

Law and Practice

Advocacy in a Post-HIPAA World

By Hilary Sohmer Dalin

Elder law practitioners or other advocates frequently need access to medical records or information from clients' medical providers, insurance carriers, contractors, or managed care organizations. However, advocates may have found that long-established practices for securing documents or discussing cases with these and other entities, called "covered entities" by the HIPAA privacy regulation, are no longer honored under HIPAA. Advocates now must determine whether or not they have the legal status to require the entity in question to disclose protected health information.

What Is the HIPAA Privacy Rule?
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The HIPAA-Compliant Authorization

Advocates generally need a HIPAA-compliant authorization to seek disclosure of medical records from health care providers and other covered entities. The regulations set forth the requirements for a HIPAA-compliant authorization.¹ The authorization must:

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Partnerships in Law and Aging

Caregiver Legal Assistance Network

By M. Stacey Hawver

There are many heartbreaking reasons why children cannot remain in the care of their parents. In California's Silicon Valley, the successful high-tech environment substantially increased the cost of living, causing a crisis for low-income families. Lower level workers received no wage increases when salaries surged upward for those with high demand skills. Multi-generational families began moving in together to share the increased cost of housing. Utilities skyrocketed. Gas prices climbed and transportation became more expensive. Everyone felt the impact of the rising cost of health care. Without sufficient income to meet daily needs, family tensions increased. Unfortunately, these issues were only exacerbated by the unexpected and swift economic reversal that impacted all of Silicon Valley and quickly filtered down to families already under stress. Many people lost their jobs. Health care options narrowed. Resources were cut because of budget constraints. For many immigrant families already fac-

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- Be separate from any other authorization or retainer agreement or financial grant of a power of attorney.²
- Be in writing and in plain language (not “legalese”).
- Identify specifically what information the patient wants to access.
- List the name and organization to which the patient wishes the information disclosed.³
- Identify the covered entity from which disclosure of protected health information is authorized.
- State the purpose of the disclosure. It is sufficient for a patient to write “at my request.”⁴
- Include an expiration date or event such as “one year from the date I signed this authorization,” or “until my appeal is concluded.”⁵
- Contain the dated signature of the patient.

To be HIPAA-compliant, the authorization must also include mandated notices to the patient.⁶ The required notification statements are:

- The patient’s right to revoke the authorization. If a patient retroactively revokes an authorization, the revocation will not apply to disclosures made by a covered entity before it became aware of the revocation.
- A warning that disclosures to non-HIPAA-covered entities may be disclosed to others who are not subject to the HIPAA privacy rule.

The preamble to the Final Rule modifications suggests that it is permissible to add to the mandated statement information about any legal or contractual obligation between the patient and a non-HIPAA-covered entity, such as the lawyer’s ethical obligation to maintain client confidentiality.⁷

Are Advocates Also Personal Representatives?

Can the lawyer or other advocate claim status as a personal representative and accordingly obtain protected health information without first obtaining a HIPAA-compliant authorization?

The privacy rule defines a personal representative as one who is authorized under other federal, state, or local law “to act on behalf of an individual who is an adult or emancipated minor in making decisions related to health care....”⁸ Examples include a parent of a minor child or guardian of an incapacitated adult. The rule applies also to records of a deceased individual, with the executor of an estate considered a personal representative. The preamble to the Final Rule states: [w]e intend this provision to apply to persons empowered under state or other law to make health-related decisions for an individual, whether or not the instrument or law granting such authority addresses health information.”⁹ The preamble does not indicate whether authority to act on behalf of an individual in decisions related exclusively to health care payment confers personal representative status sufficient to access personal health information.¹⁰

This regulatory definition of personal representative does not mesh with the services provided by lawyers and other advocates, who do not and should not have health care decisionmaking authority for their clients, but who do need access to medical records in order to provide competent representation. A narrow interpretation of the definition may make disclosure to advocates who assist health care consumers with obtaining coverage by Medicare, Medicaid, or other public and private health care insurers harder. It may also place consumers and their advocates in a difficult position—the consumer may feel compelled to relinquish more

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Inside the Commission

Commission Studies State Public Guardianship Programs

The University of Kentucky and the ABA Commission on Law and Aging are conducting a 15-month study on public guardians and their wards, with an emphasis on seven states. The study is funded by the Retirement Research Foundation, based in Chicago.

Public guardianship is for individuals who are adjudicated by a judge to be incapacitated but have no one to serve as guardian. The number of candidates for public guardianship is projected to rise significantly, due to the “graying” of the population, the aging of individuals with disabilities, advancements in medical technologies affording new health care and end-of-life choices, and the rising incidence of elder abuse, among other factors. This research is long overdue: the only comprehensive study of public guardianship was conducted in the late 1970s. The specific goals of this study are:

- To gather baseline information on public guardianship administration and clients in all 51 jurisdictions; to conduct in-depth study of public guardianship systems in seven states (Florida, Illinois, Indiana, Iowa, Kentucky, Missouri, and Wisconsin); and to compare the findings with those from the study of 25 years ago.
- To investigate differences in administration and client characteristics among five different models of public guardianship (social service agency, public administrator, court model, single state agency, and none).
- To compile state statutory provisions of public guardianship or guardianship of last resort in all U.S. jurisdictions.
- To develop recommendations for policymakers and identify promising practices for public guardianship programs.

Study results should aid policymakers, public guardianship practitioners, and advocates to promote better public guardianship programs and, consequently, more meaningful lives for wards of the state.

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Project to Examine Medicaid Estate Recovery Programs

In September 2003, the ABA Commission began its one-year project to study state Medicaid estate recovery programs, with support from the AARP Public Policy Institute. The project aims to examine the scope, variations, and operation of these state programs within the framework of federal and state law. Ten years have passed since the inception of the federal estate recovery mandate in the 1993 Omnibus Budget Reconciliation Act. In 1996, the ABA Commission conducted a national survey of Medicaid estate recovery programs with funding from AARP, resulting in a report published by AARP’s Public Policy Institute. The current study will update those findings, in light of increased state activity in this area in the interim, current fiscal constraints, and federal consideration of changes to the Medicaid program. The project has four related components:

- A national survey to provide a descriptive overview of the key features of the state Medicaid estate recovery programs. Many of the questions will parallel those of the 1996 survey, thus highlighting trends over time as well as variation across states.
- A collection of state estate recovery laws and regulations and a statutory table of authorities useful for policy-makers and practitioners.
- A background literature search of legal publications and key federal and state court cases, and a summary and analysis of these cases.
- An in-depth analysis of law, policy, and practice in ten selected states. The Commission will identify a legal practitioner/Medicaid expert to assist in the analysis of the jurisdiction’s law, policy, and practice on Medicaid estate recovery and its effect on Medicaid beneficiaries. These elder law practitioners will bring expertise in understanding nuances in state property, marital, and debt collection laws and their interaction with Medicaid law. They will provide written analyses of the Medicaid estate recovery picture in their states.

Based on these research activities, a comprehensive report will be produced for the AARP Public Policy Institute. For further information, contact Erica Wood, ericawood@staff.abanet.org, (202) 662-8693, Naomi Karp, nkarp@staff.abanet.org, (202) 662-8691, or Charlie Sabatino, sabatino@staff.abanet.org, (202) 662-8686.

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What Is the HIPAA Privacy Rule?

The HIPAA privacy rule became effective on April 14, 2003. It implements provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA)¹ and is intended to safeguard patient privacy while enhancing individuals' access to their own health information.² It bars **covered entities** from using or disclosing **protected health information (PHI)** except as the rule permits or requires, or as authorized by the patient or the patient's **personal representative**.

- ⊗ **Covered entities** are those that create, maintain, and use patient-identifiable health information (PHI), or transmit that information electronically.³ Health care providers are considered covered entities *only* if they transmit PHI electronically. Other covered entities include health insurers, managed care organizations or other health plans, and governmental entities that administer health benefits such as Medicaid, Medicare, and Veterans Administration benefits, as well as health care clearinghouses such as billing services that work with health care providers and insurers and help to process health information.
 - ✖ Covered entities **must disclose** most protected health information to patients or their personal representatives. Covered entities **may disclose** records to a person or organization with a valid HIPAA-compliant authorization to make health care decisions on behalf of the individual. Covered entities **may use or disclose** protected health information under certain circumstances without written consent or authorization if the individual is informed in advance and is given the opportunity to consent or object to the disclosure, or if the person seeking the information is a family member involved in the patient's treatment or payment for treatment.
 - ✖ Covered entities **are not required to disclose** psychotherapy notes, records prepared in anticipation of litigation or administrative proceedings, and certain designated laboratory records. They are **not required to disclose** information to personal representatives or others if they reasonably believe that there is a risk of domestic violence or other endangerment, or that disclosure would not be in the patient's best interest.⁴
- ⊗ **Protected health information** includes medical records or other health information that identifies or can reasonably be used to identify an individual patient.
- ⊗ **Personal representatives** are expressly authorized by the patient or designated by law to make health care decisions on behalf of the patient. With some exceptions, covered entities must "treat a personal representative as the individual" with respect to disclosure of protected health information.⁵ Personal representatives do not need written authorization to obtain protected health information.
- ⊗ **Health oversight agencies** include public agencies, as well as private entities working under contract with public agencies to oversee the health care system or enforce civil rights laws.⁶ Health oversight agencies have special rights of access to otherwise protected health information, and can obtain and share PHI without patient authorization, if it is relevant to their oversight duties (*e.g.*, determining eligibility for governmental health benefits, monitoring compliance with program standards or with civil rights laws).⁷
- ⊗ **Enforcement.** HIPAA requires reasonable and good faith compliance efforts, and imposes a \$100 fine for each disclosure violation. If the violation is a knowing one, penalties could be as much as \$50,000 and up to one year in prison.⁸ HIPAA does not include a private right of action for individuals aggrieved by disclosure; health care consumers file complaints with the HHS Office of Civil Rights.

Notes:

1. Health Insurance Portability and Accountability Act of 1996 (HIPAA), P. L.104-191, title XI, part C.
2. For a discussion of past abuses, see preamble to Final Rule, 65 Fed. Reg. 82462, 82464-82469 (Dec. 28, 2000).
3. 45 C.F.R. §160.103(3).
4. *Id.* §§164.510-512.
5. *Id.* §§164.502(g) and 164.524.
6. *Id.* §164.501.
7. *Id.* §164.512(d).
8. 42 U.S.C. §§1302d-5 and 1302d-6.

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authority over health care than she wishes in order to grant her advocate personal representative status, while the advocate could find herself with the authority to make health care decisions on behalf of a client when all she needs is to review files for a coverage claim. Advocates may need to pursue other avenues for obtaining this information, as discussed below.

Disclosure to Others

As noted above, the HIPAA privacy rule allows covered entities to “disclose to any other person identified by the individual, protected health information directly relevant to such person’s involvement with the individual’s care or payment related to the individual’s health care.”¹¹ The regulation also provides other opportunities for disclosure of protected health information to those involved with the individual’s health care. A covered entity may disclose the location, general condition, or death of an individual to anyone who is “responsible for the care of the individual.”¹² When the patient is not present, or lacks the capacity to consent or object to such disclosures, “. . . the covered entity may, in the exercise of professional judgment, determine whether the disclosure is in the best interests of the individual and, if so, disclose only the protected health information that is directly relevant to the person’s involvement with the individual’s health care.”¹³

State Health Insurance Assistance Program (SHIP) Network

The federal Centers for Medicare and Medicaid Services (CMS) has devised an alternative system to permit telephone disclosure of protected health information to selected paid and volunteer staff of the State Health Insurance Assistance Program (SHIP) network. Called the “Customer Service Representative (CSR) procedure,” the process enables SHIPs to get claims information from Medicare fiscal intermediaries or carriers.

SHIPs are directed to submit written HIPAA-compliant authorizations whenever possible. In the alternative, they are urged to arrange for a three-way telephone conversation during which the CSR can ask the client to divulge confidential information (such as a Social Security number) to confirm identity. The client is asked by the CSR to articulate an authorization to disclose protected health information to the SHIP staff. Only when the SHIP is not able to arrange for the con-

tractor’s CSR to see a written authorization or hear an expression of consent from the SHIP client on the telephone does the CSR procedure come into play. The procedure features a special unique identifier number that has been issued to key SHIP personnel, both staff and volunteer, in each state. The SHIP staff presents the unique identifier number to the carrier or fiscal intermediary CSR and the CSR discloses the requested protected health information.

The SHIP CSR procedure is premised upon the regulation providing that covered entities may “disclose to any other person identified by the individual, protected health information directly relevant to such person’s involvement with the individual’s care or payment related to the individual’s health care.”¹⁴

Adult Protective Services

Privacy questions for Adult Protective Services (APS) programs involve reporting requirements and confidentiality of records. Does HIPAA permit covered entities, *e.g.*, health care providers, to report suspected elder abuse or neglect to APS without patient authorization? What responsibility does APS have to maintain confidentiality of that information, or to allow the individual access to it?

APS is not a covered entity and, even if it was, HIPAA would not affect state elder abuse reporting requirements. HIPAA allows covered entities to disclose protected health information without authorization when required by state law. This includes when related to public health and when reporting abuse or neglect when the disclosure is made to a government authority, including a social service or protective services agency authorized by law to receive such reports.¹⁵ A covered entity making such a report must inform the individual in question or the personal representative that such a report has been made, unless the entity reasonably believes that informing the individual would place the individual at risk of serious harm, or that the personal representative is responsible for the injuries in question.¹⁶

Long-term Care Ombudsman Program

The U.S. Administration on Aging has determined that Long-term Care Ombudsman Programs are health oversight agencies because they have oversight responsibilities regarding the health care system. As such, the ombudsman has access to resident clinical records. Nursing homes may share other resident protected health information with the ombudsman, even in the absence of a HIPAA-compliant authorization.¹⁷

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The May Versus Must Dilemma

While disclosure to personal representatives is mandated, disclosure to others, even to those who hold HIPAA-compliant authorizations, is generally discretionary. The regulation expressly allows covered entities to share relevant medical information with family and friends or others involved in the patient's care if the covered entity could reasonably infer, based on professional judgment, that the patient does not object. For example, a doctor may give information about a patient's mobility limitations to a friend driving the patient home from the hospital, may discuss payment options with the patient's adult daughter, or may instruct family members about medication dosages. In an emergency, a doctor may share medical information about the patient's condition with a spouse or other family member. The standard for such disclosures is professional judgment and best interests of the patient.¹⁸

Some covered entities have reportedly declined to disclose protected health information to advocates. For example, a blind and ill consumer who was not physically able to receive her own medical records was not able to persuade the health care provider to disclose the records to the advocate working on her behalf to obtain the Medicare-covered services that she needed.

If a covered entity refuses access to a client's personal health information, the following strategies may be effective:

- If you have a HIPAA-compliant disclosure, give the covered entity a copy plus, if necessary, a reminder that HIPAA allows disclosure pursuant to a valid authorization.
- Ask your client to request disclosure and then turn the records over to you.
- Ask your client to request disclosure and direct the covered entity to send the information to you.¹⁹
- Arrange for your client to make the request for disclosure in person and in your presence.²⁰
- If your client is unable to request disclosure, ask the client's family member to request disclosure of such protected health information as is necessary and relevant to the family member's involvement in the care of the patient, and then send the information to you.²¹
- Arrange for disclosure to another covered entity with which the patient has a relationship. Ask the second

covered entity to make disclosure to an advocate who has been given a HIPAA-compliant authorization and/or to help the patient obtain access or coverage of a disputed treatment option.

Note: While covered entities may charge reasonable fees for photocopying records, they are not permitted to charge for searching or retrieving medical records.

Obtaining Protected Health Information for An Administrative Appeal

As noted in the sidebar "What is the HIPAA Privacy Rule?" on page 4, there are some exceptions to the obligation of covered entities to disclose protected health information to a patient.

The exception for records compiled in reasonable anticipation of, or for use in, a civil, criminal, or administrative action or proceeding is particularly problematic for advocates. Individuals frequently need their medical records in order to pursue an administrative appeal when Medicaid or Medicare denies eligibility, access to a facility, or payment for care. The need for medical records is especially critical in the context of managed care decisions in Medicaid or Medicare, or when an individual must pursue external reviews of a private managed care plan decision. Medical records are also essential for clients wishing to appeal administrative decisions about their entitlement to disability benefits.

While covered entities are not compelled to disclose protected health information compiled in anticipation of a legal proceeding, nor are they prohibited from disclosing that information. The preamble to the Final Rule supports this position.²²

"... [W]e permit covered entities to disclose protected health information in a judicial or administrative proceeding if the request for such information is made through or pursuant to an order from a court or administrative tribunal or in response to a subpoena or discovery request."²³

Moreover, the preamble explains that absent a judicial or administrative subpoena, covered entities may disclose medical records only after obtaining "... either (1) satisfactory assurances that reasonable efforts have been made to give the individual whose information has been requested notice of the request, or (2) satisfactory assurances that the party seeking such information has made reasonable efforts to secure a protective order that will guard the confidentiality of the information."²⁴ In the context of administrative hearings, usually the client is the one whose information is sought to be

disclosed, so that person's consent should resolve most problems. Fortunately, we are not yet aware of any instance in which this provision has been used to deny advocates access to medical records needed to pursue an administrative appeal regarding a health care consumer's entitlement to health care or coverage. However, if the issue should arise, advocates could use the language of the preamble to argue that the drafters were not considering the typical public benefit eligibility or coverage appeal, but rather were concerned about adversarial proceedings in which a patient's records could be used against her interests.

Other laws give individuals access to certain medical records in the context of administrative appeals, and the privacy regulations can create confusion among covered entities as to their responsibilities regarding disclosure of medical records to those appealing administrative decisions about their own health care access or coverage. Advocates may argue that the HIPAA rule should not be construed to preempt laws that give health care consumers greater rights of access to their own medical records for the essential purpose of obtaining needed health care or coverage.²⁵

When Does HIPAA Preempt State Law?

State laws that are more protective of the privacy of protected health information (*e.g.*, HIV or AIDS information) or that make it easier for patients to gain access to their own protected health information generally are still applicable. For example, the privacy rule allows covered entities to charge patients reasonable fees for photocopying medical records, but many states limit the charges that may be imposed for copies of medical records, or direct that certain records are available to certain categories of patients without charge or at minimal cost. HIPAA would not preempt those state rules.

Engaging Covered Entities in Discussions About Clients' Cases

It is not always practical for an advocate to obtain a signed authorization for disclosure of protected health information from a client. Where time is of the essence, such as when a client has an urgent or emergency need for care, it may be impossible to obtain a written authorization for disclosure to the advocate for access to the care. In other situations, such as significant geographic distance between the client and the covered entity, an advocate will have no choice but to try to discuss protected health information with the covered entity by phone. The advocate may need to leave a message for covered entity personnel, or the client might not be available at the time when the covered entity staff is available to discuss a matter. Some vulnerable clients have no access to a

telephone, or rely upon public telephones. Few clients have ready access to fax machines. Mailing an authorization and waiting for the client to sign and return it by mail can cause substantial delays to needed advocacy.

Strategies that might help in such situations include:

- Fax the client's signed authorization to the covered entity. While some covered entities have questioned the validity of faxed authorizations, the U.S. Department of Health and Human Services' Office of Civil Rights (OCR) appears to allow this practice. Their Web site includes a question about whether covered entities may fax protected health information among themselves. The answer is in the affirmative, with the caveat that the covered entities should take all reasonable steps to safeguard the privacy of the faxed information.²⁶ The same considerations would apply when individuals fax an authorization to disclose protected health information to a covered entity.
- Hold a three-way phone conversation for the patient, the advocate, and the covered entity. This might open communications and allow advocacy to proceed. During the phone call, the patient can notify the covered entity of her consent to the disclosure.
- Discuss coverage criteria with covered entity and request information pertaining generally thereto. This could be a satisfactory alternative to asking for disclosure of protected health information.
- Provide the information necessary to advocate on the client's behalf to the covered entity without requesting disclosure of protected health information.

Practical Considerations for Advocates

Medical Authorizations

Attorneys and other advocates who expect to need access to protected health information should make sure their authorizations to release medical records that they give to their clients contain HIPAA-compliant language. The HIPAA-compliant authorization can be on firm or program letterhead or plain paper; it need not be on the covered entity's letterhead or form.

Advance Directives

An attorney-in-fact under a financial power of attorney is not considered a personal representative for HIPAA purposes, and would not have the right to disclosure of private health information. However, if the attorney in fact is responsible

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for paying for the patient's health care, he or she would have access to the health information necessary to undertake that task.

An individual authorized to make health care decisions on behalf of an incapacitated person under a health care power of attorney or state health care consent law would be considered a personal representative. A health care surrogate whose authority is limited to emergency or end-of-life decisions may not have the right to access information that is unrelated to emergency or end-of-life decisions.²⁷

Some attorneys who draft advance directives are, to be unequivocal and thorough, including language in the document that expressly mentions HIPAA and identifies the health care agent as the personal representative. This is not technically necessary since a health care agent under state law is a personal representative for HIPAA disclosure purposes, but it may serve to facilitate communications between the agent and the health care provider.

One issue still to be clarified concerns the use of springing powers of attorney (POA)—both for property and for health decisions. The proposed agent does not have the status of personal representative until the power has sprung, but how does the proposed agent get medical information about the principal's capacity in order to make the power effective? It is possible to draft a separate patient advocate designation form that, in effect, creates a limited power of attorney as to the release of medical records, rather than authorizing all health care decisions. Another option would be to include a release provision in the POA that is immediately effective, although the remaining powers must still be triggered in order to spring.²⁸ Some elder law attorneys have suggested avoiding the use of springing powers of attorney unless state law requires them.

Guardianship

Guardians of the person of an incapacitated adult, including public guardians, qualify as personal representatives under HIPAA because they are designated by state law to make health decisions for the ward. No additional language is needed in the court order appointing the guardian of the person, but as with the health care power of attorney, including in that document HIPAA-compliant language authorizing the guardian to access private health information from covered entities might forestall misunderstandings with health care providers.

Guardians or conservators of the property are not personal representatives because they do not make treatment decisions. They would, however, have access to private health information to the extent necessary to pay for care, but likely would need specific authorization to obtain additional information.

HIPAA privacy issues may arise in those states where petitions for guardianship must be accompanied by medical certificates or affidavits in support of the allegations in the petition. If the petitioner is not a covered entity with whom the doctor could share patient identifiable information, the doctor may be reluctant to complete a certificate without the authorization of the patient or patient's personal representative. It might be possible for the practitioner to argue that the certificate or affidavit is a requirement of state law, and therefore a permitted disclosure. If the requirement is in court rules, but not state guardianship law, one solution might be to amend state guardianship laws to require covered entities to provide the necessary information without consent or authorization, thereby fitting within the "required by law" exception. Meanwhile, a petitioner might need to ask the court to order the release of the necessary information. These issues will require further exploration.

Conclusion

The HIPAA privacy rule has presented many problems, as well as questions, for elder law attorneys and other advocates and their elderly clients. A close reading of the regulations in the context of the important dual purposes of the privacy rule, will help advocates to seek and identify solutions to the many barriers to accessing information that advocates have encountered since the HIPAA privacy rule was implemented. The Health Assistance Partnership and the National Health Law Project have suggested to OCR modifications to the HIPAA privacy regulations to redress some of the critical issues for advocates as discussed in this article.²⁹

Notes

1. 45 C.F.R. §164.508(c). An authorization to disclose psychotherapy notes must be separate from a general authorization to disclose protected health information. 45 C.F.R. §164.508(b)(3)(ii).
2. 45 C.F.R. §164.508(b)(3). A health care proxy appointment may, indeed *should*, grant the surrogate decision-maker authority to receive disclosure of protected health information. It is advisable to include language making it clear that the substitute decision-maker is to be treated as a personal representative. See Office of Civil Rights, U.S. Department of Health and Human Services-HIPAA, "Can I access someone's medical record if I have that person's health care proxy?" at www.answers.hhs.gov/.
3. The regulations permit an authorization to designate a class of parties from or to whom disclosure is authorized, such as "from my

- physicians” or “to any advocate employed or volunteering for the XYZ consumer assistance program.” 45 C.F.R. §164.508(c)(iii).
4. 45 C.F.R. §164.508(c)(iv).
 5. Advocates have reported that some covered entities are unreasonably dictating restrictive expiration dates, such as requiring a new authorization every two months. The regulation does not contemplate such a practice. It requires that the authorization contain an expiration date or event that relates to the individual or the purpose of the use or disclosure.” 45 C.F.R. §508(c)(v).
 6. 45 C.F.R. §164.508(c)(2).
 7. *See*, 67 Fed.Reg. 53182, 53222 (Aug. 14, 2002), http://www.access.gpo.gov/su_docs/fedreg/a020814c.html.
 8. 45 C.F.R. §164.502(g)(2). *See also* 45 C.F.R. §502(g)(3) for treatment of parents and guardians of unemancipated minors.
 9. 65 Fed. Reg. 82500 (Dec. 28, 2000).
 10. *See* 45 C.F.R. §164.502(g), stating that a personal representative is a person who has authority under other law “to act...in making health care decisions,” on behalf of an adult or an unemancipated minor or a deceased individual. This section should be read in conjunction with 45 C.F.R. §160.103, which defines health care for purposes of the HIPAA privacy rule as “care, services, or supplies related the health of the individual.” Accordingly, a grant of authority to make health decisions confers personal representative status under HIPAA. Conversely, a person who is granted limited authority to make particular decisions is not likely to have access to PHI.
 11. 45 C.F.R. §164.508(b)(i).
 12. *Id.* §164.508(b)(ii).
 13. *Id.* §164.508(b)(3).
 14. *Id.* §164.508 (b)(i).
 15. *Id.* §164.512 (b) and (c).
 16. *Id.* §164.512 (c)(A).
 17. U.S. Dept. of Health and Human Services, Administration on Aging, Information Memorandum AOA-IM-03-01, Feb. 4, 2003, <http://www.aoa.gov>.
 18. 54 C.F.R. §164.510(b).
 19. Note: this is an informal suggestion offered to HAP by the HHS Office of Civil Rights.
 20. 45 C.F.R. §164.510(b)(92).
 21. *Id.* §164.508(b)(1)(i).
 22. 65 Fed. Reg. 82462, 82529-82531 (Dec. 28, 2000).
 23. *Id.* at 82529.
 24. *Ibid.* at 82530.
 25. *See* 45 C.F.R. §160.202.
 26. *See* Office of Civil Rights, U.S. Dept. of Health and Human Services-HIPAA, “Can a physician’s office FAX patient medical information to another physician’s office?” at www.answers.hhs.gov/.
 27. *See* Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg., 82464, 82634 (Dec. 28, 2000).
 28. Thomas J. Murphy, *Drafting Health Care Powers of Attorney to Comply with the New HIPAA Regulations*, 15 NAELA NEWS 4, Aug. 2003.
 29. For information about HAP, and NHeLP’s request for modifications dated August 7, 2003, please contact Cheryl Fish-Parcham, Medicaid Coordinator, Health Assistance Partnership at cparcham@healthassistancepartnership.org or Steve Hitov, Managing Attorney, National Health Law Project, at hitov@healthlaw.org.

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Caregiver Legal Assistance

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ing language, culture, education, and economic barriers, these new obstacles proved overwhelming. For other families, these problems were exacerbated by drug or alcohol addiction, spousal abuse, parental neglect, and even incarceration.

When families disintegrate, the children are the first to suffer. For some, a grandparent or elderly family member is able to offer the love and concern every child needs to stabilize her life, but this frequently creates new issues that need resolving. The caregiver is generally living in reduced circumstances on a fixed, low-income, and has no knowledge of a guardian's legal rights and responsibilities. Frequently, children in these circumstances need additional services due to developmental difficulties, emotional or physical abuse, and serious health care needs. Creating a new family is imperative for the children, but the process is filled with obstacles unless there is legal assistance.

Legal Aid Society of San Mateo County, with funding from the Partnerships in Law and Aging Program of the ABA Commission on Law and Aging and the Albert and Elaine Borchard Foundation Center on Law and Aging, developed a project specifically designed to expand advocacy services to low-income grandparents and other relatives age 60 and over who are raising minor children.

Community Outreach

An important step to reaching the caregivers was the development of an 18-minute video in both English and Spanish. The video was distributed to the Family Caregivers Support Program, a county-supported collaboration of six agencies serving family caregivers.

In addition, presentations were developed to inform the community and other social service agencies about the rights and responsibilities of guardians. Since many caregivers are elderly, a special section was included regarding estate planning. Elderly caregivers often have great concerns about who will care for the children if something happens to them. Legal Aid enlisted the assistance of pro bono attorneys with expertise in estate planning to provide critical legal advice to caregivers at two education presentations. The importance of this information was underscored when two local law firms and an emeritus attorney committed to training future clients specifically on estate planning.

Information on special education and welfare benefits available to the children were also included in the presentations. These additional benefits and services are often critical

to a child's growth and frequently provide the best opportunity for developing a child's potential. Many of the children being raised by family members have special education needs that require additional services. Legal Aid developed an Individual Education Plan (IEP) workbook that was used in conjunction with some training sessions.

As a result of this outreach, grandparents were empowered to approach social service groups, government agencies, and educational institutions to advocate for their rights and benefits, as well as the rights and benefits for the children. This essential change in behavior is required if the children are to have ongoing assistance and services throughout their childhood. In addition, this empowerment acts as a model for the children themselves as they continue to be influenced by the adults responsible for their care.

Pro Bono Development

Another critical step in reaching the growing community of elderly caregivers was developing an effective group of well-trained pro bono attorneys. At the beginning of the project, a staff attorney from the Legal Aid Society of San Mateo County was assigned as pro bono coordinator and a two-hour MCLE credit-approved training module was developed on guardianships.

In the early training sessions a significant number of the volunteers came from two private firms located in Silicon Valley. Twenty attorneys from Cooley Godward and seven attorneys and thirteen paralegals from Wilson Sonsini Goodrich and Rosati participated. Later in the year, twelve more private attorneys were added to the roster. As other firms became interested in the project, the number of volunteers continued to escalate. Twenty attorneys from Gray Cary Ware & Freidenrich and an additional five attorneys and ten law students from Cooley Godward came aboard. Five additional practitioners were recruited to serve on the program's advisory committee and act as experts in legal areas affecting elderly caregivers.

Direct Representation

The core of this program has been the provision of high quality legal services to elderly caregivers in need of legal authority to adequately care for the minor children they are raising. Legal Aid was fortunate to receive the support of several Silicon Valley law firms to ensure that this client need was met. After Legal Aid's Pro Bono Coordinator screens cases for merit, all guardianship cases are handled by trained pro bono attorneys at Silicon Valley firms or in private practice. Due to the incredible level of support from the firms, Legal Aid has placed every meritorious guardianship case with a

pro bono lawyer for representation. As a result, Legal Aid has provided legal advice and assistance to 31 caregivers age 60 and older raising the minor children of another relative.

Given the reported prevalence of grandparents raising grandchildren in San Mateo County, Legal Aid had anticipated serving 50 senior caregivers during the grant period. As it turned out, however, many of the grandparents seeking legal assistance were between the ages of 40 and 59. Legal Aid served an additional 16 grandparents under the age of 60 during the grant period. These younger grandparents face the same legal barriers as grandparents 60 and older.

Discovering the need for assistance to all grandparents raising grandchildren, regardless of age, was an unexpected but positive result of this pilot project.

The following story illustrates the type of assistance the program has been able to provide.

Case Example 1

Maria and Miguel Sanchez (not their real name) had cared for their eleven-year-old grandson, Alfredo, since he was a baby. Alfredo has significant learning and emotional disabilities, and the Sanchez's had worked very hard throughout their young grandson's life to ensure that he received the services he needed, including creating a special education program at school. Alfredo's mother, the Sanchez's daughter, was still involved in his life through frequent visits, but she could not care for him adequately and left that responsibility to her parents. Alfredo had no contact with his father, who had relocated to another state, remarried, and provided no financial support despite existing child support orders.

As Alfredo grew older, Mr. and Mrs. Sanchez realized that they needed to seek the legal authority to continue to care for Alfredo. With their daughter's approval, Mr. and Mrs. Sanchez filed papers with the court seeking legal guardianship. When the father showed up at the guardianship hearing with an attorney, challenging the guardianship and arguing that Alfredo should be sent to live with him, the Sanchez family approached Legal Aid for help. Meanwhile, the guardianship judge set the matter for a short cause trial.

Legal Aid quickly assessed the situation and advised Mr. and Mrs. Sanchez about their options. The family agreed that Alfredo's father was not the appropriate person to care for Alfredo, since the father had no idea about the extent of Alfredo's disabilities and, particularly, since Alfredo's behavioral issues now had worsened at the thought of being forced to leave his grandparents. Legal Aid then found a pro bono attorney who agreed to represent Mr. and Mrs. Sanchez at the trial. The attorney conducted substantial research uncovering the father's criminal and violent past, prepared witnesses, wrote a comprehensive legal brief detailing Alfredo's special

needs, and donated more than 70 pro bono hours to the case. The pro bono attorney represented Mr. and Mrs. Sanchez at trial and prevailed, obtaining an order that Alfredo would remain with his grandparents while allowing Alfredo's family to gradually reintroduce his father into his life.

Agency Collaboration

Kinship Support Network

During the course of the project, Legal Aid formed a close collaborative relationship with Edgewood Kinship Support Network, a local agency providing social services and support to elderly caregivers of grandchildren and other minor relatives. Early on, Edgewood staff received training from project attorneys about legal issues affecting elder caregivers. This background knowledge allowed Edgewood staff to recognize legal issues affecting the caregivers and encouraged a process of cross-referrals. Legal Aid was also available to provide routine legal backup to Edgewood as questions arose from their clients.

The following story highlights two larger advocacy issues that became apparent during the course of representing an elderly caregiver.

Case Example 2

Rose (not her real name), a 60 year-old woman, had been living alone in a one bedroom apartment with the help of a federal housing subsidy for several years. Her daughter, Diedra (not her real name) and her five children, ages 6 months to 10 years, arrived unexpectedly at Rose's home. Diedra, suffering from mental health and other life problems, could no longer handle the pressure of taking care of her children. In response, she brought them to her mother's home intending to leave them under Rose's care or to voluntarily surrender them to Child Protective Services. Rose could not bear the idea of her grandchildren growing up without family, and quickly agreed to house and raise them in her one bedroom apartment. Rose contacted the county housing authority to ask if she and her grandchildren could move into a larger living space. The county responded to Rose by telling her that this was possible only if she became the legal guardian of her grandchildren. To further complicate the situation, Rose's landlord had threatened to evict her from her apartment because she was housing too many people.

Rose, worried about losing housing for both herself and her family, came to Legal Aid for assistance in filing for legal guardianship of her grandchildren. Because Rose needed help immediately and the current program was still being

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developed, Julia Wilson, pro bono coordinator, handled the case and represented Rose in court. Rose received a temporary guardianship that allowed the housing authority to provide a larger living space for Rose and her grandchildren. The court later appointed Rose the legal guardian of her grandchildren.

After carefully considering Rose's original request to the housing authority and their subsequent refusal to increase the living space until Rose was appointed legal guardian, it was concluded that the housing authority decision might constitute discrimination. According to Section 8 Housing, restricting housing under these circumstances may be deemed illegal conduct.

Legal Aid continues to do research into this issue and is working collaboratively with Kinship Support to seek systemic change. Until the issue is resolved at the system level, Legal Aid continues to advise Kinship Support clients about their legal options when they encounter housing problems.

Kinship Support and Legal Aid identified another systemic problem when grandparents raising grandchildren were rejected after applying for welfare benefits for the children. Although parents applying for cash aid for children must supply information on the absent parent for the purposes of pursuing a child support action, state statute specifically excludes grandparents and other nonparent relatives from this requirement. However, when grandparents went to apply for welfare, the benefits workers were incorrectly applying this requirement. If grandparents refused to supply the information, their applications for cash aid for the children were incorrectly denied. This created a barrier to much-needed financial support for elderly caregivers who were reluctant to provide information that would allow a child support action against their own adult child. Usually they were afraid that the parent, upon receiving notice of an attempt to collect child support, might return and take the minor children.

Legal Aid approached senior staff at the welfare department and presented legal documentation of the provisions excluding relative caregivers from the requirement. The welfare department agreed with Legal Aid's assessment and distributed a memo to all front-line staff advising them that relative caregivers were not required to provide this information. The department also provided Legal Aid with a copy of the memo, and Legal Aid distributed the information and the memo to the community workers at Kinship Support. Now caregivers can apply for welfare with a copy of the memo stating they are excluded from the child support requirements. This allows senior caregivers to apply for and receive

the financial support to which the minor children are entitled. This systemic advocacy benefited a large number of senior caregivers, well beyond the 31 that received individual legal assistance from the project.

Legal Advocates for Permanent Parenting

As more clients came to Legal Aid for assistance, it became clear that many caregivers were helping children who had been taken from their parents because of abuse. These caregivers need legal advice about the dependency court system, an area in which Legal Aid does not practice. Because of the widespread nature of the problem, Legal Aid expanded the program and now collaborates with Legal Advocates for Permanent Parenting (LAPP), an agency committed to providing advice to relative caregivers with whom children have been placed because of parental abuse or neglect. Although there is a tremendous need to locate services for the children, many caregivers do not have sufficient expertise to address the problems. LAPP and Legal Aid are collaborating to jointly open a caregivers legal assistance center. This center will provide vital information on how the system works for a dependent child, how to advocate for a child, how to interact with social workers to obtain services a child needs and, most importantly, how to obtain and provide information to the judge who determines a child's best interests.

Probate Court

In San Mateo County, the probate division of the Superior Court handles guardianships. While the project was in the development stage, the staff attorney/pro bono coordinator invited the Probate Court chief investigator's input into the structure and functioning of the project. Impressed with the program and services, the Probate Court investigator routinely refers cases to Legal Aid and helps publicize intake sessions by displaying flyers at the probate desk. This effort guides many people to Legal Aid who would otherwise try to become guardians without legal assistance.

Project Challenges

One area where Legal Aid anticipated that it might have difficulty was in the recruitment of attorneys in private practice to take on guardianship cases, due to the demands of private practice and the fact that the substantive area is unfamiliar to most law firm attorneys. Because of the significant client demand, pro bono involvement was essential to the project's success. Without an adequate supply of committed pro bono attorneys, many grandparents would be unable to negotiate through the legal system. Children who needed legal

guardians might be forced into foster care thereby losing the long-term stability of a loving relative as caregiver.

Legal Aid overcame the difficulty by asking local law firms what arrangements would work for them and inquiring how it could benefit from their skills. The response was overwhelming. Legal Aid was able to create a unique partnership with several Silicon Valley law firms, which committed firm resources to representing low-income caregivers. As other Silicon Valley firms became involved, Legal Aid was able to greatly expand the program. The total number of attorneys trained was 64.

In order to facilitate firm involvement, Legal Aid developed high-quality training and offered it at the beginning of the volunteer cycle. This allowed the attorneys to become familiar with the legal aspects of guardianship, as well as the issues and possible resolutions to common guardianship problems. In addition, ongoing technical assistance is available from Legal Aid to each pro bono lawyer throughout the course of representation. And finally, intake sessions are scheduled for the group at a specific location. This allows lawyers to share information and discuss issues immediately after the intake period.

This model has proven to be so successful that its effectiveness has spread by word-of-mouth. Firms are now calling Legal Aid and asking to participate in the program. We plan to incorporate this pro bono model into additional Legal Aid programs and provide it to other legal services agencies.

Another challenge that arose early on in the project was when volunteers could not be found to participate in com-

munity outreach. During the first months the project coordinator gave all presentations, but other project responsibilities prohibited an ongoing commitment to outreach events. The solution was found by asking volunteers to identify discreet areas of expertise that they could share with the senior caregivers. This was the key to finding several attorneys who enthusiastically committed time to sharing their particular knowledge with an appreciative audience.

Conclusion

As a result of the Caregiver Legal Assistance project, trained pro bono attorneys now staff guardianship intake sessions at Legal Aid on a weekly basis. The program has also been expanded in collaboration with Stanford Community Law Clinic (SCLC) to offer monthly intake sessions in East Palo Alto. At SCLC, pro bono attorneys and law students have completed the training originally developed for the project. During scheduled guardianship intake sessions, the next generation of lawyers committed to pro bono is now available to do intake under the direction of experienced attorneys.

By offering training in the needs of these children and their guardians, Legal Aid is impacting the behavior of attorneys in private practice. An increased number of attorneys are committing their time and expertise as they become aware of the problems surrounding this population. By providing free legal services, the new resources are dramatically increasing the number of guardianship cases that can be handled.

Advocacy

Our Failure to Care for Individuals with Alzheimer's Disease and Behavioral Complications

By Leslie B. Fried, Esq.

Over the past few years, an increasing number of individuals with Alzheimer's have been incarcerated or involuntarily committed due to uncontrolled aggressive behaviors. Many of these behaviors can be modified by therapeutic interventions, including psychotherapy, behavior management, and medication. Yet, few health care providers have the expertise, willingness, or funding to meet the needs of this suffering population. Rather, health care and mental health providers close their doors and their services, leaving the afflicted individual and family members with little recourse.

The plight of individuals with Alzheimer's disease, or other dementia-related diseases, may result in the matter landing in the judicial system in a criminal, commitment, or guardianship proceeding. The failure of our mental health system and providers to address the needs of older individuals suffering from Alzheimer's disease and a co-existing behavioral or psychotic disturbance is reaching tragic proportions.

A current situation in a New England state is a prime example of the failure of health care and mental health providers to provide the necessary services to an elderly, retired banker, I will call Mr. Money. Mr. Money has Alzheimer's disease. He lived with his daughter for several years until she could no longer provide the care he needed, while also caring for her own family needs. In

addition, Mr. Money began to exhibit aggressiveness and his daughter feared he would injure her or her family.

Mr. Money was admitted to a nursing facility but his combative behavior persisted. The nursing facility staff lacked expertise to address the aggressiveness and called the

daughter continuously, threatening to discharge her father because the staff could not control him. Due to fear that Mr. Money would injure another resident or a staff member, the nursing facility sought to have him committed to a psychiatric unit at the community hospital. After a short stay in the psychiatric unit, where they concluded that injections of long acting Haldol was the appropriate treatment, Mr. Money was discharged back to the nursing facility. Within one week, he was back at the same community hospital, where he spent 24 hours in their emergency room awaiting admission to the medical unit.

Mr. Money's behavior stabilized but he remains in the hospital because there is no facility that will accept responsibility for his care. The nursing facility insists that it cannot handle him and refuses to allow him to return to their facility due to his severe aggressive behavior. No other facility in the state will accept him as a resident and the hospital discharge planners are looking for placement outside of the state. Hospitals and psychiatric units which specialize in mental health and behavior issues will not accept him as a patient because his primary diagnosis is Alzheimer's disease, not a mental health diagnosis. Mr. Money's daughter is his health care agent but is overwhelmed and frustrated. The family has been torn apart by Mr. Money's crisis. She will no longer act as her father's health care agent and advises hospital staff that they will have to find someone else to handle her father's decisions. Most likely, the hospital attorney will seek appointment of a guardian of Mr. Money's person to assist with discharge plans from the hospital.

There are several layers to the problem that resulted in Mr. Money languishing in a hospital for several weeks. It is a domino effect of the unwillingness to properly treat Mr. Money's behavioral complications due to his Alzheimer's disease. What is Mr. Money's guardian going to be confronted with when the court makes the appointment? Let's look back at how the health care and mental health systems failed to treat Mr. Money.

Breakdown in the Community

Mr. Money may have been able to continue to live in the community with his daughter's family but he could not access mental health services in the community. Due to significant state budget cuts, the state mental health agency would not provide services to Mr. Money because Alzheimer's disease is not a "mental illness." Although Medicare covers mental health services, the Medicare payment is limited to 50 percent of the Medicare approved amount. 42 C.F.R. §410.155. Some mental health providers refuse to treat Medicare beneficiaries because of the meager reimbursement amount.

Leslie B. Fried is associate staff director of the ABA Commission on Law and Aging. She joined the Commission in September 1998 as the Medicare Advocacy Project attorney, a collaborative project with the Alzheimer's Association. She specializes in Medicare issues and responds to Alzheimer's-related Medicare inquiries from local Alzheimer's Association chapters.

Breakdown in the Nursing Facility

When Mr. Money was admitted to the nursing facility, federal law requires that a multidisciplinary team within the nursing facility complete a comprehensive assessment of his functional capacity. Once the assessment is completed, the team must develop a plan of care to meet Mr. Money's medical, nursing, mental, and psychosocial needs identified in the assessment. See Nursing Home Reform Law, 42 U.S.C. §1395i-3 *et seq.* and 42 U.S.C. §1396r *et seq.* The facility is required to provide the necessary care so that Mr. Money will "attain or maintain the highest practicable physical, mental, and psychosocial well-being in accordance with the assessment and care plan." 42 C.F.R. §483.25. The purpose of the assessment and care plan is to identify with specificity the services the nursing facility must provide to address Mr. Money's needs. The nursing facility must provide specialized mental health services to Mr. Money, which may include individual and group therapy, behavior management, and drug therapy. Mr. Money's aggressiveness required significant interventions by nursing facility staff and providers.

Stranded in the Hospital

Frustrated with their inability to stabilize Mr. Money, the nursing facility staff took Mr. Money to the community hospital emergency room. Some hospitals refuse to admit individuals with Alzheimer's disease and behavioral disturbances because of difficulties in finding an appropriate placement upon discharge. Federal regulations require that

hospitals provide a discharge evaluation and plan for patients who would likely suffer adverse health consequences upon discharge from the hospital. 42 C.F.R. §482.43. In Mr. Money's situation, his nursing facility refused to readmit him and the hospital is prohibited from discharging him until an appropriate facility agrees to accept him as a resident.

Need for a Coordinated Approach

Frustration abounds and Mr. Money languishes in a hospital bed. Many individuals with Alzheimer's disease have experienced Mr. Money's predicament. The health care and mental health systems are fragmented and fail to accept responsibility for providing care to this fragile population. There is limited access to specialized mental health units when the primary diagnosis is Alzheimer's disease, yet there are few specialized Alzheimer's units willing to accept patients with severe behavioral problems.

While these systems crumble, the judicial system, under the guise of a guardianship proceeding, a commitment hearing or even a criminal action, is left to pick up the pieces.

The challenge facing advocates is to ascertain the appropriate agencies and providers of mental health services in their communities. In Mr. Money's case, it would be beneficial to bring together representatives from the area office on aging, the long-term care ombudsperson, the mental health agency, the community hospitals and the Alzheimer's Association. In all cases, the pressure is on to develop a coordinated approach to address the complex needs of this increasing population.

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