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2d Session }

SENATE

{ REPORT
{ 111-244

ROSA'S LAW

AUGUST 3, 2010.—Ordered to be printed

Mr. HARKIN, from the Committee on Health, Education, Labor, and Pensions, submitted the following

REPORT

[To accompany S. 2781]

The Committee on Health, Education, Labor, and Pensions, to which was referred the bill (S. 2781) to change references in Federal law to mental retardation to references to an intellectual disability, and to change references to a mentally retarded individual to references to an individual with an intellectual disability, having considered the same, reports favorably thereon with an amendment in the nature of a substitute and recommends that the bill (as amended) do pass.

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I. PURPOSE AND SUMMARY OF LEGISLATION

The purpose of “Rosa’s Law” is to replace variations of the term “mental retardation” in certain existing Federal laws with variations of the term “intellectual disability.” Recognizing that the term “mental retardation” was previously considered appropriate to describe individuals with significant limitations in intellectual and cognitive functioning, the committee believes that such terms are no longer suitable and advocates a substitution of these terms with

“intellectual disability” or “an individual with an intellectual disability” in all existing Federal laws under this committee’s purview including: the Higher Education Act of 1965; the Individuals with Disabilities Education Act; the Elementary and Secondary Education Act; the Rehabilitation Act of 1973; the Health Research and Health Services Amendments of 1976; the Public Health Service Act; the Health Professions Education and Partnerships Act of 1998; Public Law 110–154; the National Sickle Cell Anemia, Colley’s Anemia, Tay-Sachs, and Genetics Diseases Act; and the Genetic Information Nondiscrimination Act of 2008. The term “intellectual disability” is consistent with language used by the American Psychiatric Association, the Federal Department of Health and Human Services, the Office of the President of the United States, and the health arm of the United Nations.

S. 2781 is the product of an extensive bipartisan effort and input from stakeholders.

II. BACKGROUND AND NEED FOR LEGISLATION

S. 2781—Rosa’s Law—was introduced on November 17, 2009. This legislation would change references in Federal law to mental retardation to references to an intellectual disability, and change references to a mentally retarded individual to references to an individual with an intellectual disability. This bill follows similar past congressional action to update and modify, in Federal statutes, the specific terms used to refer to individuals, or broad categories of individuals, as the earlier terminology became outdated, offensive, or otherwise inappropriate.

III. HISTORY OF LEGISLATION AND VOTES IN THE COMMITTEE

The committee believes that the terms “mentally retarded,” “mental retardation,” and variations of these terms, to describe individuals with intellectual disabilities are anachronistic, needlessly insensitive and stigmatizing, and clinically outdated. Terms to describe individuals with intellectual disabilities have gone through a steady evolution over the past two centuries, each iteration describing those living with the condition in a pejorative way. At the turn of the 20th century, people who were viewed as having limitations in intellectual advancement and social behavior were institutionalized. The prevailing sentiment at the time being that such people could not, should not, interact with people without disabilities.

“Imbecile,” “moron,” “idiot,” and “feeble-minded” are all terms which have been used to reference people with cognitive disabilities by the public and in our Federal statutes. Each of these terms focused on perceived deficiencies to describe such individuals. The most recent term—“mental retardation”—was used to characterize those with cognitive disabilities as having general diminished capacities for cognitive functioning. Physicians, advocates, and law makers now understand that this term does not accurately describe these individuals. Within the past 30 years, the terms “mental retardation” and “mentally retarded,” or derivatives of those terms, have also developed into colloquial slurs and pejorative phrases used to demean and insult both persons with and without disabilities.

Congress has recognized that these negative attributions towards people with disabilities should not be tolerated. Through the passage and subsequent enactment of such pieces of legislation as the *Americans with Disabilities Act* and the *Individuals with Disabilities Education Act*, Congress demonstrated that people with disabilities should be afforded equal opportunity, full participation, independent living, and economic self sufficiency, to the greatest extent possible, and the appropriate services and supports as necessary. While our efforts reflect a commitment to these goals for the more than 6 million people diagnosed with intellectual disabilities in this country, it is also essential that we ensure these individuals are provided the respect they deserve as part of our American family. Thus it is important to revise our terminology in Federal statutes, as appropriate, to further and support the equality of all individuals, without regard to disability.

The committee voted unanimously by voice vote to report the amendment in the form of a substitute for favorable consideration before the full Senate.

IV. EXPLANATION OF BILL AND COMMITTEE VIEWS

The bill would specify that the term “intellectual disability” would carry the same meaning as references to “mental retardation” in the laws that this bill would amend. The same would apply for references to “individuals with intellectual disabilities.”

The bill would stipulate that before regulations concerning the affected laws are amended to reflect the change in terms, any reference to “mental retardation” would be considered a reference to “intellectual disability.” It also would require Federal agencies, when the regulations are amended, to state in their regulations that “intellectual disability” was previously referred to as “mental retardation” and that “individuals with intellectual disabilities” were previously termed “mentally retarded.”

In one instance, however, the term “mental retardation” would not be substituted. This would be done in order to avoid redundancy in amending the Higher Education Act of 1965. During the most recent reauthorization of the Higher Education Act in 2008, the committee added a new provision that would offer certain benefits and services to “students with an intellectual disability.” The term “student with an intellectual disability” was purposefully defined in a broad manner, to mean “a student with mental retardation or a cognitive impairment” (with certain characteristics), who is currently or formerly eligible for a free appropriate education under the Individuals with Disabilities Education Act (IDEA). The intent for specifying a student with a “cognitive impairment” was to include students in the Higher Education Act definition who may not be diagnosed or identified under IDEA as having “mental retardation” (now changed by Rosa’s Law to intellectual disability) but who have limitations in intellectual and cognitive functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills. For example, it is possible that a student evaluated and found eligible for IDEA services under the “multiple disability,” “autism,” or another category, could be included in the definition of “intellectual disability” in the Higher Education Act in 2008 as a student with a “cognitive impairment,” and still benefit from the new provisions. In this bill, the committee decided to re-

move the term “mental retardation” from the definition of a “student with an intellectual disability” as the definition would continue to provide the same benefits to students previously termed as having “mental retardation,” even without their explicit mention. Also, the term “student with an intellectual disability” is unique to the Higher Education Act of 1965, and it is not the committee’s intent to extend that particular definition of a “student with an intellectual disability” to any other Federal laws, nor to interpret the amendments in this bill as an effort to codify, or otherwise define the term “intellectual disability.”

It is also not the committee’s intent to modify current regulations implementing the Higher Education Opportunity Act regarding the method of determining that a student meets the definition of a “student with an intellectual disability.” Those regulations specify that the institution shall obtain a record from a local educational agency (LEA) to determine if the student is or was eligible for special education and related services under IDEA. If the record from the LEA indicates that the student has an “intellectual disability” (formerly “mental retardation”) and that the student is or was eligible for IDEA services, then the student meets the definition of a “student with an intellectual disability” under the Higher Education Act. However, if the record indicates that the student is or was eligible for IDEA services but has a disability other than an “intellectual disability,” then additional specified documentation must be provided by the student in order to meet the definition in the Higher Education Act.

The committee understands that there may be some concern in defining “a student with an intellectual disability” in Federal law without including all the terms and conditions associated with “mental retardation.” The commonly accepted definition of “intellectual disability” in the professional field is provided by the American Association on Intellectual and Developmental Disabilities and currently includes, “Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.” The AAIDD definition has evolved over the years and was formerly referred to as “mental retardation.” However, the committee recognizes that there is no existing Federal definition for “mental retardation” and finds it unnecessary to codify into law a term whose definition may change as a result of future information regarding the condition among practicing physicians and medical researchers.

This bill also would specify that the measure is not intended to change coverage, eligibility, rights, responsibilities or definitions in existing laws or to require States to make similar changes in State laws. While the committee would encourage States to change the terminology used in their respective statutes so that “mentally retarded” and variants of this term are no longer used, the committee respects a State’s prerogative to use terminology as they see fit. Indeed, it is because States currently have this right that changes to terminology governing people with intellectual disabilities have already been made at the State level in Maryland, Wyoming, Tennessee, and others. Without the considerable efforts made by State legislators on behalf of their constituents and the subsequent call for Federal action, the committee may not have considered a

change in terminology for quite some time. The committee also recognizes that some States have chosen to use the phrase “cognitive disability” or other phrases rather than “intellectual disability” as they remove “mental retardation” and similar phrases from State law. The Rule of Construction, therefore, is meant to clarify the committee’s position that nothing in this act shall compel States to modify their State statutes or regulations to reflect the change effected by Rosa’s Law.

V. COST ESTIMATE

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, June 23, 2010.

Hon. TOM HARKIN,
*Chairman, Committee on Health, Education, Labor, and Pensions,
U.S. Senate, Washington, DC.*

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed cost estimate for S. 2781, Rosa’s Law.

If you wish further details on this estimate, we will be pleased to provide them. The CBO staff contact is Justin Humphrey.

Sincerely,

ROBERT A. SUNSHINE
(For Douglas W. Elmendorf, Director).

Enclosure.

S. 2781—Rosa’s Law

S. 2781 would amend several Federal laws and regulations relating to education and health care to change references to mental retardation to references to intellectual disability. CBO estimates that implementing the bill would cost less than \$500,000, subject to the availability of appropriated funds. The bill would have no impact on direct spending or revenues; therefore, pay-as-you-go procedures would not apply.

S. 2781 contains no intergovernmental or private-sector mandates as defined in the Unfunded Mandates Reform Act and would not affect the budgets of State, local, or tribal government.

The CBO staff contact for this estimate is Justin Humphrey. This estimate was approved by Peter H. Fontaine, Assistant Director for Budget Analysis.

VI. REGULATORY IMPACT STATEMENT

Pursuant to the requirements of paragraph 11(b) of rule XXVI of the Standing Rules of the Senate, the committee has determined that the bill would not have a significant regulatory impact.

VII. APPLICATION OF LAW TO THE LEGISLATIVE BRANCH

The committee has determined there would be no impact of this law on the legislative branch.

VIII. SECTION-BY-SECTION ANALYSIS

Section 1. Short title

Section 1 specifies the short title of the legislation as “Rosa’s Law.”

Section 2. Individuals with intellectual disabilities

Section 2 makes amendments to The Individuals with Disabilities Education Act, the Elementary and Secondary Education Act of 1965, the Rehabilitation Act of 1973, the Health Research and Health Services Amendments of 1976, the Public Health Service Act, the Health Professions Education Partnership Act of 1998, and the National Sickle Cell Anemia, Colley’s Anemia, Tay-Sachs and Genetic Diseases Act, and the Genetic Information Nondiscrimination Act of 2008.

Section 2 further clarifies that for each of the above amended provisions, references to an “intellectual disability” shall have the same meaning as “mental retardation” and that “an individual with an intellectual disability” shall have the same meaning as the term “mentally retarded.”

Section 3. Regulations

Section 3 makes clear that before regulations are changed to carry out this act, references to “mental retardation” shall carry the same meaning as a reference to an “intellectual disability” and that references to the “mentally retarded” shall carry the same meaning as a reference to an “individual with an intellectual disability.” Section 3 further stipulates that when regulations are changed to carry out this act that Federal agencies shall state in regulations that an intellectual disability was formerly termed “mental retardation” and that an individual with an intellectual disability was formerly termed “mentally retarded.”

Section 4. Rule of construction

Section 4 ensures that the changes made in this bill shall not alter the eligibility, rights, coverage, or responsibilities of people covered under the amended provisions of this bill nor does it alter any definitions. Section 4 further stipulates that this act does not compel States to make any conforming changes to terminology in State laws.

IX. CHANGES IN EXISTING LAW

In compliance with rule XXVI paragraph 12 of the Standing Rules of the Senate, the following provides a print of the statute or the part or section thereof to be amended (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italic, and existing law in which no change is made is shown in roman):

HIGHER EDUCATION ACT OF 1965

* * * * *

SEC. 760. DEFINITIONS.

In this part:

(1) COMPREHENSIVE TRANSITION AND POSTSECONDARY PROGRAM FOR STUDENTS WITH INTELLECTUAL DISABILITIES.— * * *

* * * * *

(2) STUDENT WITH AN INTELLECTUAL DISABILITY.—The term “student with an intellectual disability” means a student—

(A) with [mental retardation or] a cognitive impairment, characteristic by significant limitation in—

(i) * * *

* * * * *

PART VI—EDUCATION OF INDIVIDUALS WITH DISABILITIES

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

PART A—GENERAL PROVISIONS

SEC. 601. SHORT TITLE; TABLE OF CONTENTS; FINDINGS; PURPOSES.

(a) SHORT TITLE.— * * *

* * * * *

(c) FINDINGS.—Congress finds the following:

(1) * * *

* * * * *

(12)(A) * * *

* * * * *

(C) African-American children are identified as [having mental retardation] *having intellectual disabilities* and emotional disturbance at rates greater than their White counterparts.

* * * * *

SEC. 602. DEFINITIONS.

Except as otherwise provided, in this title:

(1) ASSISTIVE TECHNOLOGY DEVICE.—

(A) IN GENERAL.— * * *

* * * * *

(3) CHILD WITH A DISABILITY.—

(A) IN GENERAL.—The term “child with a disability” means a child—

(i) [with mental retardation] *with intellectual disabilities*, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (referred to in this title as “emotional disturbance”), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and

* * * * *

(30) SPECIFIC LEARNING DISABILITY.—

(A) IN GENERAL. * * *

* * * * *

(C) DISORDERS NOT INCLUDED.—Such term does not include a learning problem that is primarily the result of vis-

ual, hearing, or motor disabilities, [of mental retardation] of intellectual disabilities, of emotional disturbance, or of environmental, cultural, or economic disadvantage.

* * * * *

ELEMENTARY AND SECONDARY EDUCATION ACT OF 1965

PART B—NATIVE HAWAIIAN EDUCATION

SEC. 7201. * * *

SEC. 7202. FINDINGS.

Congress finds the following:

(1) * * *

* * * * *

(16) * * *

(A) * * *

* * * * *

(E) Native Hawaiian students continue to be over-represented among students qualifying for special education programs provided to students with learning disabilities, [mild mental retardation,] mild intellectual disabilities, emotional impairment, and other such disabilities;

* * * * *

REHABILITATION ACT OF 1973

SEC. 7. DEFINITIONS.

For the purposes of this Act:

(1) ADMINISTRATIVE COSTS.— * * *

* * * * *

(21) INDIVIDUAL WITH A SIGNIFICANT DISABILITY.—

(A) IN GENERAL.—Except as provided in subparagraph (B) or (C), the term “individual with a significant disability” means an individual with a disability—

(i) * * *

* * * * *

(iii) who has one or more physical or mental disabilities resulting from amputation, arthritis, autism, blindness, burn injury, cancer, cerebral palsy, cystic fibrosis, deafness, head injury, heart disease, hemiplegia, hemophilia, respiratory or pulmonary dysfunction, [mental retardation] intellectual disability, mental illness, multiple sclerosis, muscular dystrophy, musculo-skeletal disorders, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia, and other spinal cord conditions, sickle cell anemia, specific learning disability, end-stage renal disease, or another disability or combination of disabilities determined on the basis of an assessment for determining eligibility and vocational rehabilitation needs de-

scribed in subparagraphs (A) and (B) of paragraph (2) to cause comparable substantial functional limitation.

* * * * *
 SEC. 204. (a)(1) * * *

* * * * *
 (b)(1) * * *

(2)(A) Research grants may be used for the establishment and support of Rehabilitation Research and Training Centers, for the purpose of providing an integrated program of research, which Centers shall— * * *

* * * * *
 (C) The research to be carried out at each such Center may include—

(i) basic or applied medical rehabilitation research;

* * * * *
 (vi) continuation of research that will improve services and policies that foster the productivity, independence, and social integration of individuals with disabilities, and enable individuals with disabilities, including individuals with [mental retardation and other developmental disabilities] *intellectual disabilities and other developmental disabilities*, to live in their communities.

* * * * *
 SEC. 501. (a) There is established within the Federal Government an Interagency Committee on Employees who are Individuals with Disabilities (hereinafter in this section referred to as the “Committee”), comprised of such members as the President may select, including the following (or their designees whose positions are Executive Level IV or higher): the Chairman of the Equal Employment Opportunity Commission, (hereafter in this section referred to as the “Commission”), the Director of the Office of Personnel Management, the Secretary of Veterans Affairs, the Secretary of Labor, the Secretary of Education, and the Secretary of Health and Human Services. Either the Director of the Office of Personnel Management and the Chairman of the Commission shall serve as co-chairpersons of the Committee or the Director or Chairman shall serve as the sole chairperson of the Committee, as the Director and Chairman jointly determine, from time to time, to be appropriate. The resources of the [President’s Committees on Employment of People With Disabilities and on Mental Retardation] *President’s Disability Employment Partnership Board and the President’s Committee for People with Intellectual Disabilities* shall be made fully available to the Committee. It shall be the purpose and function of the Committee (1) to provide a focus for Federal and other employment of individuals with disabilities, and to review, on a periodic basis, in cooperation with the Commission, the adequacy of hiring, placement, and advancement practices with respect to individuals with disabilities, by each department, agency, and instrumentality in the executive branch of Government and the Smithsonian Institution, and to insure that the special needs of such individuals are being met; and (2) to consult with the Commission to assist the Commission to carry out its responsibilities under subsections (b),

(c), and (d) of this section. On the basis of such review and consultation, the Committee shall periodically make to the Commission such recommendations for legislative and administrative changes as it deems necessary or desirable. The Commission shall timely transmit to the appropriate committees of Congress any such recommendations.

* * * * *

**HEALTH RESEARCH AND HEALTH SERVICES
AMENDMENTS OF 1976**

* * * * *

SEC. 1001. All appointments to advisory committees established to assist in implementing the Public Health Service Act, [the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963,] and the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970, shall be made without regard to political affiliation.

* * * * *

PUBLIC HEALTH SERVICE ACT

SEC. 317C. (a) IN GENERAL.—

(1) NATIONAL CENTER.— * * *

* * * * *

(4) CERTAIN PROGRAMS.—

(A) * * *

(B) RELEVANT PROGRAMS.—The programs and functions described in this subparagraph are all programs and functions that—

(i) relate to birth defects; folic acid; cerebral palsy; [mental retardation;] *intellectual disabilities*; child development; newborn screening; autism; fragile X syndrome; fetal alcohol syndrome; pediatric genetic disorders; disability prevention; or other relevant diseases, disorders, or conditions as determined by the Secretary; and

* * * * *

SEC. 448. The general purpose of the National Institute of Child Health and Human Development (hereafter in this subpart referred to as the “Institute”) is the conduct and support of research, training, health information dissemination, and other programs with respect to gynecologic health, maternal health, child health, [mental retardation,] *intellectual disabilities*, human growth and development, including prenatal development, population research, and special health problems and requirements of mothers and children.

* * * * *

[MENTAL RETARDATION RESEARCH]

[SEC. 450. The Director of the Institute shall conduct and support research and related activities into the causes, prevention, and treatment of mental retardation.]

SEC. 450. RESEARCH ON INTELLECTUAL DISABILITIES.

The Director of the Institute shall conduct and support research and related activities into the causes, prevention, and treatment of intellectual disabilities.

* * * * *

SEC. 641. (a) In administering this title, the Surgeon General shall consult with a Federal Hospital Council consisting of the Surgeon General, who shall serve as Chairman ex officio, and twelve members appointed by the Secretary of Health, Education, and Welfare. Six of the twelve appointed members shall be persons who are outstanding in fields pertaining to medical facility and health activities, and three of these six shall be authorities in matters relating to operation of hospitals or other medical facilities, one of them shall be an authority in [matters relating to the mentally retarded] *matters relating to individuals with intellectual disabilities*, and one of them shall be an authority in matters relating to mental health, and the other six members shall be appointed to represent the consumers of services provided by such facilities and shall be persons familiar with the need for such services in urban or rural areas.

* * * * *

SEC. 753. EDUCATION AND TRAINING RELATING TO GERIATRICS.

(a) GERIATRIC EDUCATION CENTERS.—

(1) IN GENERAL.— * * *

* * * * *

(b) GERIATRIC TRAINING REGARDING PHYSICIANS AND DENTISTS.—

(1) IN GENERAL.— * * *

(2) REQUIREMENTS.— * * *

(A) * * *

* * * * *

(E) provide training in geriatrics and exposure to the physical and mental disabilities of elderly individuals through a variety of service rotations, such as geriatric consultation services, acute care services, dental services, geriatric behavioral or mental health units, day and home care programs, rehabilitation services, extended care facilities, geriatric ambulatory care and comprehensive evaluation units, and community care programs for [elderly mentally retarded individuals] *elderly individuals with intellectual disabilities*; and

* * * * *

SEC. 1252. STATE GRANTS FOR DEMONSTRATION PROJECTS REGARDING TRAUMATIC BRAIN INJURY.

(a) IN GENERAL.— * * *

* * * * *

(f) USE OF STATE GRANTS.—

(1) * * *

* * * * *

(3) STATE CAPACITY BUILDING.—A State may use amounts received under a grant under this section to—

(A) * * *

* * * * *

(E) tailor existing State systems to provide accommodations to the needs of individuals with brain injury (including systems administered by the State departments responsible for health, mental health, labor/employment, education, [mental retardation/developmental disorders,] *intellectual disabilities or developmental disorders*, transportation, and correctional systems);

* * * * *

U.S. CODE 42

§ 280f. Establishment of Fetal Alcohol Syndrome Prevention and Services Program

* * * * *

HISTORICAL AND STATUTORY NOTES

* * * * *

Congressional Findings and Purpose

* * * * *

“(a) FINDINGS.—Congress finds that—
“(1) Fetal Alcohol Syndrome is the leading preventable cause of [mental retardation] *intellectual disabilities*, and it is 100 percent preventable;

* * * * *

Public Law 110–154

* * * * *

SECTION 1. EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT.

(a) FINDINGS.—

(1) * * *

* * * * *

(2) * * *

(A) * * *

(B) develop the Haemophilus Influenza B (Hib) vaccine, credited with nearly eliminating the incidence of [mental retardation] *intellectual disabilities*; and

* * * * *

U.S. CODE 42

§ 300b–1. Reserach project grants and contracts

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HISTORICAL AND STATUTORY NOTES

* * * * *

Congressional Declaration of Purpose

Section 402 of Pub. L. 94-278, as amended by Pub. L. 95-626, Title II, § 205(a), Nov. 10, 1978, 92 Stat. 3583, provided that: "In order to preserve and protect the health and welfare of all citizens, it is the purpose of this title [see section 401 of Pub. L. 94-278, set out as a Short Title of 1976 Amendment note under section 201 of this title] to establish a national program to provide for basic and applied research, research training, testing, counseling, and information and education programs with respect to genetic diseases, and genetic conditions, such as Sickle Cell anemia, Cooley's anemia, Tay-Sachs disease, cystic fibrosis, dysautonomia, hemophilia, retinitis pigmentosa, Huntington's chorea, muscular dystrophy, and genetic conditions [leading to mental retardation] *leading to intellectual disabilities* or genetically caused mental disorders."

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U.S. CODE 42

§ 2000ff. Definitions

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HISTORICAL AND STATUTORY NOTES

* * * * *

Findings

* * * * *

"(1) * * *

"(2) The early science of genetics became the basis of State laws that provided for the sterilization of persons having presumed genetic 'defects' such as [mental retardation,] *intellectual disabilities*, mental disease, epilepsy, blindness, and hearing loss, among other conditions. The first sterilization law was enacted in the State of Indiana in 1907. By 1981, a majority of States adopted sterilization laws to 'correct' apparent genetic traits or tendencies. Many of these State laws have since been repealed, and many have been modified to include essential constitutional requirements of due process and equal protection. However, the current explosion in the science of genetics, and the history of sterilization laws by the States based on early genetic science, compels Congressional action in this area.

* * * * *