FOIA Number: 2018-0756-F

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Meeting with American Health Information Management Association 1/21/94

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THE WHITE HOUSE

WASHINGTON

December 29, 1993

Kathleen Frawley, Director
American Health Information
Management Association
1919 Pennsylvania Avenue, N.W. Suite 300
Washington, D.C. 20006

Dear Ms. Frawley:

This letter confirms your meeting with Kristine M. Gebbie, National AIDS Policy Coordinator, on Friday, January 21, 1994. The 45 minute meeting begins at 8:30 a.m. and will be held in her office at, 750 17th Street, N.W., Suite 1060 in Washington, DC.

The purpose of the meeting is to discuss health care reform and the disclosure of health information.

If you have questions or need further clarification, please call me at (202) 632-1090.

Sincerely,

W. Steve Lee

W. Steve Lee, Executive Assistant
and Scheduler to
National AIDS Policy Coordinator

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w/ George

AHIMA
AMERICAN HEALTH INFORMATION MANAGEMENT ASSOCIATION

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December 6, 1993

Steve Lee
Office of the National AIDS
Policy Coordinator
750 17th Street NW, Suite 1060
Washington, DC 20503

Dear Mr. Lee:

This is in reference to conversations with your office regarding a meeting with Kristine M. Gebbie. The American Health Information Management Association (AHIMA) is the professional organization of more than 35,000 credentialed specialists responsible for health information management in facilities throughout the United States. AHIMA is committed to excellence in the management of health information which benefits patients and providers.

AHIMA is a long time advocate of proper disclosure of health information. On a daily basis, our members must balance the requests for health information against the patient's right to privacy, in the context of myriad federal and state laws and regulations.

AHIMA has taken a leadership role in addressing this issue. Enclosed is the model legislation language regarding confidentiality of health information which was submitted to The White House Task Force on Healthcare Reform and to several Congressional members.

I had the opportunity to talk briefly with Ms. Gebbie regarding the need for federal legislation when she addressed a meeting hosted by National Organizations Responding to AIDS (NORA). AHIMA has been an active participant in NORA and has worked closely with Congressman Waxman and other congressional members in assuring that confidentiality protections are an important component of legislation addressing the AIDS crisis.

AHIMA is committed to supporting the Administration's healthcare reform plan. We would be happy to provide Ms. Gebbie and her staff with the same type of resources and information that have been of value to the White House and the Congress. I hope that we will be able to schedule a mutually convenient time to meet.

Sincerely,

Kathleen A. Frawley, JD, MS, RRA
Director, Washington DC Office

1919 Pennsylvania Avenue, NW, Suite 300 ▲ Washington, DC 20006 ▲ (202) 736-2155

AMERICAN HEALTH INFORMATION MANAGEMENT ASSOCIATION

HEALTH INFORMATION MODEL LEGISLATION LANGUAGE

SEC. 101. PREAMBLE

The Congress finds that:--

(a) The right of privacy is a personal and fundamental right protected by the Constitution of the United States;

(b) Health care information is personal and sensitive information that, if improperly used or released, may do significant harm to a patient's interests in privacy and in health care, and may affect a patient's ability to obtain employment, education, insurance, credit, and other necessities;

(c) Patients need access to their own health care information as a matter of fairness to enable them to make informed decisions about their health care and correct inaccurate or incomplete information about themselves;

(d) Persons maintaining health care information need clear and certain rules for the disclosure of health care information;

(e) Persons other than health care providers obtain, use, and disclose health care information in many different contexts and for many different purposes. A patient's interest in the proper use and disclosure of the personal health care information continues even when the information has been initially disclosed and is held by persons other than health care providers; and

(f) The movement of patients and their health care information across state lines, access to and exchange of health care information from automated data banks and networks, and the emergence of multi-state health care providers and payors creates a compelling need for Federal law, rules and procedures governing the use and disclosure of health care information.

SEC. 102. GENERAL DEFINITIONS.

In this [Act] (except as otherwise provided):

(a) AUDIT.--The term "audit" means an assessment, evaluation, determination, or investigation of a person maintaining health care information or health care rendered by such a

person by a person not employed by or affiliated with the person audited to determine compliance with--

(1) statutory, regulatory, fiscal, administrative, medical, or scientific standards;

(2) the requirements of a private or public program of payment for health care; or

(3) requirements for licensure, accreditation, or certification.

(b) COMPULSORY DISCLOSURE.--The term "compulsory disclosure" means any disclosure of health care information mandated or required by Federal or State law in connection with a judicial, legislative, or administrative proceeding, including but not limited to, disclosure required by subpoena, subpoena duces tecum, request or notice to produce, court order, or any other method of requiring a person maintaining health care information to produce health care information under the criminal or civil discovery laws of any State or Federal government or administrative agency thereof.

(c) HEALTH CARE.--The term "health care" means:--

(1) any preventive, diagnostic, therapeutic, rehabilitative, maintenance, or palliative care, counseling, service, or procedure provided by a health care provider:--

(A) with respect to a patient's physical or mental condition; or

(B) affecting the structure or function of the human body or any part thereof, including, but not limited to, banking of blood, sperm, organs, or any other tissue; and

(2) any sale or dispensing of any drug, substance, device, equipment, or other item to a patient or for a patient's use, pursuant to a prescription.

(d) HEALTH CARE INFORMATION.--The term "health care information" means any data or information, whether oral or recorded in any form or medium, that identifies or can readily be associated with the identity of a patient or other record subject; and--

(1) relates to a patient's health care; or

(2) is obtained in the course of a patient's health care from a health care provider, from the patient, from a member of the patient's family or an individual with whom the patient has a close personal relationship, or from the patient's legal representative.

(e) HEALTH CARE PROVIDER.--The term "health care provider" means a person who is licensed, certified, registered or otherwise authorized by law to provide health care in the ordinary course of business or practice of a profession.

(f) INSTITUTIONAL REVIEW BOARD.--The term "institutional review board" means any board, committee, or other group formally designated by an institution, or authorized under Federal or State law, to review, approve the initiation of, or conduct periodic review of, research programs to assure the protection of the rights and welfare of human research subjects.

(g) MAINTAIN.--The term "maintain," as related to health care information, means to create, collect, handle, hold, possess, preserve, retain, store, control or transmit such information.

(h) PATIENT.--The term "patient" means an individual who receives or has received health care. The term includes a deceased individual who has received health care.

(i) PATIENT'S AUTHORIZATION.--The term "patient's authorization" means an authorization that is valid under the provisions of Section 104.

(j) PATIENT REPRESENTATIVE.--The term "patient representative" shall mean any individual legally empowered to make decisions concerning a patient's health care or the administrator or executor of a deceased patient's estate.

(k) PERSON.--The term "person" means--

(1) an individual, corporation, business trust, estate, trust, partnership, association, joint venture, or any other legal or commercial entity; and

(2) except for purposes of Section 111 and 112, a government, governmental subdivision, agency or authority.

(l) SECRETARY.--The term "Secretary" means the Secretary of Health and Human Services.

SEC. 103. DISCLOSURE.

(a) DISCLOSURE.--No person other than a patient or patient representative may disclose health care information to any other person without the patient's authorization, except as authorized in Section 105. No person may disclose health care information under a patient's authorization, except in accordance with the terms of such authorization. The provisions of this paragraph shall apply both to disclosures of health care information and to redisclosures of health care information by a person to whom health care information is disclosed.

(b) RECORD OF DISCLOSURE.--Each person maintaining health care information shall maintain a record of all external disclosures of health care information made by such person concerning each patient, and such record shall become part of the health care information concerning each patient. The record of each disclosure shall include the name, address and institutional affiliation, if any, of the person to whom the health care information is disclosed, the date and purpose of the disclosure and, to the extent practicable, a description of the information disclosed.

SEC. 104. PATIENT'S AUTHORIZATION; REQUIREMENTS FOR VALIDITY.

(a) To be valid, a patient's authorization must--

(1) Identify the patient;

(2) Generally describe the health care information to be disclosed;

(3) Identify the person to whom the health care information is to be disclosed;

(4) Describe the purpose of the disclosure;

(5) Limit the length of time the patient's authorization will remain valid;

(6) Be given by one of the following means--

(A) In writing, dated and signed by the patient or the patient representative; or

(B) In electronic form, dated and authenticated by the patient or the patient representative using a unique identifier; and

(7) Not have been revoked under paragraph (b).

(b) REVOCATION OF PATIENT'S AUTHORIZATION.--A patient or patient representative may revoke the patient's authorization at any time, unless disclosure is required to effectuate payment for health care that has been provided to the patient, or other substantial action has been taken in reliance on the patient's authorization. A patient may not maintain an action against a person for disclosure of health care information made in good faith reliance on the patient's authorization, if the person had no notice of the revocation of the patient's authorization at the time disclosure was made.

(c) RECORD OF PATIENT'S AUTHORIZATIONS AND REVOCATIONS.--Each person maintaining health care information shall maintain a record of all patient's authorizations and revocations thereof, and such record shall become part of the health care information concerning each patient.

(d) NO WAIVER.--Except as provided by this [Act], the signing or authentication of an authorization by a patient or patient representative is not a waiver of any rights a patient has under other Federal or State statutes, the rules of evidence, or common law.

SEC. 105. DISCLOSURE WITHOUT PATIENT'S AUTHORIZATION.

A person maintaining health care information may disclose health care information about a patient without the patient's authorization as follows:--

(a) DISCLOSURE TO THE PATIENT OR PATIENT REPRESENTATIVE.--Any disclosure of patient information to the patient or such patient's patient representative;

(b) DISCLOSURE BY FAMILY AND FRIENDS.--Any disclosure of health care information by a family member or by any other individual with whom the patient has a personal relationship, provided that:--

(1) the health care information was disclosed to such individual by the patient or otherwise not in violation of this [Act]; and

(2) the health care information was not disclosed to the individual making the disclosure in the course of providing health care to the patient;

(c) DISCLOSURE TO EMPLOYEES AND AGENTS.--Disclosure, to the extent necessary for the disclosing person to carry out its lawful activities, to the disclosing person's agent, employee, or independent contractor who is under a legal obligation to hold the health care information in confidence and not to use such health care information for any purpose other than the lawful purpose for which the health care information was obtained by the disclosing person;

(d) DISCLOSURE TO ANOTHER HEALTH CARE PROVIDER.--Disclosure to a health care provider who is providing health care to the patient, except as such disclosure is limited or prohibited by the patient;

(e) DISCLOSURE TO AVOID DANGER.--Disclosure to any person to the extent the recipient needs to know the information, if the person holding the health care information reasonably believes that such disclosure will avoid or minimize imminent danger to the health or

safety of the patient or any other individual, or is necessary to alleviate emergency circumstances affecting the health or safety of any individual;

(f) DISCLOSURE TO FAMILY.--Disclosure to a member of the patient's immediate family, or to any other individual with whom the patient is known to have a close personal relationship, if such disclosure is made in accordance with good medical or other professional practice, except as such disclosure is limited or prohibited by the patient;

(g) DISCLOSURE TO SUCCESSOR IN INTEREST.--Disclosure to a person who is a successor in interest to the person maintaining the health care information, provided, however, that no person other than a licensed health care provider or the spouse of a deceased health care provider shall be considered a successor in interest to a health care provider;

(h) DISCLOSURE TO GOVERNMENTAL AUTHORITIES.--Disclosure to Federal, State, or local governmental, authorities, to the extent the person holding the health care information is required by law to report specific health care information:--

(1) when needed to determine compliance with State or Federal licensure, certification, or registration rules or laws; or

(2) when needed to protect the public health;

(i) DISCLOSURE FOR AUDITS.--Disclosure to a person who obtains health care information solely for purposes of an audit, if that person agrees in writing:--

(1) to remove from the health care information or destroy, at the earliest opportunity consistent with the purpose of the audit, information that would enable identification of the patient;

(2) not to disclose in any public report any medical information; and

(3) not to further disclose the health care information, except to accomplish the audit or to report unlawful or improper conduct involving health care payment fraud by a health care provider or a patient, or other unlawful conduct by the health care provider;

(j) DISCLOSURE FOR RESEARCH.--Disclosure for use in a research project:

(1) that an institutional review board has determined:--

(A) is of sufficient importance to outweigh the intrusion into the privacy of the patient that would result from the disclosure;

(B) is reasonably impracticable without the use or disclosure of the health care information in individually identifiable form;

(C) contains reasonable safeguards to protect the information from redisclosure;

(D) contains reasonable safeguards to protect against identifying, directly or indirectly, any patient in any report of the research project; and

(E) contains procedures to remove or destroy at the earliest opportunity, consistent with the purposes of the project, information that would enable identification of the patient, unless the institutional review board authorizes retention of identifying information for purposes of another research project; and

(2) if the person agrees in writing:--

(A) to remove from the health care information or destroy, at the earliest opportunity consistent with the purpose of the research project, information that would enable identification of the patient;

(B) not to disclose health care information in any public report; and

(C) not to further disclose the health care information, except as necessary to conduct the research project approved by the institutional review board.

(k) COMPULSORY DISCLOSURE.--Compulsory disclosure in accordance with the requirements of Section 108;

(l) DISCLOSURE TO LAW ENFORCEMENT AUTHORITIES.--Disclosure to Federal, State or local law enforcement authorities to the extent required by law;

(m) DISCLOSURE DIRECTED BY A COURT.--Disclosure directed by a court in connection with a court-ordered examination of a patient; or

(n) DISCLOSURE TO IDENTIFY A DECEASED INDIVIDUAL.--Disclosure based on reasonable grounds to believe that the information is needed to assist in the identification of a deceased individual.

SEC. 106. STANDARDS FOR INFORMATION PRACTICES.

(a) PROMULGATION OF REQUIREMENTS.--

(1) IN GENERAL.--Between July 1, 1994, and July 1, 1995, the Secretary shall promulgate requirements for information practices of persons maintaining health care information. Such requirements shall be consistent with the provisions of this [Act] and shall be in accordance with the principles set forth in paragraph (b).

(2) REVISION.--The Secretary may from time to time revise the requirements promulgated under this paragraph.

(b) PRINCIPLES OF FAIR INFORMATION PRACTICES.--The requirements promulgated under paragraph (a) shall incorporate the following principles:

(1) PATIENT'S RIGHT TO KNOW.--The patient or the patient representative has the right to know that health care information concerning the patient is maintained by any person and to know for what purposes the health care information is used;

(2) RESTRICTIONS ON COLLECTION.--Health care information concerning a patient must be collected only the extent necessary to carry out the legitimate purpose for which the information is collected;

(3) COLLECTION AND USE ONLY FOR LAWFUL PURPOSE.--Health care information must be collected and used only for a necessary and lawful purpose;

(4) NOTIFICATION TO PATIENT. Each person maintaining health care information must prepare a formal, written statement of the fair information practices observed by such person. Each patient who provides health care information directly to a person maintaining health care information should receive a copy of the statement of the person's fair information practices and should receive an explanation of such fair information practices upon request;

(5) RESTRICTION ON USE FOR OTHER PURPOSES.--Health care information may not be used for any purposes beyond the purposes for which the health care information collected, except as otherwise provided in this [Act];

(6) RIGHT TO ACCESS.--The patient or the patient representative may have access to health care information concerning the patient, has the right to have a copy of such health care information made after payment of a reasonable charge, and, further, has the right to have a notation made with or in such health care information of any amendment

or correction of such health care information requested by the patient or patient representative;

(7) REQUIRED SAFEGUARDS.--Any person maintaining, using or disseminating health care information shall implement reasonable safeguards for the security of the health care information and its storage, processing and transmission, whether in electronic or other form;

(8) ADDITIONAL PROTECTIONS.--Methods to ensure the accuracy, reliability, relevance, completeness and timeliness of health care information should be instituted; and

(9) ADDITIONAL PROTECTIONS FOR CERTAIN HEALTH CARE INFORMATION.--If advisable, provide additional safeguards for highly sensitive health care information (such as health care information concerning mental health, substance abuse, communicable and genetic diseases, and abortions, as well as health care information concerning celebrities and notorious individuals, and health care information contained in adoption records).

SEC. 107. OBLIGATIONS OF PATIENT REPRESENTATIVES.

(a) AUTHORITY OF PATIENT REPRESENTATIVES.--A person authorized to act as a patient representative may exercise the rights of the patient under this [Act] to the extent necessary to effectuate the terms or purposes of the grant of authority; but a patient who is a minor and who is authorized to consent to health care without the consent of a parent or legal guardian under State law may exclusively exercise the rights of a patient under this [Act] as to information pertaining to health care to which the minor lawfully consented.

(b) GOOD FAITH OBLIGATION.--A patient representative shall act in good faith to represent the best interests of the patient with respect to health care information concerning the patient.

SEC. 108. COMPULSORY DISCLOSURE.

(a) LIMITS ON COMPULSORY DISCLOSURE.--No person may be compelled to disclose health care information maintained by such person pursuant to a request for compulsory disclosure in any judicial, legislative or administrative proceeding, unless:

(1) The person maintaining the health care information has received a patient's authorization to release the health care information in response to such request for compulsory disclosure;

(2) The patient has knowingly and voluntarily waived the right to claim privilege or confidentiality for the health care information sought;

(3) The patient is a party to the proceeding and has placed his or her physical or mental condition in issue;

(4) The patient's physical or mental condition is relevant to the execution or witnessing of a will;

(5) The physical or mental condition of a deceased patient is placed in issue by any person claiming or defending through or as a beneficiary of the patient;

(6)Health care information concerning the patient is to be used in the patient's commitment proceeding;

(7) The health care information is for use in any law enforcement proceeding or investigation in which a health care provider is the subject or a party; provided, however, that health care information so disclosed shall not be used against the patient, unless the matter relates to payment for the patient's health care, or unless compulsory disclosure is ordered as authorized under subparagraph (9);

(8) The health care information is relevant to a proceeding brought under Section 110, 111, or 112; or

(9) The court or Federal or State agency or Congress or the State legislature has determined, after hearing any objections made pursuant to paragraph (d), that particular health care information is subject to compulsory disclosure because the party seeking the health care information has demonstrated that the interest that would be served by disclosure outweighs the patient's privacy interest.

(b) NOTICE REQUIREMENT. Unless the court, or Federal or State agency or Congress or State legislature, for good cause shown, determines that the notification should be waived or modified, if health care information is sought under subparagraph (2), (4) or (5), or in a civil proceeding or investigation pursuant to subparagraph (9), the person requesting compulsory disclosure shall serve upon the person maintaining the health care information and upon the patient, the patient's legal guardian or other person legally authorized to act for the patient in such a matter, or on the patient's attorney, the original or a copy of the compulsory disclosure request at least thirty (30) days in advance of the date on which compulsory disclosure is requested and a statement of the right of the patient and of the person maintaining the health care information to have any objections to such compulsory disclosure heard by such court, or governmental agency or Congress or State legislature prior to the issuance of an order for such

compulsory disclosure and the procedure to be followed to have any such objection heard. Such service shall be made by certified mail, return receipt requested, or by hand delivery, in addition to any form of service required by applicable State or Federal law. The notice requirements of this paragraph shall not apply to a request for compulsory disclosure of health care information relating to a patient if made by or on behalf of a patient.

(c) CERTIFICATION UNDER OATH.

(1) A person seeking compulsory disclosure of health care information about a patient under this section shall provide the person maintaining the health care information from whom compulsory disclosure is sought with a written certification under oath by the person seeking such compulsory disclosure or an authorized representative of such person:--

(A) identifying each subparagraph of paragraph (a) under which compulsory disclosure of health care information is being sought; and

(B) stating that notice has been provided in accordance with the requirements of paragraph (b) or is not required by paragraph (b) with respect to any of the health care information sought.

(2) A person may sign a certification described in subparagraph (1), only if the person reasonably believes that the subparagraph or subparagraphs of paragraph (a) identified in the certification provide an appropriate basis for the use of a request for compulsory disclosure.

(d) OBJECTION TO COMPULSORY DISCLOSURE.--If the person maintaining health care information or the patient or the patient's legal guardian or attorney or other person legally authorized to represent the patient in such a matter files in the manner set forth in the notice described in paragraph (b) such person's objection to the request for compulsory disclosure prior to the date on which such compulsory disclosure is sought, the burden shall be on the person requesting such compulsory disclosure to seek an order from the appropriate court or Federal or State agency or State legislature or Congress an order compelling such disclosure, and the person or persons filing such objection may defend in any proceeding to compel such disclosure.

(e) MAINTENANCE OF NOTICE AND CERTIFICATION. Unless otherwise ordered by the court, State or Federal agency, Congress or State legislature, a person maintaining health care information shall maintain a copy of each request for compulsory disclosure and accompanying certification as part of the patient's health care information.

(f) NO WAIVER.--Disclosure of health care information pursuant to compulsory disclosure, in and of itself, shall not constitute a waiver of any privilege, objection, or defense existing under any other law or rule of evidence or procedure.

SEC. 110. CIVIL REMEDIES.

(a) PRIVATE RIGHT OF ACTION.--A person aggrieved by a violation of this [Act] may maintain an action for relief as provided in this section.

(b) JURISDICTION.--The district courts of the United States shall have jurisdiction in any action brought under the provisions of this section.

(c) RELIEF.--The court may order a person maintaining health care information to comply with this [Act] and may order any other appropriate relief.

(d) DAMAGES.--If the court determines that there is a violation of this [Act], the aggrieved person is entitled to recover damages for any losses sustained as a result of the violation; and, in addition, if the violation results from willful or grossly negligent conduct, the aggrieved person may recover not in excess of [$10,000], exclusive of any loss.

(e) ATTORNEYS' FEES.--If a plaintiff prevails in an action brought under this section, the court, in addition to any other relief granted under this section, may award the plaintiff reasonable attorneys' fees and all other expenses incurred by the plaintiff in the litigation.

(f) STATUTE OF LIMITATIONS.--Any action under this [Act] must be brought within two years from the date the alleged violation is discovered.

SEC. 111. CIVIL MONEY PENALTIES.

(a) Any person that knowingly discloses or health care information in violation of this [Act] shall be subject, in addition to any other penalties that may be prescribed by law--

(1) to a civil money penalty of not more than [$1,000] for each violation, but not to exceed [$25,000] in the aggregate for multiple violations, except as provided in subparagraph (2); and, in addition--

(2) to a civil money penalty of not more than [$1,000,000] if the Secretary finds that violations of this [Act] have occurred in such numbers or with such frequency as to constitute a general business practice.

SEC. 112. CRIMINAL PENALTY FOR OBTAINING HEALTH CARE INFORMATION THROUGH FALSE PRETENSES OR THEFT.

(a) Any person who, under false or fraudulent pretenses or with a false or fraudulent certification required under this [Act], requests or obtains health care information from a person maintaining health care information or a patient's authorization shall be fined not more than $10,000 or imprisoned not more than six months, or both, for each offense.

(b) Any person who, under false or fraudulent pretenses or with a false or fraudulent certification required under this [Act], requests or obtains health care information from a person maintaining health care information and who intentionally uses, sells or transfers such health care information for remuneration, for profit or for monetary gain shall be fined not more than $50,000, or imprisoned for not more than two years, or both, for each offense.

(c) Any person who unlawfully takes health care information from a person maintaining health care information and who intentionally uses, sells or transfers such health care information for remuneration, for profit or for monetary gain shall be fined not more than $50,000, or imprisoned for not more than two years, or both, for each offense.

SEC. 113. PREEMPTION OF STATE LAWS.

(a) Effective as of the effective date of this [Act], no State may establish or enforce any law or regulation concerning the disclosure of health care information, except as provided in paragraph (b).

(b) This [Act] does not supersede any restriction on the disclosure or use of health care information under:--

(1) any Federal, or State law on the inspection of, or disclosure or use of health care information relating to alcohol or drug abuse, or health care for such abuse;

(2) any Federal, or State law concerning the disclosure or use of health care information relating to psychiatric, psychological, mental health or developmental disabilities health care;

(3) Section 1106 of the Social Security Act;

(4) Section 1160 of the Social Security Act; or

(5) any Federal or State law making information, including but not limited to health care information, that is maintained, used or generated in the course of

peer review, quality assurance, or similar activities or functions privileged or confidential.

(c) Nothing in this [Act] shall be construed to make any Federal Government authority or any Federal agency subject to any State or local law not otherwise applicable.

SEC. 114. MISCELLANEOUS PROVISIONS.

(a) SEVERABILITY.--If any provision of this [Act] or its application to any person or circumstances is held invalid, the invalidity does not affect other provisions or applications of this [Act] that can be given effect without the invalid provision or application, and to this end the provisions of this [Act] are severable.