRUCTION.—

17 (1) NO NEW AUTHORITY FOR STATE AND
 18 LOCAL OFFICIALS TO RESTRICT VISITATION AT
 19 NURSING FACILITIES.—Nothing in this section or
 20 the amendments made by this section shall be con-
 21 strued as creating any new authority for State or
 22 local officials to restrict visitation at nursing facili-
 23 ties.

24 (2) NO NEW AUTHORITY FOR NURSING FACILI-
 25 TIES TO UNILATERALLY RESTRICT VISITATION.—

1 Nothing in this section or the amendments made by
2 this section shall be construed as creating any new
3 authority for a skilled nursing facility or nursing fa-
4 cility (as such terms are defined in sections 1819
5 and 1919 of the Social Security Act, respectively (42
6 U.S.C. 1395i-3, 1396r)) to restrict visitation.

7 (g) EFFECTIVE DATE.—The amendments made by
8 this Act shall take effect on the date that is 2 years after
9 the date of enactment of this Act, and shall apply with
10 respect to periods beginning on or after such date in which
11 regular visitation at nursing facilities is restricted by order
12 of a Federal, State, or local authority or by other oper-
13 ation of law.

○