End-of-Life Care/Legislative Trends

Legal Trends in End-of-Life Health Care Decision-Making

By Erin B. Furlong

The tragic demise of Terri Schiavo1 and the resulting conflict over her wishes, played out in the courts and the media, has focused the national spotlight on the importance of planning for end-of-life care. Many observers questioned whether the situation would have been different if Terri had some form of written instruction, such as an advance directive or living will. At a minimum, these documents could have provided insight to Terri’s values to help guide her family’s decision-making process.

There are many challenges to be faced in the aftermath of the Schiavo case; among them are the importance of the ongoing discussion and the appropriate role of policy in supporting and regulating individual’s end-of-life health care

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Partnerships in Law and Aging

Marriage Rights Initiative for Lesbian, Gay, Bisexual, and Transgendered Elders

By Betsey Crimmins and Deborah Filler

Most lesbian, gay, bisexual, and transgendered elders choose to remain invisible in the straight aging world. It is a population that came of age when many faced dire consequences if they acknowledged their homosexuality. Many lived, and continue to live, closeted lives. Fear of discrimination makes it less likely that these elders will reach out for the services they need. While many LGBT elders have seen sweeping social changes over the past two decades, many still feel isolated and all still confront particular legal problems because of their sexual orientation.

It is estimated that between 1.75 and 3.5 million LGBT elders live in the United States. Aging can be a difficult process for all elders because they are forced to cope with changes in income, health, support networks, and housing. These adjustments can be even more challenging for isolated and low-income LGBT elders.

Greater Boston Legal Services, with funding by the Partnerships in Law and Aging Program of the ABA Commission and the Borchard Foundation Center on Law and Aging, developed

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Betsey Crimmins and Deborah Filler are both senior staff attorneys at Greater Boston Legal Services, in Boston, Massachusetts, and members of the LGBT Aging Project.

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decisions. This article examines the statutory trends in end-of-life decision-making during the last four years (2001-2005), encompassing pre- and post-Schiavo.

The ABA Commission on Law and Aging identifies and analyzes statutory changes and developments in end-of-life decision-making each legislative session for all fifty states. New enactments are analyzed for substance, changes to prior law and resemblance to other precedent, including other state laws and uniform or model acts. These enactments are assembled and categorized into a yearly analysis chart. Over the past four years, these surveys have revealed four dominant areas of legislative activity in end-of-life health care decision-making across the nation: (1) simplification and consolidation of advance directive laws; (2) establishment of default decision-makers in the absence of advance directives; (3) institutionalization of more social prompts and tools for making advance directives more available; and (4) establishment of processes such as POLST (Physicians Orders for Life-Sustaining Treatment) to translate the patient’s care wishes into treatment plans.

These trends map state policy in the years immediately preceding and including the Schiavo case. They demonstrate where there is some statewide consensus regarding end-of-life decision-making. They may serve as a starting point to open a discussion about where a state may want to reconsider its current laws.

Simplification and Consolidation of Advance Directive Laws

Every state has one or more advance health care directive statutes. Many states have two or more statutes: one for a “living-will” type of directive and one for a proxy or durable power of attorney for health care. There are often separate statutes addressing default surrogates and out-of-hospital do-not-resuscitate orders. A slow but steady trend in legislation has been to simplify the process by combining these documents into one comprehensive statute. In the beginning of 2000, 16 states had comprehensive statutes. In 2005, 24 states, or nearly half the country, have combined advance directive statutes covering both proxies and living wills (AL, AK, AZ, CA, CT, DE, FL, HI, ID, KY, ME, MD, MN, MS, ND, NJ, NM, OK, OR, TN, VT, VA, WV, and WY). The most comprehensive statutes also recognize the authority of default surrogate decision-makers (usually next-of-kin or close friends) in the absence of appointment of a proxy. Alaska, Idaho, North Dakota, and Wyoming are the most recent states to enact combined advance directive laws.

In 1993 the Uniform Health Care Decisions Act attempted to set a national standard for advance directives. However, only a handful of states have adopted the Act, and those adopting usually added additional requirements. The Five Wishes advance directive, published by the non-profit group Aging with Dignity, has been the single nationwide attempt to provide an advance directive that could be used in all states without fear of invalidity is, in many ways, the gold standard for simplicity and uniformity in state law. Five Wishes provides one convenient measure because it is actively distributed nationwide, although other published advance directives could also be used as measuring sticks. Today, the Five Wishes advance directive meets the legal requirements in as many as 37 states, plus the District of Columbia. That is a significant number but still a long way from 50 states.
In terms of simplification of the process, more states are allowing for optional forms and less rigid witnessing requirements. For example, in 2001, North Dakota amended its living will and durable power of attorney provisions of the state’s health care advance directive laws by: (1) making clear that the statutory forms are optional, not mandatory, and that other forms consistent with the law may be used; (2) simplifying the execution requirements of advance directives to permit notarization as an alternative to the use of two witnesses; (3) simplifying the witness attestation; and (4) eliminating special witnessing procedures for residents of long-term care facilities.

The act retains certain witness disqualifications that apply likewise to notaries. Similarly, during the 2005 session, South Carolina clarified that, in addition to its statutory form, any other document or writing could be used as long as its execution and witnessing comply with the statute. Wyoming repealed its optional form, providing an advance health care directive may be in any form not inconsistent with the Wyoming Health Care Decisions Act.

This past session, Vermont enacted legislation that allows a great deal of flexibility in the use of advance directives and provides no statutory form. It also creates a state registry for advance directives, and establishes a protocol for DNR orders. However, the act does not address default surrogate decision-making in the absence of a directive or guardianship. Default surrogate decision-making remains on the legislative “to-do” list in Vermont.

Comprehensive statutes and simplification of process demonstrate the statutory preference toward support and appointment of a proxy decision-maker. Quite possibly the strongest evidence in support of this trend is that half the states now have a combined advance directive. This shift could be in response to recent criticisms of the living will serving as the primary advance directive. Appointment of a proxy alleviates some criticisms of statutory forms, because a living will type instruction best serves to guide the proxy, who in acting applies a standard of “standing in the shoes” or “best interests” of the patient. Despite the statutory preference and simplification of process, many individuals do not have an advance directive, which necessitates default surrogacy provisions.

Expansion of Default Surrogate Provisions

Surrogate consent in the absence of an advance directive has been statutorily adopted in 38 states. The Uniform Health Care Decisions Act provides a fairly simple model for surrogate decision-making statutes. In the absence of an appointed agent or guardian with health powers, the Act provides the priority of surrogates (in descending order): first, an individual who is orally designated by the patient, followed by the patient’s spouse, an adult child, a parent, sibling, and finally close friend. No limitations constrict the decisions surrogates may make. The Act also provides a decision-making standard, stating that a surrogate shall make decisions in accordance with the individual’s instructions and wishes to the extent known, or otherwise in the patient’s best interest, considering the patient’s personal values to the extent known.

Most of the 38 states adopting default surrogate provisions minimally include the patient’s spouse, adult children, parents, or siblings in the list of possible surrogates. Additionally, eight states allow an individual orally designated by the patient, as in the UHCDA (AL, DE, CA, HI, ME, MI, NM, and TN).

In an effort to recognize the realities of changing lifestyles, some states passed legislation to recognize domestic partners as surrogate decision-makers. Three states have now explicitly recognized domestic partners as surrogate decision-makers: Arizona (in certain circumstances), California, and New Jersey. In California, the rights and duties of married persons were extended to persons registered as domestic partners. Domestic partners are provided the same rights, protections, and benefits, and subject to the same responsibilities, obligations, and duties under law, whether they derive from statutes, administrative regulations, court rules, government policies, common law, or any other

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prohibiting contact with an individual family member from those who have been the subject of a civil or criminal order have been served a petition for protection from abuse, or Delaware imposed a disqualification on individuals who decision-making abilities, two states have recently included ing default surrogacy rules or decreasing limitations on their give consent to medical research for adults or emancipated minors who are incapable of giving informed consent. These acts authorize specified persons to give consent to medical research in the absence of an advance directive. These acts authorize specified persons to give consent to medical research for adults or emancipated minors who are incapable of giving informed consent. California’s 2002 enactment permits surrogate informed consent for medical experiments that relate to the cognitive impairment, lack of capacity, or serious or life-threatening diseases and conditions of research participants. Virginia, in its 2002 term, added agents appointed under advance directives, legal guardians, spouses, adult children, and adult siblings to the list of people authorized to give consent to human research under the definition of “legally authorized representative.” A 2004 Kansas provision establishes authorized surrogates, but adds that no decision or consent can be given to research protocols that are contrary to the incapacitated person’s permission that has been expressed either orally or in writing, regarding the research protocols.

Though most states are generally establishing or expanding default surrogacy rules or decreasing limitations on their decision-making abilities, two states have recently included limitations on otherwise authorized surrogates. In 2004, Delaware imposed a disqualification on individuals who have been served a petition for protection from abuse, or those who have been the subject of a civil or criminal order prohibiting contact with an individual family member from acting as a health care surrogate for that family member.

Even broader is a 2005 Louisiana enactment that disqualifies any spouse from acting as surrogate who is:

- judicially separated from the patient, is cohabited with another person in the manner of married persons, or who has been convicted of any crime of violence … against the other spouse that has resulted in the terminal and irreversible condition…. or who has violated any domestic abuse protective order affecting the other spouse.

While legislatures are enacting statutes to address the reality that many individuals do not have advance directives, preference is still given for a written declaration. In 2001, the California Legislature recognized the weight of a written appointment of an agent in an advance directive when it stated that, if an individual makes an informal oral designation of a surrogate health care decision-maker, the oral designation is effective “only during the course of treatment or illness or during the stay in the health care institution when the surrogate designation is made, or for 60 days, whichever period is shorter.” After that, the written appointment prevails, unless the patient expresses the intention to remove the agent. Thus, states need to continue efforts to encourage an intentional proactive planning process.

**More Social Prompts and Tools for Advance Planning**

In the years preceding *Schiavo*, many state policymakers had already recognized the need to encourage advance health care planning through legislation. Yet, despite the embrace of advance directives in policy for the last quarter century, most studies suggest that only about one in five Americans have an advance directive. One recent survey offers a slightly more optimistic picture—according to a survey by FindLaw.com, conducted in March 2005, 36 percent of Americans have a living will. In the search for strategies to support advance planning, some states have focused on enhancing their visibility through methods such as offering notice of advance directives on driver’s licenses and creating electronic registries for facilitating access to directives by health care facilities.

Currently, five states provide for drivers license notice of advance directives (IL, MN, MT, SD, VT). Similarly, five states have created advance directive registries (AZ, CA, MT, NC, VT). In California, residents who submit advance directives to the registry may be issued an identification card; certain hospitals are even required to check the registry for directives. Montana recently passed legislation that requires the attorney general to establish and maintain a health care declaration registry for declarations
relation to the use of life-sustaining treatment, methods for filing declarations, and granting access to the registry by certain persons, including health care providers. A further trend in this area is to make the registries available online. Residents of North Carolina, Arizona, and Vermont may register their advance directives online—to increase awareness of the document’s existence and its visibility. Vermont’s registry is currently being developed; but once available, health care providers will be obligated to check the registry for an advance directive and are to encourage and help individuals with advance directives submit them to the registry.

Over the last 15 years, many states have created task forces and dedicated funding to studying end-of-life health care decision-making issues. Continuing that trend, Louisiana in 2001 created a task force to study the current procedures authorized by law with respect to life-sustaining procedures and advance medical directives and how those procedures are being implemented. In 2002, Maryland created a State Advisory Council on Quality of Care at the End of Life. Then in 2004 Maryland passed the “Advance Directive Information Availability Act,” requiring the Department of Health and Mental Hygiene, in consultation with the attorney general, to develop and widely distribute an information sheet regarding advance directives.

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Report Urges Paradigm Shift in Approach to Dying

A special compilation of ten cutting-edge essays by The Hastings Center suggests that the key to improving end-of-life care depends on a cultural acknowledgment that the way people die is a continuum of the way they live—“in a web of complex social relationships.” Together the essays urge a new model for care and decision-making that places less emphasis on discrete medical decisions involving the dying patient and more emphasis on shared decision-making and communication between patient and loved ones.

In the 60-page compilation, which is a supplement to the November/December 2005 issue of The Hastings Center Report, some of the nation’s leading experts from the fields of law, medicine, ethics, and disability reflect on the state of care for the dying. Among the essayists is former ABA Commissioner and bioethicist Nancy Dubler, of New York City’s Montefiore Medical Center, who argues for the increased use of mediation to resolve familial conflicts surrounding end-of-life care and decision-making.

Another former Commissioner, geriatrician and researcher Dr. Joanne Lynn, argues that end-of-life no longer has a clear, time-limited final trajectory in today’s medical world and what is needed is an expansion of hospice principles far upstream into chronic care. Hospice emphasizes continuity, a patient/family focus, care at home, and enhancement of social supports.

The essays examine developments in end-of-life care over the past three decades, with an emphasis on the years since 1990. They note such progress as increased patient autonomy; recognition of palliative care as a medical specialty; and improvements in pain management. At the same time, however, they caution that the legal, medical, and ethical foundation for this progress has not been universally accepted and is currently in danger of back-sliding. The authors urge re-evaluation of the way care is provided to those nearing the end of life. Hastings Center president Thomas H. Murry and research scholar Bruce Jennings pull together the themes of the essays and articulate three specific steps towards reform:

1. Approach end-of-life care from a collective perspective, one that is less individualistic and more family oriented.

2. Reevaluate advance directives and surrogate decision-making, with a focus on education, counseling, and other support for health care agents and family members to help them make better decisions on behalf of the dying patient.

3. Provide bioethics mediation and conflict resolution services in all health care institutions.

Through its series of essays, the report encourages a widespread social investment in public education and personal discussion about how to create a system of end-of-life care that acknowledges the interpersonal nature of dying. Copies can be downloaded from The Hastings Center Web site: <http://www.thehastingscenter.org/research/health-carepolicy8.asp>. Print copies can be ordered by writing to: Publications Department, The Hastings Center, 21 Malcolm Gordon Road, Garrison, NY, 10524, or e-mail: publications@thehastingscenter.org.

—Jamie Philpotts
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and requiring the Motor Vehicle Administration to provide information relating to advance directives to applicants for a driver’s license or I.D. card.49

Most recently, in an effort to recognize the importance of advance planning post-Schiavo, two states declared a “health care decisions” planning week. In 2005, Arizona legislators proclaimed the week of November 6, 2005, as Health Care Decisions Week in the State of Arizona in order to encourage all citizens to think and talk with loved ones about their wishes for medical care.50 Georgia legislators followed suit, designating the first week of April of each year as “Living Will Week,” and encouraging the citizens of Georgia to prepare a living will or advance directive.51

Translation of Patient Care Goals or Wishes into Treatment Plans

Advance directives face a number of obstacles in achieving visibility and compliance in the clinical setting. Many health care wishes or goals are written in general or “layman’s” terms, and not in language used by the medical community. Directives often never make it into one’s medical record, and if they do, they may easily become buried in the record or fail to follow the patient from setting to setting. To address these issues, the Physicians Orders for Life Sustaining Treatment (POLST) form was developed in the early 1990s by a task force led by the Center for Ethics in Health Care at Oregon Health & Science University. The task force included representation from health care professionals, governmental, and institutional organizations.52

The POLST form is a standardized physician order form designed to convert wishes for life-sustaining treatment into medical orders. The goal is ensuring that treatment wishes are honored in the event that a patient is unable to speak for him or herself. The POLST form is designed for patients with advanced progressive chronic illness, and is used to ascertain and empower their wishes as expressed by the patient, or the patient’s surrogate, or the patient’s advance directive. Key features of the POLST include: 1) immediately actionable signed medical orders on a standardized form; 2) orders that address a range of life-sustaining interventions; 3) a brightly colored, clearly-identifiable form; and 4) portability across treatment settings.53 The document conveys physician orders about specific medical treatments in language that is understandable to both medical staff and family members.

The POLST form has been fully implemented in Oregon, Washington, and West Virginia, and partially implemented in Georgia, Michigan, Minnesota, Missouri, New Mexico, New York, North Carolina, Pennsylvania, Utah, and Wisconsin. In some states, the POLST is not a statutory device; but in others, such as West Virginia, a statute enacted in 2002 provides for a standardized physician orders for scope and treatment form, establishes the information required by the form, and sets forth procedures for the issuance, use, and transfer of the form.54 Research suggests that the POLST is successful in ensuring nursing facility residents do not receive unwanted life-sustaining treatments.55 The research also finds that POLST instructions are followed the majority of the time.56

Maryland adopted a somewhat similar strategy in 2004 with enactment of the “Patient’s Plan of Care” form.57 This is a voluntary form filled out by a physician, in accordance with the patient’s wishes (if competent) or the decisions of a surrogate, summarizing the plan of care for an individual. Similar to POLST, the form is to accompany the individual if transferred to another health care provider or discharged. Providers are also required to review a “Patient’s Plan of Care” form received from another health care provider as part of the process of establishing a plan of care for an individual. However, unlike the POLST approach, the Patient Plan of Care form is not technically a medical order.

Conclusion

In years preceding the Schiavo case, states had demonstrated a gradual movement toward simplifying surrogate decision-making laws, addressing the reality that many people do not have advance directives and supplying default statutes, attempting to establish social prompts and tools for making advance directives more available, and establishing processes to translate the patient’s care wishes into treatment plans. In the aftermath of the Schiavo case it appears that many states are continuing along this slow but steady path. While many states continued simplification and social awareness efforts, no state made drastic changes to surrogacy or artificial nutrition and hydration, at least as of the end of 2005. Much of the media frenzy has passed, but the importance of the ongoing discussion and the appropriate role of legislation in supporting and regulating individual’s end-of-life health care decisions continues. The legislative process is necessarily slow, so that full and careful consideration may be given to each issue. States should not feel pressured to force change in response to the Schiavo case, but should look to the current trends for perspective and models. If the goal of policy is to encourage health care advance planning, then it is imperative to continue identifying and implementing strategies to make advance planning more user-friendly, universal, and effective when decisions actually need to be made. There are signs of positive movement, but there is still a long way to go.
Notes

1. For a 15-year time-line of the Terri Schiavo case prepared by the University of Miami Ethics Program, available at: <http://www.miami.edu/ethics2/schiavo/timeline.htm>

2. Available at: <www.abanet.org/aging/update.html>

3. Throughout this article, we use the term “living will” to refer to an instructional directive regardless of its statutory name (e.g., declaration, directive to physicians) and the term “durable power of attorney for health care” to any written designation of a surrogate decision-maker, likewise regardless of its statutory name (e.g., health care proxy directive, appointment of health care representative, health care power of attorney).

4. 2004 Alaska Sess. L. ch. 83 (H.B. 25), approved June 25, 2004, effective January 1, 2005 (passing the Health Care Decisions Act, codifying health care decisions into one chapter relating to health care decisions, including do not resuscitate orders, anatomical gifts, and mental health treatment decisions, and to powers of attorney relating to health care, including anatomical gifts and mental health treatment decisions).

5. 2005 Idaho Session Laws ch. 120 (S.B. 1068), approved March 23, 2005, creating the “Medical Consent and Natural Death Act.”


10. See generally, Charles P. Sabatino, National Advance Directives: One Attempt to Scale the Barriers, 1 NAELA J. 131 (Spring 2005).


14. See supra n. 18.

**Funding Opportunity**

**Partnerships in Law and Aging Program 2006-07**

The ABA Commission on Law and Aging and the Borchard Foundation Center on Law and Aging are pleased to announce a new cycle of funding under the Partnerships in Law and Aging Program. Now in its eighth year, the Partnerships in Law and Aging Program is designed to:

- Spur collaboration and develop effective partnerships among providers of law-related services to older persons;
- Enhance legal awareness and autonomy and promote the rights of elders who are poor or otherwise isolated;
- Improve elder access to the legal system;
- Serve as a catalyst for development of effective, permanent partnerships and resources and replication of successful projects.

The program will fund up to ten projects of $7,500 each, from July 1, 2006, through June 30, 2007.

**Applications must be postmarked on or before March 1, 2006.**

The Partnerships in Law and Aging Program is a project of the ABA Commission on Law and Aging and the Borchard Foundation Center on Law and Aging, with ongoing support from the Marie Walsh Sharpe Endowment and 2006 support from FJC, a Foundation of Donor Advised Funds.

For additional information, contact Stephanie Edelstein via e-mail at sedelstein@staff.abanet.org.

Read descriptions of previous grantees’ projects and download the Request for Proposals form from the ABA Commission’s Web site at: [http://www.abanet.org/aging](http://www.abanet.org/aging)

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**LGBT Marriage Rights Initiative**

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The LGBT Elder Rights Initiative to address the unique legal issues facing this often-hidden population. The goals of the project were to provide legal advice and assistance for coupled LGBT elders who were about to become legally married following the historic November 18, 2003, ruling by the Massachusetts Supreme Judicial Court and to provide assistance for the legal problems faced by single LGBT elders in such critical areas as housing, health care decisions, guardianships and conservatorships, nursing home rights, and access to benefits. Since most of these elders do not openly acknowledge their LGBT identity, many service providers are unaware that they even have them as clients. As a result, another goal of the initiative was to encourage a more inclusive and supportive services delivery system for LGBT elders.

When the staff of Greater Boston Legal Services began working on LGBT elder issues, the initial approach was to identify a governmental program that discriminated against LGBT same-sex couples. Staff pinpointed the MassHealth long-term care program. The idea was to advocate for the state office of MassHealth to file a section 1115 waiver requesting the federal government to allow Massachusetts to start a pilot program that would treat same-sex couples as “married” for purposes of spousal benefits under the Medicaid program. This was as the Goodridge case was wending its way through the state’s court system (*Goodridge v. Department of Public Health*, 440 Mass. 309 (2003)). On November 18, 2003, the Massachusetts Supreme Judicial Court ruled that the exclusion of same-sex couples from civil marriage is unconstitutional under the equality and liberty provisions of the Massachusetts Constitution.

Following the *Goodridge* decision, Greater Boston Legal Services staff decided to develop a focused project to ensure that the mandate of *Goodridge*, which explicitly stated that “...limiting the protections, benefits, and obligations of civil marriage to opposite sex couples violates the basic premises of individual liberty and equality under the law protected by the Massachusetts Constitution,” be upheld. The focus on marriage was not only a result of the unique circumstances that the *Goodridge* decision brought, but also because of the enormous benefits that marriage provides to couples. There are some 400 benefits, protections, rights, and responsibilities that the Commonwealth of Massachusetts confers upon people with a marriage license. In addition, the federal General Accounting Office has identified 1,138 additional federal
benefits and protections. A marriage license determines how one is treated in hospitals, nursing homes, and cemeteries. It determines how one is treated by landlords, courts, creditors, insurers, the IRS, Social Security, and any means-tested government assistance program. While married couples are allowed to function as an economic unit, LGBT couples in long-term relationships are most often treated as legal strangers regardless of the amount of financial interdependence they have created.

Project Structure and Activities

As a means of achieving its primary goals, the LGBT Elder Rights Initiative was designed to operate on several different levels, with at least five related components:

- legal research on the issues faced by LGBT elders;
- public policy advocacy and education;
- outreach to LGBT elders and service providers;
- legal training for service providers; and
- direct legal assistance for LGBT elders.

Legal Research

As same-sex couples began marrying in Massachusetts, staff began looking at how these couples would be able to access public benefits, both state and federal, in light of the 1996 Defense of Marriage Act (DOMA). The project collaborated with staff from Gay and Lesbian Advocates and Defenders (GLAD), who represented the Goodridge plaintiffs, to coordinate the legal work and to consult with other legal experts on a variety of issues, including state and federal benefits programs, pension issues, and other matters directly impacted by DOMA. In the summer of 2004, the project convened a summit meeting with lawyers from other legal services and elder organizations to discuss these issues. At the summit, each lawyer was assigned a particular benefits program and was responsible for researching and reporting back on whether or not DOMA would be implicated. The end result of this research was the creation of a legal framework within which to bring a legal challenge to DOMA if and when the right case presented itself.

Public Policy Advocacy and Education

Much of the work over the course of the grant-funded year was devoted to developing both litigation and policy strategies to assist LGBT elders who have married or are contemplating marriage and who may not receive the same benefits or legal protections as heterosexual married couples. It is clear that this country’s public policy structure at the federal and state levels discriminates against LGBT elders and undermines the ability of this population to age in health and wellness. The Social Security system fails to recognize long-term relationships outside of marriage in its provision of benefits. Surrogate decision making and inheritance and probate decisions often default to blood relatives, who may not be the individuals most connected to the LGBT elder. The Medicaid program does not recognize unmarried partners in the provision of critical financial protections for spouses when one member of a couple becomes ill and enters a nursing home. Some of these issues, which are controlled solely by state law, have been eliminated in Massachusetts in the aftermath of Goodridge. However, the overwhelming majority of rights and benefits that marriage provides are still denied to couples in Massachusetts due to DOMA.

The project’s major piece of public policy advocacy was to develop legislation, which was filed with the Massachusetts Legislature in December 2004. The bill, entitled “The MassHealth Equality Bill,” seeks to codify the Goodridge decision by providing equal access to MassHealth benefits for same-sex married couples. The bill has one lead sponsor and twenty six co-sponsors from the House and Senate. The bill received a hearing before the joint Committee on Healthcare Financing in September 2005; since then project staff has been lobbying key members of that Committee in an effort to get the bill favorably voted out of Committee so that it can be taken up by the full legislature in the 2006 session. Staff also is working with a lobbyist from the Massachusetts Gay and Lesbian Political Caucus and has received tremendous support from traditional elder services providers across the state for our efforts.

The other major public policy initiative was to meet with and work with the state’s Executive Office of Elder Affairs to

Noted with Sadness

It is with sadness that we note the passing of Richard Ingham, long-time Oklahoma Legal Services Developer. Richard died of a heart attack on December 22, 2005.

As anyone who had known Richard, he was a passionate advocate for older people in general, and older Oklahomans in particular. Over the years, Richard contributed several articles to Bifocal and shared many more thoughts on Elderbar. He was as generous with his professional expertise as he was with his humour.
help ensure that LGBT issues were being addressed from a systemic reform perspective. These efforts included two separate meetings with the director of the agency and her staff. The focus at both meetings had been to advocate that EOEA develop statewide policies for all contracted service providers regarding the needs of LGBT elders, and specifically, enforce full marriage rights for LGBT spouses. A very positive result from the second meeting was that the director agreed to set up a diversity workgroup that would be run under the auspices of EOEA and include representatives from members of different racial, ethnic, and cultural elder communities across the state.

Outreach

Funding of the LGBT Elder Rights Initiative began in April 2004. On the evening of May 16, 2004, more than 10,000 people gathered outside of Cambridge City Hall as that city decided to be the first in the state to allow same-sex couples to apply for marriage licenses. The LGBT Elder Rights Initiative’s first outreach effort took place at that gathering. Project staff distributed to hundreds of people a flyer about the project. Later that month, staff also distributed the flyer to more than 40 LGBT and aging organizations, including state elder agencies, local Area Agencies on Aging and Councils on Aging, the local gay newspaper, the local bar associations, and the Massachusetts chapter of the National Academy of Elder Law Attorneys.

Additional outreach included attending and distributing information about the project at the grand opening of the first LGBT elder meal site in Massachusetts; a presentation to a local coalition of elder service providers in Cambridge and Somerville; a presentation to staff at Greater Boston Legal Services; participation in the Massachusetts Gerontology Institute’s 2004 Annual Meeting, at which LGBT elders’ needs and same-sex marriage issues were the featured focus for speakers and workshops; a presentation to the state-wide directors of the Area Agencies on Aging; and an outreach table at the first annual gay pride elder dance.

Legal Training

An important facet of the project was to provide legal education and training on the new rights and protections for LGBT couples who married. Staff also educated LGBT elders and service providers about basic estate planning documents, including wills, health care proxies, powers of attorney, and homestead declarations. Training of elder services providers was coupled with efforts to improve Area Agencies on Aging outreach efforts to LGBT elders, generally.

Direct Legal Assistance

Many of the current generation of LGBT elders choose to remain invisible. As a result, the project’s outreach and collaborative efforts with other elder services providers yielded very few actual clients. There were a number of phone calls from members of LGBT couples who were about to get married; many wanted advice about how certain benefits that they receive would be affected. Project staff also provided advice to other providers who were assisting LGBT elderly clients.

Measurable Outcomes

One result of the project is the increased visibility and awareness of the unique legal needs of LGBT elders for senior services providers, as well as for key state government administrators and policymakers. Through the many service provider trainings, client outreach efforts, policy advocacy meetings, and legislative campaigning for passage of “The MassHealth Equality Bill,” the project has helped to begin a discussion about LGBT elders’ rights, and in other cases, has furthered the discussion along. In addition, the working relationships established between project collaborators have helped to make legal services advocates in Massachusetts more aware of, and more sensitive to, the needs of their LGBT clients.

Looking Forward

As a result of the homophobic decades through which many of these individuals lived, the current generation of LGBT elders tends to be closeted and intent on remaining invisible. Therefore, despite substantial efforts, it remains a challenge to find these isolated elders and to provide them with the services they need and are entitled to. As the LGBT Elder Rights Initiative proceeds past the expiration of the Partnerships in Law and Aging-funding year, staff continues to work with elder service providers and LGBT advocacy groups to develop strategies to connect with these elders who are in need of specialized legal services.
Legal Services Delivery

Serving Elders of Diverse Lifestyles

By Jamie Philpotts

As people get older, there is a corresponding increase in their need to access health care and social services. These services include medical treatment, legal assistance, financial planning, benefits programs, case management, in-home support, and long-term care, to name just a few. For many gay, lesbian, bisexual, and transgendered elders, however, the fear of discrimination by service providers precludes them from reaching out for the assistance they need.

Even today, as the current of society is drifting seemingly towards increased understanding of and sensitivity to non-heterosexual lifestyles, many LGBT people endure daily prejudice in nearly all aspects of life. LGBT individuals and couples face discrimination in health care, social services, housing, employment, insurance, and benefits programs.

While many LGBT elders’ needs are the same as their heterosexual counterparts, some are unique. Care must be taken on the part of elder services professionals to increase their knowledge of the needs of this population. One way to achieve that goal is for those in the aging network to collaborate with LGBT-focused organizations to develop educational and training programs for elder services providers.

One such cooperative venture is between the Arlington, Virginia, Area Agency on Aging and the Merrifield, Virginia-based Senior Health Resources, an organization dedicated to providing health-related services to the aging LGBT Metropolitan Washington community. The two organizations co-developed a series of three events to address issues surrounding aging in the LGBT community. The first of the tripart series was a one-day conference entitled Aging GLBT Sexuality Issues.

The conference’s keynote speaker was Michael Shankle, M.P.H., a researcher at the Graduate School of Public Health at the University of Pittsburgh. Mr. Shankle spoke about the alarming paucity of research on this particular population. This is due, in part, because many of today’s LGBT elders hide or even deny their sexual identity.

According to Mr. Shankle, the research that does exist suggests that today’s LGBT elders have not quite come to terms with their sexual identity, and are isolated from aspects of mainstream society as a result. For example:

- Many older LGBT individuals suffer from social isolation. Statistics show that 60 percent to 65 percent of LGBT adults live alone after age 65 (compared to 35 percent of heterosexuals).
- While 80 percent of heterosexual elders have adult children as caregivers, fewer than 20 percent of LGBT seniors have adult children to support them.
- Many older LGBT elders are estranged from their family. These individuals tend to create familial structures from their social network. Thus, within the LGBT community, oftentimes care is provided by friends.
- Most LGBT elders say that they do not know who will care for them in later life.
- LGBT elders are less likely to receive supplemental insurance through a partner.
- African American LGBT elders have unique needs related to their culture; most do not identify as being LGBT.
- Ten percent of HIV infection occurs in individuals over age 50.
- Elder lesbians tend to have an increased rate of breast and cervical cancer; higher body mass index; and higher rates of problems with alcohol and drugs, with a decreased likelihood to get precautionary health screening—primarily due to a lack of health insurance.
- Amongst elder gay males, HIV and STD infections rates are higher than compared to the rest of the population; there are higher rates of drug, tobacco, and alcohol addictions; and they have more problems related to body image.
- There is even less research on bisexual and transgendered elders. What is known is that these individuals often suffer from health issues related to the introduction of hormones; and there is an increased risk in the incidence of

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Serving Elders of Diverse Lifestyles

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substance abuse, suicide, and depression and other mental health issues.

◆ Older LGBT veterans who have been dishonorably discharged from the military due to their sexual identity receive no health care or military pension benefits.

According to Mr. Shankle, in the face of these challenges, LGBT elders have developed strong coping mechanisms and have become resourceful in caring for themselves and for others.

The first step that elder care professionals, including elder law attorneys and legal services providers, can take in increasing their sensitivity towards LGBT elders is not to assume that all clients are heterosexual. Providers should be encouraged to use gender-neutral language in talking with clients, and to avoid making assumptions about relationships or support networks.

In addition, Mr. Shankle recommends that elder services providers:

◆ Gather information about the LGBT community to educate themselves and the people they work with;

◆ Assess needs and develop services, and affect changes to existing services, to accommodate LGBT elders’ unique needs;

◆ Ensure that service systems can respond in an educated and caring manner;

◆ Evaluate whether existing agencies are meeting the needs of this population;

◆ Raise awareness of LGBT elders in the community;

◆ Form partnerships to more effectively accommodate the needs of LGBT elders;

◆ Post LGBT-positive materials in their client waiting areas (for example, include LGBT magazines in waiting rooms).


Elder Rights: Building on the Past, Strengthening the Future

We are proud to announce the Sixth Annual National Aging and Law Conference, sponsored by the AARP Foundation, ABA Commission on Law and Aging, The Center for Social Gerontology, The Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Consumer Law Center, National Association of State Units on Aging, and the National Senior Citizens Law Center.

The conference affords advocates an exciting opportunity to identify creative approaches to the emerging legal needs of older persons and serves as a catalyst for valuable collaborative cross-disciplinary advocacy initiatives. Highlights of this year’s conference include:

◆ A pre-conference day on April 20 with sessions on the “nuts and bolts” of aging and law topics;

◆ 50+ workshops and roundtables focusing on cross-cutting issues in the law; and

◆ Opportunity to network with legal services and aging advocates nationwide.

Participants represent Administration on Aging-funded and Legal Services Corporation-funded legal assistance providers, the private bar, law school faculty, state and area agency staff, trainers, social services providers, long-term care ombudsmen, and state and federal legislative staff. Watch for conference developments and registration information in upcoming issues of Bifocal and on the Elderbar listserve.
Resources

Estate Planning for Same-Sex Couples
(Book with CD-ROM)

Attorneys who represent lesbian and gay clients must be able to offer creative solutions that protect their clients’ partners, their children, and their future. Estate Planning for Same-Sex Couples, by Joan M. Burda, is a new book from the American Bar Association that provides lawyers with the help they need to solve the unique problems faced by lesbian and gay clients. Of particular interest to lawyers who work with older persons is a chapter devoted to legal issues concerning lesbian and gay seniors. Topics addressed in this chapter include the Older Americans Act, nursing home care, healthcare issues affecting lesbian and gay seniors, Social Security, Medicare and Medicaid, and insurance concerns.

Other chapters featured in the book are: Representing Lesbian and Gay Clients; Understanding Legal Issues Affecting Lesbian and Gay Clients; Agreements and Contracts; Taxes and Trusts and Wills; Avoiding Probate; Children; Essential Estate Planning Documents; and Finding and Marketing to the Gay Community.

The 200-page book comes with a CD-ROM containing forms and documents. Price: $59. To order, phone the ABA Service Center at (800) 285-2221 or visit on the Web: <http://www.ababooks.org>

Legal Writing Competition

The Paralyzed Veterans of America (PVA) is proud to announce its 2005-06 annual legal writing competition. The topic this year is:

Should the U.S. Court of Appeals for Veterans Claims adopt a mediation program for claims appealed from the Department of Veterans Affairs?

The competition is open to law students and law school graduates. There are cash prizes and PVA will assist the winning entrants with having their work published in an appropriate professional journal. PVA sponsors this annual legal writing competition for the purpose of fostering discussion and debate on important issues in veterans law.

In 1988 the Veterans Judicial Review Act passed and created the Court of Appeals for Veterans Claims. As the court has matured, it has encountered growing pains similar to other parts of our judiciary system. A veteran who appeals is now more likely to be part of a growing backlog of cases at the court, after already having waited an average of three years for a decision from VA. In order to improve the administration of justice, courts around the country are successfully experimenting with alternative dispute resolution methods, such as mediation and arbitration. As many members of our armed forces continue to be deployed overseas and engaged in combat with hostile forces, and as the backlog of VA claims grows, this year’s topic is both timely and important to our nation’s veterans.

The deadline for submitting entries is April 28, 2006.

For more information, go to: <http://www.pva.org>, or contact contact Associate General Counsel Linda Blauhut at 801 18th Street, N.W., Washington, DC 20006; or phone (800) 424-8200, ext. 793.

Elder abuse fatality review teams review deaths resulting from or related to elder abuse to learn about and improve the responses of adult protective services, health care providers, law enforcement officers, prosecutors, victim assistance providers, and others to elder abuse victims. Elder abuse is a serious and growing problem. Research indicates that elder abuse hastens mortality and practitioner experience indicates that it often directly causes an older person’s death. However, the responses of the justice, health, and social services systems to elder abuse lag far behind their responses to the similar problems of child abuse or domestic violence. Fatality review teams for child abuse and domestic violence have had an impact in improving systems’ responses to victims. Yet states and communities are only just starting to establish elder abuse fatality review teams.

To support the development of such teams, the Office for Victims of Crime at the U.S. Department of Justice funded the ABA Commission and its subcontractor, the National Adult Protective Services Association, to establish four demonstration projects throughout the nation and prepare and disseminate a replication manual. The ABA Commission provided seed funding to new teams in Houston, Texas; Maine; Orange County, California; and Pulaski County, Arkansas. Four other teams were started just before or at about the same time—in Pima County, Arizona; Sacramento, California; San Diego; and San Francisco—and those teams also shared their experiences for this manual. The members of the eight teams are trailblazers for undertaking this challenging work and sharing their experiences and materials to benefit others. Their contributions to the manual and the elder abuse field are invaluable.

The manual raises the issues and challenges that a team may face and shares ideas for addressing them that have been used by existing elder abuse fatality review teams or by child abuse or domestic violence fatality review teams. It also provides examples and analyses of key documents that the elder abuse fatality review teams have prepared, such as mission statements; memoranda of understanding, policies and procedures, or protocols; confidentiality forms; and data collection forms. It includes ideas for financially supporting a team; the Maine team’s report and links to reports produced by the Houston and Sacramento teams; copies of the team authorizing laws from California, Maine, and Texas; and materials on avoiding vicarious traumatization.

The replication manual may be downloaded at no cost from the ABA Commission on Law and Aging Web page at: <http://www.abanet.org/aging>. A limited number of print copies are available, also for free, to state or community agencies that are (1) interested in establishing an elder abuse fatality review team and (2) unable to download a copy from the Internet. To request a copy, please provide your name, agency, address, phone number, e-mail address, and your reason for needing a print copy to the ABA Commission on Law and Aging at 740 15th Street, N.W., Washington, DC 20005, phone (202) 662-8690, or email abaaging@staff.abanet.org. Technical assistance on team development is available from Lori Stiegel, phone (202) 662-8692 or email lstiegel@staff.abanet.org. A free listserv for members of elder abuse fatality review teams or staff of agencies that are seriously interested in establishing a team is also available. Contact Lori Stiegel by e-mail to request membership.

Lori A. Stiegel is associate staff director of the ABA Commission on Law and Aging.
Law Day 2006

Liberty Under Law: Separate Branches, Balanced Powers

It is important that all Americans understand what this nation’s founders intended and accomplished in creating a government of separate powers. The founders were very concerned that the government they established not have all its powers concentrated in the hands of a few officials. They agreed with Montesquieu that if “the right of making and of enforcing the laws is vested in one and the same man, or the same body of men . . . there can be no liberty.”

The founders were also concerned that the powers granted to one branch would be balanced by powers granted to others. Congress’s power to legislate, for example, is balanced by the executive’s power to veto legislation and by the judiciary’s power to declare legislation unconstitutional. This system of checks and balances ensures that each branch serves as a constraint on, and is constrained by, the powers of the other branches.

This year’s theme enables Law Day planners to show how the branches have their separate spheres and separate powers, but work together for the common good. The theme also is central to building understanding of the rule of law, which has always been a primary purpose of Law Day.


- Background, Planning—Planning tips, time-line
- Publicizing—Media tips, sample proclamations
- Teaching—Lessons, strategies for k-12 presentations
- Community Outreach and Program Ideas
- Speaking on Law Day—Talking points
- Winning—Contest entry information
- Sample Programs Related to This Year’s Theme.

How will your group use this year’s theme to expand knowledge about the rights of elders and to meet their law-related needs? E-mail Bifocal, at Philpotj@staff.abanet.org, with your project ideas and we’ll share them in upcoming issues!

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Legal Services

Multilingual Hotlines Help Asian/Pacific Islander Elders with Medicare Part D Enrollment

The National Asian Pacific Center on Aging (NAPCA) has a national toll-free hotline to help Asian and Pacific Island elders obtain direct multilingual enrollment assistance and access to translated information about the new Medicare prescription drugs benefit.

Since October 2004, the NAPCA hotline has responded to nearly 15,000 calls and assisted more than 2,000 elders to enroll in the transitional assistance program under the Medicare prescription drug discount card program.

Elders that call the hotline are sent their language specific forms designed by NAPCA to screen their eligibility. In many cases, hotline staff complete these forms for the elders over the phone. Once an elder is found to be eligible, staff help identify the best discount card programs for the elder and enroll them in the card of their choice by filling out the enrollment form for the elder to sign or by enrolling online. Helpline staff also assist elders who were wrongfully denied transitional assistance or have not received their card 30 days after enrolling in the Medicare appeal and reconsideration process.

The NAPCA national, multilingual toll-free hotline numbers are:

- English: (800) 582-4218
- Chinese: (800) 582-4218
- Korean: (800) 582-4259
- Vietnamese: (800) 582-4336

For Spanish Speaking Elders

The National Alliance for Hispanic Health has created a bilingual hotline to assist individuals with the Medicare prescription drugs benefit enrollment process. Individuals can receive one-on-one counseling, assistance applying for low-income subsidies, as well as finding a plan to meet their individual needs. The hotline is available Monday through Friday from 8:00 a.m. to 6:00 p.m. ET. **The number to call is: 1 (866) 783-2645.**
The National Aging and Law Award, given in the spirit of the previous Arthur S. Flemming and Paul Lichterman awards, honors individuals who have made significant contributions to justice for older persons. The award recognizes the contributions of individuals who perform outstanding work for older persons in the categories listed below. An awards committee, representing National Aging and Law Conference co-sponsors, will review nominations and select the candidate. The award will be presented at NALC in April 2006. Previous award recipients include:

- **Joan O’Sullivan**, Clinical Professor, University of Maryland School of Law (2004)
- **Natalie Thomas**, Legal Services Developer, Georgia (2002)

**Award Nomination Criteria**

Candidates should demonstrate significant achievement in:

- Advancement of quality legal assistance for older persons
- Establishment of principles of justice benefiting older persons
- Promoting access to the system of justice for older persons
- Contributing law, aging, or social policy on national, state, or local level

**Submissions**

- Provide a brief description of the nominee’s contributions based on the award criteria.
- Provide background of the award nominee (or attach CV). Nominees must not be members or staff of the NALC co-sponsor organizations, nor should they be a past recipient of the Fleming, Letterman, or National Aging and Law Award.
- Nominations should consist of the application form, a narrative letter describing the achievements, and any supporting attachments, e.g., letters of support, list of accomplishments, list of publications, etc.

**2006 National Aging and Law Award Nomination Form**

Submissions should be e-mailed to: anadavis@aarp.org or faxed to: (202) 434-2110.

For more information, please contact Marcy Gouge, director, AARP Foundation, National Legal Training Project, phone (202) 434-2197 or e-mail: mgouge@aarp.org
GET CONNECTED TO ELDERBAR

Join Elderbar, the listserv that brings together public sector law and aging advocates and the private bar. Elderbar is for you if you are a:

- Title IIIB legal services provider, legal services developer, long-term care ombudsman, or other Older Americans Act-funded elder rights advocate;
- Legal Services Corporation, other non-profit, or public sector legal advocate;
- Law school elder law or clinical staff;
- Bar association elder law section or committee leader; or
- National law and aging advocate.

Elderbar will give you the opportunity to communicate across the boundaries of the law and aging networks and the public and private sectors. You will be able to share ideas and information about bar sections and committee structures and activities, and to learn what others are doing in the face of funding shortages and practice restrictions to meet the legal needs of older people. Elderbar is a project of the ABA Commission’s National Legal Assistance Support Center. It is a closed list; messages can only be posted and read by members.

To subscribe, please send your name, e-mail address, and professional affiliation to Stephanie Edelstein at sedelstein@staff.abanet.org.

Subscribe to Bifocal

The ABA Commission on Law and Aging is pleased to announce the merging of its electronic and print periodicals—the bi-monthly e-Bulletin to Elder Bar Section and Committee Chairs and the print quarterly Bifocal (Bar Associations in Focus on Aging and the Law).

The new Bifocal is distributed six times a year and in a PDF format utilizing listserv technology. Subscribers will receive their subscriptions electronically—with expanded content, substantive articles by experts in the field, new columns of interest to law and aging advocates, as well as reports on state elder bar activities, funding and other opportunities, law day ideas, reviews of pertinent resources, and contacts for technical assistance.

It’s Free

The ABA Commission on Law and Aging is distributing this new information service for free to legal services providers, elder bar section and committee members, private practitioners, judges, court staff, elder advocates, policymakers, law schools, clinics, and libraries, and other professionals in the law and aging network.

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