118th CONGRESS 2D Session **S**.

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

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

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 Caregivers5 Act of 2024".

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1 SEC. 2. FINDINGS.

2 Congress finds the following:

(1) According to the National Center for Health
Statistics of the Centers for Disease Control and
Prevention, an estimated 1,300,000 individuals resided in nursing homes in 2020 at the onset of the
COVID-19 pandemic and nearly half of all nursing
home residents were living with a diagnosis of Alzheimer'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.

(4) Many long-term care residents declined dra matically or died prematurely from "failure to
 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

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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),
21 22	the facility must first provide a warn-
22	the facility must first provide a warn-

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-

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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-

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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-

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riod of emergency in which regular
visitation is restricted by order of a
Federal, State, or local authority or
by other operation of law; and
"(II) amend such designation at
any time.
"(ii) Presumption of designa-
TION.—For purposes of clause (i), in the
case of a resident who is unable, by reason
of cognitive or mental disability, to make
an election described in such clause, the
resident representative (as defined in sec-
tion 483.5 of title 42, Code of Federal
Regulations) of such resident shall be per-
mitted to make such designation for such
resident.
"(iii) Access to essential care-
GIVERS DURING EMERGENCY PERIODS
WHEN VISITATION IS OTHERWISE RE-
STRICTED.—During a period of emergency
in which regular visitation is restricted by
order of a Federal, State, or local author-
ity or by other operation of law, including
any period in which a waiver or modifica-

1	tion of requirements pursuant to section
2	1135 is in effect, a nursing facility shall—
3	"(I) not deny in-person access to
4	a resident by an essential caregiver of
5	the resident except as provided in this
6	subparagraph;
7	"(II) allow at least 1 essential
8	caregiver to have access to and pro-
9	vide assistance to such resident at
10	such facility every day and at any
11	time; and
12	"(III) enforce the agreement de-
13	scribed in clause (vii)(III) with respect
14	to an essential caregiver.
15	"(iv) Restrictions on access.—
16	"(I) IN GENERAL.—During a pe-
17	riod of emergency in which regular
18	visitation is restricted by order of a
19	Federal, State, or local authority or
20	by other operation of law, including
21	any period in which a waiver or modi-
22	fication of requirements pursuant to
23	section 1135 is in effect, a nursing fa-
24	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-

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1	ceed \$5,000) if such facility fails
2	to implement the corrective ac-
3	tion plan with the 7-day period
4	specified in item (bb).
5	"(vii) Definition of essential
6	CAREGIVER.—For purposes of this sub-
7	paragraph, the term 'essential caregiver'
8	means, with respect to a resident of a
9	nursing facility, an individual who—
10	"(I) is designated by or on behalf
11	of the resident pursuant to clause (i)
12	or clause (ii);
13	"(II) will provide assistance to
14	such resident, which may include as-
15	sistance with of activities of daily liv-
16	ing or providing emotional support or
17	companionship to such resident; and
18	"(III) agrees to follow all safety
19	protocols established by such facility,
20	which shall be clearly specified in
21	writing and may be no more restric-
22	tive than the safety protocols (includ-
23	ing safety standards and entry re-
24	quirements) applicable to staff of such
25	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	$((\mathbf{Z})$ in the case of an inpatient rehabilitation
25	facility that is located on the same campus (as de-

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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.—

(1) NO NEW AUTHORITY FOR STATE AND
LOCAL OFFICIALS TO RESTRICT VISITATION AT
NURSING FACILITIES.—Nothing in this section or
the amendments made by this section shall be construed as creating any new authority for State or
local officials to restrict visitation at nursing facilities.

24 (2) NO NEW AUTHORITY FOR NURSING FACILI25 TIES TO UNILATERALLY RESTRICT VISITATION.—

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Nothing in this section or the amendments made by
 this section shall be construed as creating any new
 authority for a skilled nursing facility or nursing fa cility (as such terms are defined in sections 1819
 and 1919 of the Social Security Act, respectively (42
 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.