

Mental Health Liaison Group

May 11, 1998

The Honorable James M. Jeffords
Chairman
Committee on Labor and Human Resources
United States Senate
Washington, DC 20510-6300

Dear Chairman Jeffords:

As consumer, provider, family and volunteer organizations concerned about the confidentiality of medical records, we welcome the recent introduction of the "Health Care Personal Information Nondisclosure Act," S. 1921, by yourself and Senator Christopher Dodd. Since one of the issues with which most of our groups are particularly concerned is the protection of the privacy of mental and public health records from inappropriate use and disclosure, we commend you and Senator Dodd for specifically preserving from federal preemption the range of mental and public health laws which states have chosen to enact to protect the confidentiality of these records.

While S. 1921 represents an important step toward the passage of federal medical records confidentiality legislation, we take this opportunity to express our strong reservations about some provisions of the legislation as currently drafted and in particular with four provisions, which if enacted in their present form, would jeopardize the privacy of mental health and public health records and reduce the quality of health care that patients receive. At the same time, we offer legislative solutions regarding these provisions, which we urge you to include in the legislation before it is enacted.

! Disclosures of patient identifiable medical records for "health care operations" should normally be unnecessary. S. 1921 should ensure that these disclosures are limited to only those situations where identifiable information is essential, and such operations can not be performed without identified data. Patients who seek and receive mental health services are particularly vulnerable in this instance. As the United States Supreme Court recognized when examining the psychotherapist-patient relationship in its recent decision, *Jaffee v. Redmond*, the success of a patient's therapy depends upon "an atmosphere of confidence and trust in which the patient is willing to make a frank and complete disclosure of facts, emotions, memories, and fears."

We assume that the term "utilization review," as contained in the health care operations definition, is a general reference to review as an overall management function and not review of individual services provided to patients. Therefore, most of our groups recommend that the words "carrying out utilization review, precertification or preauthorization of services," as contained in paragraph (8)(F) of the "health care operations" definition, be moved to the definition of "payment." With regard to the remaining functions which fall under the health care operations definition, we recommend that information obtained pursuant to such operations be non-identifiable except in very narrow circumstances. Even in these few cases the necessity of using identifiable data may no longer exist due to technological advances, which can be utilized

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to strip identifiers from records. It is particularly crucial to use de-identified data, because of the adverse impact that use and disclosure of identifiable data can have on patients.

It is our recommendation that the current language permitting disclosure of medical records for health care operations be narrowed and amended to require that entities may only use or disclose medical records for health care operations which is non-identifiable information. Congress should provide the Secretary of Health and Human Services the authority to issue regulations on when patient identifiable information may be disclosed for health care operations with clear directions that Congress expects that this flexibility will be granted only: 1) where there is clearly no other means to perform the health care operation without disclosure of patient identifiable information, and 2) the disclosure would provide a significant public health benefit that would outweigh the patient's confidentiality need.

Relatedly, patients would not then need to be required to provide a blanket consent up-front for disclosing their otherwise protected health information for health care operations, other than for those limited purposes defined by the Secretary. Therefore we recommend that procurement of authorization for health care operations purposes be moved from section 202 to section 203.

! The medical records of patients receiving mental health services should be partitioned to ensure confidentiality of the most private and sensitive information shared with their treating providers. Unlike treatment for most other medical disorders, treatment of mental disorders typically requires divulgence by the patient of highly personal information. The treating provider records this information, usually in the form of psychotherapy notes, as part of the patient's medical record. Successful and appropriate treatment of mental disorders, as discussed above, imperatively depends upon the patient's trust in the confidentiality of the relationship with his or her treating provider and in the related confidentiality of the records.

Patients should be afforded the ability to limit the access to highly personal mental health information through partitioning of their records. The authorization provisions of S. 1921, as drafted, do not permit patient partition of records. We strongly urge that the bill be amended as follows to permit appropriate partitioning of mental health records¹:

1) In section 201, add the following new subsection:

(i) DISCLOSURE OF PSYCHOTHERAPY NOTES.--Notwithstanding any other provision of this Act, psychotherapy notes shall not be shared with any party, except with a health oversight agency or public health authority (consistent with sections 206 and 207), unless the individual who is the subject of the information, gives separate and specific, informed consent, in addition to that provided under section 202, for purposes of continuity of care.

2) In the section 4 definitions, renumber paragraphs 23 through 28 as 24 through 29 respectively, and insert the following new paragraph:

(23) PSYCHOTHERAPY NOTES.--The term "psychotherapy notes" means a reference to personal notes, taken by a mental health professional who is the originating provider, which contain highly personal details of a patient's life, or

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of the lives of family members or other third parties. Such term does not include the provider's documentation of the clinical diagnosis, severity of illness, signs and symptoms, or brief notes which document improvement.

- ! **Patient consent to disclosure of their medical records must be voluntary, informed and include adequate privacy protections.** Under S. 1921, employers and health plans may deny health plan enrollment absent authorization for disclosure of protected health information, as defined in the bill. Clearly, individuals will find themselves unable to obtain health care without providing authorization for disclosure. Such a situation would force patients to choose between maintaining privacy and having access to health care coverage. It is critical that appropriate protections be included in S. 1921.

Thus, the recommendations we have submitted above, regarding health care operations and partitioning of records, are essential, and we would oppose the use of broad consent requirements tied to the ability to obtain health care if these issues are not addressed in an appropriate manner. Additionally, we believe that individuals should be informed when they sign such consents that they may avoid disclosure of their records if they choose, but in which case, they will need to pay for services.

We offer a final recommendation related to authorization for emergency or urgent care. Individuals who suffer from mental disorders may at times be in need of emergency or urgent care but unable to give informed and knowing authorization due to their mental state. We recommend that section 202 be amended, with regard to authorization for the provision of health care services by providers and for the uninsured, to exempt from the authorization requirement those individuals with mental disorders who require emergency or urgent care services and who, due to their mental state, have refused to grant the necessary authorizations.

- ! **We are extremely concerned about employer access to identifiable health care information; this is particularly a concern for self-insured plans where the employer may potentially have access to all of the health care information which a plan acquires.** Such access may have consequences for individuals who are diagnosed or receive services for mental disorders or other diseases or disorders which remain stigmatized in the workplace. There are widespread reports of individuals who have lost their jobs or promotions due to inappropriate employer access to medical information. Often, an employer's misunderstanding of an employee's illness will lead to an action adverse to an employee's interest.

We urge you to consider additional protections, including a requirement on employers for the partitioning of all medical records from personnel files and for the employer to establish explicit policies which limit access to identifiable health care information to only those few individuals who may have need of it for treatment purposes. Such individuals could possibly include nurses or other health care professionals whom the employer may utilize to provide health care services to employees, or those persons who provide services as part of an employee assistance program. We recommend that employers further be required to establish explicit policies regarding the partitioning, use, and disclosure of information to these individuals.

One approach to dealing with all the issues around consent to disclosure for employers and health plans might be to drop the legislative requirement altogether. Such a change would not alter the ability of employers and plans to require consent, but would not recognize such consent under federal law.

We appreciate your staff's explanation of the legislative intent of numerous provisions discussed with them. We look forward to continuing to reach agreement on these issues. Thank you for your attention to these suggested language changes. We hope that they are helpful in your effort to pass legislation that contains strong patient protections regarding the disclosure of medical records, and we look forward to working with you on these issues.

Sincerely,

American Academy of Child and Adolescent Psychiatry
American Association for Marriage and Family Therapy
American Counseling Association
American Federation of State, County and Municipal Employees
American Managed Behavioral Healthcare Association
American Nurses Association
American Occupational Therapy Association
American Orthopsychiatric Association
American Psychiatric Association
American Psychiatric Nurses Association
American Psychoanalytic Association
American Psychological Association
Anxiety Disorders Association of America
Association for the Advancement of Psychology
Association for Ambulatory Behavioral Healthcare
Association of Behavioral Healthcare Management
Bazelon Center for Mental Health Law
Child Welfare League of America
Clinical Social Work Federation
Corporation for the Advancement of Psychiatry
National Alliance for the Mentally Ill
National Association of Protection and Advocacy Systems
National Association of Psychiatric Health Systems
National Association of School Psychologists
National Association of Social Workers
National Council for Community Behavioral Healthcare
National Depressive and Manic-Depressive Association
National Mental Health Association