2001

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Publication Information
Michael K. McChrystal, The Privacy of Elders, Elder's Advisor, Spring 2001, at 22.

The Privacy of Elders

The right to privacy does not diminish with age. It becomes even more important and vulnerable.

By Michael K. McChrystal

Privacy is one of the hottest legal topics around. As government and business eagerly employ the full panoply of information technology in furthering their various goals, the individual's right to privacy is threatened at every turn. These threats are often difficult to assess because the prospective injury may be speculative and often varies from individual to individual. In addition, substantial benefits can be achieved through these privacy-invading technologies, so their costs do not obviously outweigh their benefits.

One recent highly publicized example is the computer program that federal law enforcement agencies want to employ to capture electronic communications sent by and to targets of criminal investigations.[1] This email-reading program, foolishly called "carnivore," is intended to advance the public interest in detecting, averting, and punishing criminal conduct. Privacy advocates worry, however, that carnivore does so by sifting through the email of an untold number of innocent bystanders as well, at a great cost not only to individual privacy but also to civil liberties more generally.

A second illustration of governmental deployment of privacy-invading technology is the increasingly common practice of state and local agencies putting their records online. Online public records help to achieve the public goals of transparent and efficient government. At the same time, however, important privacy interests are threatened when we can readily learn facts such as how much money the neighbors paid for their house or whether our doctor has ever been sued for malpractice.

Businesses are rushing headlong into the information revolution as well. Vast databases of consumer information support the marketing efforts of a wide array of businesses. Medical and financial information systems maintained by private enterprises govern whether an individual can get insurance or a loan, and even whether a doctor's recommendation that surgery be performed will receive the funding which the patient anticipated. The collection and use of personal data by businesses can improve market efficiency but at a cost to personal privacy. Again, the cost and benefit analysis is value-laden and complicated.

We find ourselves at a crossroads that is inevitable in this information age: Government and business envision great public and private benefits in employing an array of privacy-invading devices and strategies to achieve a variety of social and commercial goals. At the same time, both democracy and the market require public trust, and minimal levels of privacy protection are essential to that trust. This, then, is the context for the widespread anxiety about the appropriate strength and limits of privacy protection.

Privacy issues affect elders as much as everyone else and perhaps more so. This article discusses four aspects of privacy of special concern to elders. The privacy of medical records is especially important for elders because of the physiology of aging, the reliance by many elders on both public and private cost reimbursement systems, and the prevalence of age and disability discrimination. The privacy of

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consumer data is especially important for elders because so many elders are victimized by overreaching sales techniques and outright consumer fraud. Privacy protection in residential care facilities has obvious importance to older persons who often need the benefits of assisted-living environments. Finally, enormous privacy issues arise within the guardianship system.

Medical Records

Elders are major consumers of health care services, and they have a special need to maintain the privacy of their records of those services. Indeed, the privacy of medical records is a stark example of how privacy issues often have a particularly significant impact on elders. Elders who participate in Medicare and private insurance programs are likely to be included in a variety of medical record databases, including those maintained by state and federal governments, by private insurers and their affiliates, and by the various providers from whom they receive services. The proliferation of medical records of the elderly is a special concern by itself because as records are more numerous and easily accessible, they are more likely to be improperly disclosed and used.

Information contained in medical records can influence almost all of life's high-stakes decisions made by one person about another. Medical records can be helpful to assure quality care and appropriate reimbursement, but they can also provide a basis for denying a person a job, a loan, or insurance. They could tip the scales in deciding whether to marry a paramour, or even whether to choose someone as a travel companion. Rightly or wrongly, many people value health information as important in making judgments about others, even when those judgments do not strictly relate to medical issues.

Standards governing the confidentiality of medical records have been hotly debated for years, and the promulgation of new federal standards by the Department of Health and Human Services (DHHS)[2] has added fuel to the fire, even while trying dispositively to resolve the issues. The free flow of medical records can facilitate treatment, simplify reimbursement, and contribute to better understanding of disease and its treatment. Notwithstanding these benefits, the costs of free access to the medical records of others can be enormous.

Elders already experience widespread discrimination based upon the assumption that advancing years mean decreased health and increased risk of costly illness and death. Improper access to and use of medical records can increase the discrimination already at work. Historically, state law governs the extent to which medical records must be kept private. That is beginning to change.

When Congress passed the Health Insurance Portability and Accountability Act (HIPAA) in 1996,[3] it called upon the DHHS to develop federal rules governing privacy of medical records. Those rules have been published and, while both privacy advocates and health and insurance industry spokespersons complain about how the balance has been struck, a federal law of medical record privacy is now being developed. As medical records are improperly accessed or used to deny employment and other opportunities, remedies for such wrongful discrimination may increasingly be found not only under age and disability discrimination law but under privacy law as well.

Consumer Information

Perhaps the most obvious form of increased privacy invasion comes at the hands of marketers who rely upon databases containing demographic information about consumers, including their spending histories and preferences. The sophistication of direct mail, telemarketing, and online selling has increased with the ability to collect and access virtually limitless data about consumers. Consumer data is collected electronically whenever a transaction involves use of a credit card, debit card, merchant identification card, or personal check. In addition, marketers often request and receive information from consumers in the form of surveys, applications, and questionnaires. Once compiled, this information can provide a very informative digital profile of a consumer. Based upon this profile, marketers are in a good position to identify strong prospects for their marketing strategies.

A friend of mine, who has Alzheimer's disease, is a good illustration of how the elderly and infirm can be financially and emotionally victimized through the use of personal data. As Mary Ann[4] began experiencing dementia in her late 60s, she became increasingly disoriented in her relationships with family and friends. Perhaps in part to counteract this confusion and loss, she was drawn into the warm talkative relationships offered by cable television sales channels. Mary Ann became a frequent purchaser,

and she was often delighted by the extra gifts included in the packages she received almost daily from these television purveyors of goods. She was drawn into the salespersons' personalities, almost like characters on a soap opera, but these television personalities were real rather than actors, and were always cheerful and eager to give their friends inside information on hard-to-find bargains.

As Mary Ann spent more time watching the cable sales networks and more money buying their products, she also experienced an abrupt increase in the amount of direct mail marketing and telemarketing solicitations she received. When she began biting on contests and chances to win millions of dollars, the solicitations became even more frequent and more personal.

Mary Ann's incipient Alzheimer's disease was an essential feature of her victimization. When family and friends called, she often did not know who we were but faked it, pretending to know us as we gave her the facts she needed to play along. The telemarketers took advantage of Mary Ann's vulnerability. With their warm encouragement, Mary Ann mistook these vendors for friends, and they preyed on her misunderstanding by telling her how disappointed they would be if she did not help them out by making purchases. As her finances eroded, she felt the guilt of "letting down her friends" when she declined the sales pitches they cast in terms of "seeking her help."

Extensive consumer profiling can be used to spot financially vulnerable individuals. Such profiling depends on the ability of marketers to compile information about a consumer from a variety of sources. The federal Fair Credit Reporting Act[5] provides some protection against abuses, but electronic commerce and the consolidation of businesses into affiliated companies undermine many of its protections. Much consumer data is simply proprietary information that may be bought and sold at will. While consumer and privacy advocates aggressively seek more consumer-friendly laws, their victories have been few.[6]

Consumer protection laws generally are most needed by the most vulnerable consumers. Vulnerability can come in many forms, including low and fixed incomes, social isolation, and dementia—forms of vulnerability especially prevalent among older persons. Elders' finances would be far safer if the law did more to protect the privacy of personal data.

Privacy in Assisted Living

Persons in assisted-living settings, particularly long-term care facilities, suffer some loss of privacy as a necessary consequence of group living arrangements. Some states impose legal standards to limit the extent of privacy invasions that arises from residence in a health care facility.

Minnesota's patients' bill of rights[7] provides a comprehensive approach. It establishes a number of privacy rights on behalf of "patients and residents of health care facilities." The right to *treatment privacy*[8] extends to "[c]ase discussion, consultation, examination, and treatment." Treatment privacy also "shall be respected during toileting, bathing, and other activities of personal hygiene."

The Minnesota statutes recognize that *personal privacy*[9] extends to the "right to every consideration of [patients'] privacy, individuality, and cultural identity as related to their social, religious, and psychological well-being. Facility staff shall respect the privacy of a resident's room by knocking on the door and seeking consent before entering, except in an emergency or where clearly inadvisable."

Communication privacy[10] includes the right of patients and residents to "associate and communicate privately with persons of their choice and enter and, except as provided by the Minnesota Commitment Act, leave the facility as they choose. Patients and residents shall have access, at their expense, to writing instruments, stationery, and postage. Personal mail shall be sent without interference and received unopened unless medically or programmatically contraindicated and documented by the physician in the medical record. There shall be access to a telephone where patients and residents can make and receive calls as well as speak privately. Facilities that are unable to provide a private area shall make reasonable arrangements to accommodate the privacy of patients' or residents' calls. Upon admission to a facility where federal law prohibits unauthorized disclosure of patient or resident identifying information to callers and visitors, the patient or resident, or the legal guardian or conservator of the patient or resident, shall be given the opportunity to authorize disclosure of the patient's or resident's presence in the facility to callers and visitors who may seek to communicate with the patient or resident."

Under the Minnesota statute, the *right to associate*[11] provides that "[r]esidents may meet with visitors and participate in activities of commercial, religious,

political, . . . and community groups without interference at their discretion if the activities do not infringe on the right to privacy of other residents or are not programmatically contraindicated. This includes the right to join with other individuals within and outside the facility to work for improvements in long-term care."

With respect to *marital privacy*,[12] the statute provides that "[r]esidents, if married, shall be assured privacy for visits by their spouses and, if both spouses are residents of the facility, they shall be permitted to share a room, unless medically contraindicated and documented by their physicians in the medical records."

The Minnesota patients' bill of rights displays uncommon breadth of understanding of privacy issues for those who require assisted-living arrangements.

Guardianships

It is difficult to conceive a more thoroughgoing nonphysical invasion of privacy than occurs as a result of guardianship. Guardians are granted access to all information about the ward that the ward herself could acquire. The sweeping power of a guardian is expressed in the Uniform Guardianship and Protective Proceedings Act: "A guardian shall make decisions regarding the ward's support, care, education, health, and welfare."[13] Implicit in this power is the duty of the guardian to gather relevant facts. This is expressed in the uniform act as the duty to "become or remain personally acquainted with the ward and maintain sufficient contact with the ward to know of the ward's capacities, limitations, needs, opportunities, and physical and mental health."[14] To some extent, this is a duty to invade privacy. A guardian may well be violating her duty to the ward by respecting too much the ward's interest in privacy.

The very phenomenon that allows guardians to invade the ward's privacy provokes the concern that guardians might do so too much. It is common to hear caregivers speaking freely about those in their charge. We are often inclined to talk most freely about that which is most important to us, including the everyday experiences of life. For guardians and other caregivers, this can mean talking about the elder to whom care is given.

As lawyers know so well through our acculturation to confidentiality concerns, the impulse to talk about those we serve can be very powerful. Privacy is important, though, even for someone like my friend Mary Ann who has Alzheimer's and who would not know we were speaking about her. Invasions of privacy are invasions of dignitary interests. To invade the privacy of an unwitting victim is akin to physically molesting an unconscious victim. The principal wrong is in the affront to human dignity.

Conclusion

We often think of elders as persons we care for and talk about. There is goodness and service in doing so. We must remain conscious, however, that the right to privacy should not wear out with age. Rather, the need for privacy becomes all the more immediate because of the special challenges that aging can entail.

Endnotes

1. *See* Statement for the Record of Donald M. Kerr, Assistant Director Laboratory Division Federal Bureau of Investigation on Internet and Data Interception Capabilities Developed by FBI Before the United States House of Representatives, The Committee on the Judiciary, Subcommittee on the Constitution (visited on Dec. 4, 2000) http://www.fbi.gov/pressrm/congress/congress00/kerr072400.htm.
2. Standards for Privacy of Individually Identifiable Health Information *at* http://erm.aspe.hhs.gov/ora_web/plsql/erm_rule.rule?user_id=&rule_id=228.
3. Pub. L. No. 104-191, 110 Stat. 1936.
4. The name is fictitious, the story is real.
5. 15 U.S.C. § 1681 et seq.
6. By comparison, the European Union Directive on Data Protection, Directive 95/46/EU, sharply restricts the selling of consumer data.
7. MINN. STAT. § 144.651 (2000).
8. MINN. STAT. § 144.651 (16).
9. MINN. STAT. § 144.165 (19).
10. MINN. STAT. § 144.165 (21).
11. MINN. STAT. § 144.165 (26).

12. MINN. STAT. § 144.651 (28).

13. The National Conference of Commissioners on Uniform State Laws, Uniform Guardianship and Protective Proceedings Act, § 313 (a) (1997).

14. Id. at § (b)(1).