

Mental Health Liaison Group

February 20, 2001

The Honorable Jim Jeffords
Chairman
Committee on Health, Education, Labor
and Pensions
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

This letter is submitted on behalf of the Mental Health Liaison Group for inclusion in the Record of the Hearings on Medical Records Privacy, held by the Committee on Health, Education, Labor and Pensions of the United States Senate, on Thursday, February 8, 2001.

The 36 organizations listed below, as consumer, family, advocate, professional and provider organizations concerned about the confidentiality of medical records, strongly support the regulations recently issued by the Department of Health and Human Services. These new rules represent an historic and important step, and are urgently needed in this era of electronic innovation and of mergers which create large health care entities. These trends heighten the need for policies and procedures that will protect individuals from the inappropriate sharing of their personal health information. The potential for abuse of highly sensitive information, such as information on mental health treatment, is enormous. We are only too aware of the many individuals whose lives have been ruined by the sharing of such information, and have growing concern about those who are delaying or avoiding treatment for fear of such disclosures. Due to the discrimination which frequently follows disclosure of mental health treatment, the protection of mental health medical record information is a critical concern.

It is particularly important that these new rules not only set a uniform national floor for privacy protection, but also do not pre-empt any state laws that give greater privacy protection. States are thus free to act promptly in response to the rapidly-changing world of information technology and to address state-specific issues.

We are also extremely pleased to see the following protections in the proposed new rule:

- The right to know how one's medical records will be used and, in general terms, to whom medical information will be disclosed.

National organizations representing consumers, family members, advocates, professionals and providers
c/o Chris Koyanagi, Bazelon Center for Mental Health Law, 1101 15th Street, NW, Suite 1212, Washington, DC 20005

- The opportunity to give informed consent before health care information can be used or disclosed even for routine purposes such as treatment, payment and the operation of a health plan.
- The right to request restrictions on uses or disclosures of health information (such as requesting that information not be shared with a particular individual).
- The right to request that communications from the provider or plan be made in a certain way (such as prohibiting phone calls to the individual's home).
- The right to see and copy one's own health information, with the exception of psychotherapy notes, and to be provided documentation on who has had access to this information and the right to request amendment to the record if it contains incorrect information.

The rules also provide special protections for highly sensitive mental health information shared during psychotherapy. Psychotherapy notes may not be disclosed without the consumer's specific written authorization and health plans may not condition enrollment or eligibility for benefits on the individual's providing this authorization. We had strongly urged that such a protection be included in the rule for this uniquely private and highly sensitive information. Therapists must have the freedom to document their conversations with patients in a separate protected part of the medical record and this information is not necessary for purposes of payment and health care operations.

We are also extremely supportive of the provisions which provide for appropriate privacy practices in health care settings, such as:

- Limiting information shared to the minimum necessary to accomplish the intended purpose of the use, except if information is shared for treatment purposes, when the entire record can be shared.
- Incentives for health plans and providers to create and use de-identified information.
- The requirement that providers and health plans establish privacy-conscious business practices to protect health records, such as training employees, designating a "privacy officer" to assist individuals with complaints and ensuring that appropriate safeguards are in place to protect the privacy of information.

We are also pleased to see that the rules restrict the use of health information by employers so that self-insured employers may not use health care information for purposes unrelated to health care, such as making personnel decisions. Again, because of the significant possibility of discrimination, such a barrier between those who need information in order to run an efficient health plan and other staff of the employer is a critical protection for mental health information.

We also support the provisions requiring that health information developed in public and private research studies be reviewed by Institutional Review Boards (IRBs). We also note that the rule adds

new criteria that IRBs must apply in making their decisions. The rule also appropriately permits health information to be disclosed for necessary public health activities, such as for prevention or control of disease, child abuse or neglect, domestic-violence reporting and quality control of products.

One area where we are concerned that protections are too weak is that of sharing information with law enforcement officials. Information can be shared with law enforcement officials in response not only to a judge's order but also through an administrative request. This administrative request may be obtained without a judge's review and in some cases can be written by the law enforcement officer him- or herself. We are similarly concerned that information can be shared in civil litigation without judicial review. For example, the rule permits records to be released in response to a discovery request or other legal processes. In this regard, courts have ruled that plaintiffs waive the psychotherapist-patient privilege when claiming emotional distress or placing their mental condition at issue.

However, we are disappointed that the rule permits individuals to be contacted for marketing and fundraising purposes. Although we appreciate that this activity is limited under the rule and that consumers are given the opportunity to opt out of further communications of either type we strongly believe that personal health information should never be shared for the purposes of marketing or fundraising.

However, despite some areas of concern, we are generally extremely pleased with the final rule. Its most significant weaknesses are in areas where the Department did not have the authority to act. We strongly urge Congress to consider legislation that would ensure that individuals have the right to act when their health care privacy has been violated, by providing for a private right of action. Only Congress can create this right, without which there will continue to be little recourse for those whose rights have not been protected in accordance with this rule.

Thank you for considering our views.

Sincerely,

Alliance for Children and Families
American Association of Pastoral Counselors
American Association of Private Practice Psychiatrists
American Association for Marriage and Family Therapy
American Board of Examiners in Clinical Social Work
American Counseling Association
American Family Foundation
American Federation of State, County & Municipal Employees
American Group Psychotherapy Association
American Mental Health Counselors Association
American Psychoanalytic Association
American Psychological Association
American Society of Clinical Psychopharmacology
Anxiety Disorders Association of America
Association for Ambulatory Behavioral Healthcare

Association for the Advancement of Psychology
Bazelon Center for Mental Health Law
Children and Adults with Attention-Deficit/Hyperactivity Disorder
Clinical Social Work Federation
Employee Assistance Professionals Association
Federation of Behavioral, Psychological and Cognitive Sciences
Federation of Families for Children's Mental Health
Legal Action Center
National Alliance for the Mentally Ill
National Association for Rural Mental Health
National Association of Anorexia Nervosa and Associated Disorders
National Association of County Behavioral Health Directors
National Association of Protection and Advocacy Systems
National Association of School Psychologists
National Association of Social Workers
National Council for Community Behavioral Healthcare
National Depressive and Manic-Depressive Association
National Foundation for Depressive Illness
National Mental Health Association
Tourette Syndrome Association