

Withdrawal/Redaction Sheet

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. memo	Allison Herwitt and Donna Crane to Commerce Committee and Reproductive Health Staff (partial) (1 page)	03/28/2000	P6/b(6)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Heather Howard (Subject Files)
OA/Box Number: 21195

FOLDER TITLE:

Children's Health Bill

2012-0254-S

rc658

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

Freedom of Information Act - [5 U.S.C. 552(b)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or
financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President
and his advisors, or between such advisors [(a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of
personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed
of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C.
2201(3).

RR. Document will be reviewed upon request.

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of
an agency [(b)(2) of the FOIA]
b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
b(4) Release would disclose trade secrets or confidential or financial
information [(b)(4) of the FOIA]
b(6) Release would constitute a clearly unwarranted invasion of
personal privacy [(b)(6) of the FOIA]
b(7) Release would disclose information compiled for law enforcement
purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of
financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information
concerning wells [(b)(9) of the FOIA]

Children's Health -
Children's Health
Bill

THE WHITE HOUSE

Office of the Press Secretary

For Immediate Release

October 17, 2000

STATEMENT BY THE PRESIDENT

Today I am pleased to sign into law H.R. 4365, the "Children's Health Act of 2000." This legislation authorizes expanded research and services for a wide variety of childhood and prenatal health problems, reauthorizes programs of the Substance Abuse and Mental Health Services Administration (SAMHSA) within the Department of Health and Human Services (HHS), and addresses the problem of substance abuse and associated violence.

This Act calls on HHS to continue providing services to children whose lives have been affected by diseases such as diabetes, asthma, lead poisoning, cancer, and autism, and to expand research in these and other areas such as birth defects and brain injuries so that we can better understand their causes and develop treatments. I am pleased that H.R. 4365 authorizes a new research effort, a national long-term study of environmental influences on children's health and development, that will provide critical information about environmental, social, and economic factors that affect children's health. We hope that with increased understanding of children's diseases, we will get closer to ultimately finding cures or preventing these conditions from ever occurring. I am gratified to see that this bill's focus on children's health addresses several priority areas identified by the President's Task Force on Environmental Health Risks and Safety Risks to Children.

I am also pleased that H.R. 4365 authorizes new funds to improve the health and safety of children in child care. Available, affordable, safe, high-quality child care is a concern for any working parent. I have committed my Administration to achieving this goal, and today we are making substantial strides forward.

As a Nation, we continue to face the challenges of curbing substance abuse, especially among our youth, preventing youth violence, and addressing the mental health needs of our citizens.

For this reason, I am especially proud of the comprehensive manner in which this legislation addresses illegal drug abuse, beginning with the reauthorization of SAMHSA. The Act will improve mental health and substance abuse services for children and adolescents by authorizing grants for youth drug treatment and early intervention, suicide prevention, and programs to help children deal with violence, and will address the mental health needs of individuals in the criminal justice system. The bill also lays the groundwork for giving States even more flexibility in the use of block grant funds in exchange for greater accountability.

This bill includes a provision making clear that religious organizations may qualify for SAMHSA's substance abuse prevention and treatment grants on the same basis as other nonprofit organizations. The Department of Justice advises, however, that this provision would be unconstitutional to the extent that it were construed to permit governmental funding of organizations that do not or cannot separate their religious activities from their substance abuse treatment and prevention activities that are supported by SAMHSA aid. Accordingly, I construe the Act as forbidding the funding of such organizations and as permitting Federal, State, and local governments involved in disbursing SAMHSA funds to take into account the structure and operations of a

religious organization in determining whether such an organization is constitutionally and statutorily eligible to receive funding.

The Act also builds upon our ongoing efforts to address the emerging threats posed by methamphetamine and Ecstasy use, especially among our Nation's youth. It makes medical treatments for heroin addiction more available and accessible by allowing qualified physicians to prescribe certain medications in their offices, and avoids the centralized clinic approach that many addicts find inaccessible and stigmatizing. In addition to expanding drug treatment, including innovations in medication development, the bill supports increased resources for drug programs in the criminal and juvenile justice systems. This legislation also supports our law enforcement entities as they carry out their responsibilities to make certain that those who traffic in these deadly poisons are taken off the streets and are punished in a manner commensurate with the seriousness of their offenses.

The programs contained in this bill to improve and expand research and services for our children's physical and mental health, and to prevent substance abuse and violence, are important investments in the well-being of our Nation. For these reasons, I am pleased to sign H.R. 4365.

WILLIAM J. CLINTON

THE WHITE HOUSE,
October 17, 2000.

#

THE WHITE HOUSE

Office of the Press Secretary

For Immediate Release

October 17, 2000

STATEMENT BY THE PRESIDENT

Today I am pleased to sign into law the Children's Health Act of 2000. This bipartisan legislation builds on my Administration's long-standing commitment to improve the health and well-being of our nation's children. I am particularly pleased that this legislation provides new authority to expand research for the treatment of chronic and acute diseases affecting children, improve the safety of child care centers, and ensure safe and quality mental health treatment services. This important legislation also addresses the critical need for substance abuse and mental health services, especially for our nation's youth, through the reauthorization of the Substance Abuse and Mental Health Services Administration (SAMHSA), supporting state and community efforts to reduce youth drug use, and improving research and treatment services. In addition, the legislation will allow us to strengthen our efforts to curtail the emerging use of the drugs methamphetamine and Ecstasy, which imperil the health and safety of our nation's young people.

I want to pay special tribute to my Administration's number one advocate for children, First Lady Hillary Rodham Clinton. Hillary has called the nation's attention to the special health needs of children through her work on children's health insurance coverage, asthma, pediatric labeling, juvenile diabetes and so much more. She has led the Administration's effort to improve access to health care for children, has fought hard for improving the quality and safety of child care, and has done more than anyone to improve the lives of millions of our nation's children.

30-30-30



EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

May 9, 2000 (SENT)
(House)

STATEMENT OF ADMINISTRATION POLICY

(THIS STATEMENT HAS BEEN COORDINATED BY OMB WITH THE CONCERNED AGENCIES.)

H.R. 4365 - Children's Health Act of 2000
(Reps. Bilirakis (R) FL and Brown (D) OH)

The Administration does not object to House passage of H.R. 4365, which is primarily designed to promote increased support for research on children's health problems. The Administration does, however, have serious concerns with numerous flaws in H.R. 4365 and will work with the Senate to address them. The most significant flaws are discussed below.

The Administration will seek an amendment to delete Title XII, Subtitle A (Infant Adoption Awareness) because it is unnecessary. The grants for adoption awareness training in Title XII, Subtitle A are unnecessary because Title X of the Public Health Service Act already allows training activities on a wide range of service delivery fronts, including training on adoption information as part of non-directive pregnancy options counseling. While the Administration strongly supports adoption, Title XII, Subtitle A of the bill, regarding the Title X family planning program, unduly emphasizes adoption information and referral training, in a context where pregnant women are entitled to expect to be informed of all of their pregnancy-related options in a balanced manner and in a non-directive fashion, as well as to be referred for services as requested.

The Administration is very supportive of efforts to improve autism surveillance and education activities and advance autism research. In recent years, NIH has significantly enhanced its investment in autism research. Unfortunately, H.R. 4365 contains a number of specific mandates that would limit the flexibility of NIH to effectively conduct, support, and respond to the needs for autism and autism spectrum disorders. For example, requiring: (1) the conduct of activities through specified components of NIH limits the agency's ability to respond to changing research needs and to take advantage of future scientific opportunities and discoveries; and (2) the funding of a specific number of extramural Centers of Excellence with specific research activities is wasteful and ineffective. Funding should be based on the quality of the research center applications received rather than on a statutorily-prescribed minimum number.

The Administration is also concerned about: (1) the creation of a National Center on Birth Defects and Developmental Disabilities, which will cause significant scientific, programmatic, and administrative problems for the delivery of essential public health services; and (2) provisions affecting the programs of the Health Resources and Services Administration that will duplicate existing programs and inhibit the agency's ability to effectively provide much needed public health services.

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For Immediate Release

Contact: Christy Stefadouros (202-225-5755)

House Approves Bilirakis Initiative to Improve Children's Health

Washington, D.C., May 9, 2000 – Congressman Mike Bilirakis (R-FL), Chairman of the Health and Environment Subcommittee, today secured passage by the House of Representatives of key legislation to improve children's health and well-being. H.R. 4365, the Children's Health Act of 2000, was approved by a vote of 419 to 2.

"Every mother knows that America's children are its future," Bilirakis said. "On Sunday, we will celebrate Mother's Day to honor millions of women for the loving care they provide. I can think of no better gift than passage of legislation to protect their children from the threat of disease."

H.R. 4365 includes provisions to significantly increase federal research and prevention efforts targeted at children's diseases. Bilirakis introduced the bipartisan measure with Rep. Sherrod Brown (D-OH), the Ranking Member of the Health and Environment Subcommittee.

"We can never estimate the human toll of childhood diseases," Bilirakis emphasized. "But they also have an enormous financial impact through billions of dollars in increased health care costs. Therefore, every dollar spent by the federal government on disease research and prevention is an extremely wise investment."

Among its provisions, H.R. 4365 establishes a new Pediatric Research Initiative within the National Institutes of Health (NIH). It also authorizes additional federal resources targeted at many areas of concern, including: autism, fragile X, birth defects, early hearing loss, poison prevention, epilepsy, asthma, juvenile arthritis, skeletal malignancies, juvenile diabetes, adoption awareness, traumatic brain injury, injury prevention, Healthy Start, oral health, vaccine injury compensation, hepatitis C, autoimmune diseases, graduate medical education in children's hospitals, organ transplantation needs of children, and rare diseases in children.

"As a parent and grandparent, I know that nothing is more heart-wrenching than watching your own child suffer with an illness," Bilirakis concluded. "Today's action by the House is a critical step forward in efforts to end the scourge of many childhood ailments. Equally important, it will give hope to families devastated by disease."

www.bilirakis.gov



EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

May 9, 2000 (SENT)
(House)

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The Administration does not object to House passage of H.R. 4365, which is primarily designed to promote increased support for research on children's health problems. The Administration does, however, have serious concerns with numerous flaws in H.R. 4365 and will work with the Senate to address them. The most significant flaws are discussed below.

The Administration will seek an amendment to delete Title XII, Subtitle A (Infant Adoption Awareness) because it is unnecessary. The grants for adoption awareness training in Title XII, Subtitle A are unnecessary because Title X of the Public Health Service Act already allows training activities on a wide range of service delivery fronts, including training on adoption information as part of non-directive pregnancy options counseling. While the Administration strongly supports adoption, Title XII, Subtitle A of the bill, regarding the Title X family planning program, unduly emphasizes adoption information and referral training, in a context where pregnant women are entitled to expect to be informed of all of their pregnancy-related options in a balanced manner and in a non-directive fashion, as well as to be referred for services as requested.

The Administration is very supportive of efforts to improve autism surveillance and education activities and advance autism research. In recent years, NIH has significantly enhanced its investment in autism research. Unfortunately, H.R. 4365 contains a number of specific mandates that would limit the flexibility of NIH to effectively conduct, support, and respond to the needs for autism and autism spectrum disorders. For example, requiring: (1) the conduct of activities through specified components of NIH limits the agency's ability to respond to changing research needs and to take advantage of future scientific opportunities and discoveries; and (2) the funding of a specific number of extramural Centers of Excellence with specific research activities is wasteful and ineffective. Funding should be based on the quality of the research center applications received rather than on a statutorily-prescribed minimum number.

The Administration is also concerned about: (1) the creation of a National Center on Birth Defects and Developmental Disabilities, which will cause significant scientific, programmatic, and administrative problems for the delivery of essential public health services; and (2) provisions affecting the programs of the Health Resources and Services Administration that will duplicate existing programs and inhibit the agency's ability to effectively provide much needed public health services.

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DRAFT -- NOT FOR RELEASE

May 5, 2000
(House)

H.R. 4365 - Children's Health Act of 2000
(Reps. Bilirakis (R) FL and Brown (D) OH)

The Administration does not object to House passage of H.R. 4365, as introduced on May 3, 2000, which is primarily designed to promote increased support for research on children's health problems. The Administration does, however, have serious concerns with numerous flaws in H.R. 4365 and will work with the Senate to address them. The most significant flaws are discussed below.

The Administration will seek an amendment to delete Title XII, Subtitle A (Infant Adoption Awareness) because it is unnecessary and undermines Title X (Family Planning) of the Public Health Service Act, by adversely impacting on women's access to nondirective pregnancy counseling options. The grants for adoption awareness training in Title XII, Subtitle A are unnecessary because Title X already allows training activities on a wide range of service delivery activities, including training on adoption information as part of nondirective pregnancy counseling options.

Title XII, Subtitle A undermines the Title X family planning program by emphasizing adoption counseling training, rather than ensuring that pregnant women in health centers are informed of all of their pregnancy options in a balanced manner and in a nondirect fashion, as well as referred for services as requested. In addition, by requiring Title X grantees providing voluntary family planning services to "provide nondirective counseling and referrals on all the options, *including but not limited to adoption*" (emphasis supplied), Title XII, Subtitle A undermines the current Title X requirement that counseling regarding the full range of options be provided. Current Title X guidance does not single out any one option in such a fashion.

The Administration is also concerned about the new requirements imposed on community health centers by Title XII, Subtitle A, because they could be disruptive to the physician-patient relationship and raise questions about the confidentiality of patient information.

The Administration is very supportive of efforts to improve autism surveillance and education activities and advance autism research. In recent years, NIH has significantly enhanced its investment in autism research. Unfortunately, H.R. 4365 contains a number of specific mandates that would limit the flexibility of NIH to effectively conduct, support, and respond to the needs for autism and autism spectrum disorders. For example, requiring: (1) the conduct of activities through specified components of NIH limits the agency's ability to respond to changing research needs and to take advantage of future scientific opportunities and discoveries; and (2) the funding

of a specific number of extramural Centers of Excellence with specific research activities is wasteful and ineffective. Funding should be based on the quality of the research center applications received rather than on a statutorily-prescribed minimum number.

The Administration is also concerned about: (1) the creation of a National Center on Birth Defects and Developmental Disabilities, which will cause significant scientific, programmatic, and administrative problems for the delivery of essential public health services; and (2) provisions affecting the programs of the Health Resources and Services Administration that will duplicate existing programs and inhibit the agency's ability to effectively provide much needed public health services.

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(Do Not Distribute Outside Executive Office of the President)

This Statement of Administration Policy was developed by the Legislative Reference Division (Pellicci) in consultation with the Department of Health and Human Services (Tarplin/Seltman/Jee), Associate Director (), HD (), EIML (), WHLA (), and the DPC ().

OMB/LA Clearance: _____

Background

To date, the Administration has not taken a position on H.R. 4365 or its predecessor bill H.R. 3301. H.R. 4365 was introduced on May 3, 2000 and represents the Manager's Amendment that will be considered by the House. It was introduced by House Commerce Health and the Environment Subcommittee Chairman Bilirakis and ranking Democrat Sherrod Brown. H.R. 4365 (or H.R. 3301) was not subject to hearings or committee markup.

LEGISLATIVE REFERENCE DIVISION DRAFT
05/05/00 - 4:30 p.m..

The administration will seek an amendment to strike Title XII from the bill because it is unnecessary. Title X of the Public Health Service Act already allows training activities on a wide range of service delivery fronts, including training on adoption information as part of non-directive pregnancy counseling. In addition, although the language requiring clinics to provide nondirective counseling and referral on all the options ***is consistent with current Title X guidelines, which ensure that pregnant women are informed about all pregnancy options in a balanced and nondirective fashion and provided with a referral for services as requested, the phrase*** "including but not limited to adoption" ***is unnecessary and should be struck.***

The administration will seek an amendment to strike Title XII from the bill because it is unnecessary. Title X of the Public Health Service Act already allows training activities on a wide range of service delivery fronts, including training on adoption information as part of non-directive pregnancy counseling.

But
with
ally

The language requiring clinics to provide nondirective counseling and referral on all the options ***is consistent with current Title X guidelines, which ensure that pregnant women are informed about all pregnancy options in a balanced and nondirective fashion and provided with a referral for services as requested except that the phrase "including but not limited to adoption" is unnecessary and should be struck.***

www.abandonedkids.org

The administration will seek an amendment to strike Title XII from the bill because it is unnecessary. ~~and undermines the Title X program by adversely impacting women's access to non-directive counseling. The grants are unnecessary because Title X of the Public Health Service Act already allows training activities on a wide range of service delivery fronts, including training on adoption information as part of non-directive pregnancy counseling.~~

~~Title XII undermines Title X by emphasizing adoption counseling training rather than ensuring that pregnant women are informed about all pregnancy options in a balanced and non-directive fashion as well as provided with a referral for services as requested. —[Note: the bill does not discuss adoption counseling, but rather adoption information and referral. So I recommend striking this paragraph, as well as the corresponding sentence in the first paragraph.]~~

In addition,

The language requiring clinics to provide nondirective counseling and referral on all the options ***is consistent with current Title X guidelines, which ensure that pregnant women are informed about all pregnancy options in a balanced and nondirective fashion and provided with a referral for services as requested. Therefore, the phrase "including but not limited to adoption" should be struck.*** ~~undermines the nondirective counseling requirement of Title X. Current guidelines do not single out any one option.~~

The administration will seek an amendment to strike Title XII from the bill because it is unnecessary. ~~and undermines the Title X program by adversely impacting women's access to non-directive counseling. The grants are unnecessary because~~ Title X of the Public Health Service Act already allows training activities on a wide range of service delivery fronts, including training on adoption information as part of non-directive pregnancy counseling.

~~Title XII undermines Title X by emphasizing adoption counseling training rather than ensuring that pregnant women are informed about all pregnancy options in a balanced and non-directive fashion as well as provided with a referral for services as requested. [Note: the bill does not discuss adoption counseling, but rather adoption information and referral. So I recommend striking this paragraph, as well as the corresponding sentence in the first paragraph.]~~

The language requiring clinics to provide nondirective counseling and referral on all the options ***is consistent with current Title X guidelines, which ensure that pregnant women are informed about all pregnancy options in a balanced and nondirective fashion and provided with a referral for services as requested. Therefore, the phrase "including but not limited to adoption" should be struck.*** ~~undermines the nondirective counseling requirement of Title X. Current guidelines do not single out any one option.~~

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~~Title XII undermines Title X by emphasizing adoption counseling training rather than ensuring that pregnant women are informed about all pregnancy options in a balanced and non-directive fashion as well as provided with a referral for services as requested. [Note to Heather: the bill does not discuss adoption counseling, but adoption information and referral. So I recommend striking this paragraph, as well as the corresponding sentence in the first paragraph.]~~

The language requiring clinics to provide nondirective counseling and referral on all the options **is consistent with current Title X guidelines, which ensure that pregnant women are informed about all pregnancy options in a balanced and nondirective fashion and provided with a referral for services as requested.** ^{highly} However, the phrase "including but not limited to adoption;" **should be struck** because it could suggest that, as a matter of federal policy, the government is elevating adoption over all other options facing pregnancy women. ~~undermines the nondirective counseling requirement of Title X. Current guidelines do not single out any one option.~~

~~but it is inconsistent~~

~~not appropriate~~

Evelyn Keppeler - OPA - 301-594-7608
is it a mandate for training

DRAFT -- NOT FOR RELEASE

May 5, 2000
(House)

H.R. 4365 - Children's Health Act of 2000
(Reps. Bilirakis (R) FL and Brown (D) OH)

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The Administration is also concerned about the new requirements imposed on community health centers by Title XII, Subtitle A, because they could be disruptive to the physician-patient relationship and raise questions about the confidentiality of patient information.

The Administration is very supportive of efforts to improve autism surveillance and education activities and advance autism research. In recent years, NIH has significantly enhanced its investment in autism research. Unfortunately, H.R. 4365 contains a number of specific mandates that would limit the flexibility of NIH to effectively conduct, support, and respond to the needs for autism and autism spectrum disorders. For example, requiring: (1) the conduct of activities through specified components of NIH limits the agency's ability to respond to changing research needs and to take advantage of future scientific opportunities and discoveries; and (2) the funding

of a specific number of extramural Centers of Excellence with specific research activities is wasteful and ineffective. Funding should be based on the quality of the research center applications received rather than on a statutorily-prescribed minimum number.

The Administration is also concerned about: (1) the creation of a National Center on Birth Defects and Developmental Disabilities, which will cause significant scientific, programmatic, and administrative problems for the delivery of essential public health services; and (2) provisions affecting the programs of the Health Resources and Services Administration that will duplicate existing programs and inhibit the agency's ability to effectively provide much needed public health services.

* * * * *

(Do Not Distribute Outside Executive Office of the President)

This Statement of Administration Policy was developed by the Legislative Reference Division (Pellicci) in consultation with the Department of Health and Human Services (Tarplin/Seltman/Jee), Associate Director (), HD (), EIML (), WHLA (), and the DPC ().

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LEGISLATIVE REFERENCE DIVISION DRAFT
05/05/00 - 4:30 p.m..

5/5

Children's Health Bill

Cynthia

chte markup never took place
(b/c tobacco, etc.)

managing package introduced as ^{HJR} 4365

~~Prof~~ Pro life comm. didn't like, complains

negotiated of chite + got some + others
will get by Monday - it may not
include some of this

5/8

Bob Pellici - ff suspension calendar
will be next week
Can get comments in by Wed.

ERICA R. MORRIS

03/30/2000 04:30:18 PM

Record Type: Record

To: Lisa M. Kountoupes/WHO/EOP@EOP, Heather H. Howard/OPD/EOP@EOP

cc:

Subject: Re: H.R. 3301 - Children's Health Research and Prevention Amendments (Bilirakis) 

Here is the press release from Rep. Bilirakis when he introduced this bill in November:

For Immediate Release

Contact: Chris Galm, (202) 225-5755

**BILIRAKIS LAUNCHES BIPARTISAN INITIATIVE
TO IMPROVE CHILDREN'S HEALTH**

Washington, D.C., November 10, 1999 – Congressman Mike Bilirakis (R-FL), Chairman of the Health and Environment Subcommittee of the House Commerce Committee, today introduced bipartisan legislation to improve children's health through increased research and prevention efforts. Bilirakis was joined by Rep. Sherrod Brown (D-OH), Ranking Member of the Subcommittee, in sponsoring the "Children's Health Research and Prevention Amendments of 1999."

"As a father and grandfather, I am committed to protecting America's children from the threat of disease," Bilirakis said. "They are our nation's future, and we should all work together to improve their health and well-being."

The bill would establish a new pediatric research initiative within the National Institutes of Health (NIH) to enhance opportunities for research and improve coordination of efforts to prevent or cure diseases affecting children. It also authorizes additional federal resources targeted at many childhood afflictions, including: autism, fragile X, birth defects, early hearing loss, poison prevention, epilepsy, asthma, juvenile arthritis, skeletal malignancies, juvenile diabetes and rare diseases in children.

"A baby born in America today has a life expectancy 30 years longer than a child born at the turn of the century," Bilirakis emphasized. "Public health initiatives are largely responsible for this vast improvement. But we cannot rest on our laurels – because much more remains to be done. I look forward to working on a bipartisan basis to enact this critical measure during the 106th Congress."

Last month, Bilirakis' Subcommittee held a hearing to examine ways to improve children's health. Actress Rene Russo testified regarding the need for increased federal support in the fight against autism, which is now the third most common developmental disorder affecting American children. Other witnesses highlighted concerns related to juvenile diabetes, asthma, poison prevention and adoption of children with special health needs.

Bilirakis has introduced separate legislation (H.R. 785) to allow taxpayers to designate a portion of any federal income tax refund to support biomedical research conducted through the National Institutes of Health. He has also been a leading advocate in Congress of doubling federal funding for NIH research

efforts.

-END-

www.bilirakis.gov

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The Tampa Tribune

November 14, 1999, Sunday, FINAL EDITION

SECTION: NATION/WORLD, Pg. 15

LENGTH: 513 words

HEADLINE: **Bilirakis** bill is for children;

BYLINE: Jacqueline Soteropoulos, of The Tampa Tribune;

BODY:

Rep. Michael **Bilirakis**, R-Palm Harbor, has introduced a bipartisan bill to establish a new pediatric research initiative at the National Institutes of Health.

It also authorizes additional money to target a variety of childhood illnesses, including autism, birth defects, epilepsy, juvenile diabetes and rare children's diseases.

"A baby born in America today has a life expectancy 30 years longer than a child born at the turn of the century," **Bilirakis** said. "Public health initiatives are largely responsible for this vast improvement. But we cannot rest on our laurels - because much more remains to be done."

Bilirakis chairs the House Subcommittee on Health and Environment. Last month, he held hearings on improving **children's health**.

Away to Amsterdam:As a member of the House International Relations Committee, Rep. Jim Davis, D-Tampa, is finishing up a four-day trip to attend NATO's annual parliamentary meeting in the Netherlands.

A 17-member bipartisan congressional delegation left Washington Thursday morning, led by Rep. Doug Bereuter, R-Neb. The focus of the meeting is to debate the alliance's role in humanitarian interventions.

The group's attendance was touch-and-go as congressional leaders struggled to decide whether lawmakers would meet Friday after Thursday's Veterans Day holiday, or postpone their wrap-up business until the following week.

Praise from first lady:First lady Hillary Clinton rallied House Democrats on Capitol Hill on Tuesday, and included words of praise for Rep. Karen Thurman, D-Dunnellon.

"It is a privilege to join so many Democratic members of Congress who are making this commitment to seniors as strong as we possibly can," Clinton said. "There are many people here I would like to recognize ... (including) Karen Thurman, who sponsored an amendment to help seniors get a discount on medications."

"Millions of older people cannot afford the prescription drugs they need to live their lives in dignity," Clinton said.

Thurman's amendment failed last month in a party-line committee vote.

But Thurman and fellow Democrats are trying to bring her measure and other like issues to the House floor by starting a discharge petition. To force a bill out of committee, members must collect 218 signatures - a majority of the House.

63 Candles: Sen. Bob Graham, D-Miami Lakes, celebrated his 63rd birthday Tuesday. Several days earlier, his staff threw an office party for the three-term senator and former Florida governor.

But on the night of his birthday, the Senate worked into the evening with a variety of votes on bankruptcy reform.

Despite Graham's urging, the Senate voted to override Florida law that allows citizens filing for bankruptcy to keep their homes from creditors. If the measure becomes law, it would allow debtors to protect the first \$ 100,000 in home equity.

Sen. Connie Mack, R-Fort Myers, joined Graham in opposing the new restriction. Jacqueline Soteropoulos covers Washington and can be reached at (202) 662-7673.

GRAPHIC: SIGNATURE

TYPE: WASHINGTON NOTEBOOK

LOAD-DATE: November 14, 1999

FOCUS™

Search: General News;children's health and Bilirakis

To narrow this search, please enter a word or phrase:

Example: House of Representatives



NARAL

Reproductive Freedom & Choice

To: Commerce Committee and Reproductive Health Staff
From: Allison Herwitt, Director of Government Relations
Donna Crane, Legislative Representative
Date: March 28, 2000
Subject: **Background Information on "Crisis Pregnancy Centers"
and Other Concerns with H.R.3301, Children's Health Act**

markup postponed
→ + april 13

In the coming days, the House Commerce Committee will be holding a full committee or Health and Environment Subcommittee mark-up of H.R.3301, the Children's Health Research and Prevention Amendments Act. **NARAL has significant concerns with the latest draft of H.R.3301, and urges members' close attention to provisions inserted since H.R.3301 was first introduced.**

In its original form, H.R.3301 was a broadly bipartisan bill that included a number of prevention, treatment and research initiatives designed to improve children's health. However, the most recent version of H.R.3301, which we understand will be used as the chairman's mark, includes several new provisions, including one based on H.R.2511, the Adoption Awareness Act. This new title of H.R.3301 would authorize grants to national adoption advocacy organizations; the funds would be used to train staff from federally funded family-planning clinics in counseling their pregnant women clients about adoption. The legislation would also require the staff of Title X clinics and community health centers to attend these trainings or risk losing their funding. Members of the reproductive-health community (NARAL, PPFA, NFPRHA and AGI) have written a set of talking points on the broad effects of these new mandates, which is enclosed for your information.

In addition to the adoption counseling language, NARAL is concerned with the provision which allows so-called "crisis pregnancy centers" to receive this federally subsidized training. "Crisis pregnancy centers" are deceptive "clinics" established to attract women facing unintended pregnancies. Although some centers do provide an open and honest setting to ensure that pregnant women receive support and information they need, many entice women under the pretense of providing the full range of reproductive options, including abortion. Instead, the staff at these deceptive centers use anti-abortion propaganda, misinformation, and intimidation to dissuade women from exercising their right to choose. Unlike legitimate family-planning clinics, crisis pregnancy centers are staffed by anti-choice volunteers who refuse to refer for abortion. **To the best of our knowledge, as currently drafted H.R.3301 would establish the first-ever federal subsidy, through training from national adoption advocacy organizations, to these deceptive and ideological "crisis pregnancy centers."**

NARAL believes the insertion of provisions that fund training for "crisis pregnancy center" staff and mandate "adoption counseling" are unwise, last-minute additions to H.R.3301. Additional material about our concerns with this bill is enclosed for your information. If you have any questions, please contact Allison Herwitt at 973-3003 or Donna Crane at 973-3047.

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Reproductive Freedom & Choice

DECEPTIVE ANTI-ABORTION CRISIS PREGNANCY CENTERS

*"At the time this happened I was angry and felt like I had been duped. There was no hint in the newspaper or on signs outside their building indicating that this was a pro-life organization. If I had known, I would have never gone there. The experience of seeing those horrible slides [showing pictures of dead fetuses] was devastating. Even after all these years I have horrible memories of those pictures. I felt like a fool that I only realized it was a pro-life organization after I pleaded for abortion information and they wouldn't give me any. Their sneaky manipulative techniques didn't work on me because I was a little older and not easily swayed. However I could see how it might work on younger more naive girls."*¹

-- Hildee C. Robinson, describing her experience at a Delaware crisis pregnancy center 11 years ago.

Just as access to abortion is threatened by anti-choice state and federal legislation, the stigmatization of women who seek abortions and the physicians who provide them, violence against clinics and providers, and the current culture of complacency, anti-choice activists have mobilized on a grassroots level to restrict access to abortion by setting up "crisis pregnancy centers" (CPCs) around the country. These fake clinics seek to attract women faced with unintended pregnancies who are "at risk" for abortion. Although some centers do provide an open and honest setting to ensure that women facing an unintended pregnancy receive the support and information they need, many of these centers entice women under the pretense of providing the full range of reproductive options, including abortion. Instead, the staff at these deceptive centers use anti-abortion propaganda, misinformation, and intimidation to dissuade women from exercising their right to choose. Unlike clinics which provide abortions, CPCs are staffed by anti-choice volunteers who refuse to refer for abortion or birth control, preaching abstinence as the only method of preventing unwanted pregnancies.

I. Tactics Used by Deceitful Crisis Pregnancy Centers to Entice Women

A. Crisis Pregnancy Centers Use Misleading Advertising.

In the Yellow Pages, crisis pregnancy centers typically list their names, numbers, and ads under "Abortion Alternatives," which comes before "Abortion Providers." Although the Yellow Pages displays a small box under the heading warning that the listed organizations do not provide abortion services or referrals, a woman faced with

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a crisis pregnancy may not notice such a disclaimer or may still be undecided about whether to carry the pregnancy to term. The advertisements placed by CPCs offer free pregnancy tests and counseling without mentioning their anti-choice stance, misleading unsuspecting women into believing that they will be provided with unbiased information about all options, including abortion. Moreover, crisis pregnancy centers advertise under more neutral or even feminist headings such as “Family Planning Information Centers,” or “Women’s Organizations.”² By placing advertisements that offer a variety of reproductive health services, CPCs attract women seeking free tests and a range of medical services, including abortion. These ads neglect to mention, however, that the goal of the centers is to deter women from obtaining abortions, that the only services actually offered are usually anti-abortion propaganda and abstinence counseling, and that the centers have no medically trained or medically supervised personnel.³

- The Pearson Foundation, which published a manual for CPCs entitled *How to Start and Operate Your Own Pro-Life Outreach Crisis Pregnancy Center*, advises centers to place their listings “under the headings of abortion, pregnancy, birth control information, clinics, social services, welfare organizations, womens’ organizations and services, and health services”⁴ in order to attract women considering abortion.
- Market research for CPCs sponsored by the Family Research Council found that centers should “approach their local Yellow Pages companies and urge that their ads be listed under the heading ‘Pregnancy’ or ‘Medical’ where applicable, since these sites are where women would turn first to find help.”⁵
- After a lawsuit alleging that a fake clinic falsely advertised in order to lure women into the center to subject them to anti-abortion counseling, a California trial court issued an order against the center prohibiting it from: presenting itself as a medical facility; advertising that it provides pregnancy testing services or abortion counseling, and advertising in directories under the headings for “clinics,” “family planning information,” “abortion service providers,” “abortion service referral providers,” “birth control information,” “or “pregnancy options counseling.”⁶
- An injunction against three fake clinics in New York prohibited them from advertising that they provide abortion services or advertising in the Yellow Pages under “Clinics,” “Medical Services,” or “Abortion Services” and required them to “state in advertisements that they are an abortion alternatives organization that provides only natural family planning methods.”⁷

B. Crisis Pregnancy Centers Choose Neutral Names That Do Not Indicate Their Anti-Abortion Position.

Rather than indicating their anti-choice agenda in the center's name, founders of CPCs assume neutral names, chosen to mislead women into thinking that they support a woman's right to choose abortion. The Pearson Foundation manual recommends that "a neutral name such as Abortion ABC'S, Abortion Advice or Pregnancy Problem Center is the most effective way to reach these women who are pregnant and who are considering abortion" since the "woman who wants an abortion may not come to the center if the center appears to be pro-life."⁸

C. Crisis Pregnancy Centers Purposely Establish Themselves Near Legitimate Women's Reproductive Health Care Clinics That Provide Abortions.

Many fake clinics not only choose neutral names in order to hide their true agenda, they may also choose names similar to those of legitimate abortion clinics and locate near those clinics to confuse women seeking abortion information and lure them into their center.

- The Pearson Foundation manual recommends this tactic, suggesting that CPCs use names similar to abortion providers in order to "compete with the abortion chambers for that mother and her baby's life." The manual advises that founders rent office space in the same building as an abortion clinic so that "if the girl who would be going to the abortion chamber sees your office first with a similar name, she will probably come into your center." That way, "the abortion chamber is paying for advertising to bring that girl to you."⁹
- In Massachusetts, an anti-choice crisis pregnancy center called Problem Pregnancy which had offices on the same floor as a Planned Parenthood clinic posted a sign on its door saying "PP, Inc." It then positioned its counselors in the corridors to harass women who were trying to reach Planned Parenthood. Eventually, Massachusetts's highest court upheld an injunction against the center's use of the initials "PP" or any other attempt to pass itself off as Planned Parenthood. The court ruled that the group infringed upon Planned Parenthood's service mark and logo through its misleading use of "PP."¹⁰

D. Crisis Pregnancy Centers Answer Questions With Evasion and Lies.

Because the ads placed by fake clinics advertise health services without specifically explaining these services, women often call to inquire which services are offered and the cost for services such as abortions. When confronted with such inquiries, the staff at CPCs may evade the question or lie outright in order to attract the woman into the center.

- Robert Pearson, the author of the Pearson Foundation manual, admitted this

duplicity when he said in a 1994 speech, “[o]bviously, we’re fighting Satan. . . . A killer, who in this case is the girl who wants to kill her baby, has no right to information that will help her kill her baby. Therefore, when she calls and says, ‘Do you do abortions?’ we do not tell her, ‘No, we don’t do abortions.’”¹¹

- In fact, the Pearson manual tells staff that “there is nothing wrong or dishonest if you don’t want to answer a question that may reveal your pro-life position by changing the caller’s train of thought by asking a question in return.” As an example, the manual recommends answering the question “Are you a pro-life center?” with “We are a pregnancy testing center. . . . What is pro-life?” After all, “[o]ur name of the game is to get the woman to come in as do the abortion chambers. Be put off by nothing. . . . Let nothing stop you. The stakes are life or death.”¹²
- Shannon Locke, who testified before a House subcommittee hearing on CPCs in 1991, said that when she called a fake clinic and asked how much an abortion would cost, the woman “asked me to come into their office because she was at home away from her desk and didn’t have the information.” At the center, Locke was subjected to an anti-abortion film and an argument with the “counselor” over whether or not she should have an abortion.¹³
- In a California case, a Superior Court required that a fake clinic disclose over the telephone to each caller that it does not perform abortions or give abortion referrals, birth control or birth control referrals, or written pregnancy verifications, and that its counseling is by volunteers and from a Biblical “anti-abortion perspective.”¹⁴
- Women facing unexpected pregnancies are not the only victims of this subterfuge. Recently in California, doctors at the HMO Kaiser Permanente were misled about the anti-choice nature of a crisis pregnancy center called First Resort. According to Shari Plunkett, the founder of First Resort, she did not tell the doctors that the center is “pro-life” since it is a “political [term] loaded with stereotypes.” Instead, she tells those who inquire, “[e]very day we go to work to reduce the desire for abortion in our community.’ The minute we say that, they know where we stand, but I’ve been careful to frame it in a way they’ve never heard before, and that has made all the difference.”¹⁵ Ignorant of First Resort’s anti-choice position, the nurses at Kaiser referred patients who were ambivalent about their pregnancy to First Resort with the belief that these women would receive unbiased counseling on the full range of pregnancy options,¹⁶ including abortion. When the California Abortion and Reproductive Rights Action League (CARAL) and other pro-choice groups exposed First Resort’s true nature, Kaiser permanently severed all ties to the center and pledged to work on “a process to ensure that our Health Plan members receive neutral and unbiased counseling as part of their full range of

reproductive rights.”¹⁷

By using misleading advertising, choosing neutral names, evading questions about their true purposes, and purposely situating near legitimate clinics, crisis pregnancy centers masquerade as clinics providing the full range of reproductive health services, including abortion, and knowingly deceive women without apology. The Reverend David Trosch, an anti-choice activist who ran a crisis pregnancy center from 1983-1990, admitted to this deception when he said, “I suppose there was some sense that women were to some degree being misled into believing this was an abortion clinic. We’re concerned with innocent human life in the womb. The rationale is to get [women] in there so we can convince them not to have an abortion.”¹⁸

II. Once Inside the Crisis Pregnancy Center, Women are Subjected to Anti-Abortion Propaganda, Misinformation, and Intimidation.

After enticing women into their center through duplicitous means, crisis pregnancy centers continue to use a variety of coercive and overbearing tactics to prevent women from exercising their right to abortion.

A. Crisis Pregnancy Centers Are Made to Look Like Medical Facilities but Are Staffed by Non-Medical Personnel.

Although CPCs list themselves as “clinics,” give pregnancy tests, inform women about “medical facts,” and present their center as a medical facility, rarely are trained medical personnel or even professional counselors on staff. Most staff are unpaid volunteers whose only training was provided by the center.

- The Pearson manual tells staff to make “certain your decor does not expose your purpose or your pro-life commitment . . .” and to “[t]ry to find a building that looks like a professional building, a medical office, as opposed to a building with a homey atmosphere. You want your office to look like an abortion clinic.” For that reason, “several white 3/4 length jackets” are on the list of equipment needed for counselors and staff working at the center.¹⁹
- In 1993, Ohio Attorney General Lee Fisher found that five crisis pregnancy centers in the state “violate the law by advertising themselves as clinics when they are not medical facilities, provide no medical services, and have no doctors on staff. Some of the centers also promise additional services they do not provide, such as offering free pregnancy tests, when the center does not perform or interpret pregnancy tests for clients.”²⁰
- After conducting the 1991 subcommittee hearing on CPCs, Representative Ron Wyden found that these centers “hold out that they are health clinics, but when

the women get there, there are no medical professionals. A very strident, very aggressive anti-abortion campaign is what they get.”²¹

B. Crisis Pregnancy Centers Use Pregnancy Tests to Hold Women Hostage.

Free pregnancy tests are often the primary reason women enter fake clinics. Knowing this, center staff use the test in order to further their anti-abortion agenda. Although pregnancy tests take two to five minutes, crisis pregnancy centers tell women that they will have the results anywhere from 30 to 45 minutes later. The Pearson manual instructs staff, “[i]f the client asks how long it takes to do the test, tell her that we offer test results in just 30 minutes. . . . You will have the results by that time. (You have not told her how long it takes you to run the test, but how long it will be before she has the results of the test.)” In this way, “when she hands you the urine specimen, you have a captive audience, as she knows . . . that the results will be in 30 minutes.”²² During the time clients wait for their results, staff subject the women to anti-abortion propaganda and counseling, effectively holding the women hostage in the center. An undercover reporter working on a story about CPCs was lectured about religion and the “baby” growing inside her before she got the result of her pregnancy test, which was negative. During this “counseling session,” she wrote, “I came in there to get a pregnancy test, and here’s my counselor going on about God and church and Jesus -- and she’s holding my test captive. We must have the results by now!”²³

C. Crisis Pregnancy Centers Subject Women to Disturbing and Misleading Anti-Abortion Films and Slide Shows.

While waiting for the results of their pregnancy tests, women in fake clinics are often forced to watch shocking films or slide shows featuring bloody, dismembered fetuses, women asserted to be dying from allegedly botched abortions, and testimonies about the devastating emotional and psychological effects of abortion. These films contain false information and are designed to scare vulnerable women into carrying pregnancies to term.

- The Pearson manual tells staff to turn on the presentation “without asking the client’s permission or opinion. . . . The girl accepts it as part of her preparation for the abortion . . .” If the client refuses to view the presentation because she “senses [the center’s] pro-life position” the manual recommends asking the woman to view the film or slide show in order to provide an evaluation. After all, “[t]he client is receiving a free service from the center, therefore, it is not an imposition to ask her to watch the presentation while she is waiting for the results of her test.”²⁴
- Carla Abbotts described her experience at a crisis pregnancy center in California as follows:

When I arrived at the “clinic,” a woman, Eileen O’Donnell, took me into another room and asked me a series of questions. . . . Eileen then looked at a chart on her desk and told me how pregnant I was. She stated, “Your baby will be born on September 17.” This was before the pregnancy test was even done. . . . Next, she turned on the machine for a slide show. I asked Eileen if I had to watch the slide show. She said yes, I had to watch it. She took my urine sample, and left the room closing the door behind her. The slide show presented pictures of large bloody fetuses and told horror stories about women dying from abortions. It claimed that abortion was a leading cause of sterility, deformed children and death. One slide was of a dead woman lying under a sheet. The voice reported that she had died during a legal abortion when the suction machine, which was hooked up wrong, blew pressure into her body, causing her uterus to explode. Another slide presented a story of a blond haired teenage girl who had undergone an abortion procedure, but in actuality wasn’t pregnant. None of the medical people involved bothered to inform her of this fact. The girl had killed herself over the guilt from the “abortion.” It then showed more pictures of bloody fetuses. By this time, I was extremely upset and angry, and turned the slide show off.²⁵

- During the House subcommittee hearings in 1991, then New York Attorney General Robert Abrams cited an example of a New York teenager who complained to his office after responding to an ad in the “Clinics” section of the phone book. The ad said, “Thinking about abortion? Call us. Free pregnancy test. No parental consent required. Financial assistance available.” After going to the center and submitting a urine sample, the young woman was shown a slide show that displayed photographs of discarded fetuses and emphasized the alleged but untrue physical risks associated with abortion. Abrams testified that “this teenager left the clinic believing that if she had an abortion, she would become insane.”²⁶
- An Arizona man took his 16 year old daughter to a fake clinic after she had been raped. After being shown “brutal footage” including pictures of dismembered fetuses, the man claimed that, “they just emotionally raped her. . . . They are advocates for the unborn, and to hell with the troubled person. They had an ax to grind, and just terrorized her.”²⁷
- A 20 year old student claimed that when she visited a CPC she got a “very biased” anti-abortion video in which pro-choice speakers were “made to look like screwheads who didn’t really know what was going on” and abortion doctors “were made to look like butchers in a butcher store, churning it out assembly-line style.” The student walked out after the tape showed a woman screaming, passing out, and convulsing during an abortion, thinking, “I’ve

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been through an abortion. What are these people trying to feed me?"²⁸

- A judgment against a San Francisco crisis pregnancy center and the Pearson Foundation said that the Foundation's slide show "could not claim that abortion carried a high risk of injury or death without a disclaimer saying that the majority of studies found a much lower risk." The judgment also said that if the center continues to show the slides, it must add statements that abortion in the first trimester has little risk and that most women "suffer no significant lasting psychological difficulties" after abortion.²⁹

D. Crisis Pregnancy Centers Provide Women with Anti-Abortion Counseling.

In addition to the misleading information presented in anti-abortion films and slide shows, crisis pregnancy centers routinely subject women to "counseling sessions" which consist of religious discussions, false "medical facts," and a refusal to provide abortion referrals.

- According to the Pearson manual, "[a]bortion is now hopefully, after viewing the presentation, a frightening thought" and counselors should then "... convince [the] woman that the act of abortion is not only violent, it is unnatural and, therefore, harmful to her in many ways."³⁰
- A volunteer counselor at a crisis pregnancy center testified that while she would tell a young client that her options were becoming a mother or placing the baby for adoption, she could not tell the client about the risks of carrying a pregnancy to term because she doesn't know them. Nor would the counselor refer her for an abortion if that was her choice.³¹
- In her response to a NARAL[®] survey on crisis pregnancy centers, [REDACTED] [001]
[REDACTED] wrote that the crisis pregnancy center she visited refused to provide abortion referrals. "They were emphatically against me having an abortion. I went in having already decided that if I was pregnant, I would abort. They tried every argument to get me to change my mind . . . I felt very cornered and they were very rude."³²
- According to an undercover reporter in Connecticut, before receiving the result of her pregnancy test, she was "counseled" by the center staff. Her counseling included a description of abortion in "gruesome detail," during which the "counselor" reminded her (falsely) that the "'baby' can feel everything. If we could hear the 'baby' scream, it would be screaming for its life." The counselor also falsely told her that doctors at abortion clinics do not use sterilized instruments, that almost 200 women in Connecticut lose their fertility every year due to botched abortions, and that most women who have abortions

suffer from Post Abortion Stress Syndrome (a medically unrecognized condition), with symptoms including depression and guilt.³³ Obviously the counselor was presenting misinformation, since former Surgeon General C. Everett Koop testified before Congress that the development of psychological problems related to abortion is “minuscule from a public health perspective.”³⁴ The counselor offered a comparison between adoption and abortion, which included statements like “Abortion: Pregnancy ends with death. Physical health at possible risk. Adoption: Pregnancy ends with life. Physical health maintained.”³⁵ However, the counselor did not warn the reporter of any risks associated with childbirth, including the fact that the mortality rate associated with childbirth is 10 times as high as that associated with legal abortion.³⁶

- Another undercover reporter in Atlanta was offered religious arguments to try to convince her to complete the pregnancy. The counselor told her that abortion “breaks into the natural order, the natural order of our lives. You know, God made man, made woman for man, and made us both to reproduce.”³⁷
- In a Texas case, Wana Lewis claimed that after insisting to a staff member at a fake clinic that she wanted an abortion, the staff member offered to arrange an abortion for her with “a respectable doctor.” Once Lewis accepted the offer and arrived at the hospital on the day of the appointment, she found that it was a Roman Catholic institution and that its doctors did not perform abortions.³⁸

E. Crisis Pregnancy Centers Will Not Provide Information About or Referrals for Birth Control.

Unlike abortion clinics, which routinely provide contraceptives and counseling on the use of contraceptives as part of a woman’s comprehensive health care treatment, the Pearson manual explicitly instructs counselors at CPCs that they should “never counsel for contraception or to refer to agencies making contraceptives available. [Doing so] is not only inaccurate but unacceptable and against the general pro-life philosophy, and Christian principles.”³⁹ Instead, center staff provide information on chastity, presenting abstinence as the only method of avoiding future unwanted pregnancies.

F. Crisis Pregnancy Centers May Resort to Extreme Measures to Prevent Women From Exercising The Freedom to Choose.

In their zeal to prevent women from obtaining an abortion, some fake clinics have been known to take extreme action. Such action may include malicious accusations, physical restraint, and false promises of financial assistance.

- A Texas woman took her 16 year old daughter to a local CPC for a free pregnancy test. When the staff learned that the young woman wanted an abortion, they brought her a stuffed doll and a pair of scissors, saying “This is what your baby looks like now, and we want you to start cutting her up because that’s what will happen if you have an abortion.”⁴⁰
- Another woman in Texas sought a free pregnancy test at a crisis pregnancy center. After submitting a urine sample, she was told she must watch a film if she wanted the test results. The film consisted of anti-choice propaganda which so upset her that she asked for them to turn it off. She tried to leave the room but “[w]hen I tried, a man in a wheelchair came through the door, shut it from behind and stayed there.” For the next 20 minutes staff members asked her personal questions, lectured her on abortion, and urged her to put the baby up for adoption. When the staff found out she had had a previous abortion, they told her that they knew she would have another, saying, “Just think, you would have a child seven years old and you killed it. You murdered this child; are you coming to murder another?”⁴¹
- During the 1991 congressional hearing, San Francisco District Attorney Arlo Smith told the story of a 14 year old who called a number listed under “clinics” as a “free pregnancy center.” Counselors told her she was pregnant and spent two and a half hours showing her anti-abortion slides. After coming back to the center on subsequent days for repeated “counseling sessions,” she discovered she was too far along in the pregnancy to have an abortion, eventually gave birth, and offered the child for adoption.⁴²
- The Pearson manual contains explicit instructions on how to handle pregnant minors, saying that if “the girl is being pressured into abortion at her home, and she is willing to go to a foster home, even though she may be a minor, take her at once.” Otherwise, “[t]ry to make every effort to keep the daughter from the parents until the parents understand the significance of what an abortion really means. . . . She may have to get lost in this way two or three times before the parents stop pushing for an abortion. She may have to slip out the back door if the parents come to take her for an abortion. Remember it is permissible not to follow authority from parents or the state if it is against the law of God and abortion is against His law.”⁴³
- In San Francisco, a staff member attempted to hide a pregnant teenager from her parents by placing her in a foster home until after she gave birth. She told the parents that the young woman was going to Europe on a special scholarship. The parents discovered the scheme when they called the school to discuss the “scholarship.” Illegal arrangements for the adoption of the child were also being made before she was reunited with her parents.⁴⁴

III. The Future of Crisis Pregnancy Centers

With more than 3,200 centers across the country, an increase from about 2000 in 1994,⁴⁵ crisis pregnancy centers are growing in number and visibility. According to the Family Research Council report, crisis pregnancy centers outnumber abortion providers by a four to three margin.⁴⁶ The report also found, however, that there has been an increase in the number of women seeking services at the center once they had already decided to carry the pregnancy to term, a trend which “could threaten the primary mission of the centers -- to reach women at risk for abortion.”⁴⁷ It is not surprising, then, that in January 1999, on the 26th anniversary of *Roe v. Wade*, the prominent anti-choice activist Reverend Robert Schenck called for a new approach to the anti-choice movement, including an agenda focused on providing alternatives to abortion at crisis pregnancy centers.⁴⁸ In order to become more effective in reaching women considering abortion, the new agenda for CPCs requires new strategies, among them changing the names of the centers, the ways in which they reach women, and the services provided.

A. Crisis Pregnancy Centers Are Changing Their Names.

In an article in the National Right to Life News, Shari Plunkett talked about the problems currently facing CPCs, one of which is the term “crisis pregnancy center.” According to Plunkett, “‘Crisis Pregnancy Center’ carries a fair amount of baggage. The women we see have grown up with legalized abortion, and many of them see an abortion decision not so much as a crisis, but simply as a personal issue to be dealt with. Few middle-class, professional, and educated women will go to a ‘crisis’ anything.”⁴⁹ For this reason crisis pregnancy centers are choosing even more neutral and misleading names in order to appeal to a greater number of women faced with unexpected pregnancies and who may be considering abortion.

- Shari Plunkett changed the name of her pregnancy center from Crisis Pregnancy Services to First Resort, a name she believes is more “positive” because it “suggests a place of empowerment for women who are making a major life decision.”⁵⁰ However, Plunkett also stated that she believes “every woman’s heart is telling her to carry to term, because God has placed truth in her heart, and the truth is that abortion is never the right answer.”⁵¹ Such a belief does not indicate a willingness to empower women to make their own decisions.
- The Family Research Council report stated that “[w]omen much preferred Women’s Resource Center . . . or Loving Care Pregnancy Center . . . to names including the phrase ‘Crisis Pregnancy.’” Of the two preferred names, “Women’s Resource Center has more strategic value because it has a much higher appeal among pro-choice women. . . .”⁵²

- In Laramie, Wyoming, a center known for 11 years as The Crisis Pregnancy Center changed its name to the more neutral Albany County Caring Center although its mission continues to be “to demonstrate Christ’s love by offering life affirming alternatives to abortion.”⁵³

B. Crisis Pregnancy Centers are Changing Their Advertising Strategies.

Just as centers are broadening their appeal by choosing even more neutral names, they are also reshaping their advertising strategies in order to reach more women who may be considering abortion.

- Because home pregnancy tests are so widely and cheaply available at pharmacies everywhere for about \$10, women are not always drawn to CPCs by the offer of a free pregnancy test. Shari Plunkett recognizes that “women head straight to the store for a pregnancy test, and then straight to their doctors.” For this reason, Plunkett explains, “We need to advertise our services right next to the pregnancy tests.” However, she cautions that the “pharmacist is more likely to stock the card if it is written in neutral language that stresses giving accurate medical information and presenting ‘all options’ in a confidential, unpressured environment.”⁵⁴ These cards will continue to mislead women into thinking that the center will provide them with unbiased medical information on all reproductive options, including abortion, although the center is anti-choice and does not provide abortion referrals.
- In order to reach women who turn to their doctor rather than a CPC, The Family Research Council recommends “[i]ntentional marketing to the medical community to promote referrals” since it “holds enormous potential and could become a major source of new CPC clients.”⁵⁵
- Plunkett also encourages contacting doctors or HMOs to provide what she calls “pregnancy consulting” for their patients, similar to what her center, First Resort, had arranged with Kaiser Permanente.⁵⁶ In light of the fact that Kaiser severed its relationship with First Resort once pro-choice groups exposed the center’s anti-abortion position, National Right to Life Committee’s Western director Brian Johnston recommends that other “pro-life centers might want to contact individual physicians and try to start such a program, rather than go through an HMO, which is vulnerable to political pressure.”⁵⁷ Needless to say, it will be much harder for pro-choice groups like NARAL® and its affiliates to educate individual doctors than HMOs about the real nature of fake clinics.
- Another advertising strategy employed by proponents of crisis pregnancy centers involves billboards and signs with a toll-free number of a pregnancy hotline. The ads usually contain a neutral message that does not indicate that the people who answer the hotline only provide referrals to fake clinics, rather

than reproductive health clinics that provide abortions, and that their positions are solidly anti-choice. One woman looking for an abortion clinic called a hotline and said she was made to feel “like absolute dirt . . . he kept trying to change my mind, he wanted me to go [with] adoption. . . . I asked him if he could even give me a [number] of someone who would give me [information] on abortion, and he said ‘Our services are for women who are having their babies.’”⁵⁸ However, this restriction on services clearly was not indicated anywhere in the advertisement.

C. Crisis Pregnancy Centers Are Changing the Nature of the Services They Provide While Remaining Firm In Their Opposition to Abortion.

The Family Research Council (FRC) report acknowledges that the crisis pregnancy center movement needs to change and adapt its “ministry paradigm” without abandoning its core values, one of which is “a determination to spare unborn children from abortion.”⁵⁹

The report suggests changes which include: offering more medical services, downplaying the religious component of the counseling, ensuring continuity in terms of “counselors” that the woman sees each time she visits the center, and choosing different images for CPC brochures. These changes would appeal to a wider variety of unsuspecting women who are seeking a professional, secular clinic. Unfortunately, once inside these centers, the women will still be subjected to anti-choice propaganda.

- The report stated that “the case is strong for centers to provide or have immediate access to medical services”⁶⁰ as long as those services do not include abortion. Instead, the medical services provided should be consistent with the centers’ anti-choice goal, including seeking anti-choice physicians who would be willing to serve the center.
- Another example is the use of ultrasound equipment. In the National Right to Life News article, Shari Plunkett pushes for directors of CPCs to put ultrasounds in their centers, saying that “[b]ecause there is no more eloquent evidence of the humanity of the unborn child than the child herself seen on ultrasound heart beating strongly, wriggling and kicking. . . we cannot afford to dismiss the technology as beyond our reach.” Plunkett instructs centers to “[i]mplore hospitals, manufacturers of medical equipment, physicians, local parishioners, and other benefactors for help” and to find “one or more pro-life nurses who would be willing to be trained in ultrasonography and who could work part-time.”⁶¹
- Finding that women in the upper socioeconomic level “are particularly turned off by any suggestion of a connection between the center and religion,” the report recommends that centers adopt a “more clinical and professional focus

and probably, overall, less interference.” However, the report also acknowledges that the movement should never compromise on the principle of “a determination to witness for Christ through faithful lives, service, and words.”⁶²

- The FRC report suggests that centers stop using images featuring worried young women and instead use “after” photographs of the “satisfied customer.”⁶³

IV. Conclusion

Unfortunately, the assault on a woman’s right to choose posed by these fake clinics has gone largely unnoticed by a complacent public. Deceptive crisis pregnancy centers continue their campaign to misinform women about abortion and use any means necessary to prevent them from choosing to terminate their pregnancy. These centers are designed to intimidate women into carrying pregnancies to term rather than to provide accurate, comprehensive medical information with which pregnant women can make their own decisions. While there are centers which do not deceive women or attempt to coerce them to keep their child, many other centers continue to use deceptive practices in order to prevent women from accessing the full range of reproductive health options.

4/13/99

The NARAL Foundation would like to collect stories from women about their experiences or their friends’ experiences with these fake clinics. If you would like to share a story about an experience at a crisis pregnancy center, please send it to naral@naral.org or fax to (202) 973-3030.

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HR 3301 IH

106th CONGRESS

1st Session

H. R. 3301

To amend the Public Health Service Act with respect to children's health.

IN THE HOUSE OF REPRESENTATIVES

November 10, 1999

Mr. BILIRAKIS (for himself, Mr. BROWN of Ohio, Mrs. EMERSON, Mr. TOWNS, Mr. GREENWOOD, Mr. UPTON, Ms. DEGETTE, Mr. SMITH of New Jersey, Mr. WAXMAN, and Mr. WALSH) introduced the following bill; which was referred to the Committee on Commerce

A BILL

To amend the Public Health Service Act with respect to children's health.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the 'Children's Health Research and Prevention Amendments of 1999'.

SEC. 2. TABLE OF CONTENTS.

The table of contents for this Act is as follows:

Sec. 1. Short title.

Sec. 2. Table of contents.

TITLE I--REVISION AND EXTENSION OF PROGRAMS

Subtitle A--Pediatric Research Initiative

Sec. 101. Short title.

Sec. 102. Establishment of a pediatric research initiative.

Sec. 103. Investment in tomorrow's pediatric researchers.

Subtitle B--Other Programs

Sec. 111. Childhood immunizations.

Sec. 112. Screenings, referrals, and education regarding lead poisoning.

Sec. 113. Prevention and control of injuries; traumatic brain injury.

TITLE II--CHILDREN'S HEALTH RESEARCH AND PREVENTION ACTIVITIES

Subtitle A--Early Detection, Diagnosis, and Treatment Regarding Hearing Loss in Infants

Sec. 201. Short title.

Sec. 202. Early detection, diagnosis, and interventions for newborns and infants with hearing loss.

Subtitle B--Autism

Chapter 1--Surveillance and Research Regarding Prevalence and Pattern of Autism

Sec. 211. Short title.

Sec. 212. Developmental disabilities surveillance and research programs.

Sec. 213. Clearinghouse.

Sec. 214. Advisory committee.

Sec. 215. Report to Congress.

Sec. 216. Definition.

Sec. 217. Authorization of appropriations.

Chapter 2--Expansion, Intensification, and Coordination of Activities of Department of Health and Human Services With Respect to Autism

Sec. 218. Short title.

Sec. 218A. Expansion, intensification, and coordination of activities of National Institutes of Health.

Sec. 219. Developmental disabilities surveillance and research programs.

Sec. 220. Information and education.

Sec. 220A. Interagency autism coordinating committee.

Sec. 220B. Report to Congress.

Subtitle C--Poison Control Center Enhancement and Awareness

Sec. 221. Short title.

Sec. 222. Definition.

Sec. 223. Establishment of a national toll-free number.

Sec. 224. Establishment of nationwide media campaign.

Sec. 225. Establishment of a grant program.

Subtitle D--Birth Defects Prevention Activities

Chapter 1--Folic Acid Promotion

Sec. 231. Short title.

Sec. 232. Program regarding effects of folic acid in prevention of birth defects.

Chapter 2--National Center on Birth Defects and Developmental Disabilities

Sec. 236. National Center on Birth Defects and Developmental Disabilities.

Subtitle E--Safe Motherhood Monitoring and Prevention Research

Sec. 241. Short title.

Sec. 242. Amendment to Public Health Service Act.

Subtitle F--Pregnant Mothers and Infants Health Promotion

Sec. 251. Short title.

Sec. 252. Establishment.

Subtitle G--Utilization of Preventive Health Services

Sec. 261. Grants regarding utilization of preventive health services.

Subtitle H--Research and Development Regarding Fragile X

Sec. 266. Short title.

Sec. 267. National Institute of Child Health and Human Development; research on fragile X.

Sec. 268. National Institute of Child Health and Human Development; loan repayment program regarding research on fragile X.

Subtitle I--Children and Epilepsy

Sec. 271. Programs of the Centers for Disease Control and Prevention; national public health campaign on epilepsy.

Sec. 272. Programs of Health Resources and Services Administration; State and local grants for seizure disorder demonstration projects in medically underserved areas.

Sec. 273. Definitions.

Subtitle J--Asthma Treatment Services for Children

Sec. 276. Short title.

Sec. 277. Children's asthma relief.

Sec. 278. Incorporation of asthma prevention treatment and services into State children's health insurance programs.

Sec. 279. Preventive health and health services block grant; systems for reducing asthma and asthma-related illnesses through urban cockroach management.

Sec. 279A. Coordination of Federal activities to address asthma-related health care needs.

Sec. 279B. Compilation of data by the Centers for Disease Control and Prevention.

Subtitle K--Juvenile Arthritis and Related Conditions

Sec. 281. Research on juvenile arthritis and related conditions.

Subtitle L--Childhood Skeletal Malignancies

Sec. 286. Programs of Centers for Disease Control and Prevention.

Subtitle M--Reducing Burden of Diabetes Among Children and Youth

Sec. 291. Programs regarding diabetes in children and youth.

Subtitle N--Miscellaneous Provisions

Sec. 296. Report regarding research on rare diseases in children.

TITLE I--REVISION AND EXTENSION OF PROGRAMS

Subtitle A--Pediatric Research Initiative

SEC. 101. SHORT TITLE.

This subtitle may be cited as the 'Pediatric Research Initiative Act of 1999'.

SEC. 102. ESTABLISHMENT OF A PEDIATRIC RESEARCH INITIATIVE.

Part A of title IV of the Public Health Service Act (42 U.S.C. 281 et seq.) is amended by adding at the end the following:

'SEC. 404F. PEDIATRIC RESEARCH INITIATIVE.

'(a) ESTABLISHMENT- The Secretary shall establish within the Office of the Director of NIH a Pediatric Research Initiative (referred to in this section as the 'Initiative'). The Initiative shall be headed by the Director of NIH.

'(b) PURPOSE- The purpose of the Initiative is to provide funds to enable the Director of NIH to encourage--

'(1) increased support for pediatric biomedical research within the National Institutes of Health to ensure that the expanding opportunities for advancement in scientific investigations and care for children are realized;

'(2) enhanced collaborative efforts among the Institutes to support multidisciplinary research in the areas that the Director deems most promising; and

★ || '(3) the development of adequate pediatric clinical trials and pediatric use information to promote the safer and more effective use of prescription drugs in the pediatric population.

'(c) DUTIES- In carrying out subsection (b), the Director of NIH shall--

'(1) consult with the Institute of Child Health and Human Development and the other Institutes, in considering their requests for new or expanded pediatric research efforts, and consult with other advisors as the Director determines appropriate;

'(2) have broad discretion in the allocation of any Initiative assistance among the Institutes, among types of grants, and between basic and clinical research so long as the--

'(A) assistance is directly related to the illnesses and conditions of children; and

'(B) assistance is extramural in nature; and

'(3) be responsible for the oversight of any newly appropriated Initiative funds and annually report to Congress and the public on the extent of the total extramural support for pediatric research across the NIH, including the specific support and research awards allocated through the Initiative.

'(d) AUTHORIZATION- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

'(e) TRANSFER OF FUNDS- The Director of NIH may transfer amounts appropriated under this

section to any of the Institutes for a fiscal year to carry out the purposes of the Initiative under this section.’.

SEC. 103. INVESTMENT IN TOMORROW’S PEDIATRIC RESEARCHERS.

Subpart 7 of part C of title IV of the Public Health Service Act (42 U.S.C. 285g et seq.) is amended by adding at the end the following:

‘SEC. 452E. INVESTMENT IN TOMORROW’S PEDIATRIC RESEARCHERS.

‘(a) IN GENERAL- The Secretary shall make available within the National Institute of Child Health and Human Development enhanced support for extramural activities relating to the training and career development of pediatric researchers.

‘(b) PURPOSE- The purpose of support provided under subsection (a) shall be to ensure the future supply of researchers dedicated to the care and research needs of children by providing for--

 ‘(1) an increase in the number and size of institutional training grants to medical school pediatric departments and children’s hospitals; and

 ‘(2) an increase in the number of career development awards for pediatricians building careers in pediatric basic and clinical research.

‘(c) AUTHORIZATION- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.’.

Subtitle B--Other Programs

SEC. 111. CHILDHOOD IMMUNIZATIONS.

Section 317(j)(1) of the Public Health Service Act (42 U.S.C. 247b(j)(1)) is amended in the first sentence by striking ‘1998’ and all that follows and inserting ‘1998 through 2003.’.

SEC. 112. SCREENINGS, REFERRALS, AND EDUCATION REGARDING LEAD POISONING.

Section 317A(l)(1) of the Public Health Service Act (42 U.S.C. 247b-1(l)(1)) is amended by striking ‘1994’ and all that follows and inserting ‘1994 through 2003.’.

SEC. 113. PREVENTION AND CONTROL OF INJURIES; TRAUMATIC BRAIN INJURY.

Section 394A of the Public Health Service Act (42 U.S.C. 280b-3) is amended by striking ‘and’ after ‘1994’ and by inserting before the period the following: ‘, and such sums as may be necessary for each of the fiscal years 2000 through 2003.’.

TITLE II--CHILDREN’S HEALTH RESEARCH AND PREVENTION ACTIVITIES

Subtitle A--Early Detection, Diagnosis, and Treatment Regarding Hearing Loss in Infants

SEC. 201. SHORT TITLE.

This subtitle may be cited as the 'Newborn and Infant Hearing Screening and Intervention Act of 1999'.

SEC. 202. EARLY DETECTION, DIAGNOSIS, AND INTERVENTIONS FOR NEWBORNS AND INFANTS WITH HEARING LOSS.

(a) **DEFINITIONS-** For the purposes of this subtitle only, the following terms in this section are defined as follows:

(1) **HEARING SCREENING-** Newborn and infant hearing screening consists of objective physiologic procedures to detect possible hearing loss and to identify newborns and infants who, after rescreening, require further audiologic and medical evaluations.

(2) **AUDIOLOGIC EVALUATION-** Audiologic evaluation consists of procedures to assess the status of the auditory system; to establish the site of the auditory disorder; the type and degree of hearing

loss, and the potential effects of hearing loss on communication; and to identify appropriate treatment and referral options. Referral options should include linkage to state IDEA Part C coordinating agencies or other appropriate agencies, medical evaluation, hearing aid/sensory aid assessment, audiologic rehabilitation treatment, national and local consumer, self-help, parent, and education organizations, and other family-centered services.

(3) **MEDICAL EVALUATION-** Medical evaluation by a physician consists of key components including history, examination, and medical decision making focused on symptomatic and related body systems for the purpose of diagnosing the etiology of hearing loss and related physical conditions, and for identifying appropriate treatment and referral options.

(4) **MEDICAL INTERVENTION-** Medical intervention is the process by which a physician provides medical diagnosis and direction for medical and/or surgical treatment options of hearing loss and/or related medical disorder associated with hearing loss.

(5) **AUDIOLOGIC REHABILITATION-** Audiologic rehabilitation (intervention) consists of procedures, techniques, and technologies to facilitate the receptive and expressive communication abilities of a child with hearing loss.

(6) **EARLY INTERVENTION-** Early intervention (e.g., nonmedical) means providing appropriate services for the child with hearing loss and ensuring that families of the child are provided comprehensive, consumer-oriented information about the full range of family support, training, information services, communication options and are given the opportunity to consider the full range of educational and program placements and options for their child.

(b) **PURPOSES-** The purposes of this subtitle are to clarify the authority within the Public Health Service Act to authorize statewide newborn and infant hearing screening, evaluation and intervention programs and systems, technical assistance, a national applied research program, and interagency and private sector collaboration for policy development, in order to assist the States in

making progress toward the following goals:

- (1) All babies born in hospitals in the United States and its territories should have a hearing screening before leaving the birthing facility. Babies born in other countries and residing in the United States via immigration or adoption should have a hearing screening as early as possible.
- (2) All babies who are not born in hospitals in the United States and its territories should have a hearing screening within the first 3 months of life.
- (3) Appropriate audiologic and medical evaluations should be conducted by 3 months for all newborns and infants suspected of having hearing loss to allow appropriate referral and provisions for audiologic rehabilitation, medical and early intervention before the age of 6 months.
- (4) All newborn and infant hearing screening programs and systems should include a component for audiologic rehabilitation, medical and early intervention options that ensures linkage to any new and existing state-wide systems of intervention and rehabilitative services for newborns and infants with hearing loss.
- (5) Public policy in regard to newborn and infant hearing screening and intervention should be based on applied research and the recognition that newborns, infants, toddlers, and children who are deaf or hard-of-hearing have unique language, learning, and communication needs, and should be the result of consultation with pertinent public and private sectors.

(c) **STATEWIDE NEWBORN AND INFANT HEARING SCREENING, EVALUATION AND INTERVENTION PROGRAMS AND SYSTEMS-** The Secretary of Health and Human Services (in this subtitle referred to as the 'Secretary'), acting through the Administrator of the Health Resources and Services Administration, shall make awards of grants or cooperative agreements to develop statewide newborn and infant hearing screening, evaluation and intervention programs and systems for the following purposes:

- (1) To develop and monitor the efficacy of state-wide newborn and infant hearing screening, evaluation and intervention programs and systems. Early intervention includes referral to schools and agencies, including community, consumer, and parent-based agencies and organizations and other programs mandated by Part C of the Individuals with Disabilities Education Act, which offer programs specifically designed to meet the unique language and communication needs of deaf and hard of hearing newborns, infants, toddlers, and children.
- (2) To collect data on statewide newborn and infant hearing screening, evaluation and intervention programs and systems that can be used for applied research, program evaluation and policy development.

(d) **TECHNICAL ASSISTANCE, DATA MANAGEMENT, AND APPLIED RESEARCH-**

- (1) **CENTERS FOR DISEASE CONTROL AND PREVENTION-** The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall make awards of grants or cooperative agreements to provide technical assistance to State agencies to complement an intramural program and to conduct applied research related to newborn and infant hearing screening, evaluation and intervention programs and systems. The program

shall develop standardized procedures for data management and program effectiveness and costs, such as--

(A) to ensure quality monitoring of newborn and infant hearing loss screening, evaluation, and intervention programs and systems;

(B) to provide technical assistance on data collection and management;

(C) to study the costs and effectiveness of newborn and infant hearing screening, evaluation and intervention programs and systems conducted by State-based programs in order to

answer issues of importance to state and national policymakers;

(D) to identify the causes and risk factors for congenital hearing loss;

(E) to study the effectiveness of newborn and infant hearing screening, audiologic and medical evaluations and intervention programs and systems by assessing the health, intellectual and social developmental, cognitive, and language status of these children at school age; and

(F) to promote the sharing of data regarding early hearing loss with state-based birth defects and developmental disabilities monitoring programs for the purpose of identifying previously unknown causes of hearing loss.

(2) NATIONAL INSTITUTES OF HEALTH- The Director of the National Institutes of Health, acting through the Director of the National Institute on Deafness and Other Communication Disorders, shall for purposes of this section, continue a program of research and development on the efficacy of new screening techniques and technology, including clinical studies of screening methods, studies on efficacy of intervention, and related research.

(e) COORDINATION AND COLLABORATION-

(1) IN GENERAL- In carrying out programs under this section, the Administrator of the Health Resources and Services Administration, the Director of the Centers for Disease Control and Prevention, and the Director of the National Institutes of Health shall collaborate and consult with other Federal agencies; State and local agencies, including those responsible for early intervention services pursuant to Title XIX of the Social Security Act (Medicaid Early and Periodic Screening, Diagnosis and Treatment Program); Title XXI of the Social Security Act (State Children's Health Insurance Program); Title V of the Social Security Act (Maternal and Child Health Block Grant Program; and Part C of the Individuals with Disabilities Education Act); consumer groups of and that serve individuals who are deaf and hard-of-hearing and their families; appropriate national medical and other health and education specialty organizations; persons who are deaf and hard-of-hearing and their families; other qualified professional personnel who are proficient in deaf or hard-of-hearing children's language and who possess the specialized knowledge, skills, and attributes needed to serve deaf and hard-of-hearing newborns, infants, toddlers, children, and their families; third-party payers and managed care organizations; and related commercial industries.

(2) POLICY DEVELOPMENT- The Administrator of the Health Resources and Services

Administration, the Director of the Centers for Disease Control and Prevention, and the Director of the National Institutes of Health shall coordinate and collaborate on recommendations for policy development at the Federal and state levels and with the private sector, including consumer, medical and other health and education professional-based organizations, with respect to newborn and infant hearing screening, evaluation and intervention programs and systems.

(3) STATE EARLY DETECTION, DIAGNOSIS, AND INTERVENTION PROGRAMS AND SYSTEMS; DATA COLLECTION- The Administrator of the Health Resources and Services Administration and the Director of the Centers for Disease Control and Prevention shall coordinate and collaborate in assisting States to establish newborn and infant hearing screening, evaluation and intervention programs and systems under subsection (c) and to develop a data collection system under subsection (d).

(f) RULE OF CONSTRUCTION- Nothing in this subtitle shall be construed to preempt any State law.

(g) AUTHORIZATION OF APPROPRIATIONS-

(1) STATEWIDE NEWBORN AND INFANT HEARING SCREENING, EVALUATION AND INTERVENTION PROGRAMS AND SYSTEMS- For the purpose of carrying out subsection (c), there are authorized to be appropriated to the Health Resources and Services Administration such sums as may be necessary for each of the fiscal years 2000 through 2003.

(2) TECHNICAL ASSISTANCE, DATA MANAGEMENT, AND APPLIED RESEARCH; CENTERS FOR DISEASE CONTROL AND PREVENTION- For the purpose of carrying out subsection (d)(1), there are authorized to be appropriated to the Centers for Disease Control and Prevention such sums as may be necessary for each of the fiscal years 2000 through 2003.

(3) TECHNICAL ASSISTANCE, DATA MANAGEMENT, AND APPLIED RESEARCH; NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS- For the purpose of carrying out subsection (d)(2), there are authorized to be appropriated to the National Institute on Deafness and Other Communication Disorders such sums as may be necessary for each of the fiscal years 2000 through 2003.

Subtitle B--Autism

CHAPTER 1--SURVEILLANCE AND RESEARCH REGARDING PREVALENCE AND PATTERN OF AUTISM

SEC. 211. SHORT TITLE.

This chapter may be cited as the 'Autism Statistics, Surveillance, Research, and Epidemiology Act of 1999 (ASSURE)'.

SEC. 212. DEVELOPMENTAL DISABILITIES SURVEILLANCE AND RESEARCH PROGRAMS.

(a) NATIONAL AUTISM AND PERVASIVE DEVELOPMENTAL DISABILITIES SURVEILLANCE PROGRAM- The Secretary of Health and Human Services (in this chapter

referred to as the 'Secretary'), acting through the Director of the Centers for Disease Control and Prevention, may make awards of grants and cooperative agreements for the collection, analysis, and reporting of data on autism and pervasive developmental disabilities. An entity may receive such an award only if the entity is a public or nonprofit private entity (including health departments of States and political subdivisions of States, and including universities and other educational entities). In making

such awards, the Secretary may provide direct technical assistance in lieu of cash.

(b) CENTERS OF EXCELLENCE IN AUTISM AND PERVASIVE DEVELOPMENTAL DISABILITIES EPIDEMIOLOGY-

(1) **IN GENERAL-** The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall (subject to the extent of amounts made available in appropriations Acts) establish not less than three, and not more than five, regional centers of excellence in autism and pervasive developmental disabilities epidemiology for the purpose of collecting and analyzing information on the number, incidence, correlates, and causes of autism and related developmental disabilities.

(2) **RECIPIENTS OF AWARDS FOR ESTABLISHMENT OF CENTERS-** Centers under paragraph (1) shall be established and operated through the award of grants or cooperative agreements to public or nonprofit private entities that conduct research, including health departments of States and political subdivisions of States, and including universities and other educational entities.

(3) **CERTAIN REQUIREMENTS-** An award for a center under paragraph (1) may be made only if the entity involved submits to the Secretary an application containing such agreements and information as the Secretary may require, including an agreement that the center involved will operate in accordance with the following:

(A) The center will collect, analyze, and report autism and pervasive developmental disabilities data according to guidelines prescribed by the Director, after consultation with relevant State and local public health officials, private sector developmental disability researchers, and advocates for those with developmental disabilities;

(B) The center will assist with the development and coordination of State autism and pervasive developmental disabilities surveillance efforts within a region;

(C) The center will provide education, training, and clinical skills improvement for health professionals aimed at better understanding and treatment of autism and related developmental disabilities; and

(D) The center will identify eligible cases and controls through its surveillance systems and conduct research into factors which may cause autism and related developmental disabilities; each program will develop or extend an area of special research expertise (including, but not limited to, genetics, environmental exposure to contaminants, immunology, and other relevant research specialty areas).

SEC. 213. CLEARINGHOUSE.

The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall carry out the following:

- (1) The Centers for Disease Control and Prevention shall serve as the coordinating agency for autism and pervasive developmental disabilities surveillance activities through the establishment of a clearinghouse for the collection and storage of data generated from the monitoring programs created by this chapter. The functions of such a clearinghouse shall include facilitating the coordination of research and policy development relating to the epidemiology of autism and other pervasive developmental disabilities.
- (2) The Secretary, acting through the Centers for Disease Control and Prevention, shall coordinate the Federal response to requests for assistance from State health department officials regarding potential or alleged autism or developmental disability clusters.

SEC. 214. ADVISORY COMMITTEE.

(a) IN GENERAL- The Secretary shall establish an Advisory Committee for Autism and Pervasive Developmental Disabilities Epidemiology Research (in this section referred to as the 'Committee'). The Committee shall provide advice and recommendations to the Director of the Centers for Disease Control and Prevention on--

- (1) the establishment of a national autism and pervasive developmental disabilities surveillance program;
- (2) the establishment of centers of excellence in autism and pervasive developmental disabilities epidemiology;
- (3) methods and procedures to more effectively coordinate government and non-government programs and research on autism and pervasive developmental disabilities epidemiology; and
- (4) the effective operation of autism and pervasive developmental disabilities epidemiology research activities.

(b) COMPOSITION-

(1) IN GENERAL- The Committee shall be composed of ex officio members in accordance with paragraph (2) and 11 appointed members in accordance with paragraph (3).

(2) EX OFFICIO MEMBERS- The following officials shall serve as ex officio members of the Committee:

- (A) The Director of the National Center for Environmental Health.
- (B) The Assistant Administrator of the Agency for Toxic Substances and Disease Registry.
- (C) The Director of the National Institute of Child Health and Human Development.
- (D) The Director of the National Institute of Neurological Disorders and Stroke.

(3) **APPOINTED MEMBERS-** Appointments to the Committee shall be made in accordance with the following:

(A) Two members shall be research scientists with demonstrated achievements in research related to autism and related developmental disabilities. The scientists shall be appointed by the Secretary in consultation with the National Academy of Sciences.

(B) Five members shall be representatives of the five national organizations whose primary

emphasis is on research into autism and other pervasive developmental disabilities. One representative from each of such organizations shall be appointed by the Secretary in consultation with the National Academy of Sciences.

(C) Two members shall be clinicians whose practice is primarily devoted to the treatment of individuals with autism and other pervasive developmental disabilities. The clinicians shall be appointed by the Secretary in consultation with the Institute of Medicine and the National Academy of Sciences.

(D) Two members shall be individuals who are the parents or legal guardians of a person or persons with autism or other pervasive developmental disabilities. The individuals shall be appointed by the Secretary in consultation with the ex officio members under paragraph (1) and the five national organizations referred to in subparagraph (B).

(c) **ADMINISTRATIVE SUPPORT; TERMS OF SERVICE; OTHER PROVISIONS-** The following apply with respect to the Committee:

(1) The Committee shall receive necessary and appropriate administrative support from the Department of Health and Human Services.

(2) Members of the Committee shall be appointed for a term of three years, and may serve for an unlimited number of terms if reappointed.

(3) The Committee shall meet no less than two times per year.

(4) Members of the Committee shall not receive additional compensation for their service. Such members may receive reimbursement for appropriate and additional expenses that are incurred through service on the Committee which would not have incurred had they not been a member of the Committee.

SEC. 215. REPORT TO CONGRESS.

The Secretary shall prepare and submit to the Congress, after consultation and comment by the Advisory Committee, an annual report regarding the prevalence and incidence of autism and other pervasive developmental disorders, the results of research into the etiology of autism and other pervasive developmental disorders, public health responses to known or preventable causes of autism and other pervasive developmental disorders, and the need for additional research into promising lines of scientific inquiry.

SEC. 216. DEFINITION.

For purposes of this chapter, the term 'State' means each of the several States, the District of Columbia, the Commonwealth of Puerto Rico, American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, the Virgin Islands, and the Trust Territory of the Pacific Islands.

SEC. 217. AUTHORIZATION OF APPROPRIATIONS.

For the purpose of carrying out this chapter, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

CHAPTER 2--EXPANSION, INTENSIFICATION, AND COORDINATION OF ACTIVITIES OF DEPARTMENT OF HEALTH AND HUMAN SERVICES WITH RESPECT TO AUTISM

SEC. 218. SHORT TITLE.

This Act may be cited as the 'Advancement in Pediatric Autism Research Act of 1999'.

SEC. 218A. EXPANSION, INTENSIFICATION, AND COORDINATION OF ACTIVITIES OF NATIONAL INSTITUTES OF HEALTH.

Part B of title IV of the Public Health Service Act (42 U.S.C. 284 et seq.) is amended by adding at the end the following section:

'AUTISM

'SEC. 409C. (a) IN GENERAL-

'(1) EXPANSION OF ACTIVITIES- The Director of NIH (in this section referred to as the 'Director') shall expand, intensify, and coordinate the activities of the National Institutes of Health with respect to research on autism.

'(2) ADMINISTRATION OF PROGRAM; COLLABORATION AMONG AGENCIES- The Director shall carry out this section acting through the Director of the National Institute of Mental Health and in collaboration with any other agencies that the Director determines appropriate.

'(b) CENTERS OF EXCELLENCE-

'(1) IN GENERAL- The Director shall under subsection (a)(1) make awards of grants and contracts to public or nonprofit private entities to pay all or part of the cost of planning, establishing, improving, and providing basic operating support for centers of excellence regarding research on autism.

'(2) RESEARCH- Each center under paragraph (1) shall conduct basic and clinical research into autism. Such research should include investigations into the cause, diagnosis, early detection, prevention, control, and treatment of autism. These centers, as a group, shall conduct research including but not limited to the fields of developmental neurobiology,

genetics, and psychopharmacology.

‘(3) SERVICES FOR PATIENTS- A center under paragraph (1) may expend amounts provided under such paragraph to carry out a program to make individuals aware of opportunities to participate as subjects in research conducted by the centers. The program may, in accordance with such criteria as the Director may establish, provide to such subjects referrals for health and other services, and such patient care costs as are required for research. The extent to which the center can demonstrate availability and access to clinical services shall be considered by the Director in decisions about awarding the grants to applicants which meet the scientific criteria for funding.

‘(4) COORDINATION OF CENTERS; REPORTS- The Director shall, as appropriate, provide for the coordination of information among centers under

paragraph (1) and ensure regular communication between such centers, and may require the periodic preparation of reports on the activities of the centers and the submission of the reports to the Director.

‘(5) ORGANIZATION OF CENTERS- Each center under paragraph (1) shall use the facilities of a single institution, or be formed from a consortium of cooperating institutions, meeting such requirements as may be prescribed by the Director.

‘(6) NUMBER OF CENTERS; DURATION OF SUPPORT- The Director shall provide for the establishment of not less than five centers under paragraph (1). Support of such a center may be for a period not exceeding 5 years. Such period may be extended for one or more additional periods not exceeding 5 years if the operations of such center have been reviewed by an appropriate technical and scientific peer review group established by the Director and if such group has recommended to the Director that such period should be extended.

‘(c) FACILITATION OF RESEARCH- The Director shall under subsection (a)(1) provide for a program under which samples of tissues and genetic materials that are of use in research on autism are donated, collected, preserved, and made available for such research. The program shall be carried out in accordance with accepted scientific and medical standards for the donation, collection, and preservation of such samples.

‘(d) PUBLIC INPUT- The Director shall under subsection (a)(1) provide for means through which the public can obtain information on the existing and planned programs and activities of the National Institutes of Health with respect to autism and through which the Director can receive comments from the public regarding such programs and activities.

‘(e) FUNDING- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003. Such authorizations of appropriations are in addition to any other authorization of appropriations that is available for such purpose.’.

SEC. 219. DEVELOPMENTAL DISABILITIES SURVEILLANCE AND RESEARCH PROGRAMS.

(a) NATIONAL AUTISM AND PERVASIVE DEVELOPMENTAL DISABILITIES SURVEILLANCE PROGRAM- The Secretary of Health and Human Services (in this chapter referred to as the ‘Secretary’), acting through the Director of the Centers for Disease Control and

Prevention, may make awards of grants and cooperative agreements for the collection, analysis, and reporting of data on autism and pervasive developmental disabilities. An entity may receive such an award only if the entity is a public or nonprofit private entity (including health departments of States and political subdivisions of States, and including universities and other educational entities). In making such awards, the Secretary may provide direct technical assistance in lieu of cash.

(b) CENTERS OF EXCELLENCE IN AUTISM AND PERVASIVE DEVELOPMENTAL DISABILITIES EPIDEMIOLOGY-

(1) **IN GENERAL-** The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall establish not less than 3, regional centers of excellence in autism and pervasive developmental disabilities epidemiology for the purpose of collecting and analyzing information on the number, incidence, correlates, and causes of autism and related developmental disabilities.

(2) **RECIPIENTS OF AWARDS FOR ESTABLISHMENT OF CENTERS-** Centers under paragraph (1) shall be established and operated through the awarding of grants or cooperative agreements to public or nonprofit private entities that conduct research, including health departments of States and political subdivisions of States, and including universities and other educational entities.

(3) **CERTAIN REQUIREMENTS-** An award for a center under paragraph (1) may be made only if the entity involved submits to the Secretary an application containing such agreements and information as the Secretary may require, including an agreement that the center involved will operate in accordance with the following:

(A) The center will collect, analyze, and report autism and pervasive developmental disabilities data according to guidelines prescribed by the Director, after consultation with relevant State and local public health officials, private sector developmental disability researchers, and advocates for those with developmental disabilities.

(B) The center will assist with the development and coordination of State autism and pervasive developmental disabilities surveillance efforts within a region.

(C) The center will identify eligible cases and controls through its surveillance systems and conduct research into factors which may cause autism and related developmental disabilities. Each program will develop or extend an area of special research expertise (including genetics, environmental exposure to contaminants, immunology, and other relevant research specialty areas).

(c) CLEARINGHOUSE- The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall carry out the following:

(1) The Secretary shall establish a clearinghouse within the Centers for Disease Control and Prevention for the collection and storage of data generated from the monitoring programs created by this chapter. Through the clearinghouse, such Centers shall serve as the coordinating agency for autism and pervasive developmental disabilities surveillance activities. The functions of such a clearinghouse shall include facilitating the coordination of research and policy development relating to the epidemiology of autism and other pervasive developmental disabilities.

(2) The Secretary, acting through the Centers for Disease Control and Prevention, shall coordinate the Federal response to requests for assistance from State health department officials regarding potential

or alleged autism or developmental disability clusters.

(d) DEFINITION- In this chapter, the term 'State' means each of the several States, the District of Columbia, the Commonwealth of Puerto Rico, American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, the Virgin Islands, and the Trust Territory of the Pacific Islands.

(e) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

SEC. 220. INFORMATION AND EDUCATION.

(a) IN GENERAL- The Secretary shall establish and implement a program to provide information and education on autism to health professionals and the general public, including information and education on advances in the diagnosis and treatment of autism and training and continuing education through programs for scientists, physicians, and other health professionals who provide care for patients with autism.

(b) STIPENDS- The Secretary may use amounts made available under this section to provide stipends for health professionals who are enrolled in training programs under this section.

(c) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

SEC. 220A. INTERAGENCY AUTISM COORDINATING COMMITTEE.

(a) ESTABLISHMENT- The Secretary shall establish a committee to be known as the 'Autism Coordinating Committee' (in this section referred to as the 'Committee') to coordinate all efforts within the Department of Health and Human Services concerning autism, including activities carried out through the National Institutes of Health and the Centers for Disease Control and Prevention under this chapter (and the amendment made by this chapter).

(b) MEMBERSHIP-

(1) IN GENERAL- The Committee shall be composed of the Directors of such national research institutes, of the Centers for Disease Control and Prevention, and of such other agencies and such other officials as the Secretary determines appropriate.

(2) ADDITIONAL MEMBERS- If determined appropriate by the Secretary, the Secretary may appoint to the Committee--

(A) parents or legal guardians of individuals with autism or other pervasive developmental disorders; and

(B) representatives of other governmental agencies that serve children with autism such as the Department of Education.

(c) ADMINISTRATIVE SUPPORT; TERMS OF SERVICE; OTHER PROVISIONS- The following shall apply with respect to the Committee:

(1) The Committee shall receive necessary and appropriate administrative support from the Department of Health and Human Services.

(2) Members of the Committee appointed under subsection (b)(2)(A) shall serve for a term of 3 years, and may serve for an unlimited number of terms if reappointed.

(3) The Committee shall meet not less than 2 times per year.

SEC. 220B. REPORT TO CONGRESS.

Not later than January 1, 2000, and each January 1 thereafter, the Secretary shall prepare and submit to the appropriate committees of Congress, a report concerning the implementation of this chapter and the amendments made by this chapter.

Subtitle C--Poison Control Center Enhancement and Awareness

SEC. 221. SHORT TITLE.

This subtitle may be cited as the 'Poison Control Center Enhancement and Awareness Act'.

SEC. 222. DEFINITION.

For purposes of this subtitle, the term 'Secretary' means the Secretary of Health and Human Services.

SEC. 223. ESTABLISHMENT OF A NATIONAL TOLL-FREE NUMBER.

(a) IN GENERAL- The Secretary shall provide coordination and assistance to regional poison control centers for the establishment of a nationwide toll-free phone number to be used to access such centers.

(b) RULE OF CONSTRUCTION- Nothing in this section shall be construed as prohibiting the establishment or continued operation of any privately funded nationwide toll-free phone number used to provide advice and other assistance for poisonings or accidental exposures.

(c) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003. Funds appropriated under this subsection shall not be used to fund any toll-free phone number described in subsection (b).

SEC. 224. ESTABLISHMENT OF NATIONWIDE MEDIA CAMPAIGN.

(a) IN GENERAL- The Secretary shall establish a national media campaign to educate the public and health care providers about poison prevention and the availability of poison control resources in

local communities and to conduct advertising campaigns concerning the nationwide toll-free number established under section 223.

(b) **CONTRACT WITH ENTITY-** The Secretary may carry out subsection (a) by entering into contracts with 1 or more nationally recognized media firms for the development and distribution of monthly television, radio, and newspaper public service announcements.

(c) **AUTHORIZATION OF APPROPRIATIONS-** For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

SEC. 225. ESTABLISHMENT OF A GRANT PROGRAM.

(a) **REGIONAL POISON CONTROL CENTERS-** The Secretary shall award grants to certified regional poison control centers for the purposes of achieving the financial stability of such centers, and for preventing and providing treatment recommendations for poisonings.

(b) **OTHER IMPROVEMENTS-** The Secretary shall also use amounts received under this section to--

- (1) develop standard education programs;
- (2) develop standard patient management protocols for commonly encountered toxic exposures;
- (3) improve and expand the poison control data collection systems;
- (4) improve national toxic exposure surveillance; and
- (5) expand the physician/medical toxicologist supervision of poison control centers.

(c) **CERTIFICATION-** Except as provided in subsection (d), the Secretary may make a grant to a center under subsection (a) only if--

- (1) the center has been certified by a professional organization in the field of poison control, and the Secretary has approved the organization as having in effect standards for certification that reasonably provide for the protection of the public health with respect to poisoning; or
- (2) the center has been certified by a State government, and the Secretary has approved the State government as having in effect standards for certification that reasonably provide for the protection of the public health with respect to poisoning.

(d) **WAIVER OF CERTIFICATION REQUIREMENTS-**

- (1) **IN GENERAL-** The Secretary may grant a waiver of the certification requirement of subsection (c) with respect to a noncertified poison control center or a newly established center that applies for a grant under this section if such center can reasonably demonstrate that the center will obtain such a certification within a reasonable period of time as determined appropriate by the Secretary.

(2) RENEWAL- The Secretary may only renew a waiver under paragraph (1) for a period of 3 years.

(e) SUPPLEMENT NOT SUPPLANT- Amounts made available to a poison control center under this section shall be used to supplement and not supplant other Federal, State, or local funds provided for such center.

(f) MAINTENANCE OF EFFORT- A poison control center, in utilizing the proceeds of a grant under this section, shall maintain the expenditures of the center for activities of the center at a level that is not less than the level of such expenditures maintained by the center for the fiscal year preceding the fiscal year for which the grant is received.

(g) MATCHING REQUIREMENT- The Secretary may impose a matching requirement with respect to amounts provided under a grant under this section if the Secretary determines appropriate.

(h) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

Subtitle D--Birth Defects Prevention Activities

CHAPTER 1--FOLIC ACID

SEC. 231. SHORT TITLE.

This chapter may be cited as the 'Folic Acid Promotion and Birth Defects Prevention Act of 1999'.

SEC. 232. PROGRAM REGARDING EFFECTS OF FOLIC ACID IN PREVENTION OF BIRTH DEFECTS.

Part B of title III of the Public Health Service Act (42 U.S.C. 243 et seq.) is amended by inserting after section 317G the following section:

'EFFECTS OF FOLIC ACID IN PREVENTION OF BIRTH DEFECTS

'SEC. 317H. (a) IN GENERAL- The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall carry out a program (directly or through grants or contracts) for the following purposes:

'(1) To provide education and training for health professionals and the general public for purposes of explaining the effects of folic acid in preventing birth defects and for purposes of encouraging each woman of reproductive capacity (whether or not planning a pregnancy) to consume on a daily basis a dietary supplement that provides an appropriate level of folic acid.

'(2) To conduct research with respect to such education and training, including identifying effective strategies for increasing the rate of consumption of folic acid by women of reproductive capacity.

‘(3) To conduct research to increase the understanding of the effects of folic acid in preventing birth defects, including understanding with respect to cleft lip, cleft palate, and heart defects.

‘(4) To provide for appropriate epidemiological activities regarding folic acid and birth defects, including epidemiological activities regarding neural tube defects.

‘(b) CONSULTATIONS WITH STATES AND PRIVATE ENTITIES- In carrying out subsection (a), the Secretary shall consult with the States and with other appropriate public or private entities, including national nonprofit private organizations, health professionals, and providers of health insurance and health plans.

‘(c) TECHNICAL ASSISTANCE- The Secretary may (directly or through grants or contracts) provide technical assistance to public and nonprofit private entities in carrying out the activities described in subsection (a).

‘(d) EVALUATIONS- The Secretary shall (directly or through grants or contracts) provide for the evaluation of activities under subsection (a) in order to determine the extent to which such activities have been effective in carrying out the purposes of the program under such subsection, including the effects on various demographic populations. Methods of evaluation under the preceding sentence may include surveys of knowledge and attitudes on the consumption of folic acid and on blood folate levels. Such methods may include complete and timely monitoring of infants who are born with neural tube defects.

‘(e) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.’.

CHAPTER 2--NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

SEC. 236. NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES.

Title III of the Public Health Service Act (42 U.S.C. 241 et seq.) is amended--

(1) in part O--

(A) by redesignating sections 399G through 399J as sections 399M through 399P, respectively;

(B) in section 399O(b) (as so redesignated), by striking ‘section 399G(d)’ and inserting ‘section 399M(d)’; and

(C) in section 399P (as so redesignated), by striking ‘section 399G(d)(1)’ and inserting ‘section 399M(d)(1)’; and

(2) by adding at the end the following part:

‘Part P--Pediatric Public Health Promotion

‘SEC. 399Q. NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES.

‘(a) ESTABLISHMENT- There is established within the Centers for Disease Control and Prevention a center to be known as the National Center on Birth Defects and Developmental Disabilities.

‘(b) PURPOSE- The general purpose of the National Center established under subsection (a) shall be to--

‘(1) collect, analyze, and make available data on birth defects, including data on the causes of such defects and on the incidence and prevalence of such defects;

‘(2) conduct applied epidemiological research on the prevention of such defects; and

‘(3) provide information and education to the public on the prevention of such defects.

‘(c) DIRECTOR- The National Center established under subsection (a) shall be headed by a director to be appointed by the Secretary.

‘(d) TRANSFERS- There shall be transferred to the National Center established under subsection (a) all activities, budgets and personnel of the National Center for Environmental Health that relate to birth defects, folic acid, cerebral palsy, mental retardation, child development, newborn screening, autism, fragile X syndrome, fetal alcohol syndrome, pediatric genetics, and disability prevention.

‘(e) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.’.

Subtitle E--Safe Motherhood Monitoring and Prevention Research

SEC. 241. SHORT TITLE.

This subtitle may be cited as the ‘Safe Motherhood Monitoring and Prevention Research Act’.

SEC. 242. AMENDMENT TO PUBLIC HEALTH SERVICE ACT.

Title III of the Public Health Service Act, as amended by section 236 of this Act, is amended by adding at the end the following part:

‘Part Q--Safe Motherhood

‘SEC. 399R. SAFE MOTHERHOOD MONITORING.

‘(a) PURPOSE- It is the purpose of this section to develop monitoring systems at the local, State, and national level to better understand the burden of maternal complications and mortality and to decrease the disparities among population at risk of death and complications from pregnancy.

‘(b) ACTIVITIES- For the purpose described in subsection (a), the Secretary may carry out the following activities:

‘(1) The Secretary may establish and implement a national monitoring and surveillance program to identify and promote the investigation of deaths and severe complications that occur during pregnancy.

‘(2) The Secretary may expand the Pregnancy Risk Assessment Monitoring System to provide surveillance and collect data in each of the 50 States.

‘(3) The Secretary may expand the Maternal and Child Health Epidemiology Program to provide technical support, financial assistance, or the time-limited assignment of senior epidemiologists to maternal and child health programs in each of the 50 States.

‘(c) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.’.

‘SEC. 399S. PREVENTION RESEARCH TO ENSURE SAFE MOTHERHOOD.

‘(a) PURPOSE- It is the purpose of this section to provide the Secretary with the authority to further expand research concerning risk factors, prevention strategies, and the roles of the family, health care providers and the community in safe motherhood.

‘(b) RESEARCH- The Secretary may carry out activities to expand research relating to--

‘(1) encouraging preconception counseling, especially for at risk populations such as diabetics;

‘(2) the identification of critical components of prenatal delivery and postpartum care;

‘(3) the identification of outreach and support services, such as folic acid education, that are available for pregnant women;

‘(4) the identification of women who are at high risk for complications;

‘(5) preventing preterm delivery;

‘(6) preventing urinary tract infections;

‘(7) preventing unnecessary caesarean sections;

‘(8) an examination of the higher rates of maternal mortality among African American women;

‘(9) an examination of the relationship between domestic violence and maternal complications and mortality;

‘(10) preventing smoking, alcohol and illegal drug usage before, during and after pregnancy;

‘(11) preventing infections that cause maternal and infant complications; and

‘(12) other areas determined appropriate by the Secretary.

‘(c) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

‘SEC. 399T. PREVENTION PROGRAMS TO ENSURE SAFE MOTHERHOOD.

‘(a) IN GENERAL- The Secretary may carry out activities to promote safe motherhood, including--

‘(1) public education campaigns on healthy pregnancies and the building of partnerships with outside organizations concerned about safe motherhood;

‘(2) education programs for physicians, nurses and other health care providers; and

‘(3) activities to promote community support services for pregnant women.

‘(b) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.’.

Subtitle F--Pregnant Mothers and Infants Health Promotion

SEC. 251. SHORT TITLE.

This subtitle may be cited as the ‘Pregnant Mothers and Infants Health Protection Act’.

SEC. 252. ESTABLISHMENT.

Title III of the Public Health Service Act, as amended by section 242 of this Act, is amended by adding at the end the following part:

‘Part R--Additional Programs

‘SEC. 399U. PROGRAMS REGARDING PRENATAL AND POSTNATAL HEALTH.

‘(a) IN GENERAL- The Secretary shall carry out programs--

‘(1) to collect, analyze, and make available data on prenatal smoking, alcohol and illegal drug usage, including data on the implications of such activities and on the incidence and prevalence of such activities and their implications;

‘(2) to conduct applied epidemiological research on the prevention of prenatal and postnatal smoking, alcohol and illegal drug usage;

‘(3) to support, conduct, and evaluate the effectiveness of educational and cessation programs; and

‘(4) to provide information and education to the public on the prevention and implications of

prenatal and postnatal smoking, alcohol and illegal drug usage.

‘(b) GRANTS- In carrying out subsection (a), the Secretary may award grants to and enter into contracts with States, local governments, scientific and academic institutions, Federally qualified health centers, and other public and nonprofit entities, and may provide technical and consultative assistance to such entities.

‘(c) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.’.

Subtitle G--Utilization of Preventive Health Services

SEC. 261. GRANTS REGARDING UTILIZATION OF PREVENTIVE HEALTH SERVICES.

Part D of title III of the Public Health Service Act (42 U.S.C. 254b et seq.) is amended by adding at the end the following section:

‘SEC. 330D. CENTERS FOR STRATEGIES ON FACILITATING UTILIZATION OF PREVENTIVE HEALTH SERVICES AMONG VARIOUS POPULATIONS.

‘(a) IN GENERAL- The Secretary, acting through the appropriate agencies of the Public Health Service, shall make grants to public or nonprofit private entities for the establishment and operation of regional centers whose purpose is to identify particular populations of patients and facilitate the appropriate utilization of preventive health services by patients in the populations through developing and disseminating strategies to improve the methods used by public and private health care programs and providers in interacting with such patients.

‘(b) RESEARCH AND TRAINING- The activities carried out by a center under subsection (a) may include establishing programs of research and training with respect to the purpose described in such subsection, including the development of curricula for training individuals in implementing the strategies developed under such subsection.

‘(c) QUALITY MANAGEMENT- A condition for the receipt of a grant under subsection (a) is that the applicant involved agree that, in order to ensure that the strategies developed under such subsection take into account principles of quality management with respect to consumer satisfaction, the applicant will make arrangements with one or more private entities that have experience in applying such principles.

‘(d) PRIORITY REGARDING INFANTS AND CHILDREN- In carrying out the purpose described in subsection (a), the Secretary shall give priority to various populations of infants, young children, and their mothers.

‘(e) EVALUATIONS- The Secretary, acting through the appropriate agencies of the Public Health Service, shall (directly or through grants or contracts) provide for the evaluation of strategies under subsection (a) in order to determine the extent to which the strategies have been effective in facilitating the appropriate utilization of preventive health services in the populations with respect to which the strategies were developed.

‘(f) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.’.

Subtitle H--Research and Development Regarding Fragile X

SEC. 266. SHORT TITLE.

This subtitle may be cited as the ‘Fragile X Research Breakthrough Act of 1999’.

SEC. 267. NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT; RESEARCH ON FRAGILE X.

Subpart 7 of part C of title IV of the Public Health Service Act, as amended by section 103 of this Act, is amended by adding at the end the following section:

‘FRAGILE X

‘SEC. 452F. (a) EXPANSION AND COORDINATION OF RESEARCH ACTIVITIES- The Director of the Institute, after consultation with the advisory council for the Institute, shall expand, intensify, and coordinate the activities of the Institute with respect to research on the disease known as fragile X.

‘(b) RESEARCH CENTERS-

‘(1) IN GENERAL- The Director of the Institute, after consultation with the advisory council for the Institute, shall make grants to, or enter into contracts with, public or nonprofit private entities

for the development and operation of centers to conduct research for the purposes of improving the diagnosis and treatment of, and finding the cure for, fragile X.

‘(2) NUMBER OF CENTERS- In carrying out paragraph (1), the Director of the Institute shall, to the extent that amounts are appropriated, provide for the establishment of at least three fragile X research centers.

‘(3) ACTIVITIES-

‘(A) IN GENERAL- Each center assisted under paragraph (1) shall, with respect to fragile X--

‘(i) conduct basic and clinical research, which may include clinical trials of--

‘(I) new or improved diagnostic methods; and

‘(II) drugs or other treatment approaches; and

‘(ii) conduct research to find a cure.

‘(B) FEES- A center may use funds provided under paragraph (1) to provide fees to individuals serving as subjects in clinical trials conducted under subparagraph (A).

‘(4) COORDINATION AMONG CENTERS- The Director of the Institute shall, as appropriate, provide for the coordination of the activities of the centers assisted under this section, including providing for the exchange of information among the centers.

‘(5) CERTAIN ADMINISTRATIVE REQUIREMENTS- Each center assisted under paragraph (1) shall use the facilities of a single institution, or be formed from a consortium of cooperating institutions, meeting such requirements as may be prescribed by the Director of the Institute.

‘(6) DURATION OF SUPPORT- Support may be provided to a center under paragraph (1) for a period not exceeding 5 years. Such period may be extended for one or more additional periods, each of which may not exceed 5 years, if the operations of such center have been reviewed by an appropriate technical and scientific peer review group established by the Director and if such group has recommended to the Director that such period be extended.

‘(7) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this subsection, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.’.

SEC. 268. NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT; LOAN REPAYMENT PROGRAM REGARDING RESEARCH ON FRAGILE X.

Part G of title IV of the Public Health Service Act (42 U.S.C. 288 et seq.) is amended by inserting after section 487E the following section:

‘LOAN REPAYMENT PROGRAM REGARDING RESEARCH ON FRAGILE X

‘SEC. 487F. (a) IN GENERAL- The Secretary, in consultation with the Director of the National Institute of Child Health and Human Development, shall establish a program under which the Federal Government enters into contracts with qualified health professionals (including graduate students) who agree to conduct research regarding fragile X in consideration of the Federal Government’s agreement to repay, for each year of such service, not more than \$35,000 of the principal and interest of the educational loans owed by such health professionals.

‘(b) APPLICABILITY OF CERTAIN PROVISIONS- With respect to the National Health Service Corps Loan Repayment Program established in subpart III of part D of title III, the provisions of such subpart (including section 338B(g)(3)) shall, except as inconsistent with subsection (a) of this section, apply to the program established in such subsection in the same manner and to the same extent as such provisions apply to the National Health Service Corps Loan Repayment Program established in such subpart.

‘(c) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.’.

Subtitle I--Children and Epilepsy

SEC. 271. PROGRAMS OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION; NATIONAL PUBLIC HEALTH CAMPAIGN ON EPILEPSY.

(a) IN GENERAL- The Secretary of Health and Human Services (in this subtitle referred to as the 'Secretary'), acting through the Director of the Centers for Disease Control and Prevention, shall develop and implement public health surveillance, education, research, and intervention strategies to improve the lives of persons with epilepsy, with a particular emphasis on children. Such projects may be carried out by the Secretary directly and through awards of grants or contracts to public or nonprofit private entities. The Secretary may directly or through such awards provide technical assistance with respect to the planning, development, and operation of such projects.

(b) CERTAIN ACTIVITIES- Activities under subsection (a) shall include--

- (1) expanding current surveillance activities through existing monitoring systems and improving registries that maintain data on individuals with epilepsy, including children;
- (2) enhancing research activities on the management and control of epilepsy;
- (3) implementing public and professional information and education programs regarding epilepsy, including initiatives which promote effective management and control of the disease through children's programs which are targeted to parents, schools, daycare providers, patients;
- (4) undertaking educational efforts with the media, providers of health care, schools and others regarding stigmas and secondary disabilities related to epilepsy and seizures, and also its affects on youth;
- (5) utilizing and expanding partnerships with organizations with experience addressing the health and related needs of people with disabilities; and
- (6) other activities the Secretary deems appropriate.

(c) COORDINATION OF ACTIVITIES- The Secretary shall ensure that activities under this section are coordinated as appropriate with other agencies of the Public Health Service that carry out activities regarding epilepsy and seizure.

(d) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

SEC. 272. PROGRAMS OF HEALTH RESOURCES AND SERVICES ADMINISTRATION; STATE AND LOCAL GRANTS FOR SEIZURE DISORDER DEMONSTRATION PROJECTS IN MEDICALLY UNDERSERVED AREAS.

(a) IN GENERAL- The Secretary, acting through the Administrator of the Health Resources and Services Administration, may make grants to States and local governments for the purpose of carrying out demonstration projects to improve access to health and other services regarding seizures

to encourage early detection and treatment in children and others residing in medically underserved areas.

(b) APPLICATION FOR GRANT- The Secretary may make a grant under subsection (a) only if the application for the grant is submitted to the Secretary and the application is in such form, is made in such matter, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out this section.

(c) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

SEC. 273. DEFINITIONS.

For purposes of this subtitle:

(1) The term ‘epilepsy’ refers to a chronic and serious neurological condition which produces excessive electrical discharges in the brain causing recurring seizures affecting all life activities. The Secretary may revise the definition of such term as the Secretary.

(2) The term ‘medically underserved’ has the meaning applicable under section 799B(6) of the Public Health Service Act.

Subtitle J--Asthma Treatment Services for Children

SEC. 276. SHORT TITLE.

This subtitle may be cited as the ‘Children’s Asthma Relief Act of 1999’.

SEC. 277. CHILDREN’S ASTHMA RELIEF.

Title III of the Public Health Service Act, as amended by section 252 of this Act, is amended by adding at the end the following:

‘Part S--Children’s Asthma Relief

‘SEC. 399V. ASTHMA TREATMENT GRANTS PROGRAM.

‘(a) PURPOSES- The purposes of this section are as follows:

‘(1) To provide access to quality medical care for children who live in areas that have a high prevalence of asthma and who lack access to medical care.

‘(2) To provide on-site education to parents, children, health care providers, and medical teams to recognize the signs and symptoms of asthma, and to train them in the use of medications to prevent and treat asthma.

‘(3) To decrease preventable trips to the emergency room by making medication available to individuals who have not previously had access to treatment or education in the prevention of asthma.

‘(4) To provide other services, such as smoking cessation programs, home modification, and other direct and support services that ameliorate conditions that exacerbate or induce asthma.

‘(b) AUTHORITY TO MAKE GRANTS-

‘(1) IN GENERAL- In addition to any other payments made under this Act or title V of the Social Security Act, the Secretary shall award grants to eligible entities to carry out the purposes of this section, including grants that are designed to develop and expand projects to--

‘(A) provide comprehensive asthma services to children, including access to care and treatment for asthma in a community-based setting;

‘(B) fully equip mobile health care clinics that provide preventive asthma care including diagnosis, physical examinations, pharmacological therapy, skin testing, peak flow meter testing, and other asthma-related health care services;

‘(C) conduct study validated asthma management education programs for patients with asthma and their families, including patient education regarding asthma management, family education on asthma management, and the distribution of materials, including displays and videos, to reinforce concepts presented by medical teams; and

‘(D) identify eligible children for the medicaid program under title XIX of the Social Security Act, the State Children’s Health Insurance Program under title XXI of such Act, or other children’s health programs.

‘(2) AWARD OF GRANTS-

‘(A) APPLICATION-

‘(i) IN GENERAL- An eligible entity shall submit an application to the Secretary for a grant under this section in such form and manner as the Secretary may require.

‘(ii) REQUIRED INFORMATION- An application submitted under this subparagraph shall include a plan for the use of funds awarded under the grant and such other information as the Secretary may require.

‘(B) REQUIREMENT- In awarding grants under this section, the Secretary shall give preference to eligible entities that demonstrate that the activities to be carried out under this section shall be in localities within areas of known high prevalence of childhood asthma or high asthma-related mortality (relative to the average asthma incidence rates and associated mortality rates in the United States). Acceptable data sets to demonstrate a high prevalence of childhood asthma or high asthma-related mortality may include data from Federal, State, or local vital statistics, claims data under title XIX or XXI of the Social Security Act, other public health statistics or surveys, or other data that the Secretary, in consultation with the Director of the Centers for Disease Control and Prevention, deems appropriate.

‘(3) DEFINITION OF ELIGIBLE ENTITY- For purposes of this section, the term ‘eligible

entity' means a State agency or other entity receiving funds under title V of the Social Security Act, a local community, a nonprofit children's hospital or foundation, or a nonprofit community-based organization.

'(c) COORDINATION WITH OTHER CHILDREN'S PROGRAMS- An eligible entity shall identify in the plan submitted as part of an application for a grant under this section how the entity will coordinate operations and activities under the grant with--

'(1) other programs operated in the State that serve children with asthma, including any such programs operated under titles V, XIX, or XXI of the Social Security Act; and

'(2) one or more of the following--

'(A) the child welfare and foster care and adoption assistance programs under parts B and E of title IV of such Act;

'(B) the head start program established under the Head Start Act (42 U.S.C. 9831 et seq.);

'(C) the program of assistance under the special supplemental nutrition program for women, infants and children (WIC) under section 17 of the Child Nutrition Act of 1966 (42 U.S.C. 1786);

'(D) local public and private elementary or secondary schools; or

'(E) public housing agencies, as defined in section 3 of the United States Housing Act of 1937 (42 U.S.C. 1437a).

'(d) EVALUATION- An eligible entity that receives a grant under this section shall submit to the Secretary an evaluation of the operations and activities carried out under the grant that includes--

'(1) a description of the health status outcomes of children assisted under the grant;

'(2) an assessment of the utilization of asthma-related health care services as a result of activities carried out under the grant;

'(3) the collection, analysis, and reporting of asthma data according to guidelines prescribed by the Director of the Centers for Disease Control and Prevention; and

'(4) such other information as the Secretary may require.

'(e) APPLICABILITY OF CERTAIN PROVISIONS- The following provisions of title V of the Social Security Act shall apply to a grant made under this section to the same extent and in the same manner as such provisions apply to allotments made under section 502(c) of such Act:

'(1) Section 504(b)(4) (relating to expenditures of funds as a condition of receipt of Federal funds).

'(2) Section 504(b)(6) (relating to prohibition on payments to excluded individuals and entities).

‘(3) Section 506 (relating to reports and audits, but only to the extent determined by the Secretary to be appropriate for grants made under this section).

‘(4) Section 508 (relating to nondiscrimination).

‘(f) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.’.

SEC. 278. INCORPORATION OF ASTHMA PREVENTION TREATMENT AND SERVICES INTO STATE CHILDREN’S HEALTH INSURANCE PROGRAMS.

(a) IN GENERAL- The Secretary of Health and Human Services (in this section referred to as the ‘Secretary’) shall, in accordance with subsection (b), carry out a program to encourage States to implement plans to carry out activities to assist children with respect to asthma in accordance with guidelines of the National Asthma Education and Prevention Program (NAEPP) and the National Heart, Lung and Blood Institute.

(b) RELATION TO CHILDREN’S HEALTH INSURANCE PROGRAM-

(1) IN GENERAL- Subject to paragraph (2), if a State child health plan under title XXI of the Social Security Act (42 U.S.C. 1397aa et seq.) provides for activities described in subsection (a) to an extent satisfactory to the Secretary, the Secretary shall, with amounts appropriated under subsection

(c), make a grant to the State involved to assist the State in carrying out such activities.

(2) CRITERIA REGARDING ELIGIBILITY FOR GRANT; RULE OF CONSTRUCTION REGARDING AUTHORITY OF SECRETARY- The Secretary shall publish in the Federal Register criteria describing the circumstances in which the Secretary will consider a State plan to be satisfactory for purposes of paragraph (1), subject to the condition that this section may not be construed as modifying (or authorizing the Secretary to modify) any requirement or authority established in or under title XXI of the Social Security Act.

(3) REQUIREMENT OF MATCHING FUNDS-

(A) IN GENERAL- With respect to the costs of the activities to be carried out by a State pursuant to paragraph (1), the Secretary may make a grant under such paragraph only if the State agrees to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 15 percent of the costs.

(B) DETERMINATION OF AMOUNT CONTRIBUTED- Non-Federal contributions required in subparagraph (A) may be in cash or in kind, fairly evaluated, including equipment or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

(4) TECHNICAL ASSISTANCE- With respect to State child health plans under title XXI of

the Social Security Act (42 U.S.C. 1397aa et seq.), the Secretary, acting through the Director of the Centers for Disease Control and Prevention, in consultation with the heads of other Federal agencies involved in asthma treatment and prevention, shall make available to the States technical assistance in developing the provision of such plans that will provide for activities pursuant to paragraph (1).

(c) FUNDING- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

SEC. 279. PREVENTIVE HEALTH AND HEALTH SERVICES BLOCK GRANT; SYSTEMS FOR REDUCING ASTHMA AND ASTHMA-RELATED ILLNESSES THROUGH URBAN COCKROACH MANAGEMENT.

Section 1904(a)(1) of the Public Health Service Act (42 U.S.C. 300w-3(a)(1)) is amended--

(1) by redesignating subparagraphs (E) and (F) as subparagraphs (F) and (G), respectively;

(2) by adding a period at the end of subparagraph (G) (as so redesignated);

(3) by inserting after subparagraph (D), the following:

‘(E) The establishment, operation, and coordination of effective and cost-efficient systems to reduce the prevalence of asthma and asthma-related illnesses among urban populations, especially children, by reducing the level of exposure to cockroach allergen through the use of integrated pest management, as applied to cockroaches. Amounts expended for such systems may include the costs of structural rehabilitation of housing, public schools, and other public facilities to reduce cockroach infestation, the costs of building maintenance, and the costs of programs to promote community participation in the carrying out at such sites of integrated pest management, as applied to cockroaches. For purposes of this subparagraph, the term ‘integrated pest management’ means an approach to the management of pests in public facilities that combines biological, cultural, physical, and chemical tools in a way that minimizes economic, health, and environmental risks.’;

(4) in subparagraph (F) (as so redesignated), by striking ‘subparagraphs (A) through (D)’ and inserting ‘subparagraphs (A) through (E)’; and

(5) in subparagraph (G) (as so redesignated), by striking ‘subparagraphs (A) through (E)’ and inserting ‘subparagraphs (A) through (F)’.

SEC. 279A. COORDINATION OF FEDERAL ACTIVITIES TO ADDRESS ASTHMA-RELATED HEALTH CARE NEEDS.

(a) IN GENERAL- The Director of the National Heart, Lung, and Blood Institute shall, through the National Asthma Education Prevention Program Coordinating Committee--

(1) identify all Federal programs that carry out asthma-related activities;

(2) develop, in consultation with appropriate Federal agencies and professional and voluntary health organizations, a Federal plan for responding to asthma; and

(3) not later than 12 months after the date of enactment of this Act, submit recommendations to Congress on ways to strengthen and improve the coordination of asthma-related activities of the Federal Government.

(b) REPRESENTATION OF THE DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT- A representative of the Department of Housing and Urban Development shall be included on the National Asthma Education Prevention Program Coordinating Committee for the purpose of performing the tasks described in subsection (a).

(c) AUTHORIZATION OF APPROPRIATIONS- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

SEC. 279B. COMPILATION OF DATA BY THE CENTERS FOR DISEASE CONTROL AND PREVENTION.

(a) IN GENERAL- The Director of the Centers for Disease Control and Prevention, in consultation with the National Asthma Education Prevention Program Coordinating Committee, shall--

(1) conduct local asthma surveillance activities to collect data on the prevalence and severity of

asthma and the quality of asthma management, including--

(A) telephone surveys to collect sample household data on the local burden of asthma; and

(B) health care facility specific surveillance to collect asthma data on the prevalence and severity of asthma, and on the quality of asthma care; and

(2) compile and annually publish data on--

(A) the prevalence of children suffering from asthma in each State; and

(B) the childhood mortality rate associated with asthma nationally and in each State.

(b) COLLABORATIVE EFFORTS- The activities described in subsection (a)(1) may be conducted in collaboration with eligible entities awarded a grant under section 399V of the Public Health Service Act (as added by section 277 of this Act).

Subtitle K--Juvenile Arthritis and Related Conditions

SEC. 281. RESEARCH ON JUVENILE ARTHRITIS AND RELATED CONDITIONS.

(a) ESTABLISHMENT- The Directors of the National Institute of Arthritis and Musculoskeletal and Skin Diseases and the National Institute of Allergy and Infectious Diseases shall expand and intensify the programs of such Institutes with respect to research and related activities concerning juvenile arthritis and related conditions.

(b) **COORDINATION-** The Directors referred to in subsection (a) shall jointly coordinate the programs referred to in such subsection and consult with the Arthritis and Musculoskeletal Diseases Interagency Coordinating Committee.

(c) **INFORMATION RESOURCE CENTER-**

(1) **IN GENERAL-** In order to assist in carrying out the purpose described in subsection (a), the Director of the National Institutes of Health shall provide for the establishment of an information resource center on arthritis and related conditions, including juvenile arthritis, to facilitate and enhance knowledge and understanding on the part of patients, health professionals, and the public through the effective dissemination of information.

(2) **ESTABLISHMENT THROUGH GRANT OR CONTRACT-** For the purpose of carrying out paragraph (1), the Director of the National Institutes of Health shall enter into a grant, cooperative agreement, or contract with a national, nonprofit private entity involved in activities regarding the prevention and control of arthritis and related conditions through the National Arthritis Action Plan.

(c) **PEDIATRIC RHEUMATOLOGY-** The Secretary of Health and Human Services, acting through the Director of the National Institutes of Health and the Administrator of the Health Resources and Services Administration, shall develop a coordinated effort to ensure that a national infrastructure is in place to train and develop pediatric rheumatologists to address the health care services requirements of children with arthritis and related conditions.

(d) **AUTHORIZATION OF APPROPRIATIONS-** For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

Subtitle L--Childhood Skeletal Malignancies

SEC. 286. PROGRAMS OF CENTERS FOR DISEASE CONTROL AND PREVENTION.

(a) **IN GENERAL-** The Secretary of Health and Human Services (in this section referred to as the 'Secretary'), acting through the Director of the Centers for Disease Control and Prevention, shall study environmental and other risk factors for childhood skeletal cancers, and carry out projects to improve outcomes among children with childhood skeletal cancers and resultant secondary conditions, including limb loss. Such projects shall be carried out by the Secretary directly and through awards of grants or contracts to public or nonprofit entities.

(b) **CERTAIN ACTIVITIES-** Activities under subsection (a) include--

(1) the expansion of current demographic data collection and population surveillance efforts to include childhood skeletal cancers nationally;

(2) the development of a uniform reporting system under which treating physicians, hospitals, clinics, and states report the diagnosis of childhood skeletal cancers, including relevant associated epidemiological data; and

(3) support for the National Limb Loss Information Center to address, in part, the primary and

secondary needs of persons who experience childhood skeletal cancers in order to prevent or minimize the disabling nature of these cancers.

(c) **COORDINATION OF ACTIVITIES**- The Secretary shall assure that activities under this section are coordinated as appropriate with other agencies of the Public Health Service that carry out activities focused on childhood cancers and limb loss.

(d) **DEFINITION**- For purposes of this section, the term 'childhood skeletal cancer' refers to any malignancy originating in the connective tissue of a person before skeletal maturity including the appendicular and axial skeleton. The Secretary may revise the definition of such term as determined necessary to carry out the intent of this effort.

(e) **AUTHORIZATION OF APPROPRIATIONS**- For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

Subtitle M--Reducing Burden of Diabetes Among Children and Youth

SEC. 291. PROGRAMS REGARDING DIABETES IN CHILDREN AND YOUTH.

(a) **NATIONAL REGISTRY ON JUVENILE DIABETES**- The Secretary of Health and Human Services (in this section referred to as the 'Secretary'), acting through the Director of the Centers for Disease Control and Prevention, shall develop a system to collect data on juvenile diabetes, including with respect to incidence and prevalence, and shall establish a national database for such data.

(b) **LONG-TERM EPIDEMIOLOGY STUDIES ON JUVENILE DIABETES**-

(1) **IN GENERAL**- The Secretary, acting through the Director of the National Institutes of Health, shall conduct or support long-term epidemiology studies in which individuals with type 1, or juvenile, diabetes are followed for 10 years or more. Such studies shall, in order to provide a valuable resource for the purposes specified in paragraph (2), provide for complete characterization of disease manifestations, appropriate medical history, elucidation of environmental factors, delineation of complications, results of usual medical treatment and a variety of other potential valuable (such as samples of blood).

(2) **PURPOSES**- The purposes referred to in paragraph (1) with respect to type 1 diabetes are the following:

(A) Delineation of potential environmental triggers thought precipitating or causing type 1 diabetes.

(B) Delineation of those clinical characteristics or lab measures associated with complications of the disease.

(C) Potential study population to enter into clinical trials for prevention and treatment, as well as genetic studies.

(c) **TYPE 2 DIABETES IN YOUTH**- The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall implement a national public health effort to address type 2

diabetes in youth, including--

- (1) enhancing surveillance systems and expanding research to better assess the prevalence of type 2 diabetes in youth and determine the extent to which type 2 diabetes is incorrectly diagnosed as type 1 diabetes among children; and
- (2) assisting States in establishing coordinated school health programs and physical activity and nutrition demonstration programs to control weight and increase physical activity among youth.

(d) **CLINICAL TRIAL INFRASTRUCTURE/INNOVATIVE TREATMENTS FOR JUVENILE DIABETES-** The Secretary, acting through the Director of the National Institutes of Health, shall support regional clinical centers for the cure of juvenile diabetes and shall through such centers provide for--

- (1) well-characterized population of children appropriate for study;
- (2) well-trained clinical scientists able to conduct such trials;
- (3) appropriate clinical settings able to house such studies; and
- (4) appropriate statistical capability, data, safety and other monitoring capacity.

(e) **DEVELOPMENT OF VACCINE-** The Secretary, acting through the appropriate agencies of the Public Health Service, shall provide for a national effort to develop a vaccine for type 1 diabetes. Such effort shall provide for a combination of increased efforts in research and development of candidate vaccines, coupled with appropriate ability to conduct large clinical trials in children.

(f) **AUTHORIZATION OF APPROPRIATIONS-** For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2000 through 2003.

Subtitle N--Miscellaneous Provisions

SEC. 296. REPORT REGARDING RESEARCH ON RARE DISEASES IN CHILDREN.

Not later than 180 days after the date of the enactment of this Act, the Director of the National Institutes of Health shall submit to the Congress a report on--

- (1) the activities that, during fiscal year 1999, were conducted and supported by such Institutes with respect to rare diseases in children, including Friedreich's ataxia; and
- (2) the activities that are planned to be conducted and supported by such Institutes with respect to such diseases during the fiscal years 2000 through 2003.

END