

# State Initiatives *in* End-of-Life Care

Issue 13, March 2002

Focus: Advance Care Planning—Part II

## Guardianship: A Neglected Piece of the Surrogate Decisionmaking Picture

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David Eulitt

*Nobody really knows how many adults are currently under the care of guardians appointed by the courts to act as surrogate decisionmakers. Most experts estimate between 500,000 and 600,000 and warn that by 2035—when elders will make up 25 percent of the U.S. population—these numbers will represent only a fraction of the demand for guardians. The supply of responsible and willing guardians is already inadequate in some areas. And, while many states have significantly reformed guardianship statutes over the past two decades, few have given any attention to decisionmaking standards and protocols for good end-of-life care, and more basic statutory reforms to protect the rights of wards are often not being translated into practice. New recommendations for policy and practice reforms offer a vision of how to improve our guardianship system.*

# Understanding Adult Guardianship

America's guardianship system has experts deeply worried. "Go to almost any local probate court, and you'll find the same guardianship abuses that have been written about for 20 years," says Winsor Schmidt, JD, LLM, director and professor of Health Policy and Administration, Washington State University. "There is a consensus about what we need to do but no political will to fund an adequate system. Not a single state has solved this guardianship problem."

Even leading states have a long way to go, according to Erica Wood, JD, associate staff director, American Bar Association Commission on Legal

Problems of the Elderly. "There are 50 different races being run out there, and even the good jurisdictions are just doing well in pieces."

What exactly is the "guardianship problem," and why did 80 leading experts, including Schmidt and Wood, recently join forces to develop an agenda for change at the "Wingspan" national symposium on guardianship reform (see pages 7–8)?

Eve's case, recently reported by the Illinois Guardianship Reform Project, is instructive. Eve, a woman with mental illness in her late sixties, was placed under the guardianship of her

son, even though her manic depression had long been effectively controlled with drugs. She was not present at the hearing in which she was declared incapacitated. Her son immediately put her in a residential facility in a different state and arranged for the sale of her property. He has been out of contact for ten years and has never filed any annual reports with the courts.

Her case suggests several common system flaws: a judicial opinion based on medical diagnosis (and perhaps discrimination on the basis of disability and age), rather than on Eve's actual functional ability; deprivation of basic

## Ten Things to Know About Adult Guardianship

### What Is a Guardian?

A person appointed by a judge to act on behalf of another person, usually known as the "ward," when the judge has determined the ward to be so incapacitated as to need such a decisionmaker. In some states the "guardian" attends to self-care and health decisions, while a "conservator" deals with financial decisions.

### What Is Capacity/Incapacity?

A model law, The Uniform Guardianship and Protective Proceedings Act defines incapacity as the inability to receive and evaluate information or make or communicate decisions that meet essential requirements for health, safety, or self-care, even with technological support.

### Who Are the Wards?

Primarily people with cognitive impairments that impose profound functional limitations. Severe dementia, untreated mental illness, developmental disabilities, head injuries, strokes, and long-standing drug addictions are common underlying conditions. The majority of wards are elderly, single women of limited means.

### Who Are the Guardians?

Most guardians are relatives or friends of their wards, but "stranger guardians" are a growing segment of the guardianship market: agencies and individuals-for-hire and publicly funded guardians for wards without resources.

### How Is a Guardian Appointed?

Any "interested person" may file a petition requesting appointment of a guardian. Statutes require a hearing on the petition before a judge (often from the probate division), notice of the petition and hearing to the ward, and a written judicial order establishing the guardian/ward relationship.

### What Are the Advantages of Guardianship to the Ward?

Well-trained and responsible guardians offer protection and support to vulnerable wards by making decisions that harmonize with their values and preferences and by ensuring respect for basic rights as well as access to benefits and entitlements.

### What Are the Disadvantages of Guardianship to the Ward?

Wards under full guardianship suffer a complete loss of personal freedom and retain fewer legal rights than convicted felons; wards are effectively reduced to the legal status of a small child.

### Where Do Wards Typically Live?

Most live in nursing homes, hospitals, or other institutions for a significant part of the guardianship period; in fact, the perceived need to transfer a person to an institution often drives the filing of a guardianship petition.

### Do Wards Have Advance Directives?

The most recent study of this issue found that of wards over 60, only 14 percent had advance directives of any kind (e.g., living wills or medical powers of attorney).

### Do All States Offer Public Guardian Services?

No. While some 40 states have statutory provisions for public guardianship services, some are unfunded and most others are underfunded.

## *A Matter of Someone's Time and Attention*

due process rights; undue influence by third-party financial interests; neglect by her guardian/son; and no monitoring by the court to redress a decision that unjustly deprived Eve of her autonomy and possessions.

While Eve's situation did not entail end-of-life decisionmaking, it is reasonable to imagine that had she been terminally ill, she might have been undertreated because of her surrogate's disregard or overtreated by providers nervous about liability issues. (To see how well-trained guardians and court visitors can enhance lives and ensure that end-of-life wishes are honored, see the adjacent sidebar.)

If experts are concerned about neglect and abuse, they are equally concerned about the supply of guardians. "The biggest policy challenge in guardianship," says Schmidt, "is the lack of guardians. With the aging of baby boomers, the whole country will look like Florida, and a percentage of the 'old-old' will need guardians. Current supply problems will be exacerbated exponentially." Sunbelt migration patterns separating elders from their adult children and the longer life expectancies of persons with disabilities also will add to demand, say experts. The need will be especially acute among people without family and resources, because the United States doesn't have a well-established public guardian system.

To further illuminate "the guardianship problem," this issue surveys major policy achievements and gaps, summarizes the Wingspan recommendations for change, and offers stories about reformers, guardians, and their wards. ■

Louis (Lou) Zaccaro likes to remember "Jack," a solitary man suffering from advanced Parkinson's disease who hadn't spoken in seven years when Zaccaro met him. As executive director of Sage Services, Inc. (New Haven, Conn.) and director of the Court Visitor/Conservator of the Person Program, Zaccaro became Jack's court visitor—a volunteer friend and confidant who could provide the personal attention Jack's overburdened conservator (guardian) could not.

Zaccaro recalls bringing Jack toiletry items, holiday cheer, and small gestures of affection in early visits. "After two weeks the dam broke," says Zaccaro, "and Jack began speaking during periods of lucidity." Later there were introductions to Zaccaro's wife and kids. During a health crisis, he made certain Jack's wish for comfort-care-only was clear to staff. Still later, when Jack needed a nursing home transfer, Zaccaro helped make it happen, and when Jack died, Zaccaro was at his interment: "He didn't go into the ground alone."

To help address Connecticut's "drastic shortage" of conservators and their high caseloads (500), Zaccaro's program works with Area Agencies on Aging to develop new conservators and visitors. Operating in four metro areas, Sage Services creates the training programs and standards, and offers technical assistance to the AAAs, while they in turn do volunteer training and serve as liaisons to participating probate courts and nursing homes.

Training covers medical problems of the elderly, end-of-life care issues, relevant law, and the special challenges of life in a nursing home. Program managers try hard to match people with



*Lou Zaccaro (left), director of the Court Visitor/Conservator of the Person Program, pictured here with James Valenti, a former ward whom Zaccaro helped "restore" to independence, and program advocate Congresswoman Rosa Delauro (D-Conn.)*

conservators and visitors according to ethnicity, professional background, nationality, and first language to maximize opportunities for building trust and connection. "Without attention," says Zaccaro, "the vulnerable elderly are likely to become physically and socially isolated and have their medical problems overlooked."

Program development was funded by grants from The Robert Wood Johnson Foundation. In spite of continuing success and Connecticut's waiting list for guardians, the state legislature has not funded program expansion, but organizations in other states are taking notice. The Fielding Institute, a Santa Barbara-based graduate school, is developing the model program in Nevada, California, and Arizona. Zaccaro has also had feasibility discussions with nonprofit agencies in Utah and Idaho.

For more information about this program, contact Sage Services at (203) 777-7401.

# Policy Achievements and Gaps Since 1980

## Two Decades of Change in Guardianship Statutes

Guardianship experts agree that the last two decades have seen significant positive reform in state laws. Since 1980, every state has made revisions to its guardianship statute, with a number of states implementing sweeping changes, according to Penelope Hommel, MSc, co-director, the Center for Social Gerontology (Ann Arbor, Michigan). These changes were propelled by both a growing awareness of system faults and by a philosophical shift away from “paternalistic approaches which fostered dependency, toward policies and laws focused on maximizing the potential for autonomy and independence among individuals of limited capacity,” says Hommel.

Changes have had several thrusts: to prevent unnecessary deprivations of liberty, to ensure the least restrictive interventions, and to minimize the potential for abuse, says Hommel. Much of the new legislation has sought to achieve these aims by revis-

ing standards for capacity determination, making limited guardianships a preferred option, and multiplying procedural safeguards:

- **Capacity Determination.** Since capacity determination is the crux of judicial decisionmaking in guardianship cases, reforms in this area have been especially important, experts agree. Whereas older laws allowed for determinations based solely on medical diagnosis or “condition of old age”—grounds that invited gross discrimination—new laws require that determinations focus on the actual functional abilities and limitations of the prospective ward. To end judicial dependence on a single, summary medical opinion, newer laws often mandate or encourage multidisciplinary assessments and detailed behavioral evidence to support claims of diminished capacity.
- **Limited Guardianship.** To maximize the rights retained by the ward, many newer laws indicate a preference for limited guardianships that provide powers to guardians

only in those areas where the ward’s functional limitations have been clearly demonstrated.

- **Procedural Safeguards.** The major theme of procedural change has been to strengthen the hand of individuals alleged to lack capacity by mandating representation by counsel and encouraging more aggressive defense, shifting the burden of proof to petitioners and intensifying scrutiny of prospective guardians’ qualifications and interests. Notice requirements for the ward and others have been added; hearing procedures encourage the ward’s participation; and findings must be stated on the record.

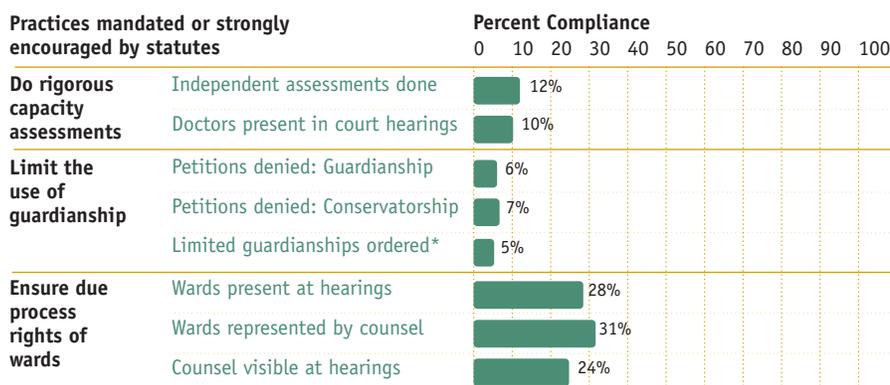
If experts agree that such changes have been important, they also agree that reforms have not fulfilled their promise in practice (see chart below). “States have not yet been willing or able to dedicate the resources needed to carry out the spirit of these guardianship reform laws; indeed, in the final analysis, the problem is largely one of money and resources,” says Charles Sabatino, assistant director of the American Bar Association’s Commission on Legal Problems of the Elderly. “If you don’t have resources to do thorough capacity assessments, for example, you’ll be dependent on petitioners for input. Policymakers need to realize that just changing statutes doesn’t necessarily change the experience of guardianship. The pressure points for changing real experience are capacity assessment, as well as the training and monitoring of guardians.”

One area of statutory reform lagging well behind current trends is health care decisionmaking. Twenty-three states have no specific standards for health care decisionmaking by guardians, and only 11 address the issue of life-sustaining treatment, says Sabatino. “On a purely statutory level, most states haven’t addressed end-of-

*“States have not yet been willing or able to dedicate the resources needed to carry out the spirit of these guardianship reform laws.”*

Charles Sabatino, JD, assistant director, Commission on Legal Problems of the Elderly, American Bar Association

### The Gap Between Statutes and Practices



\*This data excludes Minnesota, the only studied state where limited guardianship orders were common.

Source: Adapted from data in “A National Study of Guardianship Systems: Findings and Recommendations,” The Center for Social Gerontology, Ann Arbor, Michigan, 1994. The study covered 30 courts in 10 geographically diverse states.

## A Public Guardian Living the Spirit of Reform

life care guidelines for guardians. That means guardians typically follow customary practices: usually *not* withholding and withdrawing life-sustaining treatment without going to court. Guardians are very reluctant to make these decisions. That's why we need guidance in statutes. If guardians are going to have the right to make health care decisions, standards and procedures should be spelled out so there is accountability."

### Alternatives to Guardianship for Health Care

As guardianship reform has proceeded, so has the adoption of health care consent statutes and laws creating medical powers of attorney and living wills (see "Possible Alternatives to Guardianship," p.7). Most experts agree that when such advance care planning mechanisms are used ethically, they are desirable alternatives to guardianship because they allow the known preferences of patients to be honored without recourse to the courts. But utilization is a problem. "Medical powers of attorney and living wills are as good a solution as we've come up with," says Schmidt, "yet institutional compliance with the Patients Self-Determination Act is nominal, and sometimes doctors don't comply with existing documents, so in 2002, we're still talking about guardianship." Health care consent statutes garner praise and some reservations. Advocates in states like West Virginia and New Mexico—where these laws have been expanded beyond family to include friends, neighbors, and even social service agencies as default surrogates decisionmakers—report especially dramatic decreases in demand for guardians. Yet some observers worry that these statutes may not always empower the most appropriate surrogate or honor family decisionmaking styles, and that they may be shielding some cases from badly needed court scrutiny. ■

Rebecca Lake Wood doesn't want to build a bureaucratic fiefdom. As Jackson County, Missouri public guardian, she knows her power to make other people's most important decisions can be a dangerous thing: "Just because you have power doesn't mean you should use it." But she doesn't hesitate to take on the big health care establishments she interacts with daily in order to get the best possible services for her agency's 1,000 wards: "We don't act as a rubber stamp for the medical or psychiatric community; we talk about the hard issues. We know wards better than the docs do."

In spite of understaffing—a situation typical of public guardians—she and her 25 employees have managed to put courage and ethics at the center of their work. In doing so, Wood is carrying on a tradition established by a predecessor, Frank Murphy, who believes that "the effort of the guardian should be to give the wards back their lives when they have decisionmaking capacity." With regular training and consultation from the Midwest Bioethics Center (MBC), the entire staff has learned to track cases back to basic ethical principles, play toward wards' assets rather than their deficits, and honor their autonomy whenever possible.

If these commitments are clear in court when restoration of rights is the issue, they also are evident in the agency's approach to end-of-life decisionmaking for terminally ill wards. Wood, who has statutory authority to make such decisions, turns first to the ward for guidance. "We try to learn as much as possible about the terminally ill client: we listen for patterns and themes in their responses to our questions about care preferences. We search out friends, families, and ministers to establish client values and reli-



David Eulitt

*Karen Weddle, pictured on the left, at a regular Friday meeting with her public guardian, Rebecca Lake Wood, public administrator, Jackson County, Mo. With Wood's support, Weddle, who has a mental illness, recently regained her legal rights to vote, marry, and make her own medical decisions. She is now working to get all her other rights restored. "It was a good feeling getting my rights back—like a big rock lifted off my shoulders," she says of her recent triumph. "Becky testified for me in court and was for me all the way."*

gious practices—to avoid substituting our own desires for theirs." When ward preferences aren't known, Wood convenes her ethics advisory council (two ethicists from MBC, two clergy, a psychiatrist, a physician, and a social worker). "We ask ourselves: 'Do we let life continue, or do we allow life to terminate in a dignified way?' These are decisions of great magnitude, worthy of time and attention. It takes some braveness and boldness to do the right thing."

For more on ethics-based interventions for vulnerable individuals, see issues 6 and 12 of this series. For more information about Wood's initiatives, contact her at (816) 881-3775 or woodreb@gw.co.jackson.mo.us.

# The Illinois Guardianship Reform Project: Some Lessons from the Trenches

“The issues surrounding guardianship in Illinois and around the country require a timely and effective response.” These remarks by Charles E. Freeman, then chief justice of the Illinois Supreme Court, inaugurated the Illinois Guardianship Reform Project, an initiative which Freeman believes represents a model for both his state and the nation.

Since 1999, the project has sought to examine and address problems of abuse, neglect, and mismanagement of some individuals in the state’s guardianship system. Equip for Equality, a not-for-profit organization designated by the governor to operate a federally mandated protection and advocacy system for people with physical and mental disabilities, initiated the project.

For more than a year, a blue ribbon task force of experts in law, medicine, gerontology, and disability met to identify ways to bring about change. After reviewing the state’s guardianship system and combing the country for best practices, the task force last year released its conclusions. While the problems identified are all too familiar, the task force’s emphasis on field testing forms and procedures to bridge the gap between guardianship policy and practice is quite unprecedented.

To address problems at the pressure points for guardianship system reform—capacity assessment as well as the training and monitoring of guardians, the project is now working to implement:

- a new medical/psychological assessment form that assists clinicians in identifying functional limitations more easily and fully, and gives judges better information

with which to make rational and compassionate decisions, including orders for limited guardianship

- a guardianship report form and several guardianship monitoring program alternatives to quantify system problems and offer policy makers a cost-effective way to oversee guardians after they have been appointed
- model training curricula for guardians and continuing education for professionals.

The project is also considering a guardianship case file research effort to provide data illustrating actual guardianship system impacts. “We will use this data to further convince key stakeholders of the need for change,” says Zena Naiditch, president and CEO of Equip for Equality. Naiditch speaks from recent experience. The project’s initial legislative package—a modest proposal that would merely have brought the state’s Probate Act into alignment with national trends—failed to pass because of opposition from some probate judges and the bar associations, in spite of bipartisan legislative sponsorship and the endorsement of 27 disability and aging organizations.

Such opposition is not surprising, according to Erica Wood of the ABA’s Commission on Legal Problems of

**“Despite initial opposition to guardianship reform, it is an important issue that needs to be addressed to avert a future crisis. Given projected population shifts, it will make a big difference if we get it right.”**

Illinois State Senator Kathleen Parker (R-29th)

the Elderly. “Guardianship reforms are sometimes greeted initially with a natural reluctance—including demurrals by members of the legal and judicial community.”

Project leaders remain upbeat. “We recognize that there are different viewpoints based on different professional cultures and experiences,” says Morris Fred, the project’s manager. We will continue our educational efforts. We are not going away.”



Top, left to right: Morris Fred, manager, Illinois Guardianship Reform Project; Charles E. Freeman, former chief justice of the Illinois Supreme Court; Mark Heyrman, task force chairperson; Zena Naiditch, president and CEO, Equip for Equality, Inc. Bottom, left to right: legislation sponsors and senior review board members Illinois State Senator Kathleen Parker (R-29th) and Representative Kevin McCarthy (D-37th), Illinois House of Representatives

For more information about the project, visit [www.equipforequality.org](http://www.equipforequality.org)

Initial funding for the project was provided by The Chicago Community Trust, the Polk Bros. Foundation, The Field Foundation of Illinois, Inc., the U.S. Department of Health and Human Services, and The Illinois Council on Developmental Disabilities.

# Wingspan Recommendations for Policy and Practice Reform

In July 1988, the “Wingspread” national symposium on guardianship issued a set of recommendations that has helped foster reform over more than a decade. At the close of 2001, a second national guardianship conference, “Wingspan,” brought together some 80 appointed conferees—all recognized guardianship experts—to reflect on progress since 1988 and to create a set of recommendations that could serve as a map for continuing reform and as a renewed call to action for advocates and policymakers. The primary convenors of Wingspan were the National Association of Elder Law Attorneys, Stetson University College of Law, and the Borchard Foundation Center on Law and Aging. This section summarizes most of the conference’s major recommendations.

## Overarching Needs

The recommendations identify three primary requirements for successful guardianship reform:

- better education of all actors in the guardianship system, including judges, guardians, other court personnel, families, and attorneys
- further research to determine whom the system is actually serving and how it is really affecting the lives of vulnerable individuals
- adequate funding of system features mandated by reforms (e.g., multidisciplinary assessments).

## Expanding the Use of Alternatives to Guardianship

The recommendations strongly encourage the expansion and integration of mediation services into adult guardianship procedures in order to facilitate early and full exploration of alternatives to guardianship prior to court intervention (see the box at right). Recommendations call for greater availability of and access to alternatives, widespread education about the risks and benefits of alterna-

tives, and collaboration among providers of alternative services such as financial institutions, law enforcement, and adult protective services. Mandatory reviews of possible alternatives in all guardianship petitions and statements of why none are appropriate (if not used) also are endorsed.

Regarding health care decisionmaking alternatives specifically, the recommendations urge all states to adopt health care consent statutes and give preference to surrogates nominated in advanced directives when appointing guardians.

Limited guardianship is strongly supported as an alternative to full guardianship; to expand its use, the recommendations call for judicial education, enhanced funding, and the development of practical forms and procedures to assist courts with the substantial complexities of implementation.

## Due Process Protections

The recommendations urge that all state statutes adopt “substituted judgment”—following the incapacitated person’s wishes and values to the extent known—as the preferred standard of guardianship decisionmaking and uphold mandatory appointment of zealous counsel for those alleged to be incapacitated; their right to appear in court and be heard; and the primacy of their real needs in the crafting of court orders. To ensure a complete and fair appraisal of real needs, the recommendations urge the use of multidisciplinary functional assessments to be paid for by Medicaid/Medicare, as well as the routine use of court investigators (“visitors”) to act as the court’s eyes and ears and to supplant the more ambiguous and passive role of guardians *ad litem* (for an innovative use of court visitors in guardianship proceedings, see “The Metropolitan Washington Bioethics Network,” in issue 12 of this series).

## Possible Alternatives to Guardianship

### Medical Decisionmaking

- **Medical Powers of Attorney:** allow a person to choose a trusted surrogate decisionmaker for health care before incapacity strikes.
- **Living Wills:** offer advance written instructions about if/when life-support treatment should be withheld/withdrawn.
- **Health Care Consent Statutes:** authorize default surrogate decisionmakers—often in next-of-kin priority—to make medical decisions for incapacitated persons lacking advance directives.

### Other Alternatives

- Diverting inappropriate guardianship petitions to nonjudicial venues for mediation and referral to alternatives.
- Establishing trusts, joint property arrangements, durable powers of attorney, single transaction guardianships, and other limited guardianships.
- Using money management services and representative payees to handle entitlement checks.
- Involving Adult Protective Services and community-based services.

## Wingspan Recommendations for Policy and Practice Reform

Continued

### Monitoring and Accountability

More finely tuned judicial orders based on sound functional assessments, together with annual guardianship plans organized around clear goals and outcomes are at the center of the recommendations to improve monitoring and accountability. To give plans meaning, they urge aggressive, regular review and the development of better court-based data collection systems to track cases. They also suggest the need for research to determine how monitoring can be best implemented. The use of judges with specialized knowledge is strongly endorsed for guardianship proceedings as is ongoing public education on the importance of monitoring. An emerging collaboration, the National Guardianship Network, is to take the lead in such educational efforts and in the identification and generation of quality improvements in guardianship policy and practice nationally.

### Standards for Guardians

While family and friends have traditionally served as guardians, in the past 15–20 years, a new industry of paid guardian service providers has emerged, says Penelope Hommel, a Wingspan conferee who is currently conducting research on this issue.

“Only a handful of states have established certification or training requirements for such guardians, and most do not require criminal or credit checks,” she notes. “States must work quickly to establish mechanisms that will hold these practitioners to a very high standard of diligence.”

The recommendations call on states to adopt minimum standards of practice for all guardians, using the National Guardianship Association (NGA) standards as a model, and to require professional guardians to be licensed, certified, or registered, as well as guided by professional standards and codes of ethics such as those developed by the NGA (see information box below).

The conference also recommended that all states provide high-quality public guardianship services for those lacking resources. ■

For a complete summary of recommendations, see “Wingspan—The Second National Guardianship Conference” by A. Frank Johns and Charles P. Sabatino, forthcoming in the *Stetson Law Review*, volume 31, number 3 (Spring 2002). To order, contact: [www.law.stetson.edu/lawrev/subscribe.htm](http://www.law.stetson.edu/lawrev/subscribe.htm)

The National Guardianship Association (NGA), a nonprofit organization founded in 1988, is dedicated to improving the quality of life for people in need of guardian and alternative protective services. NGA has developed a comprehensive set of general guardian standards (which includes consideration of end-of-life care), a code of ethics, and guardian certification programs at both the “regular” and “master” level. NGA also has a judges’ advisory panel, an ethics committee, and an ethics hotline. For more information about NGA, call (520)881-6561, TDD (520) 326-2467, or consult its web site ([www.guardianship.org](http://www.guardianship.org)).

# State Initiatives in End-of-Life Care

### Information About the Series

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# New!

Beginning in the spring of 2002, *State Initiatives* will release the first of four new audio programs on key end-of-life care policy issues: 1. pain management, 2. policy heroes, 3. children, and 4. cultural diversity. Watch for information and order forms in series policy briefs.