

112TH CONGRESS
1ST SESSION

H. R. 3489

To require the President to call a White House Conference on Autism.

IN THE HOUSE OF REPRESENTATIVES

NOVEMBER 18, 2011

Mr. BURTON of Indiana (for himself, Mrs. MALONEY, Mr. KING of New York, and Mr. SMITH of New Jersey) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To require the President to call a White House Conference on Autism.

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 “White House Con-
5 ference on Autism Act of 2011”.

6 **SEC. 2. FINDINGS.**

7 The Congress finds the following:

8 (1) Autism Spectrum Disorders (ASD) are the
9 fastest-growing serious developmental disability in

1 the U.S. occurring in all racial, ethnic, and socio-
2 economic groups.

3 (2) According to the Centers for Disease Con-
4 trol and Prevention's Autism and Disabilities Moni-
5 toring Network the rate of autism in the United
6 States has exploded from an estimated 1 in 10,000
7 during the 1980s to the current rate of 1 in 150
8 demonstrating that the United States is facing an
9 literal epidemic of autism.

10 (3) The epidemic shows no sign of slowing as
11 a new case of autism is diagnosed almost every 20
12 minutes.

13 (4) More children will be diagnosed with autism
14 this year than with AIDS, diabetes, and cancer com-
15 bined.

16 (5) Autism costs the Nation over
17 \$35,000,000,000 per year, a figure expected to sig-
18 nificantly increase in the next decade.

19 (6) Autism is a life changing condition not a
20 life threatening condition. Our Nation's educational,
21 labor, housing and medical communities are ill-
22 equipped and undertrained to handle a generation of
23 autism individuals.

24 (7) In the long-term, this autism epidemic could
25 potentially deprive our Nation of a huge pool of fu-

1 ture military, industrial, medical, and scientific tal-
2 ent.

3 (8) Although autism spectrum disorders are an
4 urgent societal concern and comprehensive research
5 is the best hope for understanding the causes of au-
6 tism and other developmental disorders, autism re-
7 ceives less than 5 percent of the Federal research
8 funding of many less prevalent childhood diseases.

9 (9) In December 2006, Congress passed and
10 President Bush signed into law the “Combating Au-
11 tism Act of 2006,” which committed nearly
12 \$1,000,000,000 to autism research, including essen-
13 tial research on environmental factors, treatments,
14 and early identification and support services.

15 (10) A White House Conference on Autism pre-
16 sents an historic opportunity to build on the founda-
17 tion of the Combating Autism Act to advance the
18 scientific study and analysis of many promising cut-
19 ting-edge treatments and services for autism.

20 **SEC. 3. AUTHORIZATION OF THE CONFERENCE.**

21 (a) **AUTHORITY TO CALL CONFERENCE.**—Not later
22 than December 31, 2012, the President shall call the
23 White House Conference on Autism (in this Act referred
24 to as the “Conference”) to be convened not later than 18
25 months after the selection of the Policy Committee estab-

1 lished in section 4, in order to make fundamental policy
2 recommendations on ways to combat the autism epidemic
3 in the United States and to implement the purposes set
4 forth in subsection (c).

5 (b) PLANNING AND DIRECTION.—The Secretary of
6 Health and Human Services, the Secretary of Education,
7 and the Secretary of Housing and Urban Development (in
8 this Act referred to as the “Cochairs”) shall plan, conduct,
9 and convene the Conference, in consultation with the Sur-
10 geon General.

11 (c) PURPOSES OF THE CONFERENCE.—The purposes
12 of the Conference are to—

13 (1) galvanize a national effort to find the un-
14 derlying cause or causes of autism;

15 (2) identify viable solutions and valuable serv-
16 ices to help autistic individuals and families of autis-
17 tic individuals meet the challenges they face on a
18 daily basis;

19 (3) bring together the best scientific minds to
20 chart a comprehensive research agenda, including
21 the exploration of potential environmental triggers
22 or contributors;

23 (4) bring together parents of autistic children
24 and leaders in the field of education and social serv-
25 ices to begin a national dialogue about addressing

1 the life-long challenges faced by these children and
2 their families;

3 (5) highlight emerging and innovative programs
4 from the public and private sectors, including com-
5 munity-based and faith-based organizations that ef-
6 fectively serve the needs of autistic children and
7 adults and recommend such programs as can be rea-
8 sonably and cost-effectively replicated; and

9 (6) review the current structure, scope, and ef-
10 fectiveness of existing legislation and programs at
11 the Federal, State, and local levels that provide au-
12 tism research services; and to develop such specific
13 and comprehensive recommendations for legislative
14 action as may be appropriate for improving those
15 bills and programs with the aim of enhancing the
16 health, quality of life and well-being of autistic indi-
17 viduals and their families.

18 **SEC. 4. POLICY COMMITTEE; RELATED COMMITTEES.**

19 (a) ESTABLISHMENT.—Not later than September 30,
20 2011, there is established a Policy Committee comprising
21 of 17 members to be selected as follows:

22 (1) PRESIDENTIAL APPOINTEES.—Nine mem-
23 bers shall be selected by the President and shall in-
24 clude—

1 (A) 3 members who are officers or employ-
2 ees of the United States, including the Surgeon
3 General; and

4 (B) 6 members with experience in address-
5 ing the needs of people with autism spectrum
6 disorders in the United States.

7 (2) HOUSE APPOINTEES.—

8 (A) Two members shall be selected by the
9 Speaker of the House of Representatives after
10 consultation with the chairperson of the Com-
11 mittee on Education and Labor, and the chair-
12 person of the Committee on Energy and Com-
13 merce, of the House of Representatives.

14 (B) Two members shall be selected by the
15 minority leader of the House of Representa-
16 tives, after consultation with the ranking minor-
17 ity members of such committees.

18 (3) SENATE APPOINTEES.—

19 (A) Two members shall be selected by the
20 majority leader of the Senate, after consultation
21 with members of the Committee on Health,
22 Education, Labor, and Pensions, and the Com-
23 mittee on Banking, Housing, and Urban Affairs
24 of the Senate.

1 (B) Two members shall be selected by the
2 minority leader of the Senate, after consultation
3 with members of such committees.

4 (b) SPECIAL QUALIFICATIONS.—Of the members of
5 the Policy Committee appointed under paragraph
6 (a)(1)(B), (a)(2), and (a)(3), 50 percent must be drawn
7 from private industry, the nonprofit sector, or academia,
8 of whom—

9 (1) at least 1 shall be a parent or legal guard-
10 ian of individuals with autism or other pervasive de-
11 velopmental disorders;

12 (2) at least 1 other shall be knowledgeable
13 about autism intervention programs and systems, in-
14 cluding complementary and alternative therapies;

15 (3) at least 1 other shall be knowledgeable
16 about programs specifically designed to meet the
17 unique educational needs of children and adults with
18 autism;

19 (4) at least 1 other shall be knowledgeable
20 about programs specifically designed to meet the
21 unique housing needs of children and adults with au-
22 tism;

23 (5) at least 1 other shall be knowledgeable
24 about programs specifically designed to train and
25 educate law enforcement and criminal justice offi-

1 cials to respond to the unique needs of children and
2 adults with autism; and

3 (6) at least 1 other shall be knowledgeable
4 about environmental or toxic exposure of adults and
5 children as it relates to the development of autism.

6 (c) VOTING; CHAIRPERSON.—

7 (1) VOTING.—The Policy Committee shall act
8 by the vote of a majority of the members present.
9 A quorum of Committee members shall be required
10 to conduct Committee business.

11 (2) CHAIRPERSON.—The Surgeon General shall
12 serve as the chairperson of the Policy Committee.
13 The chairperson may vote only to break a tie vote
14 of the other members of the Policy Committee.

15 (d) DUTIES OF THE POLICY COMMITTEE.—The Pol-
16 icy Committee shall initially meet at the call of the Co-
17 chairs, not later than 30 days after the last member is
18 selected under subsection (a). Subsequent meetings of the
19 Policy Committee shall be held at the call of the chair-
20 person. Through meetings, hearings, and working ses-
21 sions, the Policy Committee shall—

22 (1) make recommendations to the Cochairs to
23 facilitate the timely convening of the Conference;

1 (2) submit to the Cochairs a proposed agenda
2 for the Conference not later than 90 days after the
3 first meeting of the Policy Committee;

4 (3) make recommendations for the delegates of
5 the Conference;

6 (4) establish the number of delegates to be se-
7 lected under section 5; and

8 (5) establish an executive committee consisting
9 of 3 members of the Policy Committee to work with
10 delegates of the Conference.

11 **SEC. 5. CONFERENCE DELEGATES.**

12 To carry out the purposes of the Conference, the Co-
13 chairs shall bring together delegates representative of the
14 spectrum of thought in the field of autism and
15 neurodevelopmental disorders, without regard to political
16 affiliation or past partisan activity, who shall include—

17 (1) representatives of Federal, State, and local
18 governments;

19 (2) professional people and laypeople who are
20 working in the field of autism and
21 neurodevelopmental disorders; and

22 (3) representatives of the general public who
23 are affected by autism spectrum disorders in the
24 United States.

1 **SEC. 6. CONFERENCE ADMINISTRATION.**

2 (a) ADMINISTRATION.—In administering this section,
3 the Cochairs shall—

4 (1) provide written notice to all members of the
5 Policy Committee of each meeting, hearing, or work-
6 ing session of such Committee not later than 48
7 hours before the occurrence of such meeting, hear-
8 ing, or working session;

9 (2) request the cooperation and assistance of
10 the heads of such other Federal departments and
11 agencies as may be appropriate, including the detail-
12 ing of personnel;

13 (3) make available for public comment a pro-
14 posed agenda prepared by the Policy Committee,
15 which will reflect to the greatest extent possible the
16 major issues facing the field of autism consistent
17 with the purposes of the Conference set forth in sec-
18 tion 3(c);

19 (4) prepare and make available background ma-
20 terials that the Cochairs deem necessary for the use
21 of delegates to the Conference; and

22 (5) employ such additional personnel as may be
23 necessary to carry out the provisions of this Act
24 without regard to provisions of title 5, United States
25 Code, governing appointments in the competitive
26 service, and without regard to chapter 51 and sub-

1 chapter III of chapter 53 of such title relating to
2 classification and General Schedule pay rates.

3 (b) DUTIES.—In carrying out the Cochair’s respon-
4 sibilities and functions under this section, the Cochairs
5 shall ensure that—

6 (1) the proposed agenda prepared under sub-
7 section (a)(3) is published in the Federal Register
8 not later than 30 days after such agenda is approved
9 by the Policy Committee;

10 (2) the personnel employed under subsection
11 (a)(5) are fairly balanced in terms of points of views
12 represented and are appointed without regard to po-
13 litical affiliation or previous partisan activities;

14 (3) the recommendations of the Conference are
15 not inappropriately influenced by any public official
16 or by any special interest, but instead are the result
17 of the independent and collective judgment of the
18 delegates of the Conference; and

19 (4) before the Conference is convened—

20 (A) current and adequate statistical data
21 (including decennial census data) and other in-
22 formation on autism spectrum disorders in the
23 United States; and

1 (B) such information as may be necessary
2 to evaluate Federal programs and policies relat-
3 ing to autism spectrum disorders;
4 which the Cochairs may obtain by making grants to
5 or entering into an agreement with, public agencies
6 or nonprofit organizations, are readily available in
7 advance of the Conference to the delegates.

8 (c) GIFTS.—The Cochairs may accept, on behalf of
9 the United States, gifts (in cash or in kind, including vol-
10 untary and uncompensated services), which shall be avail-
11 able to carry out this Act. Gifts of cash shall be available
12 in addition to amounts appropriated to carry out this title.
13 Gifts may be earmarked by the donor or the executive
14 committee for a specific purpose.

15 (d) RECORDS.—The Cochairs shall maintain records
16 regarding—

17 (1) the sources, amounts, and uses of gifts ac-
18 cepted under subsection (c); and

19 (2) the identity of each person receiving assist-
20 ance to carry out this Act, and the amount of such
21 assistance received by each such person.

22 **SEC. 7. REPORT OF THE CONFERENCE.**

23 (a) PRELIMINARY REPORT.—Not later than 100 days
24 after the Conference adjourns, the Policy Committee shall
25 prepare a preliminary report on the Conference which

1 shall be published in the Federal Register and submitted
2 to the chief executive officers of the States. The Policy
3 Committee shall request that the chief executive officers
4 of the States submit to the Policy Committee, not later
5 than 45 days after receiving such report, their views and
6 findings on such report.

7 (b) FINAL REPORT.—Not later than 6 months after
8 the date on which the Conference adjourns, the Policy
9 Committee shall—

10 (1) prepare a final report of the Conference
11 which shall include a compilation of the views and
12 findings of the chief executive officers of the States
13 received under subsection (a); and

14 (2) publish in the Federal Register, and trans-
15 mit to the President and to Congress, the rec-
16 ommendations for the administrative action and the
17 legislation necessary to implement the recommenda-
18 tions contained in such report.

19 **SEC. 8. STATUS REPORTS.**

20 (a) INITIAL STATUS REPORT.—Not later than 2
21 years after the date on which the Conference adjourns,
22 the Surgeon General shall—

23 (1) prepare a status report documenting the im-
24 plementation of the recommendations contained in
25 the final report described in section 7(b)(1); and

1 (2) publish in the Federal Register, and trans-
2 mit to the President and to Congress, such status
3 report.

4 (b) SUBSEQUENT STATUS REPORTS.—Not later than
5 5 years after the date on which the Conference adjourns,
6 and every 5 years thereafter until all recommendations in
7 the final report described in section 7(b)(1) are achieved,
8 the Comptroller General shall—

9 (1) prepare a status report documenting the im-
10 plementation of the recommendations contained in
11 such final report; and

12 (2) publish in the Federal Register, and trans-
13 mit to the President and to Congress, such status
14 report.

15 **SEC. 9. DEFINITION OF STATE.**

16 For the purposes of this Act, the term “State” means
17 any of the several States, the District of Columbia, the
18 Commonwealth of Puerto Rico, Guam, American Samoa,
19 the Virgin Islands of the United States, or the Common-
20 wealth of the Northern Mariana Islands.

21 **SEC. 10. AUTHORIZATION OF APPROPRIATIONS.**

22 (a) AUTHORIZATION.—

23 (1) IN GENERAL.—There are authorized to be
24 appropriated to carry out this Act—

1 (A) such sums as may be necessary for the
2 first fiscal year in which the Policy Committee
3 plans the Conference and for the following fis-
4 cal year; and

5 (B) such sums as may be necessary for the
6 fiscal year in which the Conference is held.

7 (2) LIMITATION.—Any new spending authority
8 or new authority to enter into contracts under this
9 Act, and under which the United States is obligated
10 to make outlays, shall be effective only to the extent,
11 and in such amounts, as are provided in advance in
12 appropriations Acts.

13 (b) AVAILABILITY OF FUNDS.—

14 (1) IN GENERAL.—Except as provided in para-
15 graph (3), funds appropriated to carry out this Act
16 and funds received as gifts under section 6(c) shall
17 remain available for obligation or expenditure until
18 the expiration of the 1-year period beginning on the
19 date the Conference adjourns.

20 (2) UNOBLIGATED FUNDS.—Except as provided
21 in paragraph (3), any such funds neither expended
22 nor obligated before the expiration of the 1-year pe-
23 riod beginning on the date the Conference adjourns
24 shall be returned to the United States Treasury.

1 (3) CONFERENCE NOT CONVENED.—If the Con-
2 ference is not convened before December 31, 2012,
3 a trust fund shall be established and such funds
4 shall only be available for a future Conference on
5 Autism.

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