

103^D CONGRESS
1ST SESSION

S. 1098

To amend title XIX of the Social Security Act to provide for optional coverage under State medicaid plans of case-management services for individuals who sustain traumatic brain injuries, and for other purposes.

IN THE SENATE OF THE UNITED STATES

JUNE 15, 1993

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

A BILL

To amend title XIX of the Social Security Act to provide for optional coverage under State medicaid plans of case-management services for individuals who sustain traumatic brain injuries, and for other purposes.

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 “Brain Injury Rehabili-
5 tation Quality Act of 1993”.

1 **SEC. 2. MEDICAID COVERAGE OF CASE-MANAGEMENT**
2 **SERVICES FOR INDIVIDUALS WITH TRAU-**
3 **MATIC BRAIN INJURIES.**

4 (a) IN GENERAL.—Section 1905(a) of the Social Se-
5 curity Act (42 U.S.C. 1396d(a)) is amended—

6 (1) by striking “and” at the end of paragraph
7 (21);

8 (2) by striking the period at the end of para-
9 graph (24) and inserting a semicolon;

10 (3) by redesignating paragraphs (22), (23), and
11 (24) as paragraphs (25), (22), and (23), respec-
12 tively, and by transferring and inserting paragraph
13 (25) after paragraph (23), as so redesignated; and

14 (4) by inserting after paragraph (23), as reded-
15 igned, the following new paragraph:

16 “(24) case-management services provided (in
17 accordance with section 1931) for individuals who
18 sustain traumatic brain injuries; and”.

19 (b) CASE-MANAGEMENT SERVICES DESCRIBED.—
20 Title XIX of the Social Security Act (42 U.S.C. 1396 et
21 seq.) is amended by adding at the end the following new
22 section:

23 “CASE-MANAGEMENT SERVICES FOR INDIVIDUALS WITH
24 TRAUMATIC BRAIN INJURIES

25 “SEC. 1931. (a) IN GENERAL.—For purposes of sec-
26 tion 1905(a)(24), case-management services for individ-

1 uals who sustain traumatic brain injuries are services pro-
2 vided to an eligible individual (as described in subsection
3 (d)) through a State case-management program that
4 meets the requirements of subsection (b).

5 “(b) REQUIREMENTS FOR STATE CASE-MANAGE-
6 MENT PROGRAMS.—

7 “(1) STATE COORDINATOR.—A State case-man-
8 agement program meets the requirements of this
9 subsection if the State has designated a State coor-
10 dinator for traumatic brain injuries who—

11 “(A) establishes policies, standards, and
12 procedures for providing services under this sec-
13 tion to eligible individuals,

14 “(B) contracts with qualified agencies or
15 employs staff to provide services under this sec-
16 tion to eligible individuals,

17 “(C) supervises and coordinates services
18 for eligible individuals,

19 “(D) makes necessary reports to the Sec-
20 retary, and

21 “(E) performs any other duties described
22 in this section.

23 “(2) CASE-MANAGEMENT SERVICES.—A State
24 case-management program meets the requirements
25 of this subsection if the program provides or ar-

1 ranges for the provision of the following case-man-
2 agement services for eligible individuals:

3 “(A) An initial assessment of—

4 “(i) the individual’s need for case-
5 management services, and

6 “(ii) if the individual is an appro-
7 priate candidate for receiving case-manage-
8 ment services, the individual’s need for
9 other services, with an emphasis on identi-
10 fying community-based services required to
11 prevent institutionalization or minimize the
12 need for residential rehabilitation.

13 “(B) Preparation of a treatment plan for
14 each individual requiring case-management
15 services based on consultation with the individ-
16 ual (other than an individual who is comatose)
17 and any person named by the individual. Prepa-
18 ration of the plan shall be completed—

19 “(i) as soon as possible after the indi-
20 vidual suffers the injury, but may be de-
21 layed (by one or more periods of no more
22 than 15 days each) based on a physician
23 certification that contains a brief expla-
24 nation of the reason for the delay and at-

1 tests that such a delay is in the best inter-
2 ests of the individual, or

3 “(ii) in the case of an individual who,
4 at the time the individual sustains the
5 traumatic brain injury, is not an eligible
6 individual, within 60 days after such indi-
7 vidual becomes an eligible individual.

8 “(C) Presentation of a copy of the initial
9 treatment plan and any subsequent modifica-
10 tions to the plan to the individual or the indi-
11 vidual’s legal representative.

12 “(D) Regular updates of each individual’s
13 treatment plan (based on consultation with the
14 care provider, the individual, and any person
15 named by the individual) with data and infor-
16 mation about treatments and services provided,
17 as well as specific outcome measures of the in-
18 dividual’s performance or activity relative to
19 goals previously established.

20 “(E) Assistance in obtaining services nec-
21 essary to allow the individual to remain in the
22 community, including coordination of home care
23 services with other services.

1 “(F) Advocacy services to assist the indi-
2 vidual in obtaining appropriate, accessible, and
3 cost-effective services.

4 “(G) Assessment of the individual’s need
5 for and level of home care services at appro-
6 priate intervals during the course of the individ-
7 ual’s treatment under the program.

8 “(H) Reassessment of each individual at
9 regular intervals of at least every 3 months to
10 determine the extent of each individual’s
11 progress and to ascertain whether the individ-
12 ual—

13 “(i) is being kept too long in a given
14 setting,

15 “(ii) is being provided services inap-
16 propriately, or

17 “(iii) would be better served by other
18 services or in another setting.

19 “(I) In accordance with standards estab-
20 lished by the State coordinator, verification that
21 any residential setting or facility which provides
22 services to individuals under the program meets
23 the requirements applicable to nursing facilities
24 under section 1919.

1 “(J) A complaint procedure, overseen by
2 the State coordinator, regarding any treatment
3 or service provided to an individual which pro-
4 vides that—

5 “(i) the individual or any person
6 named by the individual may make an oral
7 or written complaint;

8 “(ii) the individual or any person
9 named by the individual may receive the
10 response to the complaint;

11 “(iii) the confidentiality of any com-
12 plainant is maintained;

13 “(iv) an investigation of the complaint
14 is completed within—

15 “(I) 30 days for a routine com-
16 plaint,

17 “(II) 7 days for a complaint of
18 abuse or neglect, and

19 “(III) 24 hours if the individual’s
20 life or safety is immediately threat-
21 ened; and

22 “(v) if the complaint is with respect to
23 a publicly appointed case manager or case
24 worker, substitution of such manager or
25 worker is allowed.

1 “(3) COORDINATION AND ADMINISTRATION OF
2 BENEFITS AND SERVICES.—A State case-manage-
3 ment program meets the requirements of this sub-
4 section if the program assists in ensuring that an el-
5 igible individual is referred to and applies for other
6 benefits (through cooperative agreements with agen-
7 cies administering benefit programs) and services for
8 which the individual is eligible under other Federal,
9 State, or local programs, including—

10 “(A) employment services, including voca-
11 tional assessment, training, and placement,
12 sheltered employment, and supported employ-
13 ment;

14 “(B) education benefits, including primary,
15 secondary, and higher education programs;

16 “(C) services available under the Older
17 Americans Act of 1965;

18 “(D) disability insurance under title II;
19 and

20 “(E) independent living services under title
21 VII of the Rehabilitation Act of 1973.

22 “(c) COORDINATION OF SERVICES.—

23 “(1) IN GENERAL.—An eligible individual who
24 is receiving case-management services described in
25 subsection (b)(2) may receive the following services

1 under such individual's treatment plan for which the
2 individual is otherwise eligible under a State plan:

3 "(A) Acute rehabilitation services, focusing
4 on intensive physical and cognitive restorative
5 services in the early months following injury.

6 "(B) Subacute rehabilitation in either in-
7 patient or outpatient settings.

8 "(C) Transitional living services to train
9 the individual for more independent living, with
10 an emphasis on compensating for the loss of
11 skills which may not be restored.

12 "(D) Lifelong living services for individuals
13 discharged from rehabilitation who require on-
14 going lifetime support.

15 "(E) Home care, including comprehensive
16 training for family or other informal caregivers.

17 "(F) Day treatment and other outpatient
18 programs in nonresidential settings.

19 "(G) Independent living services to allow
20 the individual to live at home with optimal per-
21 sonal control over services.

22 "(H) Behavior disorder treatment services
23 to address or resolve patterns of behavior which
24 prevent or hinder participation in active reha-
25 bilitation.

1 “(I) Respite and recreation services to aid
2 the individual and members of the individual’s
3 family in adapting psychologically and environ-
4 mentally to residual deficits resulting from
5 brain injury.

6 “(J) Treatment for conditions related to
7 alcoholism and drug dependency.

8 “(2) WAIVER OF CERTAIN LIMITATIONS ON THE
9 EXPENDITURE OF FUNDS.—

10 “(A) IN GENERAL.—In accordance with
11 standards established by the State coordinator,
12 a State case-management program may waive
13 restrictions on the amount, duration, and scope
14 of services otherwise applicable under the State
15 plan for medical assistance under this title to
16 the extent necessary to carry out a treatment
17 plan for an individual.

18 “(B) HOME CARE SERVICES IN EXCESS OF
19 LIMITATIONS ESTABLISHED BY STATE COORDI-
20 NATOR.—In accordance with standards estab-
21 lished by the State coordinator, a State case-
22 management program may approve the use of
23 funds provided under the State plan for medical
24 assistance under this title to pay for home care

1 services when such home care services exceed
2 limitations established by the State coordinator.

3 “(C) OUT-OF-STATE PLACEMENTS FOR
4 RESIDENTIAL REHABILITATION SERVICES.—In
5 accordance with standards established by the
6 State coordinator, a State case management
7 program may approve the use of funds provided
8 under the State plan for medical assistance
9 under this title to pay for out-of-State place-
10 ments for residential rehabilitation services.

11 “(3) SPECIAL RULE FOR PROVIDERS OF LIVING
12 SERVICES.—No living services described in para-
13 graph (1) may be provided to or on behalf of any
14 individual under this section unless the State case-
15 management program with which the individual is
16 enrolled has entered into an agreement with the en-
17 tity providing such services that specifies—

18 “(A) the living services to be provided,

19 “(B) the period of time over which such
20 services will be provided, and

21 “(C) the charges to the patient for provid-
22 ing such services.

23 “(d) ELIGIBILITY OF INDIVIDUALS TO RECEIVE
24 SERVICES.—

1 “(1) IN GENERAL.—An individual is eligible to
2 receive case-management services under this section
3 if the individual resides in a State that has imple-
4 mented a case-management program that meets the
5 requirements of this section, is eligible to receive
6 medical assistance under a State plan under this
7 title, has suffered a traumatic brain injury (as de-
8 fined in paragraph (2)), and is moderately or se-
9 verely disabled (as defined in paragraph (3)).

10 “(2) TRAUMATIC BRAIN INJURY DEFINED.—
11 For purposes of this section, the term ‘traumatic
12 brain injury’ means a sudden insult or damage to
13 the brain or its coverings caused by an external
14 physical force which may produce a diminished or al-
15 tered state of consciousness, and which results in a
16 temporary or permanent impairment of cognitive or
17 mental abilities or physical functioning, or disturb-
18 ance of behavioral or emotional functioning. Such
19 term does not include any injuries of a degenerative
20 or congenital nature.

21 “(3) DEFINITIONS RELATING TO MODERATELY
22 OR SEVERELY DISABLED INDIVIDUALS.—

23 “(A) IN GENERAL.—For purposes of this
24 section, the term ‘moderately or severely dis-
25 abled’ means in the case of an individual 6

1 years of age or older, an individual who (with-
2 out regard to income or employment status) is
3 certified under the case-management program
4 as—

5 “(i) needing substantial assistance or
6 supervision from another individual with at
7 least 2 activities of daily living (as defined
8 in subparagraph (C));

9 “(ii) needing substantial supervision
10 due to cognitive or other mental impair-
11 ment and needing substantial assistance or
12 supervision from another individual with at
13 least 1 activity of daily living or in comply-
14 ing with a daily drug regimen; or

15 “(iii) needing substantial supervision
16 from another individual due to behaviors
17 that are dangerous (to the individual or
18 others), disruptive, or difficult to manage.

19 “(B) MODERATELY OR SEVERELY DIS-
20 ABLED CHILD.—

21 “(i) IN GENERAL.—For purposes of
22 this section, the term ‘moderately or se-
23 verely disabled’ means, in the case of an
24 individual under 6 years of age, an individ-
25 ual who is certified under the State case

1 management program as suffering from
2 comparable levels of disability which would
3 entitle such individual to benefits under
4 this title.

5 “(ii) COMPARABLE LEVELS OF DIS-
6 ABILITY.—For purposes of clause (i), the
7 term ‘comparable levels of disability’
8 means physical, cognitive, or other mental
9 impairments that limit the ability of an in-
10 dividual who is under 6 years of age to
11 perform activities of daily living appro-
12 priate for the age of the individual that are
13 comparable to the physical, cognitive, or
14 other mental impairments that limit the
15 ability of an individual 6 years of age or
16 older such that the individual is described
17 in clause (i), (ii), or (iii) of subparagraph
18 (A).

19 “(C) ACTIVITY OF DAILY LIVING DE-
20 FINED.—The term ‘activity of daily living’
21 means any of the following activities:

22 “(i) Bathing.

23 “(ii) Dressing.

24 “(iii) Transferring.

25 “(iv) Toileting.

1 “(v) Eating.

2 “(4) COVERAGE OF INDIVIDUALS UNDER DIS-
3 ABILITY PROTECTIONS.—Individuals receiving serv-
4 ices through a State case-management program
5 under this section shall be considered to be individ-
6 uals with disabilities for purposes of the Americans
7 with Disabilities Act of 1990.

8 “(e) ADDITIONAL DUTIES OF STATE COORDINA-
9 TOR.—

10 “(1) PREVENTION OF TRAUMATIC BRAIN IN-
11 JURY.—The State coordinator shall establish a pro-
12 gram of activities related to preventing and reducing
13 the rate of traumatic brain injuries in the State.

14 “(2) TRAUMATIC BRAIN INJURY REGISTRY.—

15 “(A) IN GENERAL.—The State coordinator
16 shall establish and maintain a central registry
17 of individuals who sustain traumatic brain in-
18 jury using standards established by the Sec-
19 retary under subsection (f) in order to—

20 “(i) collect information to facilitate
21 the development of injury prevention,
22 treatment, and rehabilitation programs;
23 and

24 “(ii) ensure the provision to individ-
25 uals with traumatic brain injury of infor-

1 mation regarding appropriate public or pri-
2 vate agencies that provide rehabilitative
3 services so that injured individuals may ob-
4 tain needed service to alleviate injuries and
5 avoid secondary problems, such as mental
6 illness and chemical dependency.

7 “(B) DISSEMINATION OF DATA.—The
8 State coordinator shall provide summary reg-
9 istry data to public and private entities to con-
10 duct studies using data collected by the trau-
11 matic brain injury registry established under
12 subparagraph (A). The State coordinator may
13 charge a fee for all expenses associated with the
14 provision of data or data analysis.

15 “(3) NOTIFICATION OF INJURIES TO JOB
16 TRAINING PROGRAMS.—Within a reasonable period
17 of time after receiving a report that an individual
18 has sustained a traumatic brain injury or spinal
19 cord injury, the State coordinator shall notify any
20 State agency responsible for employment services
21 and job training and shall forward the individual’s
22 name and other identifying information to such
23 agency.

24 “(4) STANDARDS FOR MARKETING OF BRAIN
25 INJURY SERVICES.—The State coordinator, after

1 consultation with the advisory committee established
2 under paragraph (6), shall—

3 “(A) monitor standards established by the
4 Secretary regarding the marketing of services
5 (by hospitals and other providers) to any indi-
6 vidual who has sustained traumatic brain injury
7 or family members of such individual,

8 “(B) disseminate such standards to State
9 case-management programs, and

10 “(C) furnish information about such stand-
11 ards to such individual and such family mem-
12 bers at the earliest appropriate opportunity
13 after such individual has sustained the injury.

14 Such standards shall include (at a minimum) a rule
15 prohibiting payments under a State case-manage-
16 ment program under this section for referring indi-
17 viduals to rehabilitation facilities.

18 “(5) STUDIES.—The State coordinator shall
19 collect injury incidence information (including the
20 prevalence, prevention, and treatment of traumatic
21 brain injury), analyze the information, and conduct
22 special studies regarding traumatic brain injury.

23 “(6) ESTABLISHMENT OF ADVISORY COMMIT-
24 TEE.—The State coordinator shall establish an advi-
25 sory committee (consisting of representatives of pro-

1 professionals who provide community-based services
2 under this section and individuals with traumatic
3 brain injuries and family members of such individ-
4 uals) to provide recommendations regarding the
5 needs of individuals with traumatic brain injuries,
6 provide advice on activities under paragraph (1), and
7 assist in the establishment of marketing standards
8 under paragraph (4).

9 “(7) PRIVACY.—Any data identifying specific
10 individuals which is collected by or provided to the
11 State coordinator may be used only for purposes of
12 case-management and rehabilitation and studies by
13 the State coordinator, in accordance with rules
14 adopted by the State coordinator.

15 “(8) ADOPTION OF STANDARDS FOR REPORT-
16 ING DATA AND OPERATION OF REGISTRIES.—The
17 State coordinator shall adopt such standards estab-
18 lished under subsection (f) as are necessary to carry
19 out this subsection. At a minimum, the State coordi-
20 nator shall adopt the standards relating to the mat-
21 ters identified in subparagraphs (A) through (E) of
22 subsection (f)(2).

23 “(9) ESTABLISHMENT OF REPORTING SYS-
24 TEM.—

1 “(A) IN GENERAL.—The State coordinator
2 shall design and establish a reporting system
3 which requires either the treating hospital, med-
4 ical facility, or physician to report to the State
5 coordinator within a reasonable period of time
6 after the identification of any individual with
7 ICD diagnostic codes treated for a traumatic
8 brain injury in the State. The consent of the in-
9 jured individual is not required.

10 “(B) REPORT.—A report under subpara-
11 graph (A) shall include—

12 “(i) the name, age, and residence of
13 the injured individual;

14 “(ii) the date and cause of the injury;

15 “(iii) the initial diagnosis; and

16 “(iv) other information required by
17 the State coordinator.

18 “(C) LIABILITY PROTECTION.—The fur-
19 nishing of information pursuant to the system
20 established under subparagraph (A) shall not
21 subject any individual or facility to any action
22 for damages or other relief, provided that the
23 individual or facility acted in good faith in fur-
24 nishing the information.

1 “(f) STANDARDS FOR REPORTING DATA AND OPER-
2 TION OF REGISTRIES.—

3 “(1) IN GENERAL.—Not later than January 1,
4 1995, the Secretary of Health and Human Services,
5 acting through the Director of the Centers for Dis-
6 ease Control and Prevention, shall establish stand-
7 ards for the reporting of data on traumatic brain in-
8 juries and the operation of registries of traumatic
9 brain injuries for use by State coordinators under
10 this section.

11 “(2) SCOPE.—The standards established under
12 paragraph (1) shall at a minimum provide for—

13 “(A) the specific International Classifica-
14 tion of Diseases, Ninth Revision, Clinical Modi-
15 fication, diagnostic codes (hereafter referred to
16 in this subsection as ‘ICD diagnostic codes’) in-
17 cluded in the definitions of traumatic brain in-
18 jury;

19 “(B) the type of data to be reported;

20 “(C) standards for reporting specific types
21 of data;

22 “(D) the individuals and facilities required
23 to report and the time period in which reports
24 must be submitted; and

1 “(E) criteria relating to the use of registry
2 data by public and private entities engaged in
3 research.”.

4 (c) BUDGET NEUTRALITY.—

5 (1) IN GENERAL.—During the first 12-month
6 period a State provides case-management services to
7 which the amendments made by this section apply,
8 and each 12-month period thereafter, Federal finan-
9 cial participation for all services under a State plan
10 approved under title XIX of the Social Security Act
11 provided to individuals with traumatic brain injuries
12 shall not exceed the base-year amount determined
13 under paragraph (2).

14 (2) BASE-YEAR AMOUNT.—

15 (A) FIRST YEAR.—The base-year amount
16 for the first 12-month period to which para-
17 graph (1) applies shall be equal to the sum of—

18 (i) the amount of Federal financial
19 participation attributable to all services
20 provided to individuals with traumatic
21 brain injuries under a State plan in the
22 12-month period prior to the inclusion of
23 case-management services in the State
24 plan, as certified by the Secretary, plus

1 (ii) such amount multiplied by the es-
2 timated percentage increase in the
3 Consumer Price Index for All-Urban Con-
4 sumers for the preceding 12-month period,
5 with appropriate adjustments to reflect
6 previous underestimations or overesti-
7 mations under this clause.

8 (B) OTHER YEARS.—The base-year
9 amount for any other 12-month period shall be
10 equal to the sum of—

11 (i) the base-year amount for the pre-
12 ceding 12-month period, plus

13 (ii) such amount multiplied by the es-
14 timated percentage increase in the
15 Consumer Price Index for All-Urban Con-
16 sumers for the preceding 12-month period,
17 with appropriate adjustments to reflect
18 previous underestimations or overesti-
19 mations under this clause.

20 (d) CONFORMING AMENDMENT.—Section 1915(g)(2)
21 of the Social Security Act (42 U.S.C. 1396n(g)(2)) is
22 amended by striking the period at the end and inserting
23 the following: “, but does not include any services provided
24 under section 1931.”.

1 (e) AUTHORIZATION OF APPROPRIATIONS.—There
2 are authorized to be appropriated \$5,000,000 for each fis-
3 cal year beginning with fiscal year 1995 to carry out para-
4 graphs (1) and (2) of section 1931(e) of the Social Secu-
5 rity Act (as added by subsection (b)).

6 (f) EFFECTIVE DATE.—The amendments made by
7 subsections (a), (b), and (d) shall apply to calendar quar-
8 ters beginning on or after January 1, 1995.

9 **SEC. 3. STUDY OF EFFECTIVENESS OF TRAUMATIC BRAIN**
10 **INJURY INTERVENTIONS.**

11 (a) STUDY.—The Administrator of the Agency for
12 Health Care Policy and Research shall conduct a study
13 to identify common therapeutic interventions which are
14 used for the rehabilitation of traumatic brain injury pa-
15 tients, and shall include in the study an analysis of—

16 (1) the effectiveness of each such intervention
17 in improving the functioning of traumatic brain in-
18 jury patients; and

19 (2) the comparative effectiveness of interven-
20 tions employed in the course of rehabilitation of
21 traumatic brain injury patients to achieve the same
22 or similar clinical outcome.

23 (b) REPORT.—Not later than 3 years after the date
24 of the enactment of this Act, the Administrator of the
25 Agency for Health Care Policy and Research shall submit

1 a report on the study conducted under subsection (a) to
2 the Congress.

3 (c) AUTHORIZATION OF APPROPRIATIONS.—There
4 are authorized to be appropriated \$2,000,000 for each of
5 fiscal years 1994 through 1997 to carry out the purposes
6 of this section.

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