

1 **“SEC. 1121. ADDRESSING SUDDEN UNEXPECTED INFANT**
2 **DEATH AND SUDDEN UNEXPECTED DEATH IN**
3 **CHILDHOOD.**

4 “(a) IN GENERAL.—The Secretary may develop, sup-
5 port, or maintain programs or activities to address sudden
6 unexpected infant death and sudden unexpected death in
7 childhood, including by—

8 “(1) continuing to support the Sudden Unex-
9 pected Infant Death and Sudden Death in the
10 Young Case Registry of the Centers for Disease
11 Control and Prevention and other fatality case re-
12 porting systems that include data pertaining to sud-
13 den unexpected infant death and sudden unexpected
14 death in childhood, as appropriate, including such
15 systems supported by the Health Resources and
16 Services Administration, in order to—

17 “(A) increase the number of States and ju-
18 risdictions participating in such systems; or

19 “(B) improve the utility of such systems,
20 which may include—

21 “(i) making summary data available
22 to the public in a timely manner on the
23 internet website of the Department of
24 Health and Human Services, in a manner
25 that, at a minimum, protects personal pri-

1 vacy to the extent required by applicable
2 Federal and State law; and

3 “(ii) making the data submitted to
4 such systems available to researchers, in a
5 manner that, at a minimum, protects per-
6 sonal privacy to the extent required by ap-
7 plicable Federal and State law; and

8 “(2) awarding grants or cooperative agreements
9 to States, Indian Tribes, and Tribal organizations
10 for purposes of—

11 “(A) supporting fetal and infant mortality
12 and child death review programs for sudden un-
13 expected infant death and sudden unexpected
14 death in childhood, including by establishing
15 such programs at the local level;

16 “(B) improving data collection related to
17 sudden unexpected infant death and sudden un-
18 expected death in childhood, including by—

19 “(i) improving the completion of death
20 scene investigations and comprehensive au-
21 topsies that include a review of clinical his-
22 tory and circumstances of death with ap-
23 propriate ancillary testing; and

24 “(ii) training medical examiners, coro-
25 ners, death scene investigators, law en-

1 forcement personnel, emergency medical
2 technicians, paramedics, emergency depart-
3 ment personnel, and others who perform
4 death scene investigations with respect to
5 the deaths of infants and children, as ap-
6 propriate;

7 “(C) identifying, developing, and imple-
8 menting best practices to reduce or prevent
9 sudden unexpected infant death and sudden un-
10 expected death in childhood, including practices
11 to reduce sleep-related infant deaths;

12 “(D) increasing the voluntary inclusion, in
13 fatality case reporting systems established for
14 the purpose of conducting research on sudden
15 unexpected infant death and sudden unexpected
16 death in childhood, of samples of tissues or ge-
17 netic materials from autopsies that have been
18 collected pursuant to Federal or State law; or

19 “(E) disseminating information and mate-
20 rials to health care professionals and the public
21 on risk factors that contribute to sudden unex-
22 pected infant death and sudden unexpected
23 death in childhood, which may include informa-
24 tion on risk factors that contribute to sleep-re-

1 lated sudden unexpected infant death or sudden
2 unexpected death in childhood.

3 “(b) APPLICATION.—To be eligible to receive a grant
4 or cooperative agreement under subsection (a)(2), a State,
5 Indian Tribe, or Tribal organization shall submit to the
6 Secretary an application at such time, in such manner,
7 and containing such information as the Secretary may re-
8 quire, including information on how such State will ensure
9 activities conducted under this section are coordinated
10 with other federally-funded programs to reduce infant
11 mortality, as appropriate.

12 “(c) TECHNICAL ASSISTANCE.—The Secretary shall
13 provide technical assistance to States, Tribes, and Tribal
14 organizations receiving a grant or cooperative agreement
15 under subsection (a)(2) for purposes of carrying out ac-
16 tivities funded through the grant or cooperative agree-
17 ment.

18 “(d) REPORTING FORMS.—

19 “(1) IN GENERAL.—The Secretary shall, as ap-
20 propriate, encourage the use of sudden unexpected
21 infant death and sudden unexpected death in child-
22 hood reporting forms developed in collaboration with
23 the Centers for Disease Control and Prevention to
24 improve the quality of data submitted to the Sudden
25 Unexpected Infant Death and Sudden Death in the

1 Young Case Registry, and other fatality case report-
2 ing systems that include data pertaining to sudden
3 unexpected infant death and sudden unexpected
4 death in childhood.

5 “(2) UPDATE OF FORMS.—The Secretary shall
6 assess whether updates are needed to the sudden un-
7 expected infant death investigation reporting form
8 used by the Centers for Disease Control and Preven-
9 tion in order to improve the use of such form with
10 other fatality case reporting systems supported by
11 the Department of Health and Human Services, and
12 shall make such updates as appropriate.

13 “(e) SUPPORT SERVICES.—

14 “(1) IN GENERAL.—The Secretary, acting
15 through the Administrator, shall award grants to
16 national organizations, State and local health de-
17 partments, community-based organizations, and non-
18 profit organizations for the provision of support
19 services to families who have had a child die of sud-
20 den unexpected infant death or sudden unexpected
21 death in childhood.

22 “(2) APPLICATION.—To be eligible to receive a
23 grant under subsection (1), an entity shall submit to
24 the Secretary an application at such time, in such

1 manner, and containing such information as the Sec-
2 retary may require.

3 “(3) USE OF FUNDS.—Amounts received under
4 a grant awarded under paragraph (1) may be
5 used—

6 “(A) to provide grief counseling, education,
7 home visits, 24-hour hotlines, or information,
8 resources, and referrals;

9 “(B) to ensure access to grief and bereave-
10 ment services;

11 “(C) to build capacity in professionals
12 working with families who experience a sudden
13 death; or

14 “(D) to support peer-to-peer groups for
15 families who have lost a child to sudden unex-
16 pected infant death or sudden unexpected death
17 in childhood.

18 “(4) PREFERENCE.—In awarding grants under
19 paragraph (1), the Secretary shall give preference to
20 applicants that—

21 “(A) have a proven history of effective di-
22 rect support services and interventions for sud-
23 den unexpected infant death and sudden unex-
24 plained death in childhood; and

1 “(B) demonstrate experience through col-
2 laborations and partnerships for delivering serv-
3 ices described in paragraph (3).

4 “(f) DEFINITIONS.—In this section:

5 “(1) SUDDEN UNEXPECTED INFANT DEATH.—
6 The term ‘sudden unexpected infant death’—

7 “(A) means the sudden death of an infant
8 under 1 year of age that when first discovered
9 did not have an obvious cause; and

10 “(B) includes—

11 “(i) such deaths that are explained;
12 and

13 “(ii) such deaths that remain unex-
14 plained (which are known as sudden infant
15 death syndrome).

16 “(2) SUDDEN UNEXPECTED DEATH IN CHILD-
17 HOOD.—The term ‘sudden unexpected death in
18 childhood’—

19 “(A) means the sudden death of a child
20 who is at least 1 year of age but not more than
21 17 years of age that, when first discovered, did
22 not have an obvious cause; and

23 “(B) includes—

24 “(i) such deaths that are explained;
25 and

1 “(ii) such deaths that remain unex-
2 plained (which are known as sudden unex-
3 plained death in childhood).

4 “(3) SUDDEN UNEXPLAINED DEATH IN CHILD-
5 HOOD.—The term ‘sudden unexplained death in
6 childhood’ means a sudden unexpected death in
7 childhood that remains unexplained after a thorough
8 case investigation.

9 “(g) AUTHORIZATION OF APPROPRIATIONS.—For the
10 purpose of carrying out this section, there is authorized
11 to be appropriated \$33,000,000 for each of fiscal years
12 2021 through 2024.”.

13 **SEC. 3. REPORT TO CONGRESS.**

14 (a) IN GENERAL.—Not later than 2 years after the
15 date of enactment of this Act, and biennially thereafter,
16 the Secretary of Health and Human Services shall submit
17 to the Committee on Energy and Commerce of the House
18 of Representatives and the Committee on Health, Edu-
19 cation, Labor, and Pensions of the Senate a report that
20 contains, with respect to the reporting period—

21 (1) information regarding the incidence and
22 number of sudden unexpected infant deaths and
23 sudden unexpected deaths in childhood (including
24 the number of such infant and child deaths that re-

1 main unexplained after investigation), including, to
2 the extent practicable—

3 (A) a summary of such information by ra-
4 cial and ethnic group, and by State;

5 (B) aggregate information obtained from
6 death scene investigations and autopsies; and

7 (C) recommendations for reducing the inci-
8 dence of sudden unexpected infant death and
9 sudden unexpected death in childhood;

10 (2) an assessment of the extent to which var-
11 ious approaches of reducing and preventing sudden
12 unexpected infant death and sudden unexpected
13 death in childhood have been effective; and

14 (3) a description of the activities carried out
15 under section 1121 of the Public Health Service Act
16 (as added by section 2).

17 (b) DEFINITIONS.—In this section, the terms “sud-
18 den unexpected infant death” and “sudden unexpected
19 death in childhood” have the meanings given such terms
20 in section 1121 of the Public Health Service Act (as added
21 by section 2).

