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A MHDNA ISSUE BRIEF

MENTAL HEALTH
DISSEMINATION
NETWORK OF
ARIZONA

A series of reports
highlighting
mental health issues
in Arizona.

BALANCING ACT: THE RIGHT TO PRIVACY, THE NEED TO KNOW

Confidentiality Issues in Mental Health

Mary Graham

At the time this brief went to print, a 30-day public comment period on new privacy rules involving the Health Insurance Portability and Protection Act had just ended on March 30. New rules are expected to take effect later this year that may substantially alter some of the assertions contained in this brief. We recommend a careful comparison of the new rules against recommendations and points made in this brief as the year progresses.

THE RIGHT TO PRIVACY

Safeguarding the privacy of "health information"[1] is a hot topic for legislators at both the federal and state levels, including the state of Arizona. The U.S. Department of Health and Human Services says that a "patchwork" of state laws protecting patient confidentiality highlights the need for national standards to control the flow of sensitive patient information. Two trends underscore the need:

1. Technological advances have expanded privacy concerns beyond the realm of the paper medical record file. No longer does the family doctor safeguard personal information in a locked file cabinet. Rather, health information now resides on computer databases, audiotapes and videotapes, compact disks and other storage media that is frequently transmitted among parties by facsimiles and over the Internet. In fact, many people now use the Internet for health and mental health screenings, albeit via "secure" Web sites, for referrals to clinicians and even for online psychotherapy.

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Phoenix, Arizona

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[1] The term "health information" is quite broad and is typically used to connote a person's medical record, including his or her psychiatric or psychological history, diagnosis, treatment plan, medications and even notes from psychotherapy sessions, which contain highly intimate details of people's lives.

2. As an ever-increasing number of Americans receive their health coverage through health plans, an unprecedented amount of personal health information is sorted, analyzed and otherwise held in massive databases. For example, *Forbes* magazine last year reported that the nation's second-largest health plan, UnitedHealthcare, had amassed 7 terabytes of personal health data on more than 8.6 million Americans. Health plan executives say the data will be used to improve the health and well being of its members. Among some of the ways is the creation of a predictive modeling tool that can forecast personal health risks and outcomes for members, and the creation of a personalized, secure Web site, www.myuhc.com, where plan members can examine their health histories and research medical topics. Other health plans also acknowledge collecting and storing large amounts of information about their members. The data includes both clinical and personal information. Health plans use this information to improve medical services.

For example, Forbes magazine last year reported that the nation's second-largest health plan, UnitedHealthcare, had amassed 7 terabytes of personal health data on more than 8.6 million Americans.

Because of these trends, for better or for worse, we live in a society where health plan administrators, researchers, the police and even employers now have easier access than ever before to highly personal health information. Numerous public opinion surveys show that Americans are increasingly concerned about privacy in general and want greater protection for their medical records in particular.

In addition to the potential infringement on civil rights, lack of health privacy safeguards can be devastating to people's health. A recent study released by pollsters Louis Harris and Associates indicates that one in six people either avoid health care or misinform their doctors and other health care providers out of fear that sensitive personal information may be revealed to spouses, employers, law enforcement and others.

Examples of these "privacy protecting behaviors," as the pollsters call them, include:

Misinforming or providing incomplete information to clinicians.

A person might tell his or her primary care physician that s/he is suffering from digestive problems, but omit details about excessive drinking of alcoholic beverages. This might result in misdiagnosis, and the patient might not receive care to treat the actual conditions.

Paying out-of-pocket for treatment to avoid the establishment of records.

Many people who have health benefits do not use them to pay for what they perceive to be embarrassing conditions. For instance, people who have acquired a sexually transmitted disease might pay for care out of their own wallets to ensure that nobody finds out about the condition. In doing so, they may seek financial shortcuts that result in inadequate health care services.

Postponing or forgoing assessments and treatment altogether.

Some people are so afraid of information leaks that they would rather remain ill or remain concerned that they might be ill rather than seek help. For example, a person might be too embarrassed to seek a screening for HIV or an evaluation of glandular problems for obesity.

For people with mental illnesses, the implications of lack of privacy are even more disturbing. Even in the 21st century, a societal stigma surrounds mental illness, making it difficult for people with such illnesses to gain employment opportunities, maintain friendships and otherwise thrive in their communities. This stigma underscores the importance of patient privacy for people with mental illnesses. But the issue of health privacy remains highly controversial, as it is exceedingly important (and difficult) to maintain a balance between a person's right to confidentiality and the need for appropriate sharing of selected health information among designated parties in order to provide a high quality of care.

Weighing that balance in Arizona – and developing best practices that both protect the privacy of consumers and ensure a high quality of care – is the subject of this issue brief by the Mental Health Dissemination Network of Arizona.

KEY POINTS

- People with mental illnesses should have the same rights to privacy as all others in the health care system.
- Privacy protections ensure better access to care and higher quality care.
- Health plans and states need to assume stronger roles in protecting patient privacy.
- Consumers, doctors, employers and insurance companies have distinct responsibilities to ensure privacy is protected.

BREEDING CONTROVERSY

Several special situations are a breeding ground for controversy about health and mental health privacy:

Psychotherapy Session Notes

Mental health clinicians often record and store greater quantities of more highly personal information than other types of health providers. During a psychotherapy session, for example, a person might talk with his or her therapist about fantasies, fears, use of illegal drugs, plans to cease working for a current employer, or sexual activities. It is essential for the progress of the person to feel safe sharing such details with his or her clinician. It is well documented and accepted by the medical and clinical communities that a trusting relationship with one's therapist is crucial to achieving positive outcomes.

But as with other medical illnesses, the only types of information that need to be shared with health plans in order to administer benefits, or with other health providers in order to coordinate care, are:

- Demographics
- Diagnoses
- Treatment plan
- Medications
- Progress to date

There is no justifiable reason for sharing the intimate details of a person's life among these parties – and this is true for all other medical illnesses as well. As a comparative example, if a person had herpes, it would be important for his or her health plan and any other health care providers s/he is seeing to know the diagnosis and medications prescribed. However, it would not be appropriate for these same entities to obtain information about the person's sexual orientation, frequency of sexual activities or other such details (information often present in psychotherapy session notes).

People with mental illnesses should not be subject to greater invasions of their private lives than those suffering from other conditions. Obtaining psychotherapy session notes from a person's therapist by any entity is a potentially illegal practice. If done for unethical or illegal reasons, obtaining such documents is also a violation of the rights of people suffering from psychiatric disabilities.

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Gun Control

Since 1960, more than a million Americans have died in firearm suicides, homicides and accidents. From time to time, the press has exacerbated the problem by highlighting whether or not the shooter had a mental illness, thus creating the potential for inaccurate stereotypes. These stereotypes can lead to bad public policy. For example, law enforcement officials and legislators in several states such as Texas and Utah have proposed laws and regulations that threaten to allow unregulated access to mental health records in order to deny people with mental illnesses the ability to purchase guns. A bill introduced in the 2001 session of the Arizona Legislature (SB 1108 – Mentally Ill Disclosure of Information) would allow the state Department of Public Safety to obtain a patient's name, date of birth and date of commitment to an IP facility for court-ordered treatment. This information would be maintained in a database to be utilized in the background check process for weapon permits.

Studies over the years have come to varying conclusions about whether people with mental illness are more prone than the larger population to violence. Generally, current studies seem to suggest that people with mental illnesses are no more prone to violent acts than the general population. On that basis, giving law enforcement agencies access to mental health records can be viewed as an unnecessary and discriminatory violation of constitutional rights.

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Medical Emergencies

According to federal law, information can be disclosed to health care providers for treating a condition that poses an immediate threat to the person's health. For example, if a person in an emergency room has symptoms mimicking a heart attack, it would be essential for the attending physician to be able to access information from the person's psychiatrist noting that s/he has panic disorder. Lack of information or failure to coordinate such care is neither cost-efficient nor clinically effective, and can be detrimental to a person's health.

Advanced Directives

Consumers have the right to develop an advanced directive that addresses release of information, as well as preferences about care. Such legally binding documents ensure that their wishes are followed when they become too ill to make decisions.

For example, a woman with schizophrenia who is legally separated from a verbally abusive husband might note in an advance directive that she would like him not to be informed when she is admitted to a hospital. She might further note that she would like her parents to know where she is and what treatment she is receiving, and to have them serve as decision-makers regarding her treatment while she is incapacitated.

All states require the reporting of suspected child abuse or neglect, without mandatory consumer or parent/guardian consent.

Substance Abuse

Substance abuse privacy protections have evolved separately from those for other types of mental disorders. While privacy protections regarding all other mental health problems are largely based on state laws, the current pertinent substance abuse protections are found in federal regulations.

And they are quite good – better than for the rest of mental health. They ensure that information about a person's participation in treatment, even the fact of participation, cannot be disclosed to payers, legal counsel, family/friends, the criminal justice system, central registries or others without proper consent.

Child Abuse and Neglect

All states require the reporting of suspected child abuse or neglect, without mandatory consumer or parent/guardian consent. Information requested as a follow-up to this initial report requires consent, however. If the information requested is for use in a criminal investigation or prosecution of a person, written consent is insufficient and a court order is needed.

Court Orders

According to federal regulations, the courts may authorize disclosure of confidential information where there exists good cause. Such court orders allow for but do not compel disclosure. Judges must weigh the need for disclosure against the potential harm to the person or to the person's relationship with his/her clinician and the impact on the treatment process. The order must both:

- Limit disclosure to information essential to the purpose.
- Provide protection against future public scrutiny.

Mental health privacy issues have been fodder for the courts in Arizona. Most recently, in June of 2000, a state appellate court ruled that a Pima County Superior Court judge was wrong to order a psychiatrist and psychologist to turn over the records of their clients who were not parties to a malpractice lawsuit.

The ruling stemmed from a lawsuit in which a client alleged that the psychiatrist and psychologist had misdiagnosed and negligently treated her. As part of the investigation, the records of other clients treated for similar conditions were sought. The judge from Pima County had ordered that the medical records be produced without names. However, the Arizona Center for Disability Law in Phoenix argued effectively on behalf of nine other clients who objected to having their records turned over.

Jails and Prisons

Many people with mental illness encounter the criminal justice system. They should have the right to privacy concerning their medical records and the right to not be identified as a person with mental illness – particularly if they believe this information could put them at risk from other inmates or from discriminatory actions by jail or prison staff. However, this right needs to be balanced so that mental health treatment can be provided, where appropriate.

When treatment is appropriate, there should be a requirement to obtain authorization from the person in order to access his or her medical records. If such individuals are not a danger to themselves or others, then they should have the right to refuse treatment, as well as to refuse to authorize the release of their records. In addition, jails and prisons should not share information regarding any treatment received during incarceration with external parties. Disclosing that an individual was treated for a mental illness while incarcerated could result in further stigma and discrimination, impairing the person's ability to reintegrate into society upon discharge.

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THE NEED TO KNOW

Given our culture's emphasis on individual freedom and confidentiality, one may wonder why anybody would oppose efforts to safeguard health and mental health privacy. But it is important to recognize that some parties within the health care delivery system do have a legitimate need to access some health information. A few examples follow:

Health care insurers need to have access to some patient information to perform key functions. For instance, if they are still in the business of preauthorizations, they must have information about a person's symptoms in order to approve a referral to an appropriate health care provider, and they must know what services a person is receiving in order to pay his or her health care provider's claims.

Payers such as employers, insurance companies and state agencies need to have access to some patient health information in order to monitor the quality of the services they have purchased on behalf of their beneficiaries. For example, to negotiate a better set of employee benefits from a health plan, an employer might want to examine aggregate data across the workforce about treatment costs, services provided, and the impact on outcome, absenteeism and productivity.

The need to know what medications a person is taking in order to avoid potentially serious conflicts or reactions with other medications and treatments is a common problem where mental health and physical health systems are not well integrated.

Health care providers, such as physicians and specialists, need to have access to some patient health information in order to provide the best possible care and ensure treatment is well coordinated. For example, a dentist would need to know whether the patient is taking antabuse to ensure products with alcohol are not used during dental procedures. (Antabuse is often prescribed for people recovering from alcohol addiction. It causes severe nausea if alcohol is consumed). The need to know what medications a person is taking in order to avoid potentially serious conflicts or reactions with other medications and treatments is a common problem where mental health and physical health systems are not well integrated.

> To illustrate, consider this actual case in Arizona: A man with a history of bipolar disorder is seen by his primary care physician for unsteady gait, muscle twitching and decreasing strength. In the initial interview, the physician finds the man is taking Lithium, Prozac and Risperidal. He is also taking various inhalers and hypertensives prescribed by his primary care physician because of a long history of hypertension, smoking, and recurring bouts of bronchitis. Finally, he is taking an over-the-counter anti-inflammatory (Motrin) for his chronic lower back pain. Testing reveals a Lithium level in the toxic range, for which he is admitted to the hospital. The physician discovers

> that the man had increased his use of Motrin because of his lower back pain and this led to decreased Lithium excretion and secondary toxicity.
>
> The patient is taken off Lithium and his condition improves. His bipolar condition was stable with Lithium, and unfortunately, without any contact with the patient's psychiatrist in a completely separate and non-integrated public mental health system, the patient is faced with either poorer treatment for his mental illness or worse problems with hypertension, low back pain and bronchitis. In this case, the primary care physician takes the initiative to contact the psychiatrist, and together they work out a medication and monitoring strategy that improves his bipolar disorder and still allows for effective treatment of his other conditions.
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> Problems of confidentiality and the need to know relevant medical information are exacerbated where mental and physical health are not well integrated.

Clinical researchers need access to some patient health information in order to assess the efficacy of treatment approaches. For example, a research organization might compare suicide and hospitalization rates of people with clinical depression according to the types of medication and therapy they receive. Results would be used to promote best practices.

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HOW DOES ARIZONA COMPARE TO OTHER STATES?

As noted earlier, state laws and regulations are the primary source of mental health privacy protections, with the exception of substance abuse, which is safeguarded predominantly through federal rules. On a positive note, Arizona is one of 23 states that enacted legislation affecting medical privacy during its 2000 legislative session. Some highlights:

HB 2041: Maintains that records held by a state agency or a local authority relating to genetic testing are confidential.
HB 2145: Sets minor guidelines for how and how long health care providers must store patient records.
HB 2158: Classifies the mishandling of patient records as unprofessional conduct that is subject to sanction.
HB 2482: Allows the medical director of emergency services to make recommendations for standards for maintaining the confidentiality of information considered in the course of quality assurance.
SB 1080: Provides for the maintenance and confidentiality of patients' prescription records.

For the full text of these laws, please visit www.azleg.state.az.us on the Web.

As positive as this activity is, however, these and previously passed Arizona statutes provide only modest protection and lack sufficient specificity. They contain statements supporting the concept that there is a need to protect the confidentiality of patient records, but they lack enforcement or detailed rules to address documented problems being experienced by some Arizonans, particularly with respect to the operation of health plans.

While no state has enacted comprehensive health privacy laws, a few states, such as Minnesota and New York, have passed laws that are far-reaching in some respects and might be considered as possible models for Arizona:

New York Law / Minnesota Law

Health plans are held liable for misconduct committed by their staff related to violations in privacy. These staff members have tremendous access to highly personalized information, often including psychotherapy session notes. Fear of this information being inappropriately released, especially to the patient's employer, can deter people from being fully open with their clinicians and may even cause them to not seek the care they need. Currently, most health plans will take action against employees that breach privacy, but holding them directly accountable for their staff's behavior adds a greatly needed safeguard. Health information can only be collected by a health plan if it is pertinent to its functions (e.g. Underwriting, Claims and Referrals). This law implies that the health plan can only access information such as demographics, diagnoses, treatment plan, services utilized, medications and progress to date. The psychotherapy session notes are protected. If appropriately enforced, this law ensures that consumers will feel that they can be fully open with their clinicians about the intimate details of their lives, without fear that such information will fall into outside hands. It ensures a more effective provider-to-client relationship, and thus improved clinical outcomes.

For the full text of these laws, please contact the NMHA Advocacy Resource Center at
(703) 838-7524 or by e-mail at cmiller@nmha.org

Fortunately, while efforts to enact stronger legislative protections for confidentiality in Arizona continue, there are other avenues to explore for safeguarding health privacy. One strategy with great potential is to make specific requirements regarding some of the operations of health plans and of health care providers (which are singled out here because they currently have the greatest access to sensitive health information).

These requirements should apply to people covered under managed care plans, particularly as they meet with their providers. They should also apply to purchasers, such as employers and state agencies, which have the power to insist on improvements in health plan practices as they negotiate their contracts.

What might some of these requirements be? A recent National Mental Health Association study of more than 20 of the nation's largest managed care systems, some of which operate in Arizona, identified promising practices that could be replicated by health plans and providers:

One strategy with great potential is to make specific requirements regarding some of the operations of health plans and of health care providers.

Health insurance plans

- Require providers to submit only the diagnosis, goals, medications and treatment plan – respecting the confidentiality of psychotherapy notes.
- Provide up-front information about confidentiality protocols and benefits of information sharing to people when they join the health plan or request such information.
- Create release forms stating that consent may be withdrawn at any time, as well as providing the date or condition upon which consent will expire if it is not withdrawn.
- Implement special protections for audio and video files, and other electronic documents such as e-mail and computer databases.
- Provide increased privacy training to staff and implement stricter disciplinary responses to breaches, including termination and legal repercussions.
- Develop and monitor explicit policies for files, including storage, internal communications, off-site storage, and disposal of records. At a minimum, such policies should include marking all materials with consumer-identifying information "confidential," putting locks on paper files, using encryption for emails, and developing password systems for computer files.

Physicians and other health care providers

- Familiarize themselves with the information requirements of health plans before they make decisions about which provider networks to join.
- Discuss issues of confidentiality in detail with clients to make sure that their wishes are respected, well documented, and that they understand the benefits of sharing information in order to improve the quality of health care.
- Store psychotherapy session notes separately from the medical record.
- Provide training for office staff about confidentiality, including requiring formal acknowledgement that they agree to abide by what they learn.
- Carefully document all releases of information in their clients' records, including the date, content, to whom it was released and for what purposes.
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KEY RESPONSIBILITIES FOR STAKEHOLDERS

If Arizona – or any other state for that matter – is to continue to promote better protection of privacy and medical confidentiality in mental health, stakeholders can begin by accepting certain responsibilities:

Consumers

The consumer of health and mental health services should accept responsibility to ask about confidentiality policies when s/he joins a plan or begins care with a new clinician. S/he would ask about the types of information to be disclosed, who has the authority to disclose, to whom will it be disclosed, and for what purposes. S/he should understand the benefit of sharing information, which is to add to the body of knowledge of what works and what does not work.

S/he should review any consent forms thoroughly before signing and initiate a discussion about disclosure policies and personal preferences with his or her clinician.

S/he should create an advance directive that provides informed consent about what information can be released to whom and for what purposes – before s/he becomes ill and possibly too incapacitated to provide such consent.

Health insurance plans

Plans should collect and store only the health information necessary to perform key administrative, utilization management, and quality improvement functions, including demographics, diagnoses, symptoms, medications, treatment plan and progress notes (but not psychotherapy session notes).

As the two largest accrediting bodies – the National Committee for Quality Assurance and the Joint Commission on Accreditation of Health Plans – already insist, health plans should also:

- Develop comprehensive policies addressing their operational practices.
- Educate consumers and providers in their networks about their policies.
- Train and monitor the activities of their staff with respect to member (patient) confidentiality, taking disciplinary actions where appropriate.

Providers

Providers should share only that information with managed care organizations that is necessary for completion of administrative, utilization management and quality improvement process (but not psychotherapy session notes, which should be stored separately from the rest of the client's records).

They should ensure that office staff is trained on confidentiality guidelines.

They should review any consent forms for disclosure that had been signed by their clients and initiate a dialogue with all clients about what information will and will not be shared with outside parties.

Legislators

Legislators should become more informed about confidentiality issues and work closely with advocates and mental health care professionals to pass legislation that fills in current gaps in protections.

CONCLUSION

With the ever-increasing use of technology and managed care practices, balancing a person's right to medical privacy with the need of other parties to access such information is becoming an ever more challenging task. Not surprisingly, the very same electronic technologies that could pose a significant threat to the invasion of medical privacy also hold the promise of providing consumers and health organizations with more creative and powerful ways to protect that privacy. Even now we are witnessing the advent of a new industry focused on developing and marketing privacy protection software and services, which will no doubt have an impact on medical records and related information.

All Arizona stakeholders need to become more aware of the opportunities to effectively balance privacy with the need to know. Instead of retreating to the fringes of either pole of the privacy continuum, we need to foster dialogue and work toward mutual trust and cooperation. There is no reason to believe that we cannot develop appropriate and effective privacy guidelines that both protect the rights of Arizonans with mental health problems and allow for their most effective and efficient treatment.

ABOUT THE AUTHOR

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MHDNA

The Mental Health Dissemination Network of Arizona (MHDNA) is a public-private partnership initiated by St. Luke's Health Initiatives, a public foundation focused on community health issues in Arizona.

MHDNA's mission is to improve the lives of persons in Arizona who suffer from serious mental illnesses and disorders. Its members include all major public and private mental health education and advocacy groups, professional associations, consumer and family representatives, service providers, policy leaders and other interested individuals.

MHDNA's core goals include a focus on outcomes, integration and leadership. Its strategies include the dissemination of best practices research, targeted support for education and advocacy, the development and application of systems performance indicators, needs assessment and technical assistance, and seed funding for project development.

MHDNA maintains an extensive mental health best practices database at www.azmenthealth.org. Further information is available by contacting:
St. Luke's Health Initiatives, 2375 E. Camelback Road, Suite 200, Phoenix AZ 85016, Ph: 602-385-6500, Email: info@slhi.org

MHDNA Issue Briefs

MHDNA Issue Briefs are published on an occasional basis by St. Luke's Health Initiatives and distributed to a broad cross section of organizations and individuals interested in mental and behavioral health topics of timely relevance for policy and practice, with an emphasis on Arizona.

The intent of each brief is to provide an informed and critical context in which policy leaders, practitioners and consumers can discuss issues of common concern and collectively take steps to improve mental and behavioral health outcomes. Authors are selected on the basis of expertise and experience, and the opinions expressed in the brief are their own. MHDNA seeks to stimulate debate and provide a forum for reflective dialogue between diverse and often divergent interests, and not to favor a particular ideology or approach.

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