105TH CONGRESS 2D SESSION

H. R. 4376

To initiate a coordinated national effort to prevent, detect, and educate the public concerning Fetal Alcohol Syndrome and Fetal Alcohol Effect and to identify effective interventions for children, adolescents, and adults with Fetal Alcohol Syndrome and Fetal Alcohol Effect, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

July 31, 1998

Mrs. Morella (for herself, Mr. Bereuter, Ms. Norton, Mrs. Maloney of New York, and Ms. Delauro) introduced the following bill; which was referred to the Committee on Commerce

A BILL

To initiate a coordinated national effort to prevent, detect, and educate the public concerning Fetal Alcohol Syndrome and Fetal Alcohol Effect and to identify effective interventions for children, adolescents, and adults with Fetal Alcohol Syndrome and Fetal Alcohol Effect, 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,

1 SECTION 1. SHORT TITLE.

- This Act may be cited as the "Fetal Alcohol Syn-
- 3 drome and Fetal Alcohol Effect Prevention and Services
- 4 Act".

5 SEC. 2. FINDINGS.

- 6 Congress finds that—
- 7 (1) Fetal Alcohol Syndrome is the leading
- 8 known cause of mental retardation, and it is 100
- 9 percent preventable;
- 10 (2) each year, up to 12,000 infants are born in
- the United States with Fetal Alcohol Syndrome, suf-
- fering irreversible physical and mental damage;
- 13 (3) thousands more infants are born each year
- with Fetal Alcohol Effect, also known as Alcohol Re-
- 15 lated Neurobehavioral Disorder (ARND), a related
- and equally tragic syndrome;
- 17 (4) children of women who use alcohol while
- pregnant have a significantly higher infant mortality
- rate (13.3 per 1000) than children of those women
- 20 who do not use alcohol (8.6 per 1000);
- 21 (5) Fetal Alcohol Syndrome and Fetal Alcohol
- 22 Effect are national problems which can impact any
- child, family, or community, but their threat to
- 24 American Indians and Alaska Natives is especially
- 25 alarming;

- (6) in some American Indian communities, where alcohol dependency rates reach 50 percent and above, the chances of a newborn suffering Fetal Alcohol Syndrome or Fetal Alcohol Effect are up to 30 times greater than national averages;
 - (7) in addition to the immeasurable toll on children and their families, Fetal Alcohol Syndrome and Fetal Alcohol Effect pose extraordinary financial costs to the Nation, including the costs of health care, education, foster care, job training, and general support services for affected individuals;
 - (8) the total cost to the economy of Fetal Alcohol Syndrome was approximately \$2,500,000,000 in 1995, and over a lifetime, health care costs for one Fetal Alcohol Syndrome child are estimated to be at least \$1,400,000;
 - (9) researchers have determined that the possibility of giving birth to a baby with Fetal Alcohol Syndrome or Fetal Alcohol Effect increases in proportion to the amount and frequency of alcohol consumed by a pregnant woman, and that stopping alcohol consumption at any point in the pregnancy reduces the emotional, physical, and mental consequences of alcohol exposure to the baby; and

1 (10) though approximately 1 out of every 5
2 pregnant women drink alcohol during their preg3 nancy, we know of no safe dose of alcohol during
4 pregnancy, or of any safe time to drink during preg5 nancy, thus, it is in the best interest of the Nation
6 for the Federal Government to take an active role in
7 encouraging all women to abstain from alcohol con8 sumption during pregnancy.

9 SEC. 3. PURPOSE.

- 10 It is the purpose of this Act to establish, within the
- 11 Department of Health and Human Services, a comprehen-
- 12 sive program to help prevent Fetal Alcohol Syndrome and
- 13 Fetal Alcohol Effect nationwide and to provide effective
- 14 intervention programs and services for children, adoles-
- 15 cents and adults already affected by these conditions.
- 16 Such program shall—
- 17 (1) coordinate, support, and conduct national,
- 18 State, and community-based public awareness, pre-
- vention, and education programs on Fetal Alcohol
- 20 Syndrome and Fetal Alcohol Effect;
- 21 (2) coordinate, support, and conduct prevention
- and intervention studies as well as epidemiologic re-
- search concerning Fetal Alcohol Syndrome and Fetal
- 24 Alcohol Effect;

(3) coordinate, support and conduct research 1 2 and demonstration projects to develop effective de-3 velopmental and behavioral interventions and programs that foster effective advocacy, educational and vocational training, appropriate therapies, counsel-5 6 ing, medical and mental health, and other supportive 7 services, as well as models that integrate or coordi-8 nate such services, aimed at the unique challenges 9 facing individuals with Fetal Alcohol Syndrome or 10 Fetal Alcohol Effect and their families; and

(4) foster coordination among all Federal, State and local agencies, and promote partnerships between research institutions and communities that conduct or support Fetal Alcohol Syndrome and Fetal Alcohol Effect research, programs, surveillance, prevention, and interventions and otherwise meet the general needs of populations already affected or at risk of being impacted by Fetal Alcohol Syndrome and Fetal Alcohol Effect.

20 SEC. 4. ESTABLISHMENT OF PROGRAM.

- Title III of the Public Health Service Act (42 U.S.C.
- 22 241 et seq.) is amended by adding at the end the follow-
- 23 ing:

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1	"PART O—FETAL ALCOHOL SYNDROME
2	PREVENTION AND SERVICES PROGRAM
3	"SEC. 399G. ESTABLISHMENT OF FETAL ALCOHOL SYN-
4	DROME PREVENTION AND SERVICES PRO-
5	GRAM.
6	"(a) Fetal Alcohol Syndrome Prevention,
7	Intervention and Services Delivery Program.—
8	The Secretary shall establish a comprehensive Fetal Alco-
9	hol Syndrome and Fetal Alcohol Effect prevention, inter-
10	vention and services delivery program that shall include—
11	"(1) an education and public awareness pro-
12	gram to support, conduct, and evaluate the effective-
13	ness of—
14	"(A) educational programs targeting medi-
15	cal schools, social and other supportive services,
16	educators and counselors and other service pro-
17	viders in all phases of childhood development,
18	and other relevant service providers, concerning
19	the prevention, identification, and provision of
20	services for children, adolescents and adults
21	with Fetal Alcohol Syndrome and Fetal Alcohol
22	Effect;
23	"(B) strategies to educate school-age chil-
24	dren, including pregnant and high risk youth,
25	concerning Fetal Alcohol Syndrome and Fetal
26	Alcohol Effect:

1	"(C) public and community awareness pro-
2	grams concerning Fetal Alcohol Syndrome and
3	Fetal Alcohol Effect; and
4	"(D) strategies to coordinate information
5	and services across affected community agen-
6	cies, including agencies providing social services
7	such as foster care, adoption, and social work,
8	medical and mental health services, and agen-
9	cies involved in education, vocational training
10	and civil and criminal justice;
11	"(2) a prevention and diagnosis program to
12	support clinical studies, demonstrations and other
13	research as appropriate to—
14	"(A) develop appropriate medical diag-
15	nostic methods for identifying Fetal Alcohol
16	Syndrome and Fetal Alcohol Effect; and
17	"(B) develop effective prevention services
18	and interventions for pregnant, alcohol-depend-
19	ent women; and
20	"(3) an applied research program concerning
21	intervention and prevention to support and conduct
22	service demonstration projects, clinical studies and
23	other research models providing advocacy, edu-
24	cational and vocational training, counseling, medical
25	and mental health, and other supportive services, as

- 1 well as models that integrate and coordinate such
- 2 services, that are aimed at the unique challenges fac-
- 3 ing individuals with Fetal Alcohol Syndrome or
- 4 Fetal Alcohol Effect and their families.
- 5 "(b) Grants and Technical Assistance.—The
- 6 Secretary may award grants, cooperative agreements and
- 7 contracts and provide technical assistance to eligible enti-
- 8 ties described in section 399H to carry out subsection (a).
- 9 "(c) Dissemination of Criteria.—In carrying out
- 10 this section, the Secretary shall develop a procedure for
- 11 disseminating the Fetal Alcohol Syndrome and Fetal Alco-
- 12 hol Effect diagnostic criteria developed pursuant to section
- 13 705 of the ADAMHA Reorganization Act (42 U.S.C. 485n
- 14 note) to health care providers, educators, social workers,
- 15 child welfare workers, and other individuals.
- 16 "(d) NATIONAL TASK FORCE.—
- 17 "(1) IN GENERAL.—The Secretary shall estab-
- lish a task force to be known as the National task
- 19 force on Fetal Alcohol Syndrome and Fetal Alcohol
- 20 Effect (referred to in this subsection as the 'task
- force') to foster coordination among all govern-
- 22 mental agencies, academic bodies and community
- 23 groups that conduct or support Fetal Alcohol Syn-
- 24 drome and Fetal Alcohol Effect research, programs,
- and surveillance, and otherwise meet the general

1	needs of populations actually or potentially impacted
2	by Fetal Alcohol Syndrome and Fetal Alcohol Effect.
3	"(2) Membership.—The Task Force estab-
4	lished pursuant to paragraph (1) shall—
5	"(A) be chaired by an individual to be ap-
6	pointed by the Secretary and staffed by the Ad-
7	ministration; and
8	"(B) include the Chairperson of the Inter-
9	agency Coordinating Committee on Fetal Alco-
10	hol Syndrome of the Department of Health and
11	Human Services, and representatives from re-
12	search and advocacy organizations such as the
13	Research Society on Alcoholism, the FAS Fam-
14	ily Resource Institute and the National Organi-
15	zation of Fetal Alcohol Syndrome, the academic
16	community, and Federal, State and local gov-
17	ernment agencies and offices.
18	"(3) Functions.—The Task Force shall—
19	"(A) advise Federal, State and local pro-
20	grams and research concerning Fetal Alcohol
21	Syndrome and Fetal Alcohol Effect, including
22	programs and research concerning education
23	and public awareness for relevant service pro-
24	viders, school-age children, women at-risk, and

the general public, medical diagnosis, interven-

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1	tions for women at-risk of giving birth to chil-
2	dren with Fetal Alcohol Syndrome and Fetal
3	Alcohol Effect, and beneficial services for indi-
4	viduals with Fetal Alcohol Syndrome and Fetal
5	Alcohol Effect and their families;
6	"(B) coordinate its efforts with the Inter-
7	agency Coordinating Committee on Fetal Alco-
8	hol Syndrome of the Department of Health and
9	Human Services; and
10	"(C) report on a biennial basis to the Sec-
11	retary and relevant committees of Congress on
12	the current and planned activities of the partici-
13	pating agencies.
14	"(4) Time for appointment.—The members
15	of the Task Force shall be appointed by the Sec-
16	retary not later than 6 months after the date of en-
17	actment of this part.
18	"SEC. 399H. ELIGIBILITY.
19	"To be eligible to receive a grant, or enter into a co-
20	operative agreement or contract under this part, an entity
21	shall—
22	"(1) be a State, Indian tribal government, local
23	government, scientific or academic institution, or
24	nonprofit organization; and

- 1 "(2) prepare and submit to the Secretary an 2 application at such time, in such manner, and con-3 taining such information as the Secretary may pre-4 scribe, including a description of the activities that 5 the entity intends to carry out using amounts re-
- 7 "SEC. 399I. AUTHORIZATION OF APPROPRIATIONS.
- 8 "(a) In General.—There are authorized to be ap-
- 9 propriated to carry out this part, \$27,000,000 for each
- 10 of the fiscal years 1999 through 2003.

ceived under this part.

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- 11 "(b) Task Force.—From amounts appropriate for
- 12 a fiscal year under subsection (a), the Secretary may use
- 13 not to exceed \$2,000,000 of such amounts for the oper-
- 14 ations of the National Task Force under section 399G(d).
- 15 "SEC. 399J. SUNSET PROVISION.
- 16 "This part shall not apply on the date that is 7 years
- 17 after the date on which all members of the national task
- 18 force have been appointed under section 399G(d)(1).".

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