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The *NAELA Journal* Editorial Board invites the submission of manuscripts year-round with the following guidelines:

1. For initial approval of publication you may submit a one- to two-page outline of the intended manuscript, along with a list of sources. Alternatively, you may submit your final paper for consideration.

2. *NAELA Journal* policy is to give priority of consideration to original work not previously published. If the proposed work has been previously published, or something very similar, please provide a copy, and explain why the *NAELA Journal* Editorial Board should consider re-publishing your work.

3. Please conform text to *The Elements of Style*, by William Strunk and E.B. White and citations to *ALWD Citation Manual*.

4. A table of contents will be generated from the main and subheadings in your article, so it is not required to submit a table of contents, but the heading levels should be clearly identified.

5. Please include a cover letter containing the title of your article, your professional affiliation or school, address, telephone, email address, and a short biography with reference to recently published material.

6. Most articles are between 4,000 and 10,000 words, including the footnotes.

7. *NAELA Journal* Editorial Board members review all submissions for appropriateness and provide direction to potential authors. Author(s) will be notified by the *NAELA Journal* Editorial Board if the outline/article submitted is acceptable or not, or if changes should be made for further consideration of the article for publication. Submission does not guarantee publication. *NAELA Journal* reserves the right to reject any article submitted for publication, whether solicited or not.

8. *NAELA Journal* articles accepted for publication will be assigned to a *NAELA Journal* editor who will work with the author or authors making any necessary changes to prepare the article for publication. Articles will be edited for clarity and will be edited to fit the publication’s editorial style and length requirements. In addition, all first-person references and references to the author’s organization, products, or clients may be deleted at the editor’s sole discretion.

9. Authors should provide a brief biographical statement for publication with the article.

10. Each author will be required to sign a standard author agreement that acknowledges the material submitted is authentic, and grants NAELA the proper permissions to publish such article. The agreement, however, does not change copyright, which is maintained by the author or authors.

11. Articles should be submitted electronically in a standard word processing document (not a pdf file) to Nancy Sween, NAELA Director of Communications and Publications, nsween@naela.org.
In This Issue of *NAELA Journal*

*By Charles P. Golbert, Esq., Editor in Chief*

It is my privilege to introduce the Fall 2012 issue of *NAELA Journal*. This issue features three traditional law journal articles including a 50-state survey of advance directive laws, an original empirical study of the efficacy of advance directives, three case notes, and two book reviews.

The editorial board is proud of the breadth, depth, and quality of the articles we publish. So much so that we wish to continue the dialogue after our members have finished reading the articles. Toward that end, *NAELA Journal* seeks letters to the editor to continue discussion of the topics analyzed in this and future issues. Details are provided toward the end of this introduction.

**The Impact of State Medicaid Reform**

Due to the economic downturn, many states have been struggling to balance their budgets and have looked to the Medicaid program in their efforts to do so. Ironically, cuts in Medicaid spending come at the same time that enrollment in the program is growing. What strategies have states utilized to contain Medicaid spending, and what impact will such efforts have on vulnerable users of the program? In the opening article, Elizabeth P. Allen, Esq.; Shana Siegel, CELA; and Wendy Cappelletto, Esq., explore these questions through study of reform efforts in three states: Florida, New Jersey, and Illinois. The authors question whether certain reform efforts will actually save the states money if, as a result, poor people become sicker and require even more (or more expensive) care.

**Medicare Set-Asides in Personal Injury Cases**

Aaron D. Frishman, Esq., argues that, while use of Medicare Set-Asides (MSAs) has become routine in workers’ compensation cases, they are not always appropriate in personal injury cases because they can cause delay, increase costs, and jeopardize some settlements. Moreover, it is often difficult to allocate a specific portion of a personal injury settlement solely for future medical expenses. After analyzing the law and the arguments pro and con for the use of MSAs in the personal injury arena, including the findings of the NAELA Medicare Task Force, Frishman concludes that there is not a standard method of practice or a best practice. Frishman suggests attorneys adopt a case-specific analysis, and discusses the factors to consider.

**Advance Health Care Directives**

This issue features two articles on advance health care directives. Although such directives are recognized in all 50 states, each state’s law is different. Diana Anderson, CELA, describes the law in each state, and highlights substantive differences with a focus on the law in Illinois.
on portability and selection of a surrogate decision maker when no directive exists. Anderson’s discussion of appointment priority contains an interesting section about same-sex couples. As an appendix, Anderson provides a comprehensive chart comparing key aspects of the laws in all 50 states.

The second article about advance directives is by Susan P. Shapiro, PhD, a sociologist. In her provocative article, Prof. Shapiro questions the utility of advance directives. Not only, as Shapiro points out, have the majority of Americans not executed an advance directive, but Shapiro argues that such directives are often not followed. She bases this argument on original empirical research: A four-year observational study of more than 2,000 patients who passed through the neurological or the intensive care units of a large urban teaching hospital in Illinois. Shapiro concludes that advance directives are not followed for a variety of reasons including the directive not being in the patient’s chart, the directive not accurately reflecting the patient’s wishes, the directive being too abstract to provide meaningful guidance under the particular circumstances, and surrogate decision makers not following the directive.

Case Notes

This issue includes three case notes. The first, by Ron M. Landsman, Esq., CAP, discusses *Lewis v. Alexander*, where the Third Circuit affirmed the district court in striking a Pennsylvania statute that restricted the use of (d)(4)(C) special needs pooled trusts. The court held that Pennsylvania could not require that a pooled trust retain only 50 percent of a deceased beneficiary’s account before payback to the state of its expenditures made on behalf of the beneficiary. The court also held that Pennsylvania could not preclude persons age 65 and older from establishing a special needs pooled trust account. NAELA filed an amicus brief in *Lewis v. Alexander*, authored by Landsman and Shirley Whitney, Esq., CAP, in support of these outcomes.

In the second case note, David L. McGuffey, CELA, discusses the U.S. Supreme Court’s decision in *Marmet Health Care Center v. Brown*, where the Court held that the Federal Arbitration Act preempted a West Virginia public policy prohibiting enforcement of pre-dispute agreements to arbitrate personal injury or wrongful death claims against nursing homes. The Court remanded the case for the West Virginia court to determine whether the arbitration agreement was unconscionable under state law. McGuffey criticizes the Court’s disregard of the underlying facts and argues that the decision will allow nursing homes to avoid accountability when they fail to provide the quality of care required by federal and state law resulting in serious injury or death to residents.

The final case note, also by Ron M. Landsman, analyzes the Fourth Circuit’s decision in *E.M.A. v. Cansler*, which addresses state Medicaid liens on personal injury recoveries. In *E.M.A.*, the court applied the Supreme Court’s decision in *Arkansas Dept. of Health and Human Servs. v. Ahlborn* to invalidate a North Carolina statute that allowed it to recoup its full expenditures up to one-third of a personal injury recovery, without any determination that the plaintiff actually received such amount specifically for medical expenses.
Book Reviews

Rounding out this issue are two book reviews. First, Carol Cioe Klyman, Esq., reviews *Mom Always Liked You Best: A Guide for Resolving Family Feuds, Inheritance Battles and Eldercare Crises*, by Arline Kardasis, Rikk Larsen, Crystal Thorpe, and Blair Trippe. The book, written by experts in conflict resolution, addresses how to build consensus when dealing with irrational family members feuding over emotional issues involving an elderly relative. Klyman suggests that this book should be required reading for Elder Law attorneys.

The second review, by Spencer Bates, Esq., is of *Someday All This Will Be Yours: A History of Inheritance and Old Age*, by Hendrik Hartog. Covering the late 19th century to the present, the book documents the history of litigation to enforce promises of testamentary bequests in exchange for caring for an elderly parent. As family caretaking became more of an exception rather than the norm, the idea of compensating family care providers and enforcing promises of testamentary bequests in return for care became more common. As if taking a page from *Mom Always Liked You Best*, Bates concludes his review by observing that, in the end, Elder Law is not simply a set of legal rules, but management of interpersonal relationships.

Letters to the Editor

As mentioned earlier, we at *NAELA Journal* hope to continue discussion on these important and fascinating issues. Therefore, we are soliciting letters to the editor. We seek your thoughts, critiques, and observations. We plan to publish the most thoughtful letters, consistent with space constraints. We hope to make this a regular feature of the journal. Letters should be sent to Nancy Sween, NAELA Sr. Director of Communications and Publications, at nsween@naela.org. *NAELA Journal* reserves the right to edit letters published for length, clarity, and style.

Thank You

Finally, thanks to our authors and to the outstanding people who comprise our board of editors. Without their hard work, *NAELA Journal* would not be possible.
THE IMPACT OF STATE MEDICAID REFORM ON VULNERABLE POPULATIONS NEEDING LONG-TERM CARE SERVICES AND SUPPORTS AN ANALYSIS OF FLORIDA, ILLINOIS, AND NEW JERSEY

By Elizabeth P. Allen, Esq.; Wendy Cappelletto, Esq.; and Shana Siegel, CELA

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I. INTRODUCTION

The Medicaid Program was created at the same time as Medicare, as part of President Lyndon B. Johnson’s “Great Society.” Its purpose is to provide medical assistance and long-term care services and supports to low-income Americans. Included in this population are the nation’s elderly and individuals with disabilities — a segment of society that seems to be poorer and sicker than the rest of society. This population’s physical and emotional well-being can be dramatically impacted based upon the Medicaid coverage they receive and the manner in which they receive it. States, however, have fiscal responsibility and seek budgetary predictability and, therefore, must weigh those concerns against the need to provide basic health care to their poorest citizens. This struggle has become more apparent during the recent severe economic downturn. States have had to reduce the size of their budgets while still trying to maintain critical services to their citizenry. State Medicaid programs are one of the budgetary areas reviewed by states in their efforts to reduce costs and control growth.

State actions to control Medicaid costs have consequences. The health of the recipients dependent upon Medicaid services can be greatly affected by the way in which costs are reduced and growth is managed. Reducing or eliminating benefits, or changing distribution methods does not assist in cost reduction if the vulnerable populations affected become sicker and ultimately in need of even greater amounts of care.

This article will look at recent legislative actions taken by three states,1 Florida, Il-
The Impact of State Medicaid Reform

-part I-

Florida, Illinois, and New Jersey, relevant to their Medicaid programs in light of state fiscal crises. It will illustrate the different approaches taken by these states to control the growth of their Medicaid programs and the resulting potential or actual effect those changes have had on their respective elderly and individuals with disabilities populations. Part II will provide a primer on the Medicaid program. Part III will highlight some of the more important changes to Medicaid due to the health care reform passed by Congress and signed by President Obama in 2010 and the impact that will have on state Medicaid budgets. Part IV will provide a national overview of the condition of states’ budgetary and fiscal health. Part V will provide an overview of the types of actions states take to reduce Medicaid budgets and control growth. Part VI will then provide an analysis of specific actions taken in Florida, Illinois, and New Jersey to control Medicaid costs in light of their respective state budgetary concerns, and the impact or potential impact those actions have on the most vulnerable populations.

II. Basics of Medicaid

Medicaid, enacted in 1965 and codified at Title XIX of the Social Security Act,² is a means-tested entitlement program that was established to provide medical assistance to low-income individuals and families. Over the years, Congress has expanded Medicaid eligibility to reach more Americans living below or near poverty, and presently covers (as it relates to this article) individuals with diverse physical and mental conditions and disabilities, and the elderly.³ Medicaid is the single largest health care program in the United States covering in excess of 55 million individuals in 2011.⁴ By design, Medicaid operates as a safety net. During economic recessions, more people become eligible due to job loss and resulting loss of health insurance and the program expands thereby increasing its cost to federal and state budgets.⁵

A. The Program

Medicaid, a jointly financed partnership between the federal government and the states, is an optional grant program; though voluntary, all states participate.⁶ The federal government provides a framework of minimum standards and provides states flexibility for program design and administration.⁷ Each state’s Medicaid program, referred to as its “state plan,” is on file with the Centers for Medicare & Medicaid Services (CMS).⁸ The

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⁵ Kaiser Commn., supra n. 3, at 4.  
⁸ See 42 C.F.R. § 400.203 (2012) (“State plan or the plan means a comprehensive written commitment by a Medicaid agency, submitted under section 1902(a) of the [Social Security] Act, to administer or super-
state plan identifies the services (both mandatory and optional) that a state has elected to provide and how the state intends to comply with the requirements of the federal Medicaid statutes and regulations. States can change their Medicaid program by several methods, one of which is to make a state plan amendment if the change is something that is allowable under the federal mandates. A state can also seek a waiver to make a program change not otherwise allowable under the program rules. A “Section 1115 waiver” allows states to use funds to test new or existing approaches to financing and delivering services for a segment of the Medicaid population, while “Section 1915 waivers” allow states to mandate enrollment in managed care and provide home and community-based services. States must apply for and obtain CMS approval for waivers to their state plan.

B. Persons Covered

Federal law requires states to cover “mandatory” groups in order to receive federal matching funds. The mandatory groups include (as it relates to this article) aged and disabled individuals who have limited income. Only U.S. citizens and certain categories of lawfully residing immigrants can qualify for Medicaid. The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 barred most lawfully residing immigrants from Medicaid during their first five years in the U.S., except for emergency treatment. Medicaid is a means-tested program, which means that people must meet certain financial criteria to be eligible. Working under broad federal guidelines, states have flexibility to determine their own income and asset tests.

States can expand Medicaid eligibility beyond federal minimum standards to cover additional “optional” groups. Those groups include the elderly and individuals with disabilities with income up to 100 percent of the Federal Poverty Level (FPL), persons residing in nursing facilities with income below 300 percent of the SSI standard, and individuals who are receiving care under home and community-based services waivers but would be otherwise eligible if institutionalized.

Medicaid, the main source of long-term care coverage and financing, covers over 10 million people, including about 6 million elderly, in need of long-term care services and supports (LTCSS). Medicaid covers approximately seven of every 10 nursing home residents, with the program financing more than 40 percent of nursing home spending...
and long-term care spending overall.\textsuperscript{20} Institutional care comprises more than half of all Medicaid long-term care spending, but a growing percentage is attributable to home and community-based services.\textsuperscript{21}

\section*{C. Services Covered}

States must provide enrollees a core set of “mandatory” benefits and certain cost sharing protections in order to participate and receive matching funds.\textsuperscript{22} The mandatory benefits include physician and hospital services, nursing facility services for individuals age 21 or over, and home health services for individuals entitled to nursing facility care.\textsuperscript{23} If an individual is eligible for Medicaid, the state cannot withhold or create waiting lists for those mandatory services. States may also choose to cover “optional” benefits, including those that constitute long-term care services and supports.\textsuperscript{24} For both mandatory and optional benefits, states determine the amount, duration, and scope of covered benefits, subject to the requirement that coverage of the benefit be sufficient to achieve its purpose.\textsuperscript{25}

\section*{D. Financing}

As stated above, Medicaid is a jointly financed partnership between the federal government and participating states. The federal government provides matching dollars for state Medicaid expenditures using the federal medical assistance percentage (FMAP), which is a statutory formula\textsuperscript{26} based on state per capita income. The FMAP therefore varies among the states, with poorer states receiving more federal assistance, and varies from year to year.\textsuperscript{27} In 2011, matching rates ranged from 50 percent (the floor amount) to 75 percent.\textsuperscript{28} Under the American Reinvestment and Recovery Act of 2009 (ARRA), the federal government temporarily increased the matching rate to provide fiscal relief to states dealing with the effects of the economic downturn; the increase was originally through December 2010 but was later extended through June 2011 at a lower level.\textsuperscript{29}

\section*{E. Cost and Enrollment}

In 2008, total federal and state Medicaid spending on services was nearly $339 billion,
of which 34 percent of total spending went toward long-term care.\textsuperscript{30} The elderly and people with disabilities made up roughly 25 percent of the Medicaid population, but accounted for about 66 percent of spending: and dual eligibles (low-income individuals who were enrolled in both Medicare and Medicaid) made up 18 percent of the Medicaid population, but accounted for 46 percent of Medicaid spending.\textsuperscript{31} The above illustrates that Medicaid spending is skewed; a small group of recipients accounts for a large share of spending.

In the several years before the economic downturn, Medicaid enrollment increased at an average annual rate of 4.2 percent; however, between June 2008 and June 2009 enrollment grew by 3.3 million, or 7.5 percent.\textsuperscript{32} Several factors affect Medicaid enrollment: 1) states tend to expand Medicaid eligibility when their economies are strong; 2) in economic recessions, job loss and resulting loss of insurance cause more people to qualify for Medicaid; and 3) ongoing erosion in employer-sponsored insurance contributes to the expanded enrollment.\textsuperscript{33}

III. HEALTH CARE REFORM IMPACT ON MEDICAID

As stated before, the Medicaid program has been expanded over time. Each expansion affects states due to potential costs and savings associated with those changes. The landmark health reform legislation, the Patient Protection and Affordable Care Act of 2010 as amended by the Health Care and Education Reconciliation Act of 2010 (collectively referred to as the Affordable Care Act (ACA)),\textsuperscript{34} signed by President Barack Obama in March 2010, also has major implications for states’ Medicaid programs.\textsuperscript{35}

A. New Mandatory Group

Beginning January 1, 2014, states will have to provide Medicaid coverage for almost all individuals under age 65 with incomes (based on modified adjusted gross income) up to 133 percent of FPL without any asset test.\textsuperscript{36} Specifically excluded from this new Medicaid eligibility category are individuals who are entitled to or are enrolled in Medicare Part A or

\textsuperscript{30} Kaiser Commn., \textit{supra} n. 3, at 22.

\textsuperscript{31} \textit{Id.} at 23, 24.

\textsuperscript{32} \textit{Id.} at 25.

\textsuperscript{33} \textit{Id.}

\textsuperscript{34} Patient Protection and Affordable Care Act [herinafter PPACA], Pub. L. No. 111-148, 124 Stat. 119 (2010), as amended by the Health Care and Education Reconciliation Act of 2010 [hereinafter HCERA], Pub. L. No. 111-152, 124 Stat. 1029 (2010), collectively referred to as the Affordable Care Act (ACA)).\textsuperscript{34} signed by President Barack Obama in March 2010, also has major implications for states’ Medicaid programs.\textsuperscript{35}


\textsuperscript{36} \textit{See} PPACA §§ 2001(a), 2002.
Part B, individuals who are over 65, and individuals who are pregnant.37 Under the ACA, these newly eligible individuals will not be entitled to standard comprehensive Medicaid benefits; instead, the ACA provisions require that states provide at least a benchmark or benchmark equivalent benefit package to the majority of this newly eligible population.38

B. Long-Term Care Services and Support

LTCSS are critical for the elderly and individuals with disabilities. The ACA does not include significant changes to Medicaid’s eligibility rules or methodologies for coverage of LTCSS.39 The ACA does, however, deal with the disparity between institutional care and home and community-based services in Medicaid’s delivery of LTCSS coverage, present since Medicaid’s creation, by authorizing new programs and enhancing existing ones designed to help Medicaid recipients access community services.40 The features of the ACA’s Medicaid LTCSS provisions include:

1. the authorization of the State Balancing Incentives Payment Program;41
2. a new “Section 1915 waiver” that authorizes states to provide coverage for a comprehensive personal attendant benefit to Medicaid beneficiaries;42
3. extension of the authorization for Money Follows the Person through Fiscal Year (FY) 2016 (additionally, the original eligibility requirement that beneficiaries be institutionalized for at least six months has been reduced to three months);43 and
4. expansion of spousal impoverishment protections.44

The ACA requires that spouses of all home and community-based services waiver enrollees receive the spousal impoverishment protections presently only provided to spouses of institutionalized Medicaid beneficiaries.45

C. ACA Financing

The ACA provides increased match rates to states to fund the Medicaid expansion to newly eligible Medicaid individuals. Over the next 10 years, it is estimated the federal government will finance approximately 96 percent of the increase in Medicaid costs attributable to the ACA.46 The match rates will differ depending on whether a state is deemed to be an expansion state or a non-expansion state.47 For years 2014 through 2016, non-expansion states will receive full federal funding, and then the FMAP will drop incrementally from 95 percent in 2017 to 93 percent in 2019.48 Expansion states (states that

37 See id. at § 2001(a)(1)(C).
38 See id. at § 2001(a)(2).
40 Id. at 94.
41 See PPACA § 10202.
43 See PPACA §§ 2403(a)(1), 2403(b).
45 See PPACA § 2404.
46 Landers & Leeman, supra n. 35, at 151–152.
47 See PPACA § 10201(c).
48 Landers & Leeman, supra n. 35, at 151-152; PPACA §10201(c).
added the newly eligible category prior to the mandated date) will receive lower match rates since these states will have fewer newly eligible individuals to cover.\textsuperscript{49} Beginning in 2020, all states will receive a 90 percent FMAP.\textsuperscript{50}

As a condition of receiving federal Medicaid funding, the ACA requires (with some limited exceptions) states to maintain eligibility, enrollment, and renewal policies that were in place as of March 23, 2010.\textsuperscript{51} This Maintenance of Effort (MOE) requirement, which preserves coverage until the broader reforms are in place, remains in effect until January 1, 2014, for adults and until September 30, 2019, for children.\textsuperscript{52}

\section*{D. States' Role and Cost in ACA Implementation}

States will take part in implementing some of the major provisions of federal health care reform, such as the expansion of Medicaid coverage. Because of this, states have concerns about the costs that will accompany their actions, especially in light of the fact that state revenues are just beginning to recover from very tough fiscal times.\textsuperscript{53} Reported fiscal impacts of the ACA on individual state budgets vary widely partly due to differing methodology as to anticipated costs and savings. However, there is some consensus that new enrollment will be the largest new cost and states with the lowest Medicaid eligibility enrollment will have the largest increases in enrollment.\textsuperscript{54} The most significant source of savings to states will be related to reductions in payments for uncompensated care. However, the actual impact of the ACA on individual states will vary depending on how states choose to implement the new law.\textsuperscript{55} In contrast to some individual state estimate reports, national estimates show that aggregate savings due to reductions in uncompensated care outweigh new state costs under the ACA, although the level and ability of states to realize these savings may vary.\textsuperscript{56}

Given the fiscal obstacles in funding their Medicaid programs, some states have taken the position that Medicaid expansion costs will be too great and place substantial strains on state budgets for states that had not previously chosen to cover the newly eligibles.\textsuperscript{57} Though some states emphasize the costs of implementation, other states expect to save money as a result of the increased federal financing and the fact that the newly

\textsuperscript{49} Id.
\textsuperscript{50} Id.
\textsuperscript{51} See PPACA § 2001(b).
\textsuperscript{52} Id.
\textsuperscript{54} Id.
\textsuperscript{55} Id. at iv.
\textsuperscript{57} Landers & Leeman, supra n. 35, at 155.
eligible individuals are likely to be healthier than traditional Medicaid enrollees and that they will not be receiving full Medicaid benefits.\textsuperscript{58} Also, economists predict the economy and state budgets will improve and the unemployment rate will drop so that the number of income-eligible people to cover may decline by 2014.\textsuperscript{59}

\textbf{IV. OVERALL STATE FISCAL AND BUDGETARY OUTLOOK}

States have been experiencing the effects of the deepest economic downturn since the Great Depression, and as they adopted their budgets for fiscal year 2012, most were still experiencing the continued effects of the economic recession.\textsuperscript{60} Revenue levels were still below pre-recession levels despite some rebounding. Unemployment rates remained high as did demand for Medicaid.\textsuperscript{61} At the start of FY 2012, 42 states faced budget shortfalls and, being legally required to balance their budgets, faced using reserves or rainy day funds, increasing taxes, or cutting spending to reach their goal.\textsuperscript{62} For most states in these economic and political times, spending cuts have prevailed.\textsuperscript{63}

On average, states spend about 20 percent of their general funds on Medicaid, making it the second largest item in most states’ general fund budgets, following spending for education.\textsuperscript{64} State budget pressures to cut Medicaid spending intensify during economic downturns, when state revenues decline just as enrollment in Medicaid and other assistance programs grows.\textsuperscript{65} States will cut spending or sometimes institute hurdles to dampen Medicaid participation in an attempt to control costs.\textsuperscript{66} In FY 2011, total annual state Medicaid spending increased on average by 7.3 percent.\textsuperscript{67}

\textbf{V. STATE REFORM ACTIONS AVAILABLE TO CONTAIN MEDICAID COSTS}

In an effort to contain Medicaid spending, states have used a variety of tactics, which include provider rate freezes or reductions, limitations on benefits and use of copays, and increased use of waivers and managed care.\textsuperscript{68} Additionally, states have used the legislative process to curtail or limit the use of Medicaid planning techniques.\textsuperscript{69}

\textsuperscript{58} Leighton Ku, \textit{Ready, Set, Plan, Implement: Executing the Expansion of Medicaid}, 29 Health Affairs 1173, 1173, 1175 (June 2010).
\textsuperscript{59} Id.
\textsuperscript{61} Id.
\textsuperscript{62} Id. at 23.
\textsuperscript{63} Id.
\textsuperscript{65} Kaiser Commn., \textit{supra} n. 3, at 28.
\textsuperscript{66} Id. at 13.
\textsuperscript{67} Kaiser Commn., \textit{supra} n. 60, at 26.
\textsuperscript{68} Id. at 29.
A. Provider Rate Changes

Provider rate changes have an immediate impact on state budgets and many states have either reduced or put a freeze on Medicaid provider payments.\textsuperscript{70} Provider rates affect provider participation and access to services for Medicaid beneficiaries, so cutting Medicaid rates can jeopardize provider participation in the program as well as access.\textsuperscript{71} If access is affected due to less provider participation then vulnerable populations do not receive needed care services, which includes long-term care.\textsuperscript{72}

B. Eligibility/Copays/Limitations

Since Medicaid eligibility standards determine who qualifies for the program, enrollment procedures impact the ease with which individuals can actually access the program and its services.\textsuperscript{73} Another cost containment measure available to states is raising or imposing new copayment requirements.\textsuperscript{74} To reduce Medicaid spending, states also turn to the elimination of a covered benefit or the application of utilization controls for existing benefits.\textsuperscript{75}

C. Home and Community-Based Services Waivers

States are increasing the use of home and community-based services and LTCSS options as a method to reduce Medicaid costs with the most common action being the adoption of new home and community-based services waivers or expansion of existing waivers (including home and community-based services delivered through “Section 1115 waivers” for research and demonstration projects or through the “Section 1915(i) Home and Community-Based Services State Plan option”).\textsuperscript{76} Despite the fact that public demand for such services is high, overall home and community-based services spending represents only 43 percent of long-term care spending.\textsuperscript{77} In addition, such services waivers are optional benefits, thereby allowing for waiting lists. As of 2009, the number of individuals nationally on waiting lists for home and community-based services waiver programs totaled over 365,000.\textsuperscript{78}

D. Managed Care

In the last 30 years, there has been an increased use of various models of managed care to deliver and finance care for Medicaid enrollees with the purported goals of in-

\textsuperscript{71} Kaiser Commn., \textit{supra} n. 60, at 31.
\textsuperscript{72} Vestal, \textit{supra} n. 70.
\textsuperscript{73} Kaiser Commn., \textit{supra} n. 60, at 38.
\textsuperscript{74} Id. at 44.
\textsuperscript{76} Kaiser Commn., \textit{supra} n. 60, at 49.
\textsuperscript{78} Id.
creasing access to care, improving quality, and reducing costs.\textsuperscript{79} States establish a network of providers or contract with health plans and/or providers who agree to accept Medicaid patients and meet certain access to care requirements.\textsuperscript{80} The share of Medicaid beneficiaries enrolled in some form of managed care reached 71.7 percent as of June 30, 2009, according to CMS.\textsuperscript{81} Many states are expanding managed care to cover more medically complex and vulnerable populations and to serve the millions of adults who will become newly eligible for Medicaid in 2014 as a result of the ACA.\textsuperscript{82}

In FY 2011, 17 states expanded managed care service areas, added eligibility groups to managed care, required enrollment into managed care, or implemented new managed long-term care programs.\textsuperscript{83} For FY 2012, the changes continued and related to the inclusion of persons with disabilities and dual eligibles and new initiatives for managed long-term care directly affecting the elderly and individuals with disabilities.\textsuperscript{84}

Following the Balanced Budget Act of 1997,\textsuperscript{85} states can require Medicaid recipients, except for exempt high-need populations, to enroll in managed care and can enroll individuals in managed care on a voluntary basis, as long as certain federal requirements relating to choice of plan and consumer protection are met.\textsuperscript{86} States determine the structure of their managed care arrangements, including the extent to which they utilize capitated or noncapitated payment arrangements.\textsuperscript{87}

Some states require legislative approval of amendments to a state plan or waivers before a state Medicaid agency can move forward with a change to managed care; others require legislative notice and review of changes.\textsuperscript{88} In some states there are specific statutory requirements related to cost sharing amounts and benefits, while others have a general requirement that mandates state legislative approval prior to amendments or program changes having certain financial impact on state expenditures.\textsuperscript{89}

E. Limitations on Medicaid Planning

Over the years since the enactment of Medicaid, Congress has made changes that affect the planning ability of individuals to qualify for Medicaid. Part II of the Omnibus Budget Reconciliation Act of 1993\textsuperscript{90} (OBRA '93) made changes to the Medicaid eligibility rules (all amendments were to 42 U.S.C. § 1396 \textit{et seq.}). OBRA '93 increased the “look back” period, for purposes of calculating improper transfer penalties, from 30

\textsuperscript{79} Kaiser Commn., \textit{supra} n. 4.
\textsuperscript{80} \textit{Id.}
\textsuperscript{81} \textit{Id.}
\textsuperscript{82} \textit{Id.}
\textsuperscript{83} Kaiser Commn., \textit{supra} n. 60, at 60.
\textsuperscript{84} \textit{Id.}
\textsuperscript{87} \textit{Id.}
\textsuperscript{89} \textit{Id.}
months to 36 months for outright gifts, and to 60 months for transfers to trusts. OBRA '93 also affected the availability of trusts for eligibility purposes and recovery from estates of recipients.61 In 2005, additional significant changes to eligibility rules were put in place through the Deficit Reduction Act of 2005 (DRA '05).62 That law, among other things, lengthened the look back period to five years for all transfers and changed the beginning date for a penalty period caused by an uncompensated transfer.63 DRA '05 also revised the rules for the treatment of annuities, loans, and promissory notes as part of its effort to reform the asset transfer rules for those seeking long-term care under Medicaid.64

Efforts to limit the techniques used to qualify individuals for Medicaid are not only the province of the federal government. In the past, states have also promulgated legislation to restrict Medicaid planning options that some critics view as legal loopholes resulting in increased enrollment and cost to states’ Medicaid programs.65 Most recently, at least one of the states in this article (Florida) attempted to limit some of the options available by the legal profession in order to assist a person in need of long-term care benefits to qualify for Medicaid.

VI. SELECT STATE MEDICAID REFORM EFFORTS

State Medicaid program reform has been used by state legislatures as a means of dealing with some of the budgetary problems they face due to the recent economic downturn. This section will present recent legislative actions taken by three specific states to contain Medicaid costs: Florida, Illinois, and New Jersey. As will be shown, states have taken different approaches with differing impacts; however, all actions have the potential to negatively affect the respective states’ populations of the elderly and people with disabilities with respect to the availability and affordability of LTCSS.

A. Florida

The 2011 Florida legislative session had many issues on its plate. The main goal for the Florida legislature was to close a $4.5 billion budget shortfall.66 Medicaid was one of the programs that the legislature targeted in 2011.67 Since 1996, through rate reductions, utilization limits, fraud and abuse efforts, and other cost control initiatives, the Florida legislature cut $5.2 billion from the State’s Medicaid program.68

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61 See id. at § 13611 and § 13612.
63 Id. at § 6011.
64 Id at § 6012 and § 6016.
67 Id.
68 Fla. H., CS/HB 7107 – Medicaid Managed Care, Final Bill Analysis 3, 4, http://www.myfloridahouse.gov/Sections/Bills/billsdetail.aspx?BillId= 46712&SessionId=66; under Staff Analysis, select Final Bill.
During the economic downturn, Florida further reduced expenditures through cuts in provider payments, pharmacy cost controls, utilization program changes, and benefit reductions.\textsuperscript{99} The legislature went further in 2011 to control costs with the passage of legislation that, if ultimately approved by CMS, will significantly refigure Florida’s Medicaid program into an almost all-inclusive managed care program. Besides the passage of Medicaid managed care reform, the 2011 legislature also attempted to pass legislation that would have limited the Medicaid planning techniques presently used by individuals, including the elderly and people with disabilities populations, to access Medicaid benefits.

1. A Brief History of Florida’s Medicaid Program

Florida implemented its Medicaid program\textsuperscript{100} on January 1, 1970, and by FY 2007, it had in excess of 2.8 million enrollees.\textsuperscript{101} Enrollment has increased by 42 percent within the last several years, attributed mostly to the state’s economic condition.\textsuperscript{102} Florida’s total Medicaid spending for FY 2009 was $15.088 billion, of which almost 25 percent was


spent on the elderly, and current state and federal expenditures account for 28 percent of Florida’s state budget.

With continued Medicaid spending growth, in 2005, the Florida legislature authorized Medicaid Reform, a pilot managed-care program initiative. Florida’s Agency for Health Care Administration (AHCA) formally submitted an application for a Section 1115 Research and Demonstration Waiver to CMS. The application was approved in October 2005, and, by early December of that year, the Florida legislature had passed legislation authorizing the design and implementation of the reforms described in the waiver application. Beginning in mid-2006, Medicaid beneficiaries were transitioned into managed care organizations in two of Florida’s most geographically and demographically diverse counties: Duval and Broward. Three rural counties, Baker, Clay, and Nassau, were added in the second year of implementation. By 2011, over 290,000 people, about 10 percent of Florida’s statewide Medicaid enrollment, were in the managed-care pilot program. The pilot program, though, did not include persons in nursing homes or other fragile populations needing LTCSS. Since the waiver was scheduled to expire on June 20, 2011, the State of Florida, in June 2010, submitted an application for renewal of that waiver which CMS approved, thereby allowing the pilot program to continue in those five counties through June 30, 2014.

2. Medicaid Managed Care Reform Legislation of 2011

Building upon the pilot program, and in furtherance of controlling Medicaid spending growth and costs, the Florida legislature, in the 2011 legislative session, acted to “dramatically revamp the way the state delivers health care to those on Medicaid.” In hopes of

103 Kaiser Fam. Found., supra n. 101.
104 Fla. Ctr., supra n. 102.
106 Id.
107 Id.
109 Id.
112 Allen, supra n. 96.
saving $1 billion for the state budget, Florida passed legislation replacing its fee-for-service model with a capitated managed care for the almost 3 million Medicaid recipients.\footnote{113}

\textit{a. Medicaid Managed Care System Reform}

The 2011 legislation, Enrolled CS/HB 7107 and 7109, seeks to expand the prior Medicaid Reform pilot program statewide and add new populations.\footnote{114} The idea was to create a plan that “changes the state’s relationship with Medicaid and Medicaid health care providers.”\footnote{115} The proponents of the proposals have asserted several guiding principles to ensure a successful program, which include:

1. improved care and fiscal responsibility;
2. long-term care, home and community-based service options presented contemporaneously with nursing home alternative;
3. transformation of AHCA from a check writing and fraud chasing agency into a contract compliance and monitoring operation;
4. legislative determination of the precise amount of money to be spent on Medicaid each fiscal year; and
5. delivery of Medicaid health benefits that are comparable to health insurance benefits received by Floridians paying the taxes that fund Medicaid.\footnote{116}

Two separate components encompass the new Medicaid Managed Care program: the Florida Long-Term Care Managed Care program,\footnote{117} which is set to be implemented first, and the Florida Managed Medical Assistance program,\footnote{118} the expansion of the five-county Medicaid pilot program currently operating. AHCA is to use a capitated managed care approach for both medical and long-term care components for most Medicaid beneficiaries\footnote{119} and will administer the long-term care program in partnership with the Department of Elder Affairs.\footnote{120} If approved, Florida will be divided into 11 regions with a competitive procurement process to select long-term care managed care organizations for each region.\footnote{121}

Individuals, age 65 years or older, or those age 18 years or older and eligible for Medicaid by reason of a disability, must enroll in the new Long-Term Care Managed Care program if they presently participate in the elder and disabled waiver programs currently in operation, or if they receive nursing facility or hospice services. Individuals currently

\footnotesize{\begin{itemize}
\item \footnote{113} Id.
\item \footnote{115} Allen, \textit{supra} n. 96.
\item \footnote{117} Fla. Stat. § 409.961 through 409.977.
\item \footnote{118} Fla. Stat. § 409.978 through 409.985.
\item \footnote{120} Id.
\item \footnote{121} Id. at 3.
\end{itemize}}
enrolled in disease specific or developmental disability long-term care waivers are not required to enroll.122

As many as 84,000 current Florida long-term care Medicaid beneficiaries, as well as another 27,000 eligible individuals who are on various waiting lists for services, will be affected by the legislation if approved.123 Though the foregoing total represents a small portion of the Medicaid beneficiaries in Florida, they tend to be particularly vulnerable and costly. Moreover, significant growth (127 percent increase) in Florida’s population eligible for long-term care services (those age 65 and older) is expected between 2010 and 2030.124

Currently, for medical (non-LTCSS) care, Florida Medicaid recipients are enrolled either in Medipass125 or a managed care plan, such as an HMO.126 Under the legislation as passed, implementation of statewide expansion of Long-Term Care managed care was to begin July 2012, with recipients being required to be enrolled by December 2013. Managed Medical Assistance implementation was to begin after long-term care implementation.127 Updated timeline information has enrollment of individuals in the Long-Term Care managed care component starting January 2013, and enrollment in the Medical Assistance component beginning in June 2013.128

In addition to the above changes, the 2011 legislation included a provision that would attach a $10 monthly premium for most Medicaid recipients129 and would authorize charging beneficiaries a $100 copayment for nonemergency use of the emergency room.130

Before Florida can implement its new approach to providing services, however, CMS must grant a waiver of existing federal rules. As stated above, CMS already approved the continuation of the pilot waiver program. On August 1, 2011, AHCA submitted to CMS Section 1115 Waiver requests to expand the current pilot program statewide and implement the above referenced copays and premiums.131 In addition, for authorization of the Long-Term Care Managed Care program, Florida submitted Section 1915(b) and (c)

123 Summer & Alker, supra n. 119, at 1.
124 Id. at 3.
125 MediPass is a form of primary care case management; see Fla. Ctr., supra n. 114, at 2.
127 Summer & Alker, supra n. 119, at 3.
131 See Fla. Agency for Health Care Administration, Florida Medicaid, Managed Medical Assistance Federal Correspondence and Authorities, http://ahca.myflorida.com/Medicaid/statewide_mc/index. shtml#MMA; select Federal Correspondence and Authorities tab, then links under Request(s) for Amendment of the 1115 Medicaid Reform Waiver (accessed Mar. 30, 2012).
waivers, relying on a waiver combination approach historically used to provide managed long-term services and supports. The Section 1915 waivers would permit Florida to mandatorily enroll beneficiaries in Medicaid Long-Term Care managed care plans, selectively contract with certain service providers, and provide services in a community-based setting to select groups of individuals who otherwise would require institutional services reimbursable by Medicaid.

b. Plan Flexibility and Treatment of Optional Services

Besides changing the structure of Florida’s Medicaid Program, the 2011 Medicaid Reform legislation gives participating plans much flexibility regarding benefit levels and amounts. The present Florida Medicaid program incorporates as many as 30 optional services, which include such things as dental care for adults, prescription drugs, and hospice care, services generally consumed by Florida’s most vulnerable populations. Under the proposed legislative reform, plans have a requirement to provide benefits that are “sufficient” to meet the needs of “most” enrollees, with the state being the entity that decides if the benefits are in fact sufficient. Different benefit packages allowed could produce increased confusion in plan choice and care access for applicants and recipients. In fact, the above type of flexibility is present in a varied form in Florida’s Medicaid Reform pilot program and the anticipated negative result has already occurred as described below. Additionally, due to a lack of patient data from Florida’s existing Medicaid reform, no assessment has occurred to determine the impact of this amount of plan flexibility on access and quality of care. In a DuPont Fund Report on the five-county pilot programs, researchers found that though most HMOs did not limit benefits, those that did were HMOs that had a large market share.

Not offering certain benefits while maintaining “sufficient” benefits for “most” recipients could have negative effects. Optional Medicaid services are already limited in scope and elimination of a service, such as dental services often necessary to maintain health, could have adverse effects on recipients. Federal correspondence and authorities are available at the following link:

[See Fla. Agency for Health Care Administration, Florida Medicaid, Long-Term Care Managed Care Federal Correspondence and Authorities, http://ahca.myflorida.com/Medicaid/statewide_mc/index.shtml#LTCMC; select Federal Correspondence and Authorities tab, then links under Long-Term Care Managed Care: Request for new 1915 (b)/(c) waiver (accessed Mar. 30, 2012).]

[At the time of publication of this article, CMS had rejected the use of the $100 co-pay and $10 premium, but had not made a final decision on any of the other referenced waiver requests. See Victoria Wachino, Director, Centers for Medicare & Medicaid Services, February 9, 2012 letter to Justin M. Senior, Deputy Secretary for Medicaid, Florida Agency for Health Care Administration, http://www.fdhc.state.fl.us/medicaid/statewide_mc/pdf/mma/Final_signed_FL_amend_02-09-12.pdf.


[Fla. Ctr., supra n. 114, at 3.

[Id.

[Alker & Hoadley, supra n. 110, at 4.]
proper nutrition, could prevent an elderly person from obtaining those services altogether if the person has limited resources. Results from the pilot program illustrated that when HMOs did limit benefits, they limited durable medical equipment, home health services, physical and respiratory therapies — the types of services used by Florida’s elderly and persons with disabilities. The end result could be that the Medicaid program expends more intensive medical services at an increased cost to the system overall.

3. Florida’s Budgetary Basis for Medicaid Reform

In its analysis for Medicaid reform, the legislative materials supporting the changes in the Medicaid program noted that Florida’s current system was inefficient, and unsustainable, and that fiscal predictability was necessary. The legislative supporting materials noted that the program had over 2.9 million enrolled recipients and $20.3 billion spending in fiscal year 2010-2011, making it the second largest single program in the state, representing 28 percent of the total FY 2010-11 budget. By FY 2013-2014, the program cost was estimated to be $23.6 billion.

Part of the reason for reform in 2011 was also due to the potential impact of the ACA on the cost of the state’s Medicaid program, despite the fact that Florida has taken the position that the ACA is unconstitutional. The ACA adds a new mandatory population as stated previously in this article. Though raising the federal match rates for the new groups finances the expansion, the additional federal match is time-limited, thereby increasing the cost to the state thereafter. The legislative analysis noted that many of Florida’s uninsured individuals eligible for Medicaid coverage are not enrolled; however, the ACA’s mandate to purchase insurance could result in many eligibles enrolling (who would not have without the mandate), thereby increasing costs.

The legislative analysis supporting the 2011 Medicaid reform identified the costs of federal reform to Florida’s Medicaid program to be significant. Florida is expected to have over 379,000 new enrollees from the expanded federal reform population in 2014, at a cost of $1.5 billion, of which $142 million will be paid by the state, and by 2019, 1.9 million additional enrollees will cost over $7.7 billion, of which $1 billion will be paid by the state. The legislative staff analysis did not quantify the amount of savings, stating only that “[t]he exact savings are indeterminate but are expected to be significant.” Based on the estimated increase in program costs, the 2011 legislature found further reason for the Medicaid changes.

141 Alker & Hoadley, supra n. 110, at 4.
143 Fla. H., supra n. 98, at 1.
144 Id. at 3–4.
146 Fla. H., supra n. 143, at 5.
147 Id.
148 Id. at 5–6.
149 Id. at 38.
4. Questionable Cost Savings

The 2011 Medicaid Managed Care system reform anticipates savings based on studies asserting expenditure reductions of 10 percent per member per month and as much as a 20 percent savings overall. Supportors of managed care state that HMOs are better able to prevent, reduce, or eliminate systemic fraud and abuse. Advocates also state that the managed care model can better address healthcare disparities due to its emphasis on primary care, member education, disease and case management, and provider collaboration.

Managed care in Florida, by way of the pilot program, however, has a record of inadequate performance. In 2010, the University of Florida and Health Foundation of South Florida concluded a study of the Medicaid Reform pilot program. Per study findings, over 50 percent of surveyed providers rated access to specialists and prescription drugs as either “not working very well” or “not working at all.” Two-thirds of physicians reported that the supply of specialty care physicians was inadequate to meet Medicaid patient needs. The Medicaid pilot managed care program suffered from plans entering and exiting the system, had the largest Medicaid fraud in Florida’s history, and after five years there was still no patient encounter data needed to assess the changes in access. An April 2011, Jesse Ball DuPont Fund Report concluded that there was insufficient data available to draw conclusions as to whether the pilot program saved any money, and if it had, whether that was due to reduced access or increased efficiency of services.

In addition to the above, opposition to the creation of the mandatory program for the delivery of LTCSS in Medicaid through private proprietary health plans is increasing. Despite the lack of empirical evidence and increasing opposition, the 2012 Florida legislature continued to advance statewide application of managed care by way of House and Senate Bills seeking approval by CMS of AHCA’s waiver requests.

The intended goal of cost savings may not be within reach of Florida’s proposed

151 Id. at 3.
152 Id. at 4.
154 Id. at 3.
155 Id.
156 Fla. Ctr., supra n. 114, at 2.
157 Alker & Hoadley, supra n. 110, at 4.
LTC Managed Care Program even if allowed by CMS. Nationally, home and community-based services comprise 36 percent of Medicaid spending for long-term care, whereas in Florida, the percentage is only 21 percent (ranking it 37th in the nation). The 2011 Managed Care legislation has as a goal the shifting of services from institutional to community-based settings with financial incentives available to managed care organizations that facilitate this transition. Those goals may be difficult to achieve, however, due to the continuation of waitlists for community-based services. There are almost 27,000 people on waitlists for the waiver programs that are slated to be part of the Long-Term Care Managed Care program, and AHCA has indicated that the new program does not provide additional funding or create additional slots for home and community-based services. Therefore, those currently on waitlists will not be eligible to enroll in the Long-Term Care Managed Care program until program funds become available.63

Additionally, Florida’s present experience with long-term care managed care does not demonstrate cost savings. Of Florida’s five elderly and disabled waiver programs, the only one using a managed care approach, the Nursing Home Diversion Waiver Program, has costs that are substantially higher than the other programs.64 However, the higher frailty level of the participants may be one reason for the cost differential.65

5. 2011 Legislative Attempts to Limit Medicaid Planning Techniques

As part of its efforts to lower Medicaid costs, the 2011 Florida legislative body attempted not only to change Florida’s Medicaid system, but also to alter the planning options available to Florida citizens seeking to qualify for Medicaid. Both the Florida Senate and House of Representatives submitted bills aimed at altering the use of personal services contracts and spousal refusal.66

a. Personal Services Contracts

A personal services contract is a written contract between a person needing care and a caregiver, usually a family member, to provide those personal care services, usually for the rest of that person’s life. In consideration for those services, the person generally transfers a lump-sum payment to the caregiver in advance of the services being performed.67 These contracts can be used as a planning method for elderly persons seeking Medicaid eligibility. The contract is based upon fair market consideration, so the lump-sum payment is not an uncompensated transfer for Medicaid purposes and incurs no penalty pe-

160 Summer & Alker, supra n. 119, at 7.
161 Id.
162 Id.
163 Id.
165 Summer & Alker, supra n. 119, at 9.
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The personal services contract allows for a better quality of care for the elderly person through the remaining days of his or her life and reduced costs to the state due to care given to the elderly person that can defer entrance into a nursing home.\(^{169}\)

Despite its intended purpose, critics view Medicaid planning as a way for the wealthy to qualify for Medicaid.\(^{170}\) Identical bills were introduced into the Florida House of Representatives and Senate in the 2011 legislative session seeking to alter the use of personal services contracts as a Medicaid planning tool.\(^{171}\) The target of the bills was an amendment to Florida Statute § 409.902 by the addition of language that imposed restrictions on payments to family caregivers for care provided to an elderly relative. If family caregivers received payment in violation of the proposal, then a sanction in the form of ineligibility for necessary medical coverage would be imposed upon the aging parent.\(^{172}\) The bills died in Committee and were not passed in any form and no similar bill was introduced into the Florida 2012 legislative session.

Restrictions on personal services contacts could result in higher costs and lower level of care for recipients.\(^{173}\) Initially, the validity of personal services contracts has been judicially allowed in Florida.\(^{174}\) Personal services contracts help lessen the financial and emotional toll placed on caregivers. In a survey by Caring.com, more than a third of caregivers have been forced to quit jobs, take early retirement, reduce hours, or take leaves of absence in order to provide care for family members.\(^{175}\) To decrease Medicaid long-term care expenditures, the Florida legislature could increase the funding for home and community-based waiver programs, which help keep seniors requiring institutionalized level of care in their homes or community.

b. Spousal Refusal

The 2011 legislative bills that sought to restrict personal services contracts\(^{176}\) also had provisions that would have placed restrictions on the use of spousal refusal as a Medicaid planning technique. In spousal refusal, a spouse refuses to pay or to make his or her resources available for the long-term care expenses of the other spouse.\(^{177}\) The 2011 proposed bills sought to amend Florida law by requiring the Department of Children

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169 Solkoff & Solkoff, supra n. 167, at 3.
170 Id.
171 Fla. Sen. 1356 and Fla. H. CS/HB 1289, supra n. 166.
172 Fla. H. CS/HB 1289, at 2, lines 50-55 and at 3, lines 56-75.
173 The arguments in this article against the limitations on the use of personal services contracts in the State of Florida as referenced in the 2011 legislative bills were taken from a Joint Public Position Statement by the Elder Law Section of the Florida Bar and the Academy of Florida Elder Law Attorneys. In re: S 1356/HB 1289 (Family Member Personal Care Agreements), http://www.afela.org/images/stories/Personal%20Care%20Contract%20Analysis%203%2014%2011.pdf (Mar. 14, 2011).
176 See Solkoff, supra n. 167.
and Families (DCF) to deny eligibility for a Medicaid applicant (the “institutionalized spouse”) if his/her spouse (the “community spouse”) refused to make resources available. By way of another amendment to Florida Statute § 409.902, the bills would have created restrictions and imposed additional burdens on an institutionalized married person in the event his or her spouse exercised his or her right of spousal refusal.

The Medicare Catastrophic Coverage Act of 1988 provides that Medicaid eligibility cannot be denied when the community spouse refuses to make his or her resources available for the cost of care of the institutionalized spouse. Additionally, Florida has abrogated the common law concept of a spouse being obligated to pay for his or her spouse’s necessaries provided by a third party.

Many older citizens enter into marriages following the death of a spouse. For some of these marriages, the individuals keep assets separate or enter into pre- or post-nuptial agreements. The proposed legislation would have the result of disregarding these estate plans and would subject these individuals who remarry to the fears of potential financial ruin if their spouse became disabled or began to suffer from a long-term illness.

Like the fate of the personal services contract bills, the 2011 legislature did not pass any laws regarding spousal refusal. Instead of limiting spousal refusal, the State could seek legislative action to improve availability and affordability of long-term care insurance. In 2005, Florida passed legislation that established a partnership program between Medicaid and long-term care insurers. The program provides incentives for individuals to purchase long-term care insurance by allowing dollar-for-dollar asset protection of the amount of insurance benefits provided if the individual applies for Medicaid, thereby increasing pre-Medicaid levels of payments for care without requiring total impoverishment.

B. Illinois

1. Illinois Medicaid History

Medicaid was implemented in Illinois in 1967 through the passage of the Public Aid

179 Fla. H. CS/HB 1289.
Subsequent to its initial implementation, the Medicaid program in Illinois has grown considerably.\textsuperscript{186} Over the past decades, the numbers of Medicaid recipients have rapidly grown. In 2006, there were 2,047,038 individuals receiving Medicaid benefits in Illinois, and in 2011 the number increased to 2,743,277; out of that number, 260,228 were disabled adults, 168,943 were seniors, and 636,531 were adults who did not fall into either of those categories.\textsuperscript{187} In Cook County alone in 2011, there were 134,690 disabled adults and 93,681 seniors receiving Medicaid benefits.\textsuperscript{188} After January 1, 2014, another 500,000 adults are likely to qualify for Medicaid as a result of the Affordable Care Act.\textsuperscript{189} The State of Illinois will need to face the problem of handling a much larger caseload while struggling with antiquated computer systems, paper case files, and overcrowded offices. The staff has a very short time in which to modernize its systems.\textsuperscript{190}

2. Budgetary Concerns

Illinois is encountering the same problems as many other states in terms of an increasing number of individuals receiving Medicaid benefits, while facing growing deficits. The State is currently facing $9 billion in unpaid bills, approximately $2 billion of which are Medicaid related.\textsuperscript{191} The number of persons enrolled in Medicaid has gone from 1.4 million people in 2000 to 2.7 million people at present.\textsuperscript{192} In addition, Illinois is facing the implementation of three different consent decrees from federal lawsuits involving the Medicaid program.

As it is, Illinois Medicaid reimbursement rates are low compared with Medicare and other states, and the state’s time period for reimbursement is very slow.\textsuperscript{193} Currently the state pays approximately 50 percent of its Medicaid budget, but after January 1, 2014, the “new” Medicaid will be federally funded.\textsuperscript{194} The state’s goal is to contain costs by using more efficient service delivery while keeping clients healthy in addition to having a redesigned health care delivery system that is more patient-centered, with a focus on improved health outcomes, enhanced patient access, and patient safety.\textsuperscript{195} The state is also reexam-

\textsuperscript{185} 305 Ill. Comp. Stat. 5/1-5/15-11.
\textsuperscript{188} Ill. Dept. of Healthcare and Fam. Servs., Number of Persons Enrolled in Cook County, http://www2.illinois.gov/hfs/agency/Program%20Enrollment/Pages/Cook.aspx (accessed May 19, 2012). The city of Chicago is in Cook County.
\textsuperscript{190} Id.
\textsuperscript{191} Kristin McQueary, Illinois Medicaid Cuts Will Hit a System Already in Crisis, N.Y. Times (Feb. 17, 2012).
\textsuperscript{192} Id.
\textsuperscript{193} Id.
\textsuperscript{194} See id.
\textsuperscript{195} Id.
ining payment methodologies for hospitals and nursing homes. Illinois Department of Healthcare and Family Services (HFS) will establish new risk-based funding, incentives, and quality measurements to the provider community. The State is also hoping to build up the home and community-based service infrastructure. The State will also take advantage of federal waivers for populations with complex health and behavioral needs.\textsuperscript{196}

3. Medicaid Reforms

The state of Illinois only recently initiated significant Medicaid reforms. While at the present time only one piece of legislation has been enacted with respect to Medicaid reform, HFS is in the process of formulating other strategies to reduce the Medicaid cost to the state. Governor Quinn is proposing to cut in excess of $2 billion from the state Medicaid budget.\textsuperscript{197} He has not yet disclosed the specifics regarding the proposed reductions.

The state of Illinois has been researching better ways to manage care under the Medicaid program for several years. In 2004, the Managed Care Task Force was created by the legislature to study the use of managed care organizations such as health maintenance organizations (HMOs). In 2009, the Illinois House and Senate both created Medicaid Reform Committees.\textsuperscript{198} In February of 2010, HFS released a Request for Proposal for qualified managed care organizations to enter into risk-based contracts to provide services through an integrated care delivery system for approximately 40,000 adults with disabilities and older adults residing in five counties, including suburban Cook County.\textsuperscript{199} The initial phase was to be for all medical programs and the second and third phases would include long-term care.\textsuperscript{200}

The goal of the integrated care program is to bring together local primary care physicians, specialists, hospitals, nursing homes, and other providers in which the care is organized around the patient. HFS will make certain that the safeguards are in place by contractually requiring both pay for performance measures as incentives and payment withholds when the Managed Care Organization (MCO) does not have a quality outcome.\textsuperscript{201}

While a major goal of moving into a managed care system is the reduction of Medicaid costs, it is unclear as to how effective this move will be for the State. Illinois has an average cost per Medicaid enrollee of $4,129 per year, placing the State in the tenth lowest average cost of any state.\textsuperscript{202} Illinois has also kept the Medicaid rates down through reimbursements to providers. For example, doctors in Illinois are paid about 90 percent

\textsuperscript{196} Id.
\textsuperscript{199} Id.
\textsuperscript{200} Id.
\textsuperscript{201} Id.
of the national average.\textsuperscript{203} As Illinois is already paying doctors and providers so little, it is difficult to imagine how an MCO could pay even less.\textsuperscript{204} Elderly and disabled patients are the most expensive ones for the State. The average cost for senior citizens is $11,560 and $16,613 for disabled adults.\textsuperscript{205}

The Illinois legislature passed a significant piece of Medicaid Reform legislation and it was signed into law on January 2011.\textsuperscript{206} The purpose of this Act is to lower Medicaid costs for the state of Illinois. This statute impacts state laws beyond the Public Aid Code.

The State budget law is amended to provide for long-term care rebalancing, which is defined as “removing barriers to community living for people of all ages with disabilities and long-term illnesses by offering individuals using long-term care services a reasonable array of options, in particular adequate choices of community and institutional options to achieve a balance between the proportion of total Medicaid long-term support expenditures used for institutional services and those used for community supports.”\textsuperscript{207}

In addition, the Governor may designate amounts set aside from institutional services appropriated from the General Revenue Fund or any other state fund that receives funding for long-term care services to be transferred to all state agencies responsible for the administration of community-based long-term care programs, provided that the Director of HFS first certifies that the amounts transferred are necessary for assisting persons in or at risk of being in institutional care to transition to community-based settings.\textsuperscript{208}

Perhaps the most significant change in the Act is the mandatory Medicaid managed care programs. The new law requires 50 percent of recipients eligible for comprehensive medical benefits to be enrolled in a care coordination program no later than January 1, 2015.\textsuperscript{209} Care coordination is defined as “delivery systems where recipients will receive their care from providers who participate for providing or arranging the majority of care, including primary care physician services, referrals from primary care physicians, diagnostic and treatment services, behavioral health services, inpatient and outpatient hospital services, dental services, and rehabilitation and long-term care services.”\textsuperscript{210} In order to comply with this provision, the 50 percent will be achieved by enrolling medical assistance enrollees from each medical assistance category, including parents, children, seniors, and disabled adults to the extent that the current Medicaid payment laws would not limit the federal matching funds for recipients in the care coordination programs.\textsuperscript{211} Additionally, the services must be more comprehensively defined and more risk assumed than in the department’s primary care case management program as of the effective date of this Act.\textsuperscript{212}

\textsuperscript{203} Id.
\textsuperscript{204} Id.
\textsuperscript{205} Id.
\textsuperscript{207} 15 Ill. Comp. Stat. 20/50-30(1) (Jan. 25, 2011).
\textsuperscript{208} 30 Ill. Comp. Stat. 105/13.2(a-4) (July 1, 2012).
\textsuperscript{209} 215 Ill. Comp. Stat. 170/56(a) (Jan. 25, 2011).
\textsuperscript{210} Id.
\textsuperscript{211} Id.
\textsuperscript{212} Id.
The legislation also contains new provisions for managing the recipients of the medical programs. The state agency was given the task to come up with a plan by July 1, 2011, that will include improved systems for verifying initial and continuing eligibility by means of:\(^{213}\)

1. meeting standards subject to federal and state privacy and confidentiality laws, for timely eligibility verification and enrollment and annual redeterminations of eligibility for means tested programs;
2. receiving and updating data electronically from the Social Security Administration, the U.S. Postal Service, the Illinois Secretary of State, the Illinois Department of Revenue, the Illinois Department of Employment Security, and other governmental entities as appropriate and to the extent allowed by law to verify current and continuing eligibility;
3. meeting federal requirements for timely installation by January 1, 2014 to provide integration with a Health Benefits Exchange pursuant to the Affordable Care Act and the Reconciliation Act in order to ensure the maximum federal financial participation;
4. meeting federal requirements for compliance with architectural standards; and
5. including plans to ensure the coordination with the State of Illinois Framework Project that will expedite and simply access to Illinois Human Services programs, will streamline administration and data sharing, will enhance planning capacity, program evaluation and fraud detection or prevention with access to cross-agency data, and will simplify service reporting for contracted providers.

The new legislation also imposes significant sanctions on individuals who illegally obtain medical assistance. Pursuant to the new law, the Department may seek to recover any and all state and federal monies for which it has improperly and erroneously paid benefits as a result of a fraudulent action and any civil penalties authorized in this section, and in accordance with Section 11-14.5 of the Public Aid Code, the Department may determine the monetary value of benefits improperly and erroneously received.\(^{214}\) The Department may recover the monies paid for such benefits and interest on that amount at the rate of 5 percent per annum for the period from which payment was made to the date upon which repayment is made to the State.\(^ {215}\) Prior to the recovery of any amount paid for benefits allegedly obtained by fraudulent means, the recipient of such benefits shall be afforded an opportunity for a hearing after reasonable notice. The notice shall be served personally or by certified or registered mail or as otherwise provided by law upon their parties or their agents appointed to receive service of process.\(^{216}\)

The notice shall include the following information:\(^ {217}\)

1. the time, place, and nature of the hearing;
2. a statement of the legal authority and jurisdiction for the hearing;
3. references to the particular sections of the statutes and rules involved;

\(^{213}\) 305 Ill. Comp. Stat. 5/5-11a(a)(1-5) (Jan. 25, 2011).


\(^{215}\) Id.

\(^{216}\) Id.

4. at a minimum, a short and plain statement of the matters asserted as well as the consequences of the failure to respond;
5. the amount of the monetary benefits allegedly fraudulently received;
6. a statement that in addition to other penalties provided by law, a civil penalty in an amount not to exceed $2,000 may be imposed for each fraudulent claim for benefits or payments;
7. statement indicating that the recipient may contest the determination by requesting an administrative hearing within 30 days of the mailing of the notice; and
8. the names and addresses of the administrative law judge all parties and all other persons given notice of the hearing.

If a final administrative decision is reached indicating that a repayment is appropriate, the agency will be authorized to place a lien on all property and assets of such person, firm, corporation, etc. until the judgment is satisfied.\footnote{218}

To further the State’s efforts to verify eligibility, the statute also contains new verification requirements regarding income eligibility and residency. At the present time, CMS is blocking these provisions pursuant to a letter from the CMS to the state of Illinois.\footnote{219}

The basis for the bar is that the new requirements violate federal law. The Maintenance of Eligibility (MOE) requirements of Section 2001(b) of the Affordable Care Act state that as a condition of receiving federal payments under Section 1903, states shall not have Medicaid eligibility standards, methodologies, or procedures under the state plan that are more restrictive than those in effect on March 23, 2010.\footnote{220} In the letter sent to the Illinois Department of Human Services by CMS Director Cindy Mann the new state law requiring more documentation of both income and residency than is required under current Illinois law would be a violation of the MOE provision of the Affordable Care Act.\footnote{221}

The disputed provisions regarding financial eligibility would require verification of one month’s income from all sources during redetermination and the verification will take the form of pay stubs, business income and expense for self-employed persons, letters from employers, and any other valid documentation of income, including data obtained electronically by the department or its designees. If the recipient does not provide this information by the deadline, the recipient will lose his or her coverage.\footnote{222}

The other disputed provision authorizes the department to gain access to information from the Social Security Administration, The Illinois Secretary of State, the Illinois Department of Human Services, the Illinois Department of Employment Security, and other appropriate entities to gain information appropriate for verifying any factor of eligibility for benefits under the program.\footnote{223} In conjunction with this new law, the Illinois Vehicle Code was amended by allowing the Secretary of State to disclose information to the Department of Healthcare and Family Services solely

\footnote{218}{305 Ill. Comp. Stat. 5/8A-2.5(c) (Jan. 1, 2012).}
\footnote{221}{Pallasch, supra n. 219.}
\footnote{222}{305 Ill. Comp. Stat. 5/11-5.1(a)(2) (Jan. 25, 2011).}
\footnote{223}{305 Ill. Comp. Stat. 5/11-5.1(b) (Jan. 25, 2011).}
for the purpose of verifying Illinois residency when the residency is a requirement for benefits under the Illinois Public Aid Code or other health benefit program administered by HFS.\footnote{625 Ill. Comp. Stat. 5/2-123(h) (Jan. 1, 2012).} The two controversial provisions would have called on Medicaid applicants to provide pay stubs for an entire month as opposed to the existing policy of one pay stub, and it would have required cumulative paper evidence of Illinois residence as opposed to the current policy of signing a sworn statement under penalty of perjury. In addition, the current policy allows for electronic monitoring of both income and residency.\footnote{Id.} At the present time, CMS has denied permission to Illinois to implement these changes by virtue of a June 24, 2011, letter. In that letter, CMS Director Cindy Mann states that the new procedures would constitute a violation of the Maintenance of Eligibility (MOE) requirements in Section 201(b) of the Affordable Care Act, as the new procedures would be more restrictive than those in effect in Illinois on March 23, 2010.\footnote{Id.} As of February 29, 2012, however, it appears that CMS may have reconsidered and allowed the state to implement the verification procedure regarding residency.\footnote{Feds Give Partial OK to Illinois Medicaid Reforms, http://oakbrook.suntimes.com/news/11009762-418/feds-give-partial-ok-to-illinois-medicaid-reforms.html (last updated May 7, 2012).}

On February 17, 2012, the State published a proposal for an Illinois Medicare-Medicaid Alignment Initiative for a notice and comment period. This draft proposal seeks to integrate care for dual eligibles under one managed care plan. Dual eligibles represent 25 percent and 46 percent of Medicare and Medicaid spending, respectively, at a national level. However, dual eligible beneficiaries only constitute 16 percent and 18 percent of Medicare and Medicaid enrollment, respectively.\footnote{Medicare Payment Advisory Commn., Report to the Congress: Aligning Incentives in Medicare 131, http://www.mepac.gov/documents/jun10_entirereport.pdf (June 2010).} Per Illinois’ new proposal at a state level, full dual eligibles make up 10.3 percent of Medicaid full benefit enrollment as of December 31, 2010, and 30 percent of Medicaid calendar year 2010 net claims-based costs.\footnote{Proposal: Illinois Medicare-Medicaid Alignment Initiative 2, http://www2.illinois.gov/hfs/PublicInvolvement/cc/Documents/cc_capitatedmodelproposal.pdf (accessed May 20, 2012).}

The enrollment in the demonstration project will initially be voluntary and the State is proposing to exclude the Adults With Developmental Disabilities home and community-based waivers from the project at this time.\footnote{Id.} The covered benefits will include all Medicare and Medicaid covered services including long-term care institutional and community-based services and supports. The overall goal of the State is to create a program that “overcomes barriers to integration and improves upon a coordinated care for dual eligible beneficiaries who often have complex care needs and whose care is typically uncoordinated between Medicare and Medicaid or within either program.”\footnote{Id. at 5.} The program also has a component in which enrollees will chose a medical home with a focus on Federally

\begin{itemize}
\item \footnote{Id.}
\item \footnote{Proposal: Illinois Medicare-Medicaid Alignment Initiative 2, http://www2.illinois.gov/hfs/PublicInvolvement/cc/Documents/cc_capitatedmodelproposal.pdf (accessed May 20, 2012).}
\item \footnote{Id.}
\item \footnote{Id. at 5.}
\end{itemize}
Qualified Health Centers, Community Mental Health Centers, Primary Care Physician (PCP)-centered medical groups and private practice PCP offices. The medical homes will “coordinate care across the spectrum of the healthcare system with a particular emphasis on managing transitions between level of care and coordination between physical and behavioral health.”

The program plans will also be required to provide care coordination services to make sure that the medical homes are linked to other providers and services. Finally, the plans will need to have the technology to assist with the care coordination process. Within 90 days of enrollment in a plan, the plan should complete a health risk and behavioral health screening in order to identify needs for care management and to develop care plans. For those individuals identified to need care management, a multidisciplinary care team will assist the individual. The care coordinators will lead the multidisciplinary teams and work with the enrollee to develop and maintain the care plan and coordinate critical information sharing between the care team and the enrollee.

On June 1, 2012, Illinois Gov. Pat Quinn signed into law five pieces of legislation designed to save the state of Illinois Medicaid system from the brink of collapse and make it sustainable for the future by reaching the goal of $2.7 billion in Medicaid savings. The most significant Medicaid reform legislation is the Save Medicaid Access and Resources Together Act, or the SMART Act. This Act not only drastically cuts Medicaid funding, including eliminating several optional Medicaid covered services, it also significantly changes the state’s Medicaid laws.

One of the most significant changes is the elimination of pooled trusts for individuals age 65 and older except under certain conditions. Under the new law, “any funding by or on behalf of the person to the trust shall be treated as a transfer of assets for less than fair market value unless the person is a ward of a county public guardian or the State guardian pursuant to Section 13-5 of the Probate Act of 1975 or Section 30 of the Guardianship and Advocacy Act and lives in the community, or the person is a ward of a county public guardian or the State guardian pursuant to Section 13-5 or the Probate Act of 1975 or Section 30 of the Guardianship and Advocacy Act and a court has found that any expenditures from the trust will maintain or enhance the person’s quality of life.”

232 Id. at 11.
233 Id.
234 Id. at 12.
235 Id.
236 Id.
239 Id.
240 Id.
241 305 Ill. Comp. Stat. 5/3-1.2 (July 1, 2012).
242 Id.
Another change concerns an increase in the minimum determination of need (DON) score necessary for a person to qualify for home and community-based services, as well as skilled nursing facilities (SNFs) and supportive living facilities (SLFs). The minimum score will be increased from 29 to 37 pending approval by CMS. If CMS approves this change, many elderly persons could be deprived of placements in SNFs, SLFs, and/or home services.

The SMART Act also changes the law with regards to spousal refusal. Under the new law, “If an institutionalized spouse or community spouse refuses to … provide [the Department of Healthcare and Family Services (HFS)] the total value of assets, including income and resources, to the extent either the institutionalized spouse or community spouse has ownership interest in them …, such refusal may result in the institutionalized spouse being denied eligibility and continuing to remain ineligible for [long-term care] based on failure to cooperate.” The new law goes on to state that “The Department may seek support for an institutionalized spouse, who has assigned his or her right of support from his or her spouse to the State, from the resources and income available to the community spouse.” The law also specifies that actions may be brought in state court to establish support orders or the Department may establish administrative support orders.

An additional change made by the SMART Act is that farmland property and equipment are no longer exempt from determining a person’s eligibility for Medicaid. Farmland property and equipment will be treated the same as any other income-producing property and equipment.

Under the new law, if a farm has a net return in excess of 6 percent and an equity value of more than $6,000, the farmland property and equipment would need to be sold before a person could qualify for Medicaid. As a practical matter, it is virtually impossible for an elderly farmer to borrow funds to pay for long-term care, because the income from the farm may not cover the mortgage payments. If the farmer were forced to sell the farm, in addition to removing the community spouse’s source of income, it also would likely result in capital gains taxes.

The SMART Act also impacts the issue of exempt homestead property. Pursuant to the new law, homes held in a trust, even an individual’s personal revocable trust, no longer will be considered homestead property for Medicaid purposes. In the emergency rules that were issued, an exception is made if the long-term care resident’s spouse, minor child, or disabled child resides in the home.

The new law does not set a time limit for the transfer of the real estate into a trust or the creation of a trust. It also does not take into account the fact that many trusts are

243 Id. at 5/5-5.
244 Id. at 5/504(b)(i-iv).
245 Ill. Admin. Code tit. 89, pt. 120.379(j).
246 Id. at pt. 120.379(k)(1).
247 Id. at pt. 120.379(k)(2).
248 305 Ill. Comp. Stat. 5/3-1.2 (July 1, 2012).
249 Id.
250 Id.
251 Id.
252 Ill. Admin. Code tit. 89, pt. 120.381(a)(1)(C).
created for reasons other than Medicaid planning. The law’s impact on persons residing in their homes who are seeking to receive services from the Community Care Program (CCP), a Medicaid waiver program in Illinois, is unclear. Arguably, under the CCP, if the beneficiary of the trust is unable to convey the home out of the trust due to incapacity, the home no longer will be exempt and the beneficiary may be forced into nursing care much sooner than necessary.

The SMART Act also imposes limits on prescriptions for individuals with pharmaceutical coverage under Medicaid. Medicaid recipients will not be allowed to receive more than four prescriptions including three brand name prescriptions in a 30-day period unless approval is received for all prescriptions in excess of the four-prescription limit. The following categories of drugs are excluded from this requirement: immunosuppressant drugs, oncolytic drugs, and antiretroviral drugs.

When this article was written, no permanent administrative rules had been filed by HFS. Although HFS has promulgated emergency administrative rules, the rules are subject to being suspended by the Illinois Joint Commission on Administrative Rulemaking, a bipartisan committee composed of members from the state Senate and state House of Representatives.

4. Potential Negative Impact on Vulnerable Populations

Because Medicaid reform is relatively new in Illinois, it is too soon to evaluate its impact on the various populations. The new programs and laws certainly could create potential barriers for seniors and adults with disabilities.

One of the major barriers is access to information about providers participating in managed care plans. Participants in the initial group of Medicaid recipients placed in one of the two managed care plans, were not given any written materials that list providers. To locate providers, recipients likely will need Internet access and phone service, which they may not have.

Another barrier is that fewer providers may participate in the managed care plans than are currently participating in the Medicaid program. Fewer hospitals are participating in the managed care plans than are currently participating in Medicaid. In Chicago, for example, none of the top teaching and research hospitals are in either plan.

In addition to managed care problems, the additional documentation required to qualify for and maintain Medicaid coverage may be an onerous burden on an applicant. The elderly and persons with disabilities may be adversely impacted by the new laws.

The SMART Act will have a negative impact on vulnerable populations. In addition to the Act’s dramatic cuts in Medicaid-covered services, its elimination of pooled trusts for most individuals age 65 and older will exacerbate these cuts.

253 Id. pt. 240.815.
254 305 Ill. Comp. Stat. 5/5-5.12(j) (July 1, 2012).
255 Id.
256 Id.
C. New Jersey

New Jersey faces a much larger budget shortfall than Florida, $10.5 billion for fiscal year 2012.258 And here as well, lawmakers are eyeing Medicaid to close the deficit.259 However, Medicaid expenditures in New Jersey are substantially less than in Florida. New Jersey’s total Medicaid spending for FY 2010 was $10.22 billion.260 Still, Governor Christie is hoping that a bold and controversial proposal to reform the state’s Medicaid system will result in savings of $300 million.261 The question for advocates is how it will impact New Jersey’s most vulnerable citizens.

1. History of Medicaid in New Jersey

New Jersey serves nearly 1.3 million Medicaid beneficiaries.262 Historically, New Jersey has provided comparatively generous benefits. Going beyond the federally mandated services, the state offers many optional services (including dental, durable medical equipment, and vision) and covers additional eligibility groups such as low-income parents of eligible children.263

However, in the long-term care arena, coverage has been both inadequate and inefficient. This is despite the fact that the State spent $3.5 billion on long-term care in 2010.264 The program for home and community-based long-term care services has been particularly problematic. An income cap limits the program to those individuals with incomes below $2,094 in 2012.265 Limited slots for assisted living and beneficiary budget caps have restricted the usefulness of this program, forcing many beneficiaries to require substantially more costly care in a nursing home. Perhaps, this is why New Jersey spends approximately 70 percent of its Medicaid long-term care dollars on nursing home care, compared to 41 percent nationally.266

259 Id.
263 For more information on specific programs, see N.J. Dept. of Human Servs., Div. of Med. Assistance and Health Servs., http://www.state.nj.us/humanservices/dmahs/clients/medicaid (accessed July 4, 2012). See, e.g., http://www.state.nj.us/humanservices/dmahs/clients/medicaid/families/index.html. N.J. Admin. Code 10 includes the program manuals for all covered services (ch. 50 through 68) as well as the eligibility criteria and application rules (ch. 70 and 71) (2012).
2. Medicaid Planning Limitations

Prior to the current comprehensive waiver application discussed below, the state had attempted to limit its Medicaid long-term care budget by being one of the most restrictive environments for Medicaid planning in the country. Strategies such as gift and return, caregiver agreements, promissory notes, and annuities have either been completely eliminated or their use drastically narrowed in New Jersey.267

While there has been some case law and administrative case decisions to support these limitations, many have occurred by fiat, without regulation or legislation.268 The lack of legislative reform is highlighted by the fact that it was not until October 2011 that the Administrative Code was updated to reflect the Deficit Reduction Act of 2005 (DRA ’05); however, the State informally implemented the more restrictive DRA ’05 provisions within days of its passage in 2006.269

3. Comprehensive Waiver

Until 1995, Medicaid services in New Jersey were offered by health care providers that participated in Medicaid and billed Medicaid directly for their services. In 1995, New Jersey contracted with MCOs to provide services to all Medicaid recipients except beneficiaries who are residing in nursing facilities or community-based waiver programs, dual eligibles, and children supervised by New Jersey’s Division of Youth and Family Services.270 Last year, in an attempt to control Medicaid spending and thereby address the state budget deficit, the State proposed expanding managed care across all Medicaid segments as part of a major restructuring of its Medicaid program.271

New Jersey submitted a Medicaid comprehensive waiver application to the federal government in October 2011. The waiver has three major components: 1) expansion of managed care to all Medicaid recipients, 2) consolidation of the various Medicaid programs into one unified and streamlined system, and 3) increased flexibility in such areas as scope and duration of services and copayments.272 The waiver request was designed to result in potential cost savings of $300 million.273 Of that, $107 million would have come


268 See e.g. N.J. Dept. of Human Servs., Div. of Med. Assistance and Health Servs., Medicaid Communication 10-06, http://www.state.nj.us/humanservices/dmahs/info/resources/medicaid/2010/10-06_Clarification_of_Medicaid_Communication_10-02_Return_of_Transferred_Assets-Resources.pdf (July 19, 2010), which requires that all assets be returned (instead of partial returns) before a penalty period can be adjusted, thereby eliminating gift and return planning.

269 The proposed amendments to the regulations were issued at 43 N.J. Register 804(a) (April 4, 2011).

270 N.J. Dept. of Human Servs., supra n. 264.

271 Id. It should be noted that Medicaid expenditures are being targeted despite the fact that Medicaid per enrollee spending rose a mere 1.9% from 2004 to 2009.

272 N.J. Dept. of Human Servs., supra n. 264.

from federal reimbursement of state expenses associated with a federal error related to Social Security disability determinations.274 This request has already been denied by the Department of Health and Human Services, although it is likely that there will be some accommodation offered to all states on the issue.275 It is anticipated that the waiver will be approved shortly; however, individual provisions are still being negotiated with CMS.276

Currently, there are over 30,000 New Jersey nursing home and assisted living residents on Medicaid.277 The State seeks to require all of these beneficiaries to enroll in one of the four managed care companies that contract with the State by July 2012.278 This deadline is likely to be moved back as MCOs must first show that they have adequate services, which means contracting with facilities throughout the State.279 Residents will be required to use in-network doctors as well.280 The waiver does not address the substantial issue of what happens to beneficiaries who are currently residing at a facility that does not contract with an MCO or using other out-of-network providers. Noting that 80 percent of nursing home revenue comes from Medicare and Medicaid, industry representatives warn that many facilities may be forced to close, while others may choose to abandon the Medicaid system altogether.281 Both of which will result in capacity issues and fewer choices for consumers.

Individuals who are dually eligible for Medicare and Medicaid will also be shifted to managed care. However, since federal law requires Medicare beneficiaries to be given freedom of choice, the State has proposed incentivizing use of managed care by limiting Medicaid cost-sharing to providers who are in the patient’s Medicaid MCO’s network.282 In practice, this means that most dual eligibles will no longer be able to choose their own providers.

One of the primary goals of the comprehensive waiver is to reduce the need for institutional long-term care by expanding the use of home and community-based services, thereby saving costs. In 2009, New Jersey ranked 49th in the United States in use of home and community-based services.283 The State has proposed mandating MCO’s coordinate care and provide increased social support to allow more individuals to remain in their homes.284

A number of other important changes will allow for the increased use of home and community-based services. Under current law, an income cap prevents many individuals

274 Livio, supra n. 261.
275 Id.
277 N.J. Dept. of Human Servs., supra n. 264.
278 Id. at 87.
280 N.J. Dept. of Human Servs., supra n. 264.
283 Fitzgerald, supra n. 245.
284 N.J. Dept. of Human Servs., supra n. 264.
from receiving home and community-based services. The waiver program will implement a medically needy program for home care programs whereby beneficiary excess income would be applied to the MCO capitation premium. In addition, the budget limit for each beneficiary receiving long-term care services in the community, which is currently $2,841 per month, will be raised to the nursing facility cost, and in certain cases, higher amounts for a transition period up to six months. Obviously, this increase in funding will allow individuals with greater needs to pay for the care they need to remain in the community. The State also plans to expand its community transition program to assist individuals who could safely be transitioned from facilities to home care. The waiver also allows individuals who do not quite meet the long-term care criteria but are considered “at risk” to receive home and community-based services as well. Finally, retroactive eligibility (for prior quarter coverage) will be added for community long-term care, while being eliminated for some of the traditional Medicaid categories.

The waiver also seeks federal approval for a number of coordinated care demonstration programs including Medicaid Accountable Care Organizations, as envisioned under the Affordable Care Act. This follows legislation passed by the New Jersey Senate in August 2011 for development of a Medicaid Accountable Care Organization demonstration program.

While the shift to community-based and coordinated care is praiseworthy, one major cause for concern exists. The waiver sacrifices beneficiary freedom of choice in the quest for cost savings. The State seeks authority for MCOs to make placement decisions based on cost, including mandating placement in nursing homes or at home for home and community-based services, without regard for beneficiary or family choice. This could result in families being forced to endure difficult living situations in some cases, while other beneficiaries who wish to remain at home would not be permitted to do so. Furthermore, the State requests authority to move beneficiaries between MCOs and providers without the consent of the beneficiary. The State also would have authority to disenroll an individual from self-directed home and community-based services. Moreover, since case management would be performed by the managed care companies, care planning will likely be as much a function of profits as quality care. It seems clear that the State believes that financial concerns trump the individual’s right to be involved in their own care planning decisions.

Another major component of the comprehensive waiver is the integration of the cur-

286 N.J. Dept. of Human Servs., supra n. 264, at 27.
287 Id. at 88.
288 Id.
289 Id. at 24.
290 Id. at 76; see also N.J. Dept. of Human Servs., supra n. 273.
292 N.J. Dept. of Human Servs., supra n. 264, at 88.
293 Id. at 88–89.
294 Id. at 90.
rent Medicaid programs. New Jersey currently operates nine different waiver programs in addition to “traditional” Medicaid, which encompasses several other eligibility groups under its state plan. The comprehensive waiver proposes to consolidate virtually all services and populations under one waiver. In theory, this would be very beneficial as the current system is quite confusing and the hand-off between agencies and departments can cause additional delays. The State has also proposed an electronic system to automate eligibility decisions and allow sharing of information between workers and across programs. This will not only reduce costs for staffing, storage, and copying, but is designed to eliminate the inconsistencies between counties that are currently rampant. This, along with a new procedure for simultaneous processing of financial and clinical eligibility, will in theory expedite eligibility determinations substantially. Of course, experience tells us that reality does not always match the promise of government reform. Moreover, having experienced the delays and confusion in the roll out of prior waiver programs, it is hard to imagine how these seismic changes will be implemented all at once, especially with current staffing shortages in the Medicaid agency.

Perhaps the most troubling portion of the comprehensive waiver, though, is New Jersey’s request for an expedited process for future CMS approvals. The State has proposed a tiered approach, which would provide it with flexibility to make certain changes in its programs without seeking prior CMS approval. The State specifically requests flexibility in amount, scope, and duration of benefits. It also seeks authorization to charge co-payments to provide incentives and disincentives for certain behavior, such as enrollment in certain types of specialty plans or for perceived misuse of emergency room visits. The fear is that this provision will provide the means by which the State can whittle away at rights and services for the most vulnerable patients without public awareness or the opportunity for public comment.

Advocates have already had some impact in shaping the waiver. Initially, the Comprehensive Waiver application included a proposal to freeze enrollment for one optional category, non-disabled adults, essentially eliminating coverage for families with yearly income over $6,000 (for a family of four). After widespread criticism from the public and advocates, the State removed this proposal. However, the waiver application notes that it is restoring coverage subject to availability of funding and includes a request for expanded federal funding to allow this program to continue.

If approved, the Comprehensive Waiver will fundamentally alter the delivery of

296 Id.; see also N.J. Dept. of Human Servs., supra n. 273.
297 Id. at 27–28.
298 Id. at 13–14.
299 Id. at 34.
300 Id. at 58.
302 N.J. Dept. of Human Servs., supra n. 264, at 15.
303 Id.
services to Medicaid beneficiaries in New Jersey. The stated goal of the demonstration program is to improve service delivery and quality of care while controlling costs. Many positive aspects of the waiver exist, which will no doubt improve the lives of many beneficiaries. However, it remains to be seen what reduction in services, accessibility and freedom of choice the most vulnerable populations will suffer in order to improve the state’s bottom line.

VII. CONCLUSION

States have been looking at ways to control their budgetary growth while also implementing cost predictability for programs that provide services for their citizenry. The recent economic downturn has caused that concern to take a more prominent role. The recession left states strapped with significant budgetary shortfalls and, as shown from this article, states are still struggling to recover. Reforms to state Medicaid programs became a focus, as illustrated by the states in this article, as a way to achieve cost control and budgetary predictability. Reforms have taken various forms from reduction of provider payments to changes in the type or amount of services offered to improvements in delivery systems and technology. Reform by way of implementation of managed care was or is attempting to be implemented in the three states analyzed. Medicaid reform will definitely bring change and the elderly and individuals with disabilities will be affected as a result. This article shows that reform for the sake of saving the state money could have negative effects for those vulnerable populations. Whether the actions taken by states to save costs in their Medicaid programs, as illustrated in this article, will in fact cause harm to the health and welfare of the elderly and individuals with disabilities in many instances remains to be seen.
I. INTRODUCTION

A “Medicare Set-Aside,” also known as an MSA” or sometimes a “Medical Set-Aside,” is a legal tool that has grown more popular among Elder and Special Needs Law attorneys since its inception in the mid-1990s. While in the workers’ compensation arena the use of MSAs has become a routine practice, it remains unclear whether MSAs are always appropriate in the context of personal injury cases. This article will explore the issues and attempt to determine whether a standard of practice for or against the use of MSAs in personal injury cases exists.

An MSA is a separately administered custodial account, which operates similarly to a trust and is created in certain situations when Medicare’s interests may be affected by a settlement. For example, pursuant to federal statute, if a plaintiff is receiving Medicare or is likely to receive Medicare within a certain period of time post-settlement or post-judgment, the parties to the settlement or judgement are required to consider Medicare’s interest as it pertains to future, injury-related expenses. An MSA may be administered by a professional fiduciary or self-administered by the plaintiff. The corpus of the MSA is comprised of a pre-determined amount of settlement proceeds allocated to cover anticipated future medical expenses specifically related to the injury that was the basis for the claim resulting in the settlement. Funds from the MSA are then used over the plaintiff’s projected lifetime in order to cover future, injury-related medical expenses so that Medicare does not have to pay for those costs. If the MSA is depleted after paying for injury-related medical expenses prior to the plaintiff’s death, then Medicare would assume payments for this care.

The MSA was developed as a tool to clearly document the projected amount of anticipated future expenses related to the injury for which compensation was received while also serving to satisfy Medicare’s interest in the settlement. The goal was to pro-

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1 “MSA” in this context should not be confused with the same abbreviation used to stand for “medical spending accounts.”
tect plaintiffs, defendants, and insurers from further liability with respect to Medicare’s interest in damages for future medical payments. In the workers’ compensation action it is common for the court to make or approve allocations of the settlement for future medical care. However, such allocation is not a typical practice in personal injury cases. In contrast, most personal injury settlements are negotiated to provide a global settlement of all claims to the suit, which can include, but are not limited to future medical expenses, compensatory damages, lost wages, emotional distress, and other economic damages. Thus, it becomes very difficult to allocate any specific portion of such settlements solely to address future medical expenses.

Despite the lack of any specific statute or regulation requiring the use of MSAs in workers’ compensation settlements, the practice has achieved almost universal acceptance and use. Although originally a novel concept, the MSA was quickly adopted by the Centers for Medicare and Medicaid Services (CMS) as a standard approach in workers’ compensation settlements. CMS has published guidelines to help address the MSA process with respect to workers’ compensation litigation.

However, the use of MSAs to address future medical payments in personal injury cases has been a focus of serious debate for several years. Attorneys who advocate for the near universal use of MSAs in the context of a personal injury settlement present a broader interpretation of specific terms in the Medicare Secondary Payer Act (MSP Act), the controlling federal statute on the matter, and cite instances of CMS action with respect to personal injury suits that appear to support MSA use.

The predominant counter argument taken by other attorneys in the field is that universal use of MSAs is not necessary. This argument is based on a more narrow interpretation of the MSP Act and points out the lack of authority for mandatory use of MSAs in the personal injury context. What follows here is an exploration of the issue and an attempt to determine whether one can derive any standard method of practice from an examination of the arguments on each side of the issue.

II. BACKGROUND TO THE MSP ACT AND MSAS

The MSP Act was enacted as part of the Omnibus Budget Reconciliation Act of 1980. Congress enacted the MSP Act as a cost-saving measure with the primary goal of identifying circumstances when future Medicare expenditures could be reduced by forcing third parties liable for medical care to pay in place of Medicare. In essence, under the MSP Act Medicare’s obligation to pay became “secondary” to that of liable third parties. The statute was subsequently amended by the Medicare Act of 2003 in order to clarify issues regarding the determination of Medicare’s secondary payer role.

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2 The statutory basis for Workers’ Compensation Medicare Set-Asides (WCMSAs) is derived from an interpretation of 42 U.S.C. § 1395y (2011) and 42 C.F.R. §§ 411.46, 411.47, addressing lump-sum commutation of future benefits in workers’ compensation matters.


The MSP Act provides general examples of when Medicare will take a secondary role as an insurer of medical expenses for an individual.⁶ The MSP Act also discusses Medicare’s authority to make what are known as “conditional payments” on behalf of beneficiaries. Conditional payments are defined as medical payments made by Medicare with the condition that Medicare would hold subrogation rights to recover these conditional payments at a later time, typically from subsequent settlements or judgments received by the beneficiary from third parties.⁷ The provisions of the MSP Act regarding conditional payments and Medicare subrogation rights are relatively clear and there has been little dispute in the legal community concerning the application of these provisions in both the workers’ compensation and the personal injury context.

The idea of using MSAs in any situation in which Medicare’s interests may be affected by a settlement was first introduced by attorneys. However, with the publication of a policy memo directed to its regional offices, CMS publicly adopted the use of MSAs in workers’ compensation around 2001. This policy memo provided that compliance with the MSP Act in most workers’ compensation settlements, which included future medical expenses, required the use of MSAs.⁸ Since this policy memo was issued, CMS has created an entire application and approval process for MSAs. However, with respect to future medical payments in personal injury cases, there are ongoing divisions within the different CMS regional offices about the proper interpretation and application of certain segments of the statute and whether MSAs should be required.

III. Principal Arguments Involving the MSA

Attorneys who favor universal use of MSAs in personal injury suits argue three primary points in favor of the use: 1) an implied statutory basis of authority for MSA use; 2) evidence of MSA requirements based upon specific CMS action and action taken by its regional offices; and 3) the significant risks and potential dire consequences for failure to use an MSA in the personal injury context. Each of these arguments is addressed separately below.

A. Statutory Basis for MSAs

The MSP Act states in pertinent part:

Payment under this title [42 USCS §§ 1395 et. seq.] may not be made, except as provided in subparagraph (B), with respect to any item or service to the extent that –

(i) payment has been made, or can reasonably be expected to be made, with respect to the item or service as required under paragraph (1), or

(ii) payment has been made or can reasonably be expected to be made under a workmen’s compensation law or plan of the United States or

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a State or under an automobile or liability insurance policy or plan (including a self-insured plan) or under no fault insurance.9

It is clear, by the language of paragraph (ii) that the MSP Act references automobile and liability insurance policies, as well as self-insured or no-fault insurance plans, all of which could be available to pay damages in a personal injury suit. What is less clear is in what context this provision should apply and how this language is to be interpreted. The argument in favor of MSA use is premised on the notion that MSA guidelines and informal rules governing the process in workers’ compensation, as they were derived from this statutory provision, must also apply to other types of “primary plans” identified in the MSP Act when future medical expenses are considered.10

To support this interpretation of the MSP Act, those advocating for the regular use of MSAs cite to Title 42 of the Code of Federal Regulations (CFR) §§ 411.46 and 411.47. CFR § 411.46 explains Medicare’s secondary status as payer when a lump-sum compensation award or settlement stipulates that an amount paid is intended to compensate an individual for future medical benefits. The regulation provides that Medicare’s coverage of related future medical expenditures is suspended under these circumstances until the allocated assets for future medical expenses have been exhausted. In the following section, CFR § 411.47, a formula is provided to use in determining which assets should be applied toward future medical expenses in allocating a workers’ compensation settlement. Both of these regulations refer only to awards and settlements in the workers’ compensation context and not to other awards, such as personal injury awards.

Proponents of the use of MSAs in personal injury cases (also referred to in some contexts as “liability MSAs”) have also relied on more recent federal legislation to support their contention that the MSP Act intended their use in personal injury cases. In 2007, Congress passed the Medicare, Medicaid & SCHIP Extension Act of 2007 (MMSEA). Proponents of the use of MSAs in personal injury settlements used provisions of the MMSEA to reinforce their argument of statutory authority for MSA use in personal injury cases. MMSEA §111 imposed reporting requirements on statutorily defined, “Required Reporting Entities” or RREs. Included in the definition of RREs are liability insurance plans, no-fault insurance plans, and workers’ compensation plans. Under the MMSEA, RREs must include information in quarterly reports to give CMS the information necessary to determine whether a claimant or plaintiff is entitled to Medicare benefits. In addition, these RREs must provide additional information to CMS upon settlement of any claim by a beneficiary or plaintiff.11 The reporting requirements under the MMSEA are complex and failure to properly and timely comply could subject an RRE to a penalty of $1,000 per day per claimant.

These reporting requirements under MMSEA § 111 did not become effective until July 1, 2009. Some attorneys argue, however, that the reporting requirements spelled out

11 Id.; 42 U.S.C. § 1395y(b)(8).
in the MMSEA “are surely a sign that CMS will be increasing its efforts to enforce its secondary payer status in liability settlements, similar to its enforcement efforts in workers’ compensation settlements since July 2001.” While these attorneys recognize that the new MMSEA law does not impose any MSA requirements for liability settlements, they continue to argue that CMS is poised to similarly interpret the MSP Act to require MSAs in personal injury cases the very near future. This belief is reinforced by the fact that CMS is now requesting information similar to that gathered in workers’ compensation settlements.

Opponents of this statutory basis argument take a different approach. Their primary objection is that the statutory provision cited in the MSP Act is too vague to draw any definitive interpretation regarding the Act’s application to future medical benefits. In addition, they point to the fact that 42 CFR §§ 411.46 and 411.47 only provide specific reference to workers’ compensation matters and do not mention other claims. They point out that despite the regulations’ references to Medicare’s interest in future medical payments, the regulatory references are only with respect to stipulated or allocated future medical payments, which are common to settlements in the workers’ compensation field. However, there is no reference in the regulations to instances when future medical payments are not stipulated to or allocated as a portion of the settlement proceeds. Since allocation of settlement proceeds for specific damages rarely exists in a personal injury context, it is difficult to speculate that any referenced obligation within these regulations applies to personal injury settlements the same as to workers’ compensation settlements.

Opponents of the statutory basis argument also contend that the prior argument — that the enactment of MMSEA §111 is an indication that CMS will impose a strict interpretation of the MSP Act and require the mandatory use of MSAs in personal injury settlements — is only speculative of CMS’ intent. They contend that there is no definitive statute or regulation providing direct authority to support MSA use in the personal injury context. These individuals point out that if CMS wanted to mandate the use of MSAs in the personal injury context, it could only do so through considerable changes in federal statutes and regulations. The changes would require Congressional action or formal rule making procedures including adequate notice and comment periods. It is clear that, other than 42 CFR §§ 411.46 and 411.47, there is nothing in the statute or regulations that speaks directly to Medicare’s interest in future medical expenses and even then, these regulations only apply to workers’ compensation settlements

Finally, opponents argue that if Medicare were to attempt to impose a mandatory requirement for MSAs in personal injury settlements it would be unenforceable under the “fair notice” doctrine because of the ambiguous language of the MSP Act. The fair notice doctrine was most accurately explained by the Circuit Court of Appeals for the District of

14 Id.
Columbia in the case, General Electric Company v. United States Environmental Protection Agency.\textsuperscript{15} In General Electric Company, the court stated that “due process requires that parties receive fair notice before being deprived of property. … In the absence of notice — for example where the regulation is not sufficiently clear to warn a party about what is expected of it — an agency may not deprive a party of property by imposing civil or criminal liability.”\textsuperscript{16} Opponents suggest that under this doctrine CMS cannot arbitrarily enforce MSA use, suing those who fail to comply, without first properly providing fair notice of its intention to apply MSAs in personal injury settings, which the agency has never formally done.

\textbf{B. Actions Taken by CMS and its Regional Offices}

Many advocates, recognizing the limited legal authority supporting the mandatory use of MSAs in the personal injury context, support their argument by pointing to apparent actions and statements made by CMS and its regional offices. Advocates for the use of MSAs have stated unequivocally that:

CMS interprets this language [i.e., 42 U.S.C. § 1395 (b)(2)(A)] as providing that \textit{any} settlement that closes out future medical expenses in a claim against a primary payer represents a situation in which “payment has been made” for an item or service otherwise covered by Medicare, precluding future Medicare coverage for those items or services until the payment has been exhausted on future medical expenses related to the injury.\textsuperscript{17}

This argument gains support from the detailed procedures and guidelines of CMS for future medical payments in the workers’ compensation context. Advocates of the regular use of MSAs assert that CMS’ failure to distinguish between workers’ compensation carriers and other insurers with potential liability for a Medicare recipient’s future medical expenses justifies “similar authority to require tort victims to apply damages for future medicales toward future care arising from a tort.”\textsuperscript{18}

There is further evidence to suggest that CMS may, to some extent, support MSAs in the personal injury context. On April 22, 2003, CMS issued a policy statement to all CMS regional administrators. This memorandum provided that in situations involving both workers’ compensation and personal injury claims, Medicare is secondary to the personal injury proceeds. The intent of the memorandum was to clarify that Medicare’s obligation to pay benefits should be reduced if the personal injury settlement occurred and Medicare had paid or will pay benefits for care related to the underlying injury. The memorandum indicated that to the extent that a liability settlement is made relieving a

\begin{itemize}
  \item \textsuperscript{16} Id. at 1328–1329.
  \item \textsuperscript{17} John J. Campbell, New Medicare Secondary Payer Reporting Requirements, 21 NAELA News 22–24 (No. 6, 2009).
  \item \textsuperscript{18} Lawrence A. Friedman, Medicaid and Medicare Liens in Personal Injury Settlements, 21 NAELA News 26–27 (No. 6, 2009).
\end{itemize}
workers’ compensation carrier from any future medical expenses, a CMS-approved MSA is appropriate. The memorandum did not, however, address the situation in which there was no underlying workers’ compensation claim.

The National Academy of Elder Law Attorneys (NAELA) established a Medicare Task Force in spring 2008 to specifically investigate and review the use of MSAs in personal injury cases. The task force found that the CMS national office is aware that some attorneys create MSA arrangements in personal injury cases and that CMS is not opposed to the use of MSAs. Another finding indicated that the CMS regional office in Texas had been reviewing liability settlement arrangements in the past and another unnamed region was said to have been reviewing such arrangements when the settlement amount exceeded $750,000. This empirical evidence implies that CMS, or at least some of its regional offices, have considered favorable approaches to the regular use of MSAs in personal injury settlements.

CMS, however, has not remained consistent with its approach towards mandatory MSA use in personal injury settlements. In fact, CMS takes an indifferent position to MSA use in these contexts almost as frequently, if not more often, than it appears to endorse MSAs in the personal injury context. Statements issued by CMS and past actions of CMS (or, more specifically its ambivalence on the issue) has strongly implied, if not directly indicated that CMS does not require or enforce the regular use of MSAs in the personal injury context. For example, the CMS regional office for Region IX (covering Arizona, California, Hawaii, Nevada, and several U.S. Pacific Territories) sent a letter to an advocacy group located in Arizona stating unequivocally that, “it has been long-standing Medicare policy that Medicare is the primary payer for accident-related medical services obtained after the Date of Settlement” [Emphasis supplied.] This language implies that since Medicare views itself as the primary insurer to injured parties in a personal injury suit for future medical expenses, Medicare has no interest in future medical expenses in this context and therefore, MSAs are irrelevant and unnecessary.

The CMS San Francisco Regional office went one step further and issued a memorandum in October 2009 stating, “The Centers for Medicare & Medicaid Services (CMS) has no current plans for a formal process for reviewing and approving Liability Medicare set-aside arrangements.” Another letter issued on May 25, 2011, by the MSP Regional Coordinator located in Dallas, Texas, representing CMS Region VI stated, “Medicare’s
interests must be protected; however, CMS does not mandate a specific mechanism to protect those interests. The law does not require a ‘set-aside’ in any situation.”

The American Association for Justice (a/k/a the American Trial Lawyers Association) has released a public statement directly addressing speculation as to the connection between the MMSEA § 111 and liability MSA enforcement. The statement says the following:

It has come to our attention that some defense firms and insurance providers are now claiming that CMS requires MSAs in liability cases pursuant to Section 111 reporting requirements included in the Medicare, Medicaid & SCHIP Act of 2007 (MMSEA), Public Law No. 110-173. This is false. Section 111 contains reporting requirements for responsible reporting entities (RREs) only. Section 111 does not impact or change the requirements for plaintiffs’ attorneys…Moreover, statements from CMS, and other federal entities, make clear that the agency does not require set-asides for liability claims.

This statement includes citations to transcriptions from CMS public meetings and a CMS Alert as support. The May 2011 letter issued by CMS Region VI only supports this contention. In referring to the new statutory reporting provisions for liability insurers (i.e., MMSEA § 111), the May 2011 letter from CMS Region VI states: “The new provisions do NOT require a set-aside when there is a recovery for future medicals, in fact this legislation does not address that subject.”

On September 30, 2011, the Acting Director of the Financial Services Group in Medicare’s Office of Financial Management issued a memorandum providing some additional guidance, and a potential loophole for practitioners to satisfy Medicare’s interests in liability contexts. The memorandum states that when a Medicare beneficiary’s treating physician can certify in writing that treatment for an alleged injury related to the liability insurance settlement has been completed as of the date of the settlement and no future injury-related medical expenses are necessary, Medicare will consider its interests satisfied with respect to the settlement. The impact of this memorandum is significant as it clearly indicates that there are circumstances (particularly those where maximum medical improvement of the Plaintiff can be certified by a treating physician) when CMS has

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27 Stalcup, supra n. 24.
unequivocally indicated that no further action is necessary with respect to future medical payments.

Finally, the Medicare Secondary Payer (MSP) Manual, an internal set of detailed guidelines for CMS and regional affiliates also addresses this issue. The manual specifically states, “there should be no recovery of benefits paid for services rendered after the date of a liability insurance settlement.”29 Opponents of personal injury MSAs argue that these examples demonstrate that CMS policy does not require MSAs in that context or, at the very least, indicates that CMS and its regional offices have not taken a united stance on the issue.

C. Risk of Attorney Liability

One of the most common arguments for the use of MSAs in liability settlements has been the perceived risk of liability by the personal injury attorney who fails to establish an MSA for his or her client. Federal regulations promulgated in conjunction with the MSP Act indicate that Medicare holds a right to recover under the MSP Act against any entity, including a beneficiary, provider, supplier, physician, attorney, state agency, or private insurer that has received personal injury funds (i.e., a primary payment).30 Despite this lone regulation discussing potential liability against attorneys under the MSP Act, MSA proponents imply that attorneys involved in personal injury suits are almost certainly exposed to liability pursuant to this regulation when future medical expenses are settled. They argue that by failing to consider Medicare’s interests with respect to future medical payments in a prescribed way (or, in other words, failing to establish MSAs), a personal injury attorney could potentially be liable for damages pursuant to 42 U.S.C. § 1395y(b)(3)(A). The argument stands that by establishing an MSA for the client, and receiving approval from Medicare for a specific set-aside amount, an attorney virtually insulates him or herself as well as all parties to the suit from any chance of liability.

Opponents argue that in reality, risk of attorney liability is minimal, pointing out that, “the MSP provisions of the statute never specifically identify attorneys as individuals against whom CMS recovery rights are created….”31 Medicare’s private cause of action to collect damages under 42 USC § 1395y(b)(3)(A) appears to only apply to a primary plan that fails to provide for primary payment (or other appropriate reimbursement).32 The statute defines a primary plan as a workers’ compensation law or plan, an automobile or liability insurance policy or plan (including a self-insured plan), or no fault insurance plan.33

A careful reading of the federal regulations shows that Medicare ultimately holds “primary payers” responsible in the personal injury context. Support for this is found at 42 CFR § 411.24(i)(1), which states in pertinent part:

29 CMS, supra n. 3, ch. 7, § 50.5.
32 Id.
In the case of liability insurance settlements…the following rule applies: If Medicare is not reimbursed as required…of this section, the primary payer must reimburse Medicare even though it has already reimbursed the beneficiary or other party.

This provision is important because it references primary payer liability without any reference to attorney liability and it appears to only apply to recovery by Medicare for conditional (i.e., past) payments. This section of the CFR does not appear to reference future medical payments. Thus, opponents strongly believe that liability for attorneys in personal injury cases has only minimal authoritative support.

The MSP Act does not specifically reference attorneys as primary payers, and while some federal regulations allude to attorney liability, this liability has been argued to arise only if the attorney has actually received, and still possesses, settlement proceeds. If an attorney has never received or no longer possesses settlement proceeds subject to the referenced statute and regulation, the argument holds that it would be difficult for Medicare to hold such personal injury attorney liable for recovery for either conditional payments or future medical payments.

Opponents to mandatory MSAs in personal injury actions acknowledge that Medicare has only pursued recovery against attorneys in a handful of published cases and therefore there is little precedent to indicate that such liability exists.34 It is important to recognize that in each of the cases in which Medicare pursued recovery the attorney had possession of settlement funds, thereby allowing Medicare to file its claim against the attorney. Furthermore, in each of these cases, Medicare’s claim was based on the recovery of past medical payments (i.e., conditional payments) and was not a claim for estimated future medical payments or for any failure to use MSAs. Opponents argue that federal provisions logically conclude that, except for primary payers, recovery actions actually pursued by CMS indicate the agency will likely pursue recovery of funds either directly from a defined “primary payer,” or from one individual or entity to the next depending on who possesses the funds at that point in time and that such recovery shall be solely for conditional payments made by Medicare.35

IV. Standard of Practice

There are many unresolved questions with respect to the use of MSAs in personal injury settlements. Thus, it does not appear that there is a standard method of practice with respect to MSAs in the personal injury context. Nor is it clear whether attorneys, when negotiating a personal injury settlement, should always use MSAs. What is clear is that the answers to these unresolved questions appear to depend upon the circumstances of each case and require a case-by-case and cost-benefit analysis for the parties involved.

As previously mentioned, NAELA created a Medicare Task Force in spring 2008 with the specific mission to investigate and report on the use of set-aside arrangements

35 Hart, supra n. 31.
in the context of personal injury settlements involving third party liability for Medicare-covered expenses. The task force was comprised of a diverse group of attorneys experienced in the subject. The official report was issued in October 2010.

The primary findings of the Task Force were:

- CMS acknowledges that there is no Medicare requirement to establish MSAs in any context;
- CMS national office has indicated that it is not likely to issue further clarification with respect to requiring MSA arrangements for future medical expenses in liability cases;
- CMS acknowledges that some attorneys create MSA arrangements and is not opposed to such arrangements;
- Various CMS regional offices appear to differ with respect to enforcement of MSAs in liability cases and the set parameters for review of such cases;
- Although CMS believes the MSP Act applies to tort cases, the agency has not set a formal procedure with respect to protection of Medicare’s future interests; and
- Attorneys should counsel their clients to consider setting aside funds they receive from a settlement that could be covered by Medicare in the future or the attorney may be vulnerable to future client claims.36

The recommendations of the NAELA Medicare Task Force that followed also appeared indefinite. The most notable recommendations to attorneys were:

- Advise personal injury (PI) clients to establish self-administered MSAs designated for settlement amounts equal to future medical expenses that would otherwise be covered by Medicare similar to workers’ compensation cases with the caveat that the requirement for MSAs in tort cases is not as clear as it is in workers’ compensation cases;
- Inform clients that the MSP Act applies to all tort cases and that CMS considers PI plaintiffs to hold an obligation to protect Medicare’s future interests with the caveat that the requirement for MSAs in tort cases is not as clear as it is in workers’ compensation cases; and
- Advise PI clients to consider MSAs and apply to CMS for approval with the caveat that some CMS regional offices will not consider MSAs in tort cases.37

Despite issuing several recommendations with respect to use of MSAs in personal injury cases, the task force was unable to issue definitive statements without significant caveats attached. As a result, it is difficult to derive a method of practice from this study. At a minimum, the task force strongly recommends that attorneys discuss the potential use of MSAs with their clients. It also appears that the task force generally encourages the use of MSAs in personal injury settings. However, the task force did not and could not conclude that MSAs are mandatory or enforceable by CMS in any way.

The task force did not report finding any risk of liability by attorneys to Medicare for failure to establish MSAs for their client. The task force did, however, advise attorneys to fully inform their clients of the applicability of the MSP Act in liability cases in order to mitigate malpractice liability.

Thus, the task force report concludes that the MSP statute appears to apply to personal injury cases, a conclusion that is widely supported amongst attorneys in the field.

37 Id.
Unfortunately, the task force did not produce a definitive explanation as to the Act’s specific application to future medical payments and this issue remains unresolved to date.

This issue has not gone unnoticed by the American Bar Association (ABA). In February 2011, the ABA House of Delegates adopted Resolution 108A, which was intended to send a clear message to members of Congress regarding the ambiguity of MSA use in personal injury contexts. The Resolution, in part, asked Congress to enact new legislation to accomplish 10 specific goals. The most pertinent were:

- Acknowledge that there are no statutory and regulatory requirements for determining Medical Set Aside payments and the process for approving claims subject to the Medicare Secondary Payer Act for third party liability claims;
- Exempt from review by CMS all settlements in which there are no legal obligations to pay medical benefits;
- Establish an appeals process that must be completed by CMS within 90 days of request by the claimant, insurer, or their representative;
- Prohibit CMS from seeking additional moneys from the settlement proceeds after review and/or appeals processes have been concluded;
- Prohibit recovery thresholds for MSASP (Medical Set Aside Settlement Proposals) that are linked to predetermined economic indices;
- Establish a statute of limitations for MSP claims;
- Prohibit the “certification” or claim of specialization by any private individual or person or government entity of a process, practice or individual in the determination of MSASP.  

Resolution 108A was sent to Congress along with a report authored by the chair of the Tort Trial and Insurance Practice Section of the ABA. The report again requested additional regulatory clarification on the matter indicating that, “Because of the uncertainty and lack of regulatory specification with respect to the determination of Medical Set Asides, there continues to be considerable delays in the settlement process, no rules governing the process…and justified significant concern on the part of parties, insurers and their legal representatives.”

The ambiguity surrounding this issue continues however, and has reached a significant level of concern among attorneys involved in all aspects of personal injury suits. Resolution 108A and its accompanying report appear to align with several of the points made in the NAELA Task Force Report. While it is clear that the MSP Act applies to personal injury suits, how the Act applies directly in such suits remains unresolved and requires further clarification from either Congress or CMS.

The lack of authority mandating the use of MSAs in the personal injury context does not necessarily mean that MSAs should never be considered a useful tool for personal injury settlements to reasonably address Medicare’s interests. It merely indicates that MSAs are a possible solution, not the only solution. Of course, MSAs have proven to be very

useful and are a frequently applied tool in the workers’ compensation arena. However, the dogmatic approach taken by some who swear to their use in most, if not all, circumstances appears to be unsupported by authority and is inappropriate.

While the protection afforded by an MSA has its merits, the costs associated with the creation, implementation, and administration of such tools must also be reasonably balanced. When considering the use of MSAs in personal injury cases it is important to determine whether the MSA process could prove to be more financially detrimental than beneficial to plaintiffs. It appears more than coincidental that individuals most in favor of a universal approach to MSA use are the same individuals advertising their own services to prepare and establish MSAs or to provide professional administrative services for MSAs. Over the last several years, the MSA business has boomed. More and more companies offer fee-based, professional MSA administrative services despite the fact that MSAs can be self-administered. Others offer high-priced MSA training courses to provide “MSA certification” for such administrators. However, the question still remains whether these businesses and attorneys always consider the plaintiff’s best interests.

There is evidence that MSA use in personal injury cases can sometimes hamper settlements and increase costs. As previously mentioned, CMS has no formal policy in place for review and approval of MSAs in personal injury cases and it appears each regional office has set its own internal guidelines for review. As a result, inconsistency abounds resulting in significant delays to the settlement process for the parties involved. As an example, in a recent case, Smith v. Marine Terminals of Arkansas,40 a longshoreman reached a settlement in a civil suit with his employer regarding an injury. As part of the settlement agreement, the parties agreed that the settlement required a self-administered MSA and that it would be submitted to CMS for approval. CMS, however, decided for unknown reasons not to review or approve the MSA submission. Thus, resolution of the case was significantly delayed and the settlement was placed in jeopardy. These circumstances resulted in additional time and expenses for the parties in seeking court approval of the MSA as well as a declaratory judgment that they properly considered Medicare’s interests. Even so, it is unclear whether Medicare would agree that this process fully satisfies their interest in the settlement.

Until recently, CMS and Congress have provided little help to clarify the statutory ambiguity surrounding the application of the MSP Act and future medical expenses. Under these circumstances it would be logical to examine whether any precedent can be drawn from the common law. Unfortunately, common law has also yielded little guidance. Since the inception of MSAs, no cases have been decided in which the court expressly stated that MSAs are the preferred, much less required, method with which to address Medicare’s interest in future medical expenses under the MSP Act. Until 2011, there were no notable cases in which a court ever directly addressed or attempted to address the direct application of the MSP Act to future medical expenses in personal injury cases.

In January 2011, however, a New Jersey state trial court, issued an opinion (pub-
lished in May 2011) in the case of *Hinsinger v. Showboat Atlantic City* that found MSAs in third party liability cases to be synonymous with those in workers’ compensation matters. One of the court’s conclusions was that “the statutory and policy reasons for creating both [liability and workers’ compensation MSAs] are the same: to protect the government, and the Medicare system in particular, from paying medical bills for which the beneficiary has already received money from another source.”

The court justified this analysis with a reference to a transcript published by CMS of a teleconference from October 2008.

*Hinsinger* appears to be the first case of its kind and could lead to a broader interpretation of the application of the MSP Act in personal injury cases. A closer reading of the case, however, indicates that the holding is likely not as influential as one might think. The primary issue of the case was whether an attorney could, without prior court direction, pay a portion of procurement costs from a liability settlement out of funds voluntarily allocated to an MSA. The court was not asked to interpret the application of the MSP Act to liability settlements nor was it asked to determine the validity of the MSA that had been established. Further, in its opinion the court acknowledged that no statutory or regulatory requirements existed to create an MSA when future medical expenses were awarded.

The opinion appears to be an example of the court’s attempt to find previously established rules and regulations that would apply to the case before them. By applying those rules and regulations that already apply to MSAs in workers’ compensation suits, the court was able to support its decision regarding an ancillary issue involving payment for procurement costs. One should also note that as a lower state court decision, the *Hinsinger* case is not a controlling decision, and a single court opinion does not constitute a pattern worthy of establishing common law practice. It will be important, however, to see if other courts engage in similar analyses when confronted with similar issues in the future.

Surprisingly, CMS has recently taken what appears to be a significant step forward to establish a clearer policy with respect to future medical expenses and MSAs. On June 15, 2012, CMS released newly proposed rule changes in the form of an “advanced notice of proposed rule-making” (ANPRM). The ANPRM proposes rule changes to 42 CFR, Parts 405 and 411. CMS indicates in the ANPRM that it is soliciting comment on:

standardized options that [CMS is] considering making available to beneficiaries and their representatives to clarify how they can meet their obligations to protect Medicare’s interest with respect to Medi-
care Secondary Payer (MSP) claims involving automobile and liability insurance (including self-insurance), no-fault insurance, and workers’ compensation when future medical care is claimed or the settlement, judgment, aware or other payment releases (or has the effect of releasing) claims for future medical care.

CMS continued by indicating that the ANPRM issuance was in direct response to affected parties’ requests for clarity on the matter.

CMS stated in the ANPRM that while there is a formal, yet voluntary MSA process in workers’ compensation situations to address future medical costs, it has not yet recognized nor established a similar process in liability settings. Thus, it appears that one purpose of the ANPRM was to determine whether and how Medicare should implement an MSA process in liability cases as well as determine whether alternative options could or should be available to current and future Medicare beneficiaries.

CMS proposed seven options to address Medicare’s interest in future medical costs arising from liability cases. Options one through four would apply to current as well as potential Medicare beneficiaries while options five through seven would apply only to current Medicare beneficiaries. The options listed were as follows:

**Option 1**
Medicare will not pursue future medical expenses if the plaintiff assumes responsibility for the entirety of his or her injury-related medical expenses until his or her settlement is exhausted. Under this option, Medicare would not formally or routinely review any documentation under these circumstances. Informal review would still be possible.

**Option 2**
Medicare would not pursue future medical expenses if the beneficiary meets all of the requirements under either of two sets of circumstances:

a. The amount of liability insurance (including self-insurance) “settlement” is a defined amount or less and the following criteria are met:
   - The accident, incident, illness, or injury occurred on year or more before the date of “settlement;”
   - The underlying claim did not involve a chronic illness/condition or major trauma;
   - The beneficiary does not receive additional “settlements;” and
   - There is no corresponding workers’ compensation or no-fault insurance claim.

Or,

b. The amount of liability insurance (including self-insurance) “settlement” is a defined amount or less and all of the following criteria are met:
The accident, incident, illness, or injury occurred on year or more before the date of “settlement;”

The individual does not expect to become a beneficiary within 30 months of the date of “settlement;”

The beneficiary does not receive additional “settlements;” and

There is no corresponding workers’ compensation or no-fault insurance claim.

**Option 3**
Medicare will not pursue future medical expenses in most instances if the plaintiff is able to provide an attestation of completion of future medical care from his or her physician. Medicare recovery rights will be adjusted based upon the timing of such physician’s attestation.

**Option 4**
Medicare will not pursue future medical expenses if the plaintiff submits proposed Medicare Set-Aside Arrangement (MSA) amounts for CMS’ review and obtains approval.

**Option 5**
Medicare will not pursue future medical expenses if the plaintiff (who would have to be a current Medicare beneficiary) participates in one of three newly developed monetary recovery options outlined in the ANPRM.

**Option 6**
Medicare will not pursue future medical expenses if the plaintiff makes an upfront payment to Medicare for estimated future medical expenses.

**Option 7**
Medicare will not pursue future medical expenses if the plaintiff obtains a compromise or waiver of recovery.

The ANPRM did not identify whether CMS would consider incorporating one, several or all of these options into the new rules. The agency consistently implied that the rule making process and solicitation for comment was an opportunity for those interested to help shape the proposed rules themselves. Thus, it is a strong signal that currently, CMS has no firm policy or approach to future medical costs and acknowledges that MSAs are not mandatory to meet its interests in such cases. CMS’ request for outside input appears relatively obvious — some of the proposed options did not have predetermined settlement threshold amounts and summaries included in the ANPRM specifically identified these omissions and requested comment on these issues. More specifically, requests were made
for input as to whether current thresholds adopted for workers’ compensation settlements should be used or whether alternative thresholds should be employed.

While CMS has taken a significant first step to clarify (and likely codify) a position with respect to these issues, it is clear by the ANPRM that there still remain a number of glaring ambiguities that requiring its attention. The issuance of such proposed rule changes does clarify one matter – that the MSP Act does, in fact apply to personal injury cases. Other than this, the information seems to support the argument of a more balanced approach with MSA use in these circumstances rather than a mandatory use of such instruments. One can hope that once the comment submission period ends on August 14, 2012, CMS will likely review any and all comments to help develop greater clarity on the matter for practitioners.

V. CONCLUSION

Currently, there is no clearly identifiable best practice with respect to the use of MSAs in personal injury cases. The decision whether to use an MSA is case specific and will depend on the attorney’s examination of the issues, including an in-depth cost-benefit analysis of the plaintiff’s circumstances. It is clear that MSAs are not a mandatory means by which to satisfy Medicare’s interest in personal injury contexts. Even though CMS has adopted a detailed MSA approval process in the workers’ compensation context, CMS still acknowledges self-imposed limitations to its enforcement of MSAs. Of course, new revisions to federal regulations could easily change this fact. At this time, in the workers’ compensation context, CMS requires the use and approval of MSAs only when the plaintiff is a current Medicare beneficiary and the total settlement amount is greater than $25,000, or when the plaintiff has a reasonable expectation of enrolling in Medicare within 30 months from the settlement date and the anticipated total settlement amount is expected to be greater than $250,000.45 It is reasonable to assume that if an attorney chose to advise his or her client to use an MSA in a personal injury settlement, these same CMS limitations, at a minimum, would also apply, especially since CMS chose to omit specific figures from its proposed rule changes.

It is clear that the size of the settlement, as well as the plaintiff’s Medicare eligibility status, should always be taken into consideration when weighing whether to use MSAs in personal injury settlements. It is reasonable to expect that the larger the negotiated settlement in a personal injury case, the greater interest CMS may hold in future medical payments arising from the injury. The fact that personal injury settlements generally cover a wide variety of damages and typically fail to allocate amongst these damages creates additional problems for CMS. Workers’ compensation settlements, on the contrary are, by their nature, more structured with respect to allocation of settlement proceeds for future medical expenses. This makes Medicare’s alleged interest in the settlement more clearly defined and easily enforceable.

Even though MSAs are not directly mandated by any authority, attorneys are still

45 Memo. from Dir., Ctr. for Medicare Mgt., CMS, to Regl. Adminstrs., supra n. 19.
obligated to ensure that they have fully informed their clients of the issues related to future medical expenses and taken measures to consider Medicare’s interest in the settlement. At a minimum, this could be interpreted to mean that attorneys should discuss the potential use of MSAs in personal injury contexts with their clients and all parties involved, but they can refrain from insisting upon their use in all matters. The best way to accomplish this is by clearly explaining the issues involving the MSP Act and consideration of Medicare’s interest in a letter to the client. Written correspondence to one’s client should outline the various options available for the client to choose in addressing Medicare’s interest and the costs and benefits associated with each option. If an MSA appears to be the vehicle of choice by the client, it would also be advisable to have a predetermined allocation of settlement proceeds for future medicals, and if possible, request a court order to ratify the allocation. Notice should be given to CMS under such circumstances. Ultimately, it is the client’s choice as to what strategy to take and proper measures taken by the attorney to demonstrate that the client was fully informed is best to avoid any future risk of a malpractice suit.

At this time, there is no published history of any suit by Medicare against any party in a personal injury suit for the failure to establish an MSA. For this reason attorneys and their clients must continue to weigh the risks of using or not using MSAs in these contexts. It would appear that for a reasonable cost, the MSA could provide all parties with the piece of mind that Medicare’s interests are satisfied, avoiding the risk of potential future litigation with Medicare. This is especially true if the settlement in question is a significantly large sum compared to a relatively small estimated amount for lifetime future medical expenses. However, as explained earlier, the MSA process could just as easily cause significant delays and added costs to clients if the settlement is relatively small and insignificant. As has been reported, Medicare may choose not to approve an MSA or MSAs may be established when CMS policies and practices make them entirely unnecessary. Further, there is nothing to indicate that Medicare’s interests could not be otherwise satisfied when a plaintiff received all settlement proceeds from a personal injury suit after being fully informed that Medicare may not pay for certain injury-related future medical expenses.

The situation is similar to others in which the parties weigh the risk against the cost of protection. Every homeowner risks facing a multi-million dollar personal liability suit by a slip and fall victim on their property but the calculated risk of such a suit is relatively low for most individuals. Thus, it does not necessarily mean that every homeowner should pay for an exorbitantly high liability insurance policy that will never be used. A homeowner who resides on property with more treacherous conditions may have greater exposure than a typical homeowner and this is what should guide the choice to purchase insurance coverage. Similarly, in the arena of personal injury settlements the attorney and client must weigh the level of risk of Medicare’s interest against the cost to the plaintiff of establishing and maintaining an MSA before determining whether an MSA is warranted.

While the proposed rule changes by CMS are a proactive step to establish more clarity as to future medical expenses, until CMS or Congress provides firm authority regarding the application and enforcement of the MSP Act in personal injury settlements, there will continue to be uncertainty regarding MSA use in these contexts. The risks and
benefits involved with MSA use in personal injury cases should always be considered, especially the direct impact on the plaintiffs’ interests, but only after first examining the size of the settlement proceeds, whether any of the settlement has been allocated to address future medical payments, whether such an allocation should be made under the circumstances, and whether the plaintiff’s current or future Medicare eligibility falls within statutory and regulatory guidelines.
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I. INTRODUCTION

Advance health care directives\(^1\) are recognized in all 50 states and the District of Columbia, but each state’s law is different and there are surprising differences in how and when each state implements its version of the advance health care directive. In general, an advance health care directive allows a person to appoint a health care agent and to prepare instructions for future health care decisions when the person loses the ability to do so. The differences in the states’ laws have arisen from various well-known state and federal cases such as \textit{In re Quinlan} and \textit{Cruzan v. Missouri Dept. of Health}.\(^2\) In \textit{Quinlan},

\footnote{This article uses the term “advance health care directive,” but many states use terms such as “living will,” “power of attorney for health care,” “advance directive,” or “advance medical directive.”}

the New Jersey Supreme Court was the first to address the issue of the “right to die.” The Court held that, under both the United States and New Jersey constitutions, Karen Quinlan had the right to decline medical treatment because such right was incorporated into an individual’s right of privacy. In *Cruzan*, the U.S. Supreme Court recognized that every adult with capacity has the right to refuse treatment, even life-sustaining treatment, based on the 14th Amendment. The U.S. Supreme Court also upheld a state’s right to require that evidence of an incompetent’s wishes as to the withdrawal of life-sustaining treatment be proved by clear and convincing evidence.3 After the U.S. Supreme Court ruling in *Cruzan*, the various states took a number of different paths in their right-to-die jurisprudence.4 Since these cases, there have been many cases that have concerned the “right-to-die” issue, with each case adding more texture to the debate. In order to protect a person’s future health care decision-making rights, many more states began authorizing advance health care directives so health care decisions could be protected even if that person lost capacity. Due to many different influences, like religious, cultural, or bioethical, the states have come up with a plethora of different (and often contradictory) requirements in the execution and recognition of advance health care directives.

In 1990, the first federal statute dealing with the right to record future health care decisions, including what to do at the end of life, was passed and entitled the Patient Self Determination Act (PSDA).5 The PSDA requires Medicare participating health care facilities to ask all patients if they have an advance health care directive and to provide information to patients about health care decision-making rights.6 Pursuant to the PSDA, an advance health care directive is defined as a “written instruction, such as a living will or durable power of attorney for health care, recognized under state law (whether statutory or as recognized by the courts of the state) relating to the provision of health care when the individual is incapacitated.”7 The PSDA did not create the right to record health care decisions; instead it required that the public be educated about the existence of that right and the need to record their wishes.

In 1993, the National Conference of Commissioners on Uniform State Laws approved the Uniform Health-Care Decisions Act (UHCD Act).8 The prefatory note to the UHCD Act describes the development of the states’ laws on implementing advance health care directives as being in “fits and starts, resulting in an often fragmented, incomplete, and sometimes inconsistent set of rules.” The goal of the UHCD Act was to create greater uniformity “in an increasingly mobile society in which an advance health care directive

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3 *Cruzan*, supra n. 2, at 261, 262.
7 42 C.F.R. § 489.100 (2007).
given in one state must frequently be implemented in another.”9 Despite the adoption of
the UHCD Act by several states,10 there are still vast differences in the advance health
care directive laws of the 50 states and the District of Columbia.

This article describes each state’s advance health care directive law, the differences
among the states’ laws, and the challenges with portability of one state’s advance health
care directive to another state, and the priority of selection of a surrogate health care deci-
sion maker when no document is prepared.

II. DIFFERENT STATES’ REQUIREMENTS FOR ADVANCE HEALTH CARE DIRECTIVES

The advance health care directive laws of the 50 states and the District of Columbia
are different. Appendix A lists all 50 states and the District of Columbia, their laws con-
cerning advance health care directives, implementation requirements, and certain other
specific requirements showing the difference in treatment among the states. This article
analyzes some of these differences and highlights the areas wherein the practitioner will
want to understand how a different state will treat an advance health care directive created
in another state.

A. Title of Advance Health Care Directive Document Is Different

A big difference among the states is what each state calls its advance health care
directive document. The different types of documents that have been created by the states
can be divided into three general categories:

1. living wills or advance health care directives;11
2. durable powers of attorney for health care; and
3. a single document that encompasses both.12

A living will or advance health care directive can inform health care providers about
the type of medical care that an individual wants provided or withheld.13 It will give
instruction for medical treatment in the event of incapacity at the end of life, typically
because of a terminal illness or a persistent vegetative state.14 Some states will call the
advance health care directive a “declaration.” For example, Illinois law identifies the ad-
vance health care directive document as a “declaration” and defines that term to mean a
witnessed document in writing, voluntarily executed by the declarant in accordance with
the requirements of statute.15 However, the document functions in the exact manner as an
advance health care directive.

9 Id. at 1, 2.
10 Alaska, Haw., Me., Miss., and N.M. have adopted the Uniform Law. See Uniform Law Commission,
12 Colo. recognizes “five primary types of advance medical directives: 1) Living Wills; 2) CPR Orders/
Do Not Resuscitate Orders; 3) Medical/Health Care Power of Attorney; 4) Disposition of Last Remains
Declarations; and 5) Organ and Tissue Donation Declarations.” Colo. Bar Assn., http://www.cobar.org/
index.cfm/ID/20160/subID/411/Advance-Medical-Directives.
Documents, 42 Gerontologist 51–60, 51 (No. 1, 2002).
A durable power of attorney for health care is a document that identifies an agent to serve as a health care proxy or decision maker for the principal. Typically, the agent has broad decision-making authority when acting in this surrogate role and is not limited to decision making at the end of life. Certain states, e.g. New Jersey, allow a single document to accomplish both tasks of appointing an agent and listing health care instructions. Other states, like California, allow for different rights to be set forth in separate documents, or combined into one document.

B. Effective Only on Loss of Capacity

There are differences among the states as to when the various types of advance health care directives become effective or operative. Powers of attorney for health care and advance health care directive laws often require some finding that the principal is incapacitated or a determination that the principal is “incapable” of making health care decisions. A typical provision states that unless otherwise specified in a power of attorney for health care, the authority of an agent becomes effective only upon a determination that the principal lacks capacity and ceases to be effective upon a determination that the principal has recovered capacity. “Capacity” is generally defined throughout the various states as the ability to make and communicate an informed decision.

C. Effective Only If Certain Type of Condition is Triggered

In those states that have separate laws for living wills, there is often a requirement that the principal be diagnosed with a specific qualifying condition before end-of-life decisions recorded in an advance health care directive will be triggered. End-of-life decisions typically include the withholding or withdrawal of life sustaining or life supporting measures, and the removal of artificial hydration and nutrition. Before a decision to remove life sustaining measures can be made by a surrogate decision maker, most states require that the principal have a qualifying condition. States use a variety of terms to describe the qualifying or triggering condition, such as “terminal condition” or “terminal illness”, and “permanently unconscious” or “persistent vegetative state.” Each state defines these terms differently. The terms “terminal condition” or “terminal illness” are most often defined as including an irreversible or incurable illness or

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16 End-of-Life Care, supra n. 12.
17 Gunter-Hunt et al., supra n. 13.
19 In a Cal. power of attorney for health care, health care instructions can be stated and an agent can be appointed. Cal. Prob. Code § 4629 (2010). In a Cal. advance health care directive, however, only health care instructions can be stated; an agent cannot be appointed. Cal. Prob. Code § 4605.
20 A list of sections in state laws addressing when an advance health care directive becomes effective appears in Appendix B.
22 E.g. “‘Capacity’ shall mean an individual’s ability to understand the significant benefits, risks and alternatives to proposed health care and to make and communicate a health-care decision.” Del. Code § 2501 (1996). “‘Decisional capacity’ means the ability to provide informed consent to or refusal of medical treatment, or the ability to make an informed health care benefit decision.” Colo. Stat. § 15-18-103 (2010). “‘Competent person,’ a person eighteen years of age or older of sound mind who is able to receive and evaluate information and to communicate a decision.” Mo. Stat. § 459.010 (1985).
Some states add to the basic definition and include a provision that there can be no reasonable probability of recovery, or that without the provision of life-sustaining medical treatment death will occur within a short period of time. New Jersey’s definition of “terminal” includes a life expectancy of less than six months. However, the basic definition of “terminal,” as meaning an incurable or irreversible illness or injury, is consistent throughout the states that use that term.

The terms “permanently unconscious” or “persistent vegetative state” are much more subjective, the definitions used by the states are more varied, and various definitions are almost impossible to conform to a single unified standard. For example, the Kansas statutes include a medical definition of permanently unconscious as being a condition that would be “characterized by an absence of cerebral cortical functions indicative of consciousness or behavioral interaction with the environment.” Nebraska defines “persistent vegetative state” as being characterized by “a total and irreversible loss of consciousness and capacity for cognitive interaction with the environment and no reasonable hope of improvement.” Virginia’s definition of persistent vegetative state includes language indicating that the principal “has suffered a loss of consciousness, with no behavioral evidence of self-awareness or awareness of surroundings in a learned manner, other than reflex activity of muscles and nerves for low level conditioned response, and from which, to a reasonable degree of medical probability, there can be no recovery.” In Ohio, persistent vegetative state means “irreversible unawareness of one’s being and environment and total loss of cerebral cortical functioning, resulting in the declarant or other patient having no capacity to experience pain or suffering.” As described, there is little consistency between the states as to the terminology used.

More examples include the Delaware Code, which provides that the provisions of a living will become operative only if the principal has a “qualifying condition” that is defined as being diagnosed with either a terminal condition or being “permanently unconscious.” “Permanently unconscious” means a medical condition that has existed for at least four weeks and includes the term “persistent vegetative state.” In Illinois, a “qualifying condition” can also include an “incurable or irreversible condition,” which is defined as follows:

“Incurable or irreversible condition” means an illness or injury:
(i) for which there is no reasonable prospect of cure or recovery, (ii) that ultimately will cause the patient’s death even if life-sustaining treatment is initiated or continued, (iii) that imposes severe pain or otherwise imposes an inhumane burden on the patient, and (iv) for which initiating or continuing life-sustaining treatment, in light of the patient’s medical condition, provides only minimal medical benefit.33

Oklahoma defines the triggering condition for end-of-life decisions as when the principal is in the “final stage” of an illness, and is in the “dying process and will die within a reasonably short period of time.”34 Colorado’s definition is more flexible, and by its nature, will change. Colorado statutes leave the definition of persistent vegetative state purposefully ambiguous and define the condition “by reference to the criteria and definitions employed by prevailing community medical standards of practice.”35

As described above, the majority of states base the authority of a surrogate decision maker entirely on the condition of the principal. Hawaii does not, and instead allows end-of-life decisions to be made based on what is in the “best interest” of the principal, instead of the medical condition of the principal. Hawaii defines “best interest” as follows:

“Best interest” means that the benefits to the individual resulting from a treatment outweigh the burdens to the individual resulting from that treatment and shall include:
1. The effect of the treatment on the physical, emotional, and cognitive functions of the patient;
2. The degree of physical pain or discomfort caused to the individual by the treatment or the withholding or withdrawal of the treatment;
3. The degree to which the individual’s medical condition, the treatment, or the withholding or withdrawal of treatment, results in a severe and continuing impairment;
4. The effect of the treatment on the life expectancy of the patient;
5. The prognosis of the patient for recovery, with and without the treatment;
6. The risks, side effects, and benefits of the treatment or the withholding of treatment; and
7. The religious beliefs and basic values of the individual receiving treatment, to the extent that these may assist the surrogate decision-maker in determining benefits and burdens.36

Each of the states has defined the condition that triggers the effectiveness of the advance health care directive in its own terms. As a result, someone relying on an out-of-state

advance health care directive may believe that the directive is triggered at one stage of an illness, only to find that in another state, the surrogate decision maker has no authority until a different stage of the illness is reached. Thus, if the practitioner is planning for a person who may move or travel often, it is imperative that he or she understand how these terms may be interpreted among the states if the client is concerned about end-of-life decision making.

D. Effective on Principal’s Pregnancy

Many states also have particular provisions that govern whether or not the advance health care directive will be followed if the principal is pregnant. In those states that address the issue of pregnancy, most indicate that the provisions allowing for the withdrawal or withholding of life sustaining treatment will not be honored if the pregnancy could result in a live birth. Some states allow for options such as the termination of life support if it will not maintain the woman in a way to permit the continuing development and live birth of the unborn child or will be physically harmful to the woman or prolong severe pain, which cannot be alleviated by medication. Several states allow for the pregnant patient to record her own choices about what she would want if pregnant. The majority of states, in addressing issues of pregnancy, seem to place a priority on the life of the unborn child, over following the health care directive, and state that in the event of a pregnancy, the directive will not be followed.

E. Effective Execution Depends on Age of Principal

Every state, and the District of Columbia, requires that the individual executing the advance health care directive be a competent adult. Forty-eight states and the District of Columbia define the term “adult” as an individual age 18 and over. Alabama and Nebraska define the term “adult” as being age 19 or above. Several states allow for someone under the age of 18 to sign an advance health care directive if they are emancipated, married, or the parent of a child. In addition to being an adult, Oregon, Rhode Island, and Oklahoma require the principal to be a resident of the state at the time the advance health care directive is executed. Pennsylvania requires that the person executing the advance health care directive be 18 years of age or older, has graduated from high school, has married, or is an emancipated minor.

37 Appendix A includes a list of statutory citations for each state that address whether pregnancy affects the effectiveness of an advance health care directive.
38 “The declaration of a qualified patient known to the attending physician to be pregnant shall not be in effect as long as the fetus could develop to the point of live birth with continued application of life-sustaining procedures.” Iowa Code § 144A.6 (2009).
F. Effective Only on Agent’s Acceptance

The majority of the states do not require the principal to notify the person appointed as the health care agent or surrogate when establishing the document. However, several states, including Alabama, Michigan, Oregon, and North Dakota require that the attorney-in-fact accept their appointment in writing. Thus, persons moving to those states or travelling in those states must be certain that the proposed agent has consented to act in that role.

G. Effective Only if Execution Formalities are Followed

There are differences in the specifics of the formality of execution. States can require one witness, two witnesses, two witnesses and a notary, or an option of either two witnesses or a notary. New Mexico and Idaho do not require any witnesses or the signature of a notary. Both Texas and Maryland allow for electronic or digital signatures. However, Maine statutes specifically prohibit the use of digital or electronic signatures.

There are also variations as to who can serve as a witness. Many states restrict the ability of the director of any facility in which the principal is living, the principal’s primary physician, or other medical personnel from serving as a witness. A typical provision is found in the Iowa statute, which states:

The following individuals shall not be witnesses for a declaration:
1. A health care provider attending the declarant on the date of execution of the declaration.

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49 “It is recommended but not required that you request two other individuals to sign as witnesses.” N.M. Stat. Ann. § 24-7A-4(2011); “As a result of changes to Idaho law made by the 2005 legislature, it is no longer necessary to have either a witness to your execution of a Living Will, nor to have your signature notarized.” Idaho Office of the Attorney General, www.ag.idaho.gov/livingWills/livingWills_faqs.html#11.
2. An employee of a health care provider attending the declarant on the date of execution of the declaration.

3. An individual who is less than eighteen years of age.  

Other states will not allow the person who is appointed as the decision maker to also serve as a witness. Several states, including California, Connecticut, New York, Oregon, and Vermont, require special signature or witness requirements if the principal is institutionalized in either a long-term care facility or mental health facility at the time the advance health care directive is executed.

H. Effective Upon Divorce or Separation

Most states call for the automatic revocation of the ability of the spouse to serve as the health care agent in the event of a divorce, separation, or annulment of the marriage or domestic partnership unless it is specifically stated otherwise. For example, Colorado’s statutes provide that a divorce or separation causes the authority of the spouse to be revoked “unless otherwise expressly provided in the medical durable power of attorney.”

Alabama requires the immediate revocation of a durable power of attorney in the event of a divorce, but gives the principal the option of specifically allowing the spouse to continue to serve as the health care proxy. Utah and Florida acknowledge that divorce makes former spouses ineligible to continue to serve as agents, but Pennsylvania calls for the automatic revocation upon filing for divorce unless it clearly appears from the advance health care directive that the designation was intended to continue to be effective notwithstanding the filing of a divorce action by either spouse. Most states either call for the immediate revocation of the advance directive or for revocation unless specifically stated otherwise.

All of the states that call for the immediate revocation of the advance health care directive limit the events causing the revocation to a divorce or legal separation, except Louisiana. Its statute calls for the revocation of the advance health care directive if the person is no longer defined as a “spouse.” Louisiana defines the term “spouse,” to mean a “person who is legally married to the qualified patient, but does not include a spouse 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

52 Iowa Code § 144A.3(2) (2008).
53 “No person who has been named as health care agent in a health care proxy shall act as a witness to the execution of such proxy.” Mass. § 1.
55 A complete list of state statutes that address whether divorce immediately invalidates a directive appears in Appendix A.
60 Pa. § 5430 (2007).
any domestic abuse protective order affecting the other spouse.” 61 Various states treat divorce and separation differently in their respective advance health care directives, and therefore the careful practitioner will need to know the laws in the various states to make sure his or her clients are protected in all states where the clients reside. Because, as will be discussed below, the advance health care directive may not be as effective outside the state of its execution.

III. PORTABILITY OF ADVANCE HEALTH CARE DIRECTIVES FROM ONE STATE TO ANOTHER

It might be presumed that an advance health care directive written in one state will be valid in every other state, much like a driver’s license validly issued in one state is valid for driving in every state. However, because of the differences in the states’ laws, there is the potential that an advance health care directive drafted and executed in one state will be deemed “invalid” and not honored by physicians in another state.

The Full Faith and Credit Clause of the United States Constitution requires that each of the states honor the “public acts, records, and judicial proceedings of every other state.” 62 The Clause should ensure that an advance health care directive executed in one state, pursuant to that state’s laws, is valid in every other state. However, the reality may be that an out-of-state advance health care directive is not always honored. The foremost reason is that an out-of-state document gives a health care provider a “reason” to decline to honor the advance health care directive, notwithstanding full faith and credit. 63

In addition to the Full Faith and Credit Clause, most states include a provision within the advance health care directive law that addresses the reciprocity of documents executed in another state. 64 A typical provision from New Hampshire states:

Nothing in this chapter limits the enforceability of an advance directive or similar instrument executed in another state or jurisdiction in compliance with the law of that state or jurisdiction. However, any exercise of power under such a foreign advance directive or similar instrument shall be restricted by and in compliance with the requirements of this chapter and the laws of the state of New Hampshire. 65

Although the majority of states have adopted some type of reciprocity provision, there can be limitations to the reciprocity. Some states indicate that an out-of-state advance health care directive will only be honored to the extent that it complies with the laws of the state in which it is being used. The U.S. Supreme Court’s holding in Cruzan, that the State of Missouri had a legitimate interest in the preservation and protection of

62 “Full faith and credit shall be given in each state to the public acts, records, and judicial proceedings of every other state. And the Congress may by general laws prescribe the manner in which such acts, records, and proceedings shall be proved, and the effect thereof.” U.S. Const. art. IV, § 1.
64 See Appendix B for a list of statutory references of reciprocity provisions for each state.
human life, would seem to support a state’s right to limit the portability of an advance health care directive. A typical provision limiting the applicability of an out-of-state advance health care directive is the following from Iowa, which states:

A declaration or similar document executed in another state or jurisdiction in compliance with the law of that state or jurisdiction shall be deemed valid and enforceable in this state, to the extent the declaration or similar document is consistent with the laws of this state.

Oklahoma’s law includes limitations on reciprocity that pertain specifically to life-sustaining treatment. In Oklahoma, an out-of-state advance health care directive will be recognized for the purposes of withholding or withdrawing life-sustaining treatment only to the extent that the out-of-state advance health care directive specifically authorizes the withholding or withdrawing of life-sustaining treatment. The Oklahoma statute states:

Execution of an advance directive by an individual, which provides for the provision, withholding, or withdrawal of life-sustaining treatment for that individual, or for the appointment of another to give directions to provide, withhold or withdraw life-sustaining treatment executed in another state in compliance with the law of that state or of this state is valid for purposes of the Oklahoma Advance Directive Act to the extent the advance directive does not exceed authorizations allowed under the laws of this state; provided that no such advance directive shall be deemed to authorize the withholding of artificially administered nutrition and/or hydration unless it specifically authorizes such withholding or withdrawal of artificially administered nutrition and/or hydration, and either the advance directive:
1. Was executed by a person who was not a resident of Oklahoma at the time of execution; or
2. Specifically authorizes the withholding or withdrawal of artificially administered nutrition and/or hydration in the declarant’s own words or by a separate section, separate paragraph, or other separate subdivision that deals only with nutrition and/or hydration and which section, paragraph, or other subdivision is separately initialed, separately signed, or otherwise separately marked by the person executing the advance directive.

Whether an out-of-state advance health care directive that fails to specifically authorize the withholding or withdrawal of artificially administered nutrition or hydration will be honored in Oklahoma for that purpose, is unknown. As of this writing, there is no case law addressing that specific issue.

66 Cruzan, supra n. 2, at 281.
There are several states, including Kentucky, Michigan, and Missouri that seem to offer no reciprocity for an out-of-state advance directive.69 A few states that do not have specific reciprocity provisions have included language in their advance health care directive statutes that acknowledges that an individual’s existing rights regarding health care decision-making authority or responsibility are not preempted by the state’s law.70 For example, Alabama includes the following language:

Nothing in this chapter shall impair or supersede any legal right or legal responsibility which any person may have, under case law, common law, or statutory law, to effect the withholding or withdrawal of life-sustaining treatment or artificially provided nutrition and hydration in any lawful manner. In such respect the provisions of this chapter are cumulative.71

This type of language acknowledges that an individual’s rights exist and should be protected and not impaired by any provision of the advance health care directive law. Therefore, in a state that includes this type of language, the instructions of the principal should be followed even if recorded in an out-of-state advance health care directive that is not in compliance with the state’s laws. Oregon, in addition to reciprocity, includes a type of “savings clause” which directs that an instrument that would otherwise be a valid advance health care directive, except that it is not in the proper form, will still “constitute evidence of the patient’s desires and interests.”72

IV. PRIORITY OF SURROGATE DECISION MAKER WHEN THERE IS NO ADVANCE HEALTH CARE DIRECTIVE

Many states include a provision that governs who makes decisions for an incapacitated person if there is no valid advance health care directive in place.73

A. Priority of Appointment

If an advance health care directive is found to be invalid or if there is no directive in place, the “default” provisions of the law allow for the appointment of a surrogate decision maker. For example, Virginia law provides a list of persons who are eligible to serve as the surrogate decision maker in order of priority as follows:

Whenever a patient is determined to be incapable of making an informed decision and (i) has not made an advance directive in accordance with this article or (ii) has made an advance directive in accordance with this article that does not indicate his wishes with respect to the health care at issue and does not appoint an agent, the attending physician may,

69 See Appendix B for a complete list of states with statutes authorizing reciprocity.
73 See Appendix B for a complete list of laws concerning default provisions when no surrogate is named.
upon compliance with the provisions of this section, provide, continue, withhold or withdraw health care upon the authorization of any of the following persons, in the specified order of priority, if the physician is not aware of any available, willing and capable person in a higher class:

1. A guardian for the patient. This subdivision shall not be construed to require such appointment in order that a health care decision can be made under this section; or
2. The patient’s spouse except where a divorce action has been filed and the divorce is not final; or
3. An adult child of the patient; or
4. A parent of the patient; or
5. An adult brother or sister of the patient; or
6. Any other relative of the patient in the descending order of blood relationship.74

There are also several states that do not include a “default” provision but allow for the recognition of a surrogate decision maker. States that do not include such a default provision typically require some type of judicial intervention for the appointment of a guardian to make medical decisions for the incapacitated person. For example, New Jersey does not include a default provision, but instead provides for an emergent court proceeding to appoint a special medical guardian to make medical decisions for an incapacitated person.75 Of the states that provide for a surrogate decision maker to be appointed, every state establishes the “guardian” or “conservator” as the first person who has the right to make end-of-life decisions for an incapacitated person.76 For the majority of states, the next category is “spouse” followed by an “adult child” and “parent.”77 This language is also found within the UHCD Act at Section 5.

B. Priority of Appointment — Same-Sex Couples

The various laws pertaining to the spouse’s role as the surrogate decision maker are particularly troublesome because the majority of states do not recognize same-sex marriages or any form of same-sex relationship, such as a civil union or domestic partnership. As of this writing, there are only six states that recognize same-sex marriages.78 Thirteen states recognize some form of same-sex civil unions or domestic partnerships.79 The remaining states either do not recognize same-sex marriages or relationships, or prohibit them by constitution or statute.80

The Defense of Marriage Act (DOMA) states that no state or territory shall be required to recognize as a marriage a same-sex relationship that is recognized as a marriage

75 N.J. R. 4:86-12.
76 E.g. Iowa Code § 144A.7 (2008).
78 Conn., Iowa, Mass., N.H., N.Y., Vt., and D.C.
79 Cal., Colo., Del., Haw., Ill., Me., Md., Nev., N.J., Ore., R.I., Wash., Wis., and D.C.
80 See Appendix B for a list of states whose constitutions prohibit same-sex marriage.
DOMA prevents the federal government from recognizing same-sex marriages and leaves it up to each individual state to determine if that state will recognize it. Section 3 of DOMA defines the term “marriage” as the “legal union between one man and one woman as husband and wife” and the word “spouse” as “a person of the opposite sex who is a husband or a wife.” Accordingly, a valid same-sex marriage or formalized relationship such as a civil union or domestic partnership granted by one state does not have to be recognized by another state. Thus, if there is no valid advance health care directive, the principal’s same-sex spouse (or domestic partner) may not be allowed to make decisions on behalf of their loved ones.

Many states that do not recognize same-sex marriages or relationships also have laws appointing a “spouse” as a default decision maker in the absence of a valid advance health care directive. Some states protect the same-sex relationship by including a level of priority for one who is not a lawfully recognized “spouse.” Of the states that include a default provision, only Maine, New Mexico, Washington, and Washington, D.C., acknowledge the role of someone other than a “spouse” being appointed as the surrogate decision maker. The New Mexico statute uses the term “individual in a long-term relationship,” and defines “relationship” without reference to gender:

1. an individual in a long-term relationship of indefinite duration with the patient in which the individual has demonstrated an actual commitment to the patient similar to the commitment of a spouse and in which the individual and the patient consider themselves to be responsible for each other’s well-being.

Maryland, Washington, and Washington, D.C., go one step further and acknowledge the rights of a domestic partner. Washington’s statute provides:

For the purposes of this chapter, the terms spouse, marriage, marital, husband, wife, widow, widower, next of kin, and family shall be interpreted as applying equally to state registered domestic partnerships or individuals in state registered domestic partnerships as well as to marital relationships and married persons, and references to dissolution of marriage shall apply equally to state registered domestic partnerships that have been terminated, dissolved, or invalidated, to the extent that such interpretation does not conflict with federal law. Where neces-

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81 Defense of Marriage Act, Pub. L. No. 104-199, 110 Stat. 2419 (1996); 1 U.S.C. § 7 (1996); 28 U.S.C. § 1738C (1996), which states: “No State, territory, or possession of the United States, or Indian tribe, shall be required to give effect to any public act, record, or judicial proceeding of any other State, territory, possession, or tribe respecting a relationship between persons of the same sex that is treated as a marriage under the laws of such other State, territory, possession, or tribe, or a right or claim arising from such relationship.”


83 See Appendix B.


sary to implement chapter 521, Laws of 2009, gender-specific terms such as husband and wife used in any statute, rule, or other law shall be construed to be gender neutral, and applicable to individuals in state registered domestic partnerships.86

Maryland, Washington, and Washington, D.C., either allow for domestic partnerships or recognize domestic partnerships that have been granted by other states.87 Wisconsin defines the term “relative” to include a domestic partner.88 Maryland adds “friend” or other relative as the last category of persons able to serve as the surrogate decision maker.89 However, the individual purporting to be the friend or other relative has to be prepared to submit an affidavit stating “that the person is a relative or close friend of the patient; and specific facts and circumstances demonstrating that the person has maintained regular contact with the patient sufficient to be familiar with the patient’s activities, health, and personal beliefs.”90 In the absence of a valid advance health care directive, Hawaii statutes require the treating physician to “make reasonable efforts to locate as many interested persons as practicable” and then the interested persons have to “make reasonable efforts to reach a consensus as to who among them shall make health-care decisions on behalf of the patient.”91

An adult with capacity has the right to choose his or her own surrogate decision maker. If the principal chooses their same-sex spouse or partner, that choice will be honored as long as the advance health care directive document is honored. Problems may arise, however, if an out-of-state document is deemed invalid because it does not comply with the requirements of the state in which the care is being provided as described in the sections above. As set forth in this article, there are a myriad of differences between the states’ laws with regard to advance health care directives. Any one of the differences in the witnessing requirements, language used, or triggering events that make the directive operative could cause an out-of-state directive to be deemed invalid. If a state does not accept the out-of-state advance health care directive, the default provisions of how a surrogate decision maker is chosen would apply if the state’s law contains default provisions.

If the state refused to honor the advance health care directive, this may result in another family member, perhaps one who is hostile towards the same-sex spouse or partner, being given the authority to make end-of-life decisions. This conflict in the laws will affect an increasing segment of our population. According to the Public Policy & Aging Report, the number of lesbian, gay, bisexual, and transgender older adults is expected to double from 1.5 million, to more than 3 million by 2030.92 Thus, it is vitally important

86 Wash. Rev. Code § 70.122.925.
88 Wis. § 155.01 (1983).
89 Md. § 5-605(a)(3) (2010).
90 Id.
for those advising same-sex partners and spouses to maintain valid advance health care directives in every state in which they may be living or visiting.

V. Conclusion

An advance health care directive drafted and signed in one state may not be honored by another state, especially if the authority provided in the document to an agent is broader than that allowed in the state where treatment is being given. As set forth in Appendix B, several states do not offer specific reciprocity within their advance health care directive statutes. Other states offer only limited reciprocity. A document may be found to be invalid and thus not honored if it is not witnessed and executed in accordance with the requirements of the state in which the principal is receiving treatment. Many of the states’ reciprocity provisions provide for an out-of-state advance health care directive to be accepted if it complies with the laws of the state in which it was drafted. However, it is unrealistic to expect health care providers to be familiar with the exact requirements of each state in order to determine if the out-of-state advance health care directive is in compliance with the laws of the state in which it was written. Even if the out-of-state directive is honored, it may contain language or definitions that are not used or recognized or have an entirely different meaning than what would be used in another state.

For clients who routinely travel between two states, it may be sensible to have two separate advance health care directives prepared, especially if the client is in a same-sex relationship. At a minimum, any advance health care directive used should have two witnesses and a notary sign the document, even if only one witness or a notary is required in the home state. If a document is signed by more than the number of witnesses required, it will not cause a document to be invalid and may make an out-of-state document more acceptable.

There are several online resources available that provide advance directive forms tailored to each state, such as Caring Connections and New York Online Access to Health. In addition, there are sites that provide an online registry for advance health care directives, such as the U.S. Living Will Registry. It is relatively easy to prepare an advance health care directive for use in another state using one of these online resources. Many states’ statutes also include a suggested form that can be used.

The need for uniformity in the provisions of advance health care directives is apparent. The adoption of the Uniform Health Care Decisions Act was the first step in attempting to achieve uniformity. However, because it was adopted before DOMA, the default provisions in the UHCD Act now cause a conflict, and potentially disenfranchise members of the LGBT community. It is unlikely that a consistent, uniform law will be adopted by every one of the 50 states and the District of Columbia any time in the near future. Therefore, it is incumbent upon Elder Law practitioners to either attempt to draft more flexible documents that would be more readily acceptable in other states, or to recognize those clients who would be best protected by preparing a separate document specifically drafted for each state in which the client spends significant time.

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## Appendix A: Summary of Various Provisions

<table>
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<tr>
<th>State</th>
<th>Age</th>
<th>Wit.</th>
<th>Notary</th>
<th>Reg.</th>
<th>LW</th>
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<th>Effective only if incap. unless otherwise specified</th>
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<th>Reg.</th>
<th>LW</th>
<th>HCPOA</th>
<th>AD</th>
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*Option* means has the option of reaffirming the appointment of ex-spouse.

"option" means has the option of reaffirming the appointment of ex-spouse.
Appendix B: Reciprocity, Default, and Same-Sex Marriage Recognition

<table>
<thead>
<tr>
<th>State</th>
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<th>Default Provisions</th>
<th>Status of Same-Sex Marriage Status of Same-Sex Union</th>
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<td>Alabama</td>
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<td>§ 13.52.030</td>
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<td>Arizona</td>
<td>§ 36-3208</td>
<td>§ 36-3231</td>
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<td>Arkansas</td>
<td>§ 20-17-212</td>
<td>§ 20-17-214</td>
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<td>California</td>
<td>§ 4676</td>
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<td>Domestic Partnership Previous marriages valid</td>
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<tr>
<td>Colorado</td>
<td>§ 15-14-509 § 15-14-503</td>
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<td>§ 2507</td>
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<td>§ 5-805 (b)</td>
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ADVANCE DIRECTIVES: THE ELUSIVE GOAL OF HAVING THE LAST WORD

By Susan P. Shapiro, PhD

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I. INTRODUCTION

One of the more controversial elements of the debate over health care reform in the
United States concerned a rather benign proposal to compensate physicians for conversa-
tions held at most once every five years, if requested by Medicare patients, about advance
directives¹ and patient preferences regarding future medical treatment. It is curious that crit-

Susan P. Shapiro, PhD, is a sociologist and research professor at the American Bar Foundation, Chicago, Ill.
She is conducting research in two intensive care units observing how families and others make medical deci-
sions for patients who are unable to speak for themselves. Shapiro is the author of Tangled Loyalties: Conflict
of Interest in Legal Practice (winner of the Distinguished Book Award of the Sociology of Law Section of the
American Sociological Association) and Wayward Capitalists: Target of the Securities and Exchange Com-
mmission. She has written numerous articles on the role of law at the end of life, surrogate decision making,
the legal profession, ethics, conflict of interest, fiduciary relationships and trust, securities fraud and regula-
tion, white-collar crime, and the regulation of “truth” in the news media. Shapiro was formerly a professor
at Northwestern and New York Universities. She received her AB from the University of Michigan and PhD
from Yale University.

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tional Science Foundation under Grant No. SES 0752159, and an Investigator Award from the Robert Wood
Johnson Foundation. Any opinions, findings, conclusions, or recommendations expressed in this material are
those of the author and do not necessarily reflect the views of the National Science Foundation or the other
foundations. Special thanks to Rachel Billow.

¹ Advance directives are legal documents in which competent adults give instructions regarding their
health care in the event they lose decisional capacity in the future. There are generally two types of
directives: proxy directives designate one or more persons to make health care decisions on a person’s
behalf; instructional directives provide guidance about the type and amount of care desired. Instructional
ics were so fearful that this would inevitably lead to “death panels” in which infirm or elderly patients would be coerced into ending their lives. Existing research and theory have repeatedly demonstrated the extraordinary difficulty of affecting end-of-life decision making. For example, a massive social experiment undertaken 20 years ago involving 9,000 seriously ill patients across five hospitals found that an intervention: 1) enhanced communication between patients, families, and medical staff; 2) supplied greater prognostic information to each of them; and 3) provided ongoing opportunities for patients or their spokespersons to articulate their wishes and preferences regarding treatment with treating physicians, made no difference. With great surprise, the investigators reported that:

Patients experienced no improvement in patient-physician communication… or in the five targeted outcomes: incidence or timing of DNR orders… physicians’ knowledge of their patients’ preferences not to be resuscitated… number of days spent in an ICU, on a ventilator, or in a coma before death… or level of reported pain… . The intervention also did not reduce use of hospital resources… 2

They concluded that the “study certainly casts a pall over any claim that, if the health care system is given additional resources for collaborative decision making in the form of skilled professional time, improvements will occur.”3

Despite repeated campaigns for decades, coupled with regulations that require all hospitals to offer advance directives to patients upon admission, a substantial majority of Americans have not executed advance directives.4 Moreover, comprehensive reviews of the empirical and theoretical literature have documented the failure of instructional directives such as living wills as effective means of guiding medical decision making for patients unable to speak for themselves.5

In short, the prospect of giving patients the last word about their goals of medical care has received little empirical support. However, an article recently published in the influential New England Journal of Medicine6 finds advance directives both prevalent and

2 SUPPORT Principal Investigators, A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) 274 J. Amer. Med. Assn., 1591, 1591 (no. 20, 1995).

3 Id. at 1596.


Advance Directives:
The Elusive Goal of Having the Last Word
Fall 2012

The authors make three primary claims based on a large representative sample of U.S. adults 60-years-old or older who had died between 2000 and 2006:

1. “Among subjects who needed surrogate decision making, 67.6% had an advance directive. …The fact that so many elderly adults complete advance directives suggests that they find these documents familiar, available, and acceptable. Moreover, it suggests that elderly patients, their families, and perhaps their health care providers think that advance directives have value.”

2. “Patients who had prepared advance directives received care that was strongly associated with their preferences.”

3. “Both a living will and durable power of attorney for health care appear to have a significant effect on the outcomes of decision making.”

The authors conclude that “advance directives are important tools for providing care in keeping with patients’ wishes” and that their “findings support the continued use of advance directives.” The study was cited in short-lived Medicare regulations that authorized compensation for advance care planning in wellness visits for Medicare patients.

Unfortunately, the New England Journal of Medicine study (the “Proxy Study”) is compromised by four methodological limitations, some of them acknowledged by the authors, which call these findings into question. First, researchers had no independent measures of whether the subjects had actually ever executed an advance directive, what was contained therein, or the nature of their end-of-life medical care. Data were obtained from family members (called “proxy respondents”) on average 13 months after the subjects had died. As the authors themselves concede, the proxies were “subject to recall and social-desirability biases, especially with regard to subjective details such as patients’ preferences.” Proxy respondents were not asked how they knew the subject had an advance directive or whether or when they had ever seen it or even whether their recollections were of legally documented instructions. Investigators simply took their word.

These proxy respondents were usually (80 percent of them) the same persons who had made medical decisions on behalf of patients lacking capacity before they died. Over-

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7 Id. at 1216–1217.
8 Id. at 1211.
9 Id. at 1218.
10 Id.
11 Id. at 1211.
12 75 Fed. Reg. 73170, 73406 (Nov. 29, 2010).
13 Silveira et al., supra n. 6, at 1217–1218.
15 Silveira et al., supra n. 6, at 1217.
16 Id. at 1214.
whelmingly (94 percent), these proxy respondents chose to forego measures to prolong life. In essence, the interviews asked those charged with following the advance directive whether they did. The finding that these directives “have a significant effect on the outcomes of decision making” is not persuasive when there is no independent measure of either variable other than proxy reports. Rather, it appears that those who had responsibility for ending the life of a loved one remember, 13 months later, that this is what their loved one wanted.

Second, the Proxy Study’s classification of advance directives does not correspond to real-world choices. There is a plethora of legal statutes, forms, and options across the 50 states through which patients are able to express their preferences for care at the end of life. In some states, these advance directives include complex check lists and flow charts through which patients pick and choose different treatment options for different diagnoses and prognoses, expand or limit the discretion of decision makers, and allow for decisions to change over time or even by cost. Unfortunately, these detailed instructions do not correspond to the categories that the researchers gave proxy respondents to classify patients’ written directives. Rather, the Proxy Study used the following three categories, a desire to:

1. “… receive all care possible under any circumstances in order to prolong life,”
2. “… limit care in certain situations,” or
3. “… keep [her/him] comfortable and pain free but to forgo extensive measures to prolong life.”

Presumably, investigators came up with these categories as least common denominators that capture the enormous diversity in advance directives across the 50 states. In doing so, however, they may have inadvertently created the very findings they observe. The fact that interview categories were broader than the actual options available on advance-directive forms, capturing so many distinct and sometimes inconsistent contingencies, may explain why the study found that care was strongly associated with patient preferences. For example, if the advance directive indicated that life support be removed only if in an irreversible coma and life support was subsequently withdrawn from the non-comatose patient because of concerns about future quality of life, proxies would report both preferences and treatment as “limiting care in certain situations,” despite the fact that the situations are by no means equivalent.

Third, the Proxy Study’s analysis only pertains to decedents whose proxies indicated had executed advance directives. Since aggressive care is the legal default, living-will-type directives in many states only allow for requests to withhold or withdraw treatment. Those opting for full treatment to prolong life, therefore, have no reason (and in some states, no legal document in which) to make written instructions. The Proxy Study exhibits a profound selection bias that over-represents those whose goals of care are to limit treatment and under-represents those who want aggressive care. This is exacerbated by the fact that there is a correlation between the desire for aggressive care and certain de-

17  Id. at 1217 (calculations from Table 3).
18  Supplementary Appendix, supra n. 14.
mographic characteristics — race, for example — which, in turn, are correlated with the absence of formal legal directives. The Proxy Study’s focus on only those allegedly with directives may thus under-represent important demographic groups.

Fourth, interviews assume a single decision point. Proxy respondents were asked, “Did those last decisions involve a desire to give all care possible unconditionally in order to prolong life; involve limiting care in certain situations; rest largely on keeping the patient comfortable and pain free without taking extensive measures to prolong life?”

Many respondents could have answered, “yes” to all three questions. As described below, dozens of medical decisions are made in the last days or weeks of life, especially for hospitalized patients, and it is not at all unusual for decisions to shift from one category to the next, sometimes back and forth. Is fidelity to the patient’s wishes measured by what decision is ultimately made or how long it took to implement these wishes or how many interventions were pursued along the way to comfort care? The Proxy Study interviews provide no guidance.

What the Proxy Study does tell us, however, is something about how those responsible for the death of a loved one remember the end of their lives. It tells us far less about whether, how, or under what conditions advance directives have an impact on how they die or how others survive.

II. METHOD

This paper reexamines these questions about the impact of advance directives with data that do not share the methodological limitations of the Proxy Study. The data here come from a multi-year observational study of more than 2,000 patients who passed through either the neurological or the medical intensive care units (ICU) of a large urban teaching hospital in Illinois serving a demographically diverse population of patients from early 2007 until late 2009. The neurological ICU houses patients experiencing brain trauma, hemorrhages, strokes, seizures, brain cancers, and spinal cord injuries. Patients in the medical ICU suffered from organ failures, sepsis, respiratory distress, other cancers, bleeding, and so on. Two-hundred five of these patients lacked capacity to make medical decisions; observations focused on those who spoke on their behalf. These surrogate decision makers faced a host of decisions, ranging from whether to undertake surgery or other medical procedures to whether to withhold or withdraw life support or donate the patient’s organs.

From daily rounds with the critical care team, observations of more than 1,000 en-

19 Id.
20 The Proxy Study certainly has important strengths. It is based on a very large national representative sample of all deaths of Americans 60 years of age or older, not only those that occur in hospitals. Limitations of the study reported here are assessed in the conclusion of this article.
21 As shown in Table 2, patients are very diverse, reflecting demographic trends nationwide.
22 Specifically, the observational study included all ICU patients deemed by their physicians to be unable to make medical decisions and about whom at least three interactions between health care providers and patient representatives or a discussion regarding goals of care or consent to a medical procedure were observed. Many ICU patients (especially those admitted after a surgical procedure) do not lack or quickly regain competence or are discharged from the ICU in a day or two before any treatment decisions are made; for others, families never visit and there are no encounters to observe. That is why a relatively small proportion of all ICU patients were the focus of the observational study.
counters between almost 300 health care providers and more than 600 patient families and friends throughout the day, and both paper and electronic medical records, data were gathered on patient medical histories, the medical issues and decisions they faced, the interventions made on their behalf, the disposition of their hospital stay, their advance directives (if any), their demographic characteristics as well as those of other participants in the decision-making process, and what transpired in meetings and conversations with their representatives regarding their medical care.23

Observations were conducted by the author and a social worker. To minimize the risk that the act of observing might influence the activities being observed, encounters were not tape recorded nor were notes taken. At their conclusion, the observers recreated transcripts of what was said, by whom, and documented the dynamics of the interaction and characteristics of the meeting and participants. Excerpts from a few of the 1,000-plus transcripts are presented throughout this article. For each patient, the actual advance directives in the hospital chart were examined, the actual decisions made on behalf of the patients, day after day, were known, and the process by which and articulated reasons for which these decisions were made were observed.

III. Findings

In the following sections, I describe the prevalence of advance directives and the characteristics of ICU patients who have them, the content of legal directives, the verbal instructions and expressed wishes of patients reported by their significant others, the difficulties interpreting and following these written directives and verbal instructions, and the impact of advance directives on the decision-making process and outcomes, especially the likelihood that patient wishes are honored.

A. Prevalence of Advance Directives

When patients are admitted to the ICU, the patients or the persons who accompany them are asked whether they have or the patient would like to complete an advance directive — in Illinois, a power of attorney for health care, naming a proxy decision maker and possibly optional instructions, and/or a living will.24 For the majority of patients in the two ICUs in the study, the answer to both questions is “no.” Table 1 demonstrates that a little more than a third of all the patients who passed through the two ICUs or their spokespersons report an advance directive or complete one during the hospitalization.25 Powers of attorney are most common among those who do; 91 percent claim to have powers of attorney and 54 percent living wills. Despite continual prodding of family members to bring in copies of these advance directives, few ever appear in the patient’s chart; it is not clear

23 The research protocol was reviewed and approved by the hospital’s Institutional Review Board as well as that of the American Bar Foundation.
24 For the wording of Illinois power-of-attorney and living-will documents, see infra nn. 32 and 33.
25 The percentage of patients with directives among those from whom hospital staff were able to obtain such information is higher (46 percent) than that for all ICU patients; however, this is not really the relevant number. Missing information (whatever the reason) means no directive. When medical decisions invariably need to be made, only a third of patients have a legally authorized decision maker and/or legally documented wishes.
that many of them actually exist. Only one in ten of the patients have any documentation in their medical record of their wishes and/or of their legally designated medical decision maker.

**TABLE 1: ADVANCE DIRECTIVES IN THE ICUS**

<table>
<thead>
<tr>
<th>No Advance Directive (AD)(^1)</th>
<th>936</th>
<th>42%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only Power of Attorney (POA)</td>
<td>365</td>
<td>16%</td>
</tr>
<tr>
<td>Only Living Will (LW)</td>
<td>74</td>
<td>3%</td>
</tr>
<tr>
<td>Both POA and LW</td>
<td>351</td>
<td>16%</td>
</tr>
<tr>
<td>Hospital did not or could not obtain AD information(^2)</td>
<td>490</td>
<td>22%</td>
</tr>
<tr>
<td>All ICU Patients</td>
<td>2,216</td>
<td></td>
</tr>
<tr>
<td>POA and/or LW in Chart</td>
<td>212</td>
<td>10%</td>
</tr>
</tbody>
</table>

1 This includes patients who were offered the opportunity to complete an advance directive and chose not to.

2 In some cases (especially with emergency admissions), patients were comatose or incompetent and thus could not be asked about their advance directives and no family was around to ask. Although nurses were reminded to ask for this information throughout the admission, some did not or were not successful in obtaining this information.

These data are not especially reliable in the best of worlds, and even less so in an intensive care unit where many patients arrive comatose, confused, intubated, or heavily sedated. Members of the patient’s entourage may not know whether the patient had any advance directives and, if so, what the patient specified. It may depend on which member of the patient’s entourage is interviewed by hospital staff or even who conducts the interview. Significant others sometimes report their assumptions rather than actual knowledge; while other patients have no significant other to question. When asked about advance directives, patients and others are not always given explanations of the categories and frequently pick the wrong ones. Many, for example, assume that a presumptive decision maker is a power of attorney and do not realize that a witnessed and signed document is needed; others assume that a power of attorney for financial matters is the same thing as

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26 Patients may misremember, misunderstand, or tell hospital staff what they think staff want to hear. When patients lack capacity, as ICU patients often do, advance directive status is reported by significant others who are even less likely to have correct information. Fried et al. found that 13 percent of surrogates report the existence of living wills and 28 percent report the existence of health care proxy documents that patients did not complete. (Another 6 percent and 4 percent, respectively, erroneously report that these documents were not completed.) Studies that rely on anyone’s account of the existence of a directive undoubtedly overreport the prevalence of completion. Terri R. Fried, Colleen A. Redding, Mark L. Robbins, John R. O’Leary & Lynne Lannone, *Agreement Between Older Persons and Their Surrogate Decision-Makers Regarding Participation in Advance Care Planning*, 59 J. Amer. Geriatrics Socy. 1105 (2011).
one for medical decisions. In some unknown number of instances, a legal document may exist, but may not reflect the wishes of the patient. For example:

Attending Physician: I see that you brought in the power-of-attorney document. It was from 2001.

Patient’s Son: She was at [a different hospital] at the time. I believe that a chaplain brought the form in. He read it to us. She could barely understand it.

Attending Physician: I’ve looked over the form. You see here, your mother checked this box that says that she wants to have aggressive care unless she is in an irreversible coma.

Patient’s Son: Yes. I never really read the form. That’s what she is now.

Attending Physician: Unfortunately, a coma is a medical term with a very precise meaning. Your mother is not in a coma. She may experience some cognitive limitations — severe cognitive limitations — but they are not a coma, and not an irreversible coma. This hospital has a strict policy that if this box is checked, we have to provide aggressive care, even if that’s not what the patient would have wanted or even told their family...

Patient’s Son: So you are saying that she has to have a trach???

[PAUSE] You know, this document... She didn’t understand it. She was pretty demented. I was sitting there while the chaplain was reading to her. Basically, I told him what to do. I thought a coma was pretty much what she is in now. I checked the box.

Attending Physician: Unfortunately we have to follow the law. This is so difficult. I’m really sorry.

Of course, if the patient’s son (or the patient’s daughter in the previous footnote), like most families, had not brought in the power-of-attorney form, no one would have ever discovered the problem. These sorts of scenarios are undoubtedly not uncommon. Research on the social construction of advance directive documents is sorely needed.

As indicated earlier, the Proxy Study found that proxy respondents reported that two-thirds of all decedents 60 or older who lacked decision-making capacity had an advance directive. This is quite high compared with the overall rate in the two ICUs I studied and with that documented by other researchers. The difference could be attributed to the

27 One patient in the study had been in the ICU for two weeks. After days of wrenching conversations, the family decided to remove her life support. At the insistence of a physician, the patient’s daughter brought in a copy of the power-of-attorney form; however, the document only addressed the handling of financial matters. Under Illinois law, only a designated power of attorney for health care is permitted to remove life support from a patient who does not have a qualifying medical condition, which this patient did not have. The family was stunned and infuriated by the news that the life support had to continue.

28 Indeed, on examination of the form, the check mark was strong and legible, whereas the patient’s signature was a thin meandering undecipherable line across the diagonal of the page.

29 Recent studies find advance directive use ranging from 29 percent to 37 percent, Pew Research Center for the People & the Press, AARP, and ABA, supra n. 4.
Limited demographic group considered in the Proxy Study. Using the inclusion criteria employed by the Proxy Study, among the patients in the two ICUs who were also 60 or older, lacking capacity, and who ultimately died during their hospitalization, 65 percent had advance directives (compared to 36 percent of all ICU patients). The roughly two-thirds rate in both studies reflects a very narrow slice of the adult population. The Proxy Study uses this limited demographic group to celebrate the widespread prevalence and what they infer to be the acceptance of advance directives. The ICU data — with directives reported by roughly half this proportion, even among those sick enough to be in an intensive care unit — suggest otherwise.

The ICU data reveal large differences in the likelihood of having an advance directive by a variety of demographic characteristics. As reflected in Table 2, the most important

<table>
<thead>
<tr>
<th>Characteristic (N)</th>
<th>Percent of Those Asked Who Report an Advance Directive</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female (866)</td>
<td>46%</td>
</tr>
<tr>
<td>Male (860)</td>
<td>46%</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>30 or less (153)</td>
<td>21%</td>
</tr>
<tr>
<td>31-50 (457)</td>
<td>28%</td>
</tr>
<tr>
<td>51-65 (549)</td>
<td>48%</td>
</tr>
<tr>
<td>66-75 (319)</td>
<td>56%</td>
</tr>
<tr>
<td>More than 75 (248)</td>
<td>76%</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White (1127)</td>
<td>56%</td>
</tr>
<tr>
<td>Black (377)</td>
<td>27%</td>
</tr>
<tr>
<td>Hispanic (109)</td>
<td>20%</td>
</tr>
<tr>
<td>Other (77)</td>
<td>32%</td>
</tr>
<tr>
<td><strong>Wealth of Residential Neighborhood</strong></td>
<td></td>
</tr>
<tr>
<td>Poorest zip code (446)</td>
<td>35%</td>
</tr>
<tr>
<td>Medium zip code (837)</td>
<td>46%</td>
</tr>
<tr>
<td>Richest zip code (441)</td>
<td>57%</td>
</tr>
<tr>
<td><strong>Health Insurance</strong></td>
<td></td>
</tr>
<tr>
<td>No insurance (214)</td>
<td>22%</td>
</tr>
<tr>
<td>Public aid (104)</td>
<td>16%</td>
</tr>
<tr>
<td>Private insurance (768)</td>
<td>43%</td>
</tr>
<tr>
<td>Medicare (636)</td>
<td>62%</td>
</tr>
<tr>
<td><strong>Medical History</strong></td>
<td></td>
</tr>
<tr>
<td>Unexpected emergency (502)</td>
<td>39%</td>
</tr>
<tr>
<td>General health problems (295)</td>
<td>40%</td>
</tr>
<tr>
<td>Long-standing problem (929)</td>
<td>51%</td>
</tr>
<tr>
<td><strong>Elective hospitalization</strong></td>
<td></td>
</tr>
<tr>
<td>No (1446)</td>
<td>45%</td>
</tr>
<tr>
<td>Yes (280)</td>
<td>50%</td>
</tr>
</tbody>
</table>

1 Median household income, as reported in the 2000 census, for the poorest ZIP codes was less than $38,500 and for the richest zip codes exceeded $64,000; the range was $14,200 to $200,000.
predictor that an ICU patient is said to have an advance directive is age: the proportion rises in a linear fashion from 21 percent of patients 30 or younger to 76 percent of those over 75. The influence of age is also reflected in the fact that patients on Medicare have the highest rates of advance directives (62 percent) among those with different health insurance arrangements. Wealth is a second predictor with patients residing in the poorest zip codes and with no medical insurance or on public aid having substantially lower rates of advance directive use. The prevalence of advance directives also varies by race and ethnicity. African American and Hispanic patients report substantially fewer advance directives than their white counterparts. Finally, although patients with longstanding medical problems or who are hospitalized for elective procedures are more likely to have advance directives than those who are admitted to the ICU after an unexpected emergency, the differences are not as large as one might expect and certainly smaller than the other characteristics.

B. Written Instructions

Limited data are available about patients’ legally articulated wishes as only approximately 10 percent of all ICU patients (27 percent of those with advance directives) had directives brought to the hospital or executed directives while at the hospital. These limitations are also faced by medical staff; most of the time there is no document on hand indicating who the patient selected as the power of attorney or if written wishes were expressed and, if so, what they are.

Table 3 summarizes the content of the advance directives in the hospital record for the patients lacking decisional capacity who were the subject of the observational study. The Illinois power-of-attorney form offers optional check boxes regarding general treatment preferences. Eighty-two percent of patients in the observational study with a power of attorney in the chart check one of the boxes. By far, patients give their powers of attorney the most discretion, authorizing them not to prolong life if the burdens outweigh the benefits (this is

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30 The relationship between having an advance directive and age, ethnicity, and wealth remains strong when controlling for the other variables.

31 Twenty of the patients had worked in the legal or medical field, where one might expect greater use of advance directives. One quarter of them had no directive, 55 percent reported having an advance directive that never made it to the hospital, and 20 percent had their directives in the hospital record.

32 The options included the following:

- "I do not want my life to be prolonged nor do I want life-sustaining treatment to be provided or continued if my agent believes the burdens of the treatment outweigh the expected benefits. I want my agent to consider the relief of suffering, the expense involved and the quality as well as the possible extension of my life in making decisions concerning life-sustaining treatment."
- "I want my life to be prolonged and I want life-sustaining treatment to be provided or continued unless I am in a coma which [sic] my attending physician believes to be irreversible, in accordance with reasonable medical standards at the time of reference. If and when I have suffered irreversible coma, I want life-sustaining treatment to be withheld or discontinued."
- "I want my life to be prolonged to the greatest extent possible without regard to my condition, the chances I have for recovery or the cost of the procedures."

true of 79 percent of those who check an option on their power-of-attorney form). Substantially fewer (9 percent) ask that life be prolonged to the greatest extent possible or that it be prolonged unless the patient has an irreversible coma (12 percent). A number of patients also executed living wills. The Illinois living-will form contains boiler-plate language that states that death should not be artificially postponed if the individual has an incurable, irreversible, terminal condition and death is imminent;33 5 percent of the charts of the 205 patients in the observational study contained copies of living wills. See Illinois Living Will, infra n. 33.

A handful of patients added additional statements to their advance directives. A fifth specified that they did or did not want to donate organs. Four percent approved of treatment only if it is likely that they will return to their current lifestyle or level of functioning. A few addressed quality of life (2 percent), nutrition and hydration (13 percent), loss of mental capacity or being in a persistent vegetative state (8 percent), eschewed specific procedures or heroic measures (6 percent), or requested cremation (6 percent). Other individuals wrote explicitly that they do not want cost to be a consideration; do not want to be in pain; do not want dialysis, surgery, or chemotherapy; want to die of natural causes, not on life support; want to be able to eat and drink without medical assistance. One penciled in that she wanted her life prolonged as long as possible, even if it meant being kept alive on machines for years; she also indicated that she does not want blood products, but

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33 “If at any time I should have an incurable and irreversible injury, disease, or illness judged to be a terminal condition by my attending physician who has personally examined me and has determined that my death is imminent except for death delaying procedures, I direct that such procedures which would only prolong the dying process be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication, sustenance, or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care.” Illinois Living Will, in Illinois Living Will Act, http://www.state.il.us/aging/1news_pubs/publications/poa_will.pdf.
would consider blood fractions or medical procedures involving the use of her own blood. Four percent of the patients had a pre-existing “Do Not Resuscitate” order.

Advance directives provide one mechanism for individuals to have the last word about their medical care. But, as we have seen, they are infrequently completed and rarely available to medical staff. Even when the documents are included in the medical record, they often do not articulate the patient’s wishes or simply give decision-makers wide discretion (authorizing them to weigh benefits and burdens of treatment without articulating what they personally consider beneficial or burdensome or how these factors should be weighted). When they express the patient’s wishes, directives often provide abstract guidance not easily translated to the nuanced contingencies of real-world patient care. The following demonstrates the paralysis that ensues when the surrogate refuses to play an interpretive role and insists that the advance directive be literally followed.

Critical Care Fellow: Okay, why don’t I start by giving you an update of what’s going on. Earlier this morning, [Patient] needed platelets. When the nurse gave her the platelets, her blood pressure went up to the 230s, so we gave her medications to bring it down. At that point, her blood pressure fell very low and her heart stopped. We performed CPR, including aggressive chest compressions, for about 15 minutes. She suffered during that process. We were about to call it because it didn’t seem like we’d be able to bring her back. But at the last minute, she regained a pulse. We gave her the max dose of pressors to keep her blood pressure up. Then just a short time later, her heart stopped again. We did more compressions for about 8 or 9 minutes until she regained a pulse. Now, the question I know you’re wondering about is what her prognosis is. That’s what I would want to know, whether she would regain her neurological functioning. She does have brain stem functioning now, which is what you need to breathe, for your heart to pump blood. We have a neuro intensivist on staff who did a full neurological exam on her before I came in to talk to you folks. She does not have higher functioning capabilities now. So she can’t interact, or think or any of that. It’s too soon to know for certain whether that will ever come back, but given the two arrests, it is very unlikely. If you wanted us to confirm that, we could do some diagnostic tests that would determine with greater certainty, but those take three days and seven days to get the results. What we do know is that her pupils are very dilated. When her blood pressure got so high, we think there might have been a bleed in her brain.

Husband: A stroke?

Critical Care Fellow: Yes. Now we look to you, her loved ones. You know her and love her, and so it’s important for you to tell us what you think her wishes would be in this situation.

Husband: She has a living will. [HUSBAND STANDS UP AND WALKS OVER TO HIS BRIEFCASE. HE OPENS IT UP, TAKES OUT
A MANILLA ENVELOPE, AND PUTS THE LIVING WILL (WHICH IS ACTUALLY A POWER-OF-ATTORNEY FORM) ON THE TABLE IN FRONT OF THE CRITICAL CARE FELLOW.] [CRITICAL CARE FELLOW READS IT]

Critical Care Fellow: I think this is where she’s at now. I’m so sorry.

Husband: I knew this day was gonna come, I just didn’t realize it would be so soon. Oh, [Patient]! [HUSBAND STANDS UP AND WALKS OVER TO THE WINDOW. HE’S CRYING AT FIRST, AND THEN BREAKS DOWN AND BEGINS CRYING HYSTERICALLY, SOBBING LOUDLY.]

Patient’s Brother: So are we making a decision today?

Husband: No, [Brother]. I’m not making any decisions. It’s all in the living will; so don’t even go there. Don’t put this on me! [HUSBAND IS POINTING AT HIM AND SHAKING HIS FINGER AT HIM.]

Patient’s Brother: I’m not, [Husband]. So what do we do now? Do we go home?

Critical Care Fellow: It’s up to you.

Husband: We have to wait for the tests.

Critical Care Fellow: Right. Some families would say just stop. That’s why I wanted to talk to you all.

Husband: They’re saying she’s clinically dead. But she’s still hangin’ on. So now we wait for the tests.

Critical Care Fellow: Would it be helpful to have the neurologist who examined her come and answer any questions you may have?

Husband: Sure.

Critical Care Fellow: Okay, I’ll go get him.

... ... ...

ABOUT 15 MINUTES LATER, AFTER THE PATIENT HAD A THIRD CARDIAC ARREST:

Neurology Fellow: She is having another episode requiring chest compressions. There’s blood coming out of her trach. The chest compressions are very aggressive. It’s up to you as her family, but my recommendation would be to just have them stop doing the compressions and stop trying to resuscitate her. It’s a very painful process, and the chances that she would have any neurological functioning after a third cardiac arrest and resuscitation are very low.

Patient’s Sister-in-law: [IN TEARS] Just let her go!

Husband: It’s all on the paper. It’s out of my control. Look, I don’t want her to suffer any more than anyone in this room. [HE SHOVES THE ADVANCE DIRECTIVE FORM IN FRONT OF THE NEUROLOGY FELLOW.] You’re the doctor. Just read it. You’re the doctor, you figure it out. Is she gonna be brain dead?

Neurology Fellow: I can’t tell you-

Husband: Read it!!
Neurology Fellow: [GLANCES AT THE FORM AND THEN PUTS HIS HAND ON THE HUSBAND’S ARM.] I read it, and I’m very familiar with these forms. Unfortunately they’re very obscure in practice. They rarely translate well to actual situations. I can’t definitively say whether she will be in a coma. She has brain stem functioning, so she’s not brain dead. Brain death only occurs when there is no brain stem functioning even. She could have brain functioning but be in a persistent vegetative state. I can’t give you any numbers, but I would say that if her heart stops again, the chance of her having any neurological functioning would be next to zero. I think the important thing to think about is this. If she were able to sit here with us and understand what was happening to her, do you think that she would want this?

C. Verbal Instructions

A complementary or alternative strategy to have the last word is to express one’s wishes, values, and priorities directly to one’s physicians, power of attorney, loved ones, friends, and colleagues while still capable of doing so, perhaps repeatedly. There is no way of knowing how many of these conversations occur over a lifetime, with how many persons, how frequently, how recently, what provokes them, or how consistent is their message. We do know, though, how these conversations are invoked or reported at the bedside and how often families report that they never had such a conversation with the patient and are clueless about his or her wishes.34

From observing hundreds of hours of interactions and formal family meetings between physicians and patient family and friends, the researchers recorded reports of the patients’ expressed wishes, often made over the course of a lifetime.35 Meeting participants described previously expressed wishes of 43 percent of the patients (ranging from two-thirds of those whose directives were in their chart, to 36 percent of those without advance directives). Almost three-quarters of the time, family members initiated discussions of the patient’s expressed wishes (as opposed to medical staff who would ask if the patient had ever expressed any wishes). Of course, many families may not have shared the patient’s wishes during meetings with medical staff, especially if they were not asked about them; this does not mean that patients had not previously expressed their wishes or that those wishes were not instrumental in the medical decisions families made on behalf of their loved ones.

Table 4 summarizes the words conveyed by those who reported these conversations with patients, along with the frequency of expressions. Patient wishes represent several themes, many of them also expressed in the statements that patients appended to their advance directives. Patients who requested that interventions be limited and that goals of

34 When asked by physicians, family members of 7 percent of the patients reported that they had never discussed the patients’ wishes with them. Clearly, this failure to discuss wishes is more common, but many families were never asked about it directly.

35 Of course, these reports may be inaccurate, selective or incomplete, outdated, self-serving, or even fabricated. It is fairly rare, though, that one friend or family member disagrees with another’s memory of the patient’s expressed wishes or values.
care be conditional far outnumber those whose goals of care were unconditional or sought everything to be done. Goals of care were generally conditional on the likelihood of recovery, quality of life, and brain function. Few patients reportedly included a temporal dimension in their expressions — that interventions were acceptable for a brief trial, but should not be prolonged. Generally, the wishes reported by family members were consistent with instructions noted in advance directives, with one exception: Patients who had checked the box on their power-of-attorney form that everything should be done unless they are in an irreversible coma reportedly expressed wishes that were incompatible, e.g., not wanting to continue if they are in pain or if unable to function.

### Table 4: Reports of Patients’ Expressed Wishes

<table>
<thead>
<tr>
<th>Statements about medical procedures</th>
<th>Reports of Wishes (Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No surgery (1)</td>
<td></td>
</tr>
<tr>
<td>No life support/machines (6)</td>
<td></td>
</tr>
<tr>
<td>No tubes (3)</td>
<td></td>
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<tr>
<td>No intubation (6)</td>
<td></td>
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<tr>
<td>No ventilator (6)</td>
<td></td>
</tr>
<tr>
<td>No feeding tube (2)</td>
<td></td>
</tr>
<tr>
<td>No resuscitation; no “code blue” (5)</td>
<td></td>
</tr>
<tr>
<td>No blood transfusions (1)</td>
<td></td>
</tr>
<tr>
<td>Wants nutrition; does not believe in starvation (1)</td>
<td></td>
</tr>
<tr>
<td>No sedation (1)</td>
<td></td>
</tr>
<tr>
<td>Nothing invasive (1)</td>
<td></td>
</tr>
<tr>
<td>No aggressive care (3)</td>
<td></td>
</tr>
<tr>
<td>No heroic or exceptional measures (2)</td>
<td></td>
</tr>
<tr>
<td>Does not want to be brought to the hospital (1)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Unconditional goals of care</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Do everything you can to keep me alive (5)</td>
<td></td>
</tr>
<tr>
<td>Is not ready [to die] (1)</td>
<td></td>
</tr>
<tr>
<td>Wants to live (2)</td>
<td></td>
</tr>
<tr>
<td>Doesn’t want to be kept alive (1)</td>
<td></td>
</tr>
<tr>
<td>Wants to be allowed to pass naturally and peacefully (1)</td>
<td></td>
</tr>
<tr>
<td>Doesn’t want to continue living the way he/she is living (3)</td>
<td></td>
</tr>
<tr>
<td>Doesn’t want to suffer any more (1)</td>
<td></td>
</tr>
<tr>
<td>Patient chose this intervention; knew it was going to be tough (i.e., doesn’t want to quit) (3)</td>
<td></td>
</tr>
<tr>
<td>Wants hospice (1)</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Contingent goals of care</th>
<th>Reports of Wishes (Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unless about to die, wants to be brought back (1)</td>
<td></td>
</tr>
<tr>
<td>Does not want to live unless will recover (14)</td>
<td></td>
</tr>
<tr>
<td>If good chance of a “meaningful outcome” (3)</td>
<td></td>
</tr>
<tr>
<td>Not if prognosis is “dire” (1)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Statements about quality of life or functional status on which goals of care are contingent</th>
<th>Reports of Wishes (Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wants a quality of life (8)</td>
<td></td>
</tr>
<tr>
<td>Ability to “function” (2)</td>
<td></td>
</tr>
<tr>
<td>Cognitive abilities (1)</td>
<td></td>
</tr>
<tr>
<td>Does not want to be in a vegetative state, does not want to be a “vegetable,” “if brain not working right” (7)</td>
<td></td>
</tr>
<tr>
<td>Does not want to be dependent (1)</td>
<td></td>
</tr>
<tr>
<td>Does not want to be impaired (1)</td>
<td></td>
</tr>
<tr>
<td>As long as she is a “viable” person (1)</td>
<td></td>
</tr>
<tr>
<td>No nursing home, does not want to end up in a facility (4)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Temporal contingencies</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Life support is okay, if temporary (3)</td>
<td></td>
</tr>
<tr>
<td>Don’t prolong things (2)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General statements</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Wants to have a chance (2)</td>
<td></td>
</tr>
<tr>
<td>No pain, never wants to be in pain like that (4)</td>
<td></td>
</tr>
</tbody>
</table>

Total patients whose expressed wishes were reported (71)

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1 For many patients, more than one expressed wish was reported.
Frequently, friends and family described how they knew the patient’s wishes. Some reported repeated conversations over the years; others, a specific formal family gathering for this purpose. Some described the context in which the conversation occurred: “I asked her what her wishes were; over Christmas; before coming to the hospital; when her sister was so sick (or triggered by some other family illness or medical procedure); the last time she was in a nursing home, she pleaded with me; we were lying in bed and she told me; we made an agreement; when I spoke with him about my estate, we talked about this; he had conversations about this with his internist; there were witnesses.” And others referred to tangible evidence: “it is written down; it’s on (or isn’t on) her driver’s license.” Family members often also responded with what they thought the patients’ wishes might be — inferences based on related conversations, features of their personality, or medical decisions patients had made on behalf of someone else. These inferences are not addressed in this paper, which considers only the patient’s direct expressions and actions.

D. Interpretive Difficulties

The reprised wishes share some of the same difficulties as those expressed in legal documents. First, they lack operational definitions. For example, one patient reportedly told her mother that she wants to be treated aggressively as long as she is “viable.” Her mother never asked what she meant by “viable,” and it occasioned many frustrating conversations as the patient, now riddled with breast cancer, swirled close to death. And what is a “meaningful outcome?” What constitutes an ability to “function” — to drive? go to work? pay one’s bills? walk? eat or go to the bathroom without assistance?

Second, many instructions use medical terminology that patients do not understand and profoundly constrain treatment options when subsequently interpreted by medical staff. The term “coma” in the middle option offered on the Illinois Power-of-Attorney form occasioned many conflicts in the ICU. Most patients and families consider the term “coma” to reflect non-responsiveness and do not realize that it must meet precise medical criteria that do not apply to many situations in which families consider the patient comatose; the use of “vegetative state” or “vegetable” presents similar problems. So does the wish about not being on a “machine” or eschewing “tubes.”

Third, many patient wishes are contingent on prognosis (e.g., “unless I will recover”). But accurate prognostic information about functional status as well as survival can be especially hard to come by. The literature documents the difficulty of generating accurate prognostic information, the cognitive barriers physicians face when applying generic scientific models to unique individuals, and the reluctance of physicians to share prognoses with their patients or those who act on their behalf. Out of fear of being

36 For a more comprehensive review of these issues, see Susan P. Shapiro, When Life Imitates Art: Surrogate Decision Making at the End of Life, 14 Topics in Stroke Rehab. 80 (No. 4, 2007).
37 Illinois Statutory Short Form Power of Attorney for Health Care, supra n. 32.
wrong, they may offer nothing at all. 40 Few physicians, especially in the first weeks or months after injury, are willing to say that the injury is irreversible. Few will offer sufficient information to make inferences about likely quality of life or the other outcomes that are critical to honoring patients’ pre-existing wishes.

Fourth, with few exceptions, wishes are expressed in absolute terms — no dialysis, no ventilator, no tubes, no heroic treatments, do everything. But sometimes very time-limited aggressive treatments are necessary to get over a small bump in the road — a pneumonia diagnosis, for example — or an iatrogenic outcome of the treatment itself (e.g., a few days of dialysis to get rid of the fluid or toxins that built up from the treatment). In other instances, a time-limited trial of aggressive treatments may be appropriate to see whether the problem will resolve itself. On the other end of the continuum of wishes, do patients truly want “everything done” when treatment is futile, harmful to the patient, or likely to cause needless suffering? What are the appropriate stopping points? When are time-limited trials acceptable? For how long? What are the criteria? Patients rarely provide this guidance.

In other cases, absolute wishes were uttered (or remembered) years or decades ago, when the state of medical knowledge or available treatments were more limited (or less benign or successful) or when the patient was healthier and could not fathom the infirmities that come with aging, illness, or disability. This raises a fifth problem, generally captured by the notion of future selves and the extent to which their treatment should be bound by the wishes of former selves. Research on affective forecasting has demonstrated that individuals are quite bad at predicting how they will feel about medical problems in the future. 41 Considerable empirical research has also established the instability of patient preferences, even over relatively short periods of time. 42 The wishes documented in an advance directive or reprised from one or more conversations may be artifacts of the moment at which they were heard and recorded as well as of the context in which the words were spoken and of the relationship between the speaker and receiver.

The various hurdles faced by proxy decision makers in interpreting a patient’s wishes suggest that having the last word may well turn out to be the wrong word. It should be no surprise that instructions given long ago, in the abstract, and without medical guidance will poorly anticipate the very specific choices, interventions, risks, side effects, and

40 Christakis, supra n. 38.
42 Ditto et al., supra n. 41; Kristi L. Kirschner, When Written Advance Directives Are Not Enough, 21 Clinics in Geriatric Med. 193 (2005).
potential outcomes faced down the road. It is for this reason that many ethicists advise patients to pick the option on the advance directive form that provides few specific instructions and empowers surrogate decision makers with the discretion to weigh the benefits and burdens of treatment and then encourage patients to talk at length with decision makers about their values and preferences. Still, in a moment of crisis and despair, a word dropped in random conversation may nonetheless turn out to be the last. The extended example below provides a poignant sense of how a conversation may become inflexibly written in stone:

Critical Care Fellow: So, last night he developed what he had before, called septic shock. The infections are over-taking [Patient’s] body despite the optimal antibiotic treatments that we’re giving him. Because of the tumor, the infections went into his blood stream. His blood pressures dropped to a point that is not consistent with life. We have him on three medications to keep his blood pressures up, and even still his blood pressure is pretty low. ...We’re doing everything we can, but his body is not able to fight off all these infections.

I know that you love him so much. I can see how much you love him. The main reason I wanted to talk to you is because his blood pressures are dropping, and so we’re concerned that his heart may stop. If he were to have a cardiac arrest, we would try to resuscitate him by doing chest compressions. This is an absurdly painful process. In situations where we think that someone could recover, we often do cardiac resuscitation. But in [Patient’s] case, because so many of his organ systems are down — his blood pressure, the cancer overtaking his body, his immune system, the infections — the chances of being able to bring him back are pretty much as close as they get to the smallest chance. I would not want to put [Patient] through that pain, since I don’t believe it would allow him to come back.

Mother: I don’t have a choice. This is what [Patient] wanted. [Patient] told his doctor, [Oncologist]. He said, “Mama, I do not want DNR.”

Critical Care Fellow: I do not want to what?

Mother: Do Not Resuscitate, or whatever. Do not Do Not Resuscitate. Well he didn’t say it that way, but he said he wanted to be resuscitated. I wish that I could do it differently, but that’s what [Patient] wanted.

Father: I know you probably think we don’t care about him.

Critical Care Fellow: No, I absolutely think you do.

Father: I’ve heard the comment, “How could you?” And that hurts so much. This is what [Patient] wanted. He was insistent. He said it in front of [Oncologist] and his mother. [Patient] is very strong willed. ...He decided exactly what he wanted, where he wanted his funeral and everything. We have to do everything we can to honor his wishes,
as hard as that may be. So the question is not, “How could we?” The question is, “How could we not?” I can’t be in the room; I have to walk out every time I hear the machine beeping when his blood pressure drops. I can’t watch it happen. It’s so hard. When I see him—[FATHER GETS CHOKED UP AND BEGINS SOBBING.]

Mother: We were talking to [Oncologist], and he was telling [Patient] that it’s so painful to go through, and he should just be DNR. [Patient] said, “Mama, we talked about this. I want everything done.” I wish that at this point we could just take him off the machines. But I would feel guilty for the rest of my life if I didn’t carry out his wishes. I don’t have a choice. I need to follow his wishes to let him keep his dignity. We understand; we really do. We know what’s happening. And you know that. But this is what he wanted, and so I will fight tooth and nail to do everything I can for him, because that is what he wanted. I don’t want to talk about any of this again. I just want to go back and be with [Patient]. Your mother would do the same thing for you. She’d fight for you.

The day after this conversation the patient died after four aggressive unsuccessful rounds of resuscitation. Ironically, hospital records written before the patient was transferred to the ICU suggest that he may only have wanted aggressive treatment if his cancer prognosis was good. Multiple notes in the records describe conversations between medical staff and both the patient and his girlfriend about the patient’s parents pressuring him to keep pursuing aggressive treatment and his discomfort expressing his desire to change course and fear of letting them down.

In a handful of cases, families discounted, disregarded, or countermanded the patient’s wishes, instructions, or consents the latter had expressed directly to medical staff. Surrogates countered that the patient tended to vacillate or observed that these wishes were colored by depression, confusion, dementia, fear, loneliness, or were predicated on misunderstandings, misinformation, or hopeful prognoses that were no longer realistic. In most instances, this reversal resulted in instructions to withhold or withdraw treatment to which the patient had consented, but occasionally in escalation of care. In a rather indelicate example:

*Attending Physician:* I’m going to look at his heart and lungs, and then I know you have concerns about the vent.

*Wife:* Pull the plug.

*Daughter-in-Law:* This is not what he would have wanted.

*Attending Physician:* Would he feel differently if he was able to potentially get a transplant?

*Daughter-in-Law:* No.

*Attending Physician:* If the cancer is confined to his liver, they wouldn’t rule him out as a transplant candidate. It’s a long shot, I’ll be honest. But they haven’t ruled him out yet.
Wife: I thought they found fluid in his abdomen and so he can’t get a transplant.

Attending Physician: They haven’t told us that he’s definitely not a candidate.

Wife: Just pull the damn plug!

Attending Physician: See, we’re in a bit of a bind. He told the nurses last night that he wanted to be intubated and in effect retracted his living will. But sometimes when people are in distress they’ll make decisions differently. You don’t think this is what he wanted?

Wife: No.
Family Member #3: No.
Family Member #4: No.
Family Member #5: No.
Daughter-in-Law: He talked about this at length with me in the last three months. He told me in detail what he wanted. It’s not this.

Wife: I think he was just frightened.
Daughter-in-Law: Yes I think he was scared. He thought he was just coming here for stents for his liver. Now he’s on pressors and levo.

Attending Physician: We’ll have to consult with our ethics committee to make sure that we’re doing the right thing, that we’re following his wishes.

Daughter-in-Law: Yes, we understand.

Attending Physician: We’ll talk to ethics and the nurses who were here as soon as possible to get their thoughts. Unfortunately during the night things sometimes are complicated because the primary team and the family aren’t around.

A few forthright surrogates admitted that they disregarded the patient’s wishes simply because they wanted something different. 43

Partner: I don’t mean to be dramatic, but if you were his brother or father [GETS REALLY CHOKED UP; WHISPERS THE REST OF THE SENTENCE], what would you do?

Attending Physician: I think it would really depend on what his wishes were. I know you’ve had conversations about that with him before. What would he want?

Partner: I’d stick around until the cows came home.

43 However, many more surrogates expressed disagreement with the patient’s wishes while acknowledging that it was their responsibility nonetheless to honor the patient’s wishes rather than their own. Other surrogates struggled with reconciling the patient’s wishes with their own personal religious values, which would dictate a different course. See also Susan P. Shapiro, Conflict of Interest at the Bedside: Surrogate Decision Making at the End of Life, in Conflict of Interest in Global, Public and Corporate Governance (Anne Peters & Lukas Handschin eds., Cambridge U. Press 2012).
Attending Physician: Yes, but what would [Patient] want?
Partner: [ROLLS HIS EYES AND LAUGHS] He didn't want all this.
I'm keeping him alive for me. I know it's selfish, but I can't help it.

In other instances, especially with domineering family members, patients express one thing when alone with medical staff and something else (or passively assent to treatments they had just refused) when family is present.

E. The Impact of Advance Directives

The Proxy Study made two related claims (one correlational and one causal) about the impact of advance directives — that “[p]atients who had prepared advance directives received care that was strongly associated with their preferences” and that “both a living will and durable power of attorney for health care appear to have a significant effect on the outcomes of decision making.”\textsuperscript{44} Since the investigators only had data on proxy reports of outcomes and the content of directives, these claims are one and the same. Their causal claim is based solely on the correlation between or concordance of the outcomes and preferences reported. Without getting into a statistical discussion, such a causal claim could be spurious — directives and decisions may appear related because the same thing causes them both. The classic example: the fact that cities with lots of firefighters have lots of fires does not mean that firefighters are setting the fires. Similarly, it could be that being very sick or very young or very religious may affect both what you put in your directive and the decisions about your treatment, even if the directive is not directing the decisions. Indeed, the same treatment decisions may be made on behalf of very young or sick or religious patients without directives at all. In short, it is insufficient merely to observe a concordance between directives and outcomes; one needs to examine if the directive is actually playing a role to make a causal claim about a significant effect.

How do these two claims hold up to evidence about actual directives and sustained observation of the process of making treatment decisions? Although data available to the Proxy Study authors only permit the first claim — that patients with directives received care associated with their preferences — the ICU data provide insights on both claims: Do instructional directives and treatment decisions correspond? How, if at all, were directives used in the decision-making process and to what effect? Does the process look any different from that for patients without any advance directives at all?

Answers to some of these questions reflect all 205 patients in the observational study. Others, that require knowledge of the actual instructions specified in the advance directive, are based on the 40 patients with copies in their hospital chart that expressed treatment preferences. Two-hundred twenty-six of the observed meetings concerned these 40 patients. For each patient, the two observers each assessed the extent to which the patient’s written treatment preferences were followed throughout the ICU admission, the role of the advance directive in these encounters, and the extent to which the advance directive furthered the implementation of the patient’s wishes. After a first pass through

\textsuperscript{44} Silveira et al., supra n. 6, at 1211, 1218.
the data, assessments corresponded 85 percent or more of the time; after discussion there was 100 percent consensus.

1. Do Instructional Directives and Treatment Decisions Correspond?

Unlike the advance directive options offered informants in the Proxy Study regarding specific interventions, most of the ICU patients who expressed wishes, in asking that surrogates weigh the benefits and burdens of treatment, specify processes rather than outcomes in their preferences about end-of-life care. More than nine out of 10 surrogates for patients who checked the box on their power-of-attorney form directing decision makers to weigh benefits and burdens seemingly followed this script. They asked or opined about risks and benefits, prognosis, likely functional abilities, probabilities, pain and suffering, quality of life, likelihood of returning home, time horizons, the patient’s personality, values, prior statements, and so forth. Whether mindful of the document or not (since many never referred to it), they were engaged in advocating for the patient, seeking information, asking questions, soliciting multiple opinions and expressing frustration when they were not forthcoming or were inconsistent, sorting through options, negotiating limited interventions, continually reevaluating the proper course and changing course when appropriate, and trying to bring the patient’s voice back into the dialogue. One or two seemed paralyzed by the process, unable to make a decision (while the patient languished in the hospital for months). Others did not seem up to the responsibility of serving as a power of attorney as demonstrated by their failure to pay attention, stay on task, distinguish the forest for the trees, or keep the interests of the patient ahead of their own.

Most surrogates charged with weighing the benefits and burdens of treatment followed the instructions. It is difficult to fail when the patient simply asks that you exercise discretion. Of course, it also means that instructional directives give surrogates very little guidance about how to exercise this discretion; a check box does not provide much of a definitive “last word.” Perceptions of burdensome treatment or quality of life are highly subjective and thus there is no objective standard to evaluate whether surrogates’ discretionary judgments were made well.

The evidence is mixed regarding the relatively small number of directives with specific instructions among the ICU patients. All patients with living wills asking that life support be withheld or withdrawn if they had an incurable and irreversible terminal illness and death is imminent got their wish. For some of these patients, the living will served as a mechanism for surrogates or physicians to invoke, manipulate, or settle on goals of care. For others the document remained in the background, either disregarded or consistent with what surrogates felt appropriate in any case. In none of these cases was a living will rejected or abrogated nor did the letter of the document get in the way of honoring the spirit of the patient’s wishes. On the other hand, the living wills provided little direction for patients whose demise was not imminent — a substantial number even of very sick ICU patients.

Only three patients requested that their lives be prolonged to the greatest extent possible. All three received treatment consistent with their instructions. Two were eventually released from the hospital after many interventions and extremely long hospital stays; the third, as noted earlier, died after four futile attempts at cardiopulmonary resuscitation
despite many entreaties in the last days by physicians to the surrogate to consider changing goals of care.

Checking the “coma” box on the power-of-attorney form, requesting aggressive care unless in an irreversible coma, proved a bit more problematic for the four ICU patients whose directives did so. One patient was not in a coma, did not require any difficult medical decisions, and was eventually discharged to a rehabilitation facility. For a second comatose patient, the directive was followed after some delay. The third patient, whose son checked the “coma” box on her behalf, misunderstanding the meaning of coma, was described earlier. Her one request of her son — that she not be in pain — could not be honored because the patient was not technically comatose and, therefore, her son was not permitted to remove life support. The fourth case was also described earlier, of the husband who absolutely refused to take any responsibility for medical decision making and insisted that the advance directive spoke for itself and that doctors implement it. As you recall, the patient’s neurologist refused, indicating that the medical situation was far more nuanced and indeterminate than the check box on the power-of-attorney form.

With the exception of these “coma” directives, the ICU data (like the Proxy Study) show a concordance between instructions and outcomes. This result largely occurs because the most common instruction permits virtually any outcome. Perhaps a more meaningful question than whether the instructions and outcomes or decision-making processes are consistent considers the second (causal) claim that advance directives actually play a role in implementing patient preferences regarding end-of-life care.

2. How, If At All, Were Directives Used in the Decision-Making Process and to What Effect?

The ICU study provides evidence of the invocation and use of advance directives in conversations about specific interventions and overall goals of care. For two-thirds of the patients with directives in their chart, the subject of advance directives was raised during one or more conversations or meetings between families, friends, and medical staff. Often parties discussed logistical matters — whether the patient had an advance directive, whether there was a copy in the hospital record, or that families need to bring it in (28 percent) or confirmed or asserted who was the power of attorney (38 percent). For 38 percent of these patients, advance directives came up as parties talked about the patient’s wishes: physicians sometimes asked what the advance directives said or what box was checked on the power-of-attorney form; families sometimes reported on prior conversations with the patients about their advance directives; physicians or families read from the documents or summarized or interpreted the patient’s wishes articulated in the documents; or parties decried the difficulties of using the documents to formulate appropriate medical decisions.

Advance directives seemed to provoke conversations only when they were physically in the hospital. Curiously, any mention of them — even logistical questions — was almost as common for patients without directives at all (24 percent) as for those claiming to have directives that were never brought to the hospital (30 percent). For only 4 percent of the former and 13 percent of the latter were the patients’ documented treatment preferences ever inquired about or described (compared to 38 percent with in-house directives). Someone asked about or described treatment preferences specified in the advance direc-
tive in only 9 percent of meetings in which goals of care were addressed (ranging from 2 percent of patients without directives to 23 percent of those with a copy in the hospital record).

The fact that the topic is never discussed or that surrogate decision making corresponds with written instructions does not mean that advance directives are or are not exerting an influence on how information is processed, how decisions are made, or who is making them. Still, for 45 percent of patients with directives in their charts (and therefore whose wishes are known), there is no evidence that directives made a difference in the process or outcomes of decision making. For these patients, there was no reference to the advance directives in any of the conversations or decision makers were adamant about knowing and honoring the patient’s wishes and any reference to directives fell on deaf ears.

For a little more than a quarter of the patients, the directives seemingly helped honor the patients’ wishes. The document gave authority to the person who advocated the patient’s wishes when the default surrogate decision maker (had there been no power of attorney) did not. In some cases, decision makers seemed clear on patient preferences, but rereading or talking about the advance directives corroborated their understanding or provided closure. In other instances physicians reminded decision makers of the content of the advance directive, explained how the patient’s medical condition met its terms, or affirmed the family’s interpretation of the document. For these patients, physician inter-

45 In one case, the patient chose her granddaughter over her children to be power of attorney. The children entreated physicians to withdraw life support; the granddaughter, who prevailed, insisted that her grandmother wanted to have a chance. When the patient did regain consciousness and began making her own decisions, they accorded with those made by her power of attorney. Had the patient not designated her granddaughter as power of attorney, the law in Illinois would have assigned her children as surrogate decision makers.

46 One patient was a Florida resident who had the longest and most complex living will I have ever seen; it was prepared by a Florida lawyer post–Terri Schiavo, one of the most famous residents of that state. The patient, who had lung cancer, had been given six months to live when she experienced a devastating stroke. The family authorized experimental surgery to remove the clot in her brain in the hope that it would restore her consciousness and improve the quality of her last few months, consistent with her wish that her life not be prolonged if she were in a permanent vegetative state. The surgery was not successful and her spouse summarized the patient’s living will, which expressed her wishes that life support be withdrawn under such circumstances, to several different teams of physicians. However, before doing so, the spouse asked that the family be given time to enable his daughters to read their mother’s living will, understand her wishes, and have an opportunity to talk about it. The living will, for him, was an intrinsic part of the decision-making process, a channel for the patient’s voice.

47 The family of a 61-year-old woman was told that she was gravely ill. Family members explained that she would not want to be on life support if she were in a vegetative state but initially requested that physicians do everything they could until there was no more to do and see whether she would improve. On the second day in the ICU, the critical care fellow asked to meet with the family.

Critical Care Fellow: Whenever possible, we like to discuss goals of care with patients themselves. But unfortunately, your loved one is not in a position to discuss that with us. I was looking over her chart though, and I found her living will. We were reviewing it earlier as a team. As her family, you make the decisions on her behalf. But this document is a way for her to express herself, since she is not able to right now. It says:
Advance directives probably failed in implementing patient wishes at least as often (29 percent of the time) as they probably helped (26 percent). Failures occurred for a number of reasons: Wishes stated in the advance directive were flouted, disregarded, or ignored by the decision maker. Surrogates insisted on following their own wishes or stated that it was their decision whether or not to honor the patient’s wishes. In some instances, the problem was that the advance directive did not correspond with the patient’s wishes — either because the form had been filled out by someone else, used medical terms that the patient misunderstood, had been completed by the patient under pressure from a family member, or because the patient’s preferences, as expressed to hospital staff before losing decision-making capacity, had changed. And for a few patients, the advance directive, itself, stood in the way of making the right decision — whether because it was misinterpreted by a physician or family member or because the decision maker hid behind the document and refused to make a decision. Failures to further patient wishes were most common for directives that seek to prolong life under all or most circumstances (67 percent vs. 25 percent for directives opting for benefits/burdens or imminent death).

My dying shall not be artificially prolonged under the circumstances set forth below, and I declare: If at any time my attending physician certifies in writing that: 1) I have an incurable injury, disease, or illness; 2) my death will occur within a short time; and 3) the use of life prolonging procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the performance or provision of any medical procedure or medication necessary to provide me with comfort care or to alleviate pain, and have so indicated below; the provision of artificially supplied nutrition and hydration.

Now, sometimes these documents can be quite obscure. But I believe that this one is quite clear.

Husband: We have a lawyer friend who came over and went through this with her. It’s what her wishes were. I think it’s very clear.

Critical Care Fellow: Yes. So as for the three criteria, her cancer is not curable. I don’t know when she would otherwise die from it, but the oncologists have determined that it is not treatable. And now with the septic shock on top of that, the chances are very low that she would survive. I believe she would die very quickly if we were to withdraw support. And she is on artificial life support, the ventilator and the blood pressure medications. In terms of futility, is it 100 percent? No. I can never make that judgment. Just like the oncologists can never say for sure what the prognosis is for the cancer. But what I can say is that the chances of her surviving this hospitalization and going home and resuming any of her normal activities are pretty much zero.

Shortly thereafter, the family came to a consensus and withdrew life support.

48 Recall the case of the partner who said, “He didn’t want all this. I’m keeping him alive for me.”
49 Recall the son who checked the “coma box” for his mother, who had dementia.
50 Recall the young man who indicated to hospital staff that he only wanted aggressive care if his prognosis was good but, feeling pressure from his parents, never changed his advance directive. He died after four grueling efforts to resuscitate him because his parents felt an obligation to fight for him.
51 One dramatic failure was caused by a physician’s misunderstanding of the meaning of an advance directive, wrongly assuming that asking the power of attorney to weigh the burdens and benefits of treatment meant that the patient wanted no life-saving measures.
52 Recall the case of the husband who brandished the power-of-attorney document and insisted that the physicians implement it.
Unfortunately, these observations are based on a very small number of cases and may not be representative, even though they reflect every patient (out of more than 2,000 passing through the two ICUs over three years) requiring a surrogate decision whose treatment preferences were in their hospital chart. Some may interpret these results as a glass half empty (they help only about a quarter of the time) and others a glass half full (they fail less than a third of the time). The latter will see justification for ongoing efforts to get more Americans to write instructional directives, the former to get them to appoint powers of attorney to speak on their behalf, given how difficult it is to have the last word.

To truly understand the role or efficacy of advance directives on end-of-life decision making, one must also look at the patients whose advance directives, if they existed at all, were never brought in to the hospital as well as the majority who had no advance directives, and track the process and outcomes of medical decisions made on their behalf. They may have fared equally well or even better in getting the last word than those with properly documented wishes. That is beyond the scope of the present paper. However, a complex statistical analysis shows that the decision-making process and outcomes are not significantly different between patients without advance directives and those whose directives appear in the hospital record.53 Though surrogates for the former are less likely to mention advance directives or invoke expressed wishes, they are no less likely to talk about what they believe the patients’ wishes would be. Of course there is no way to know whether these memories, perceptions, or inferences are accurate.

IV. CONCLUSION

The data regarding surrogate decision making in the two ICUs confirm the finding of the Proxy Study that patients who have advance directives receive care that is strongly associated with their preferences. The ICU study suggests, however, that this correlation arises in part because many patient preferences are open-ended and therefore allow any outcome. A more meaningful conclusion supported by the ICU data would be that, in the long run, patients whose wishes are known do not often receive medical care that is clearly antithetical to them.

The ICU data do not support the causal argument from the Proxy Study that advance directives “appear to have a significant effect on the outcomes of decision making.” The

53 A logistic regression assessed whether the process of surrogate decision making differs for patients with advance directives in their chart or those claiming directives that are not in their chart and those without directives at all. The analysis considered 41 features of ICU conversations, patient outcomes, and impacts on families. They included: whether anyone ever asked about or mentioned the advance directive (substantively or logistically); whether and how representatives of patients initiated discussions about the patient’s wishes or whether physicians initiated these discussions (perhaps to compensate for the disinclination of some families to talk about this); whether patient representatives initiated discussion of decision-making criteria or process or whether instead physicians initiated these conversations; how long it took for an issue to be addressed or resolved (rather than whether it was addressed); outcome measures; and characteristics of the meetings. Because demographic characteristics associated with having an advance directive are also related to the process and outcomes of surrogate decision making, the logistic regressions controlled for patient gender, age, ethnicity, income of residential neighborhood, whether illness was pre-existing or came out of the blue, and whether the patient or family member is a lawyer or health care provider. Contact the author for more information.
data are equivocal about whether advance directives do more harm than good. Proxy directives or powers of attorney alone are more benign, in that they allow patients to designate a trusted decision maker, particularly when the legal default order would assign someone who they do not believe to be up to the task. And certainly powers of attorney are desirable for patients who would ask that life support be withheld or withdrawn for infirmities short of imminent death or permanent unconsciousness. In Illinois and elsewhere, only patients or powers of attorney are permitted to make that request.  

But the value of instructional directives is certainly debatable. This is a limited study, of course. Although the patient population was very diverse and hundreds of medical staff were observed in interaction with families, the data nonetheless reflect a single teaching hospital in a single city in a single state. Moreover, although 40 percent of Medicare enrollees visit an ICU in the last six months of life and ICUs disproportionately collect patients unable to make their own medical decisions, surely what happens inside an ICU is quite different from what surrogates do outside of the hospital. Perhaps advance directives help keep some patients out of the ICU in the first place. Moreover, important variation can be expected in laws, types of advance directives available, practices and protocols, norms, values, incentives, resources, even medical issues and available technologies in other settings. Nonetheless, while we await observational research from other settings, the ICU study provides the largest and most extended and systematic look at how end-of-life decisions are made in real time, on the one hand, and at the legal documents that potentially shape that process, on the other.

Back to the death panels and the allegations by those opposed to health care reform that conversations about our wishes at the end of life would create death panels that pressure the elderly or infirm into ending their lives. It is impossible to know how many of the directives reported by patients in the ICU study resulted from the kind of counseling to which critics of health care reform objected. Still, there is no evidence in the ICU data to support the “death-panel” charge: 56 percent of patients without advance directives died or went into hospice during their hospital stay; this was true of 55 percent of those whose advance directive was in the hospital record as well as 55 percent of those whose directive never made it to the hospital. Of course, the three groups are different in many respects,
both demographic and medical, that undoubtedly affect the likelihood that patients would die as well as how decision makers would choose their treatment. But, after controlling for these factors, there is still no significant difference between the three groups in the likelihood of hospital death or hospice. It does not appear that keeping one’s wishes to oneself increases the odds of survival, nor, for that matter, having the last word about the treatments one does or does not receive.

Perhaps because of the furor over death panels, the provision to permit Medicare to compensate physicians for discussing patient wishes about future medical treatment and/or advance directives did not make it into the final health care bill. And a provision to reinstate compensation for advance care planning through subsequent Medicare regulations was introduced and then swiftly withdrawn. Though my study provides little support for the paranoia envisioned by the death panel crowd, neither does it find advance directives a panacea for the inevitable and wrenching decisions that await many of us at the end of life. The Proxy Study found that 42 percent of the decedents “required decision making about treatment in the final days of life” and that 70 percent of them lacked decision-making capacity. Studies of ICUs, where patients are much sicker, have found that of all decisions to withhold or withdraw life support, only 3 to 4 percent were made by the patients themselves; the others lacked decisional capacity. In short, the most important life-and-death decisions of many of our lives will be made by someone else.

It certainly seems desirable for most of us to get to pick who that someone else is (or at least exclude a few potential candidates) and to talk with them and those who will seek to influence or silence them about our values, priorities, and fears. Is it possible to have the last word? Absolutely. The price, as the ICU study illuminates, is that it may be the wrong word.

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58 A logistic regression between advance directive status and hospital death or hospice (controlling for age, ethnicity, gender, neighborhood income, whether hospitalization came from an unexpected emergency or pre-existing medical problems, and how sick the patient was) was not significant (i.e., there is no difference among the three advance directive groups in the likelihood of hospital death or hospice). Contact the author for more information.

59 75 Fed. Reg. at 73406.


61 Silveira et al., supra n. 6, at 1214.

62 Luce & Prendergast, supra n. 56.
CASE NOTE

LEWIS v. ALEXANDER VINDICATES PRIMACY OF FEDERAL LAW OF SPECIAL NEEDS TRUSTS

By Ron M. Landsman, Esq., CAP

In Lewis v. Alexander,1 the U.S. Court of Appeals for the Third Circuit affirmed a district court decision2 striking down a Pennsylvania statute that severely restricted the use of pooled special needs trust (PSNT) accounts and limited trust retention of post-mortem account balances to 50 percent. In doing so, it held that state Medicaid programs are required to treat as exempt the assets and income in pooled trusts meeting the requirements of 42 U.S.C. § 1396p(d)(4)(C) (referred to hereinafter as “d-4-C”) — and only those requirements — for Medicaid eligibility purposes, rejecting the contrary view of the Second and Tenth Circuits.3 In the parlance now used, the federal special needs trust provisions of d-4-C are mandatory for the states.

The Pennsylvania statute at issue, codified at 62 Pa. Stat. Ann. § 1414, was enacted in 2005 to regulate special needs trusts and, as put rather generously by the Third Circuit, “to ensure that these trusts were not abused.”4 The Act:

• required that all special needs trusts be for the “sole benefit” of a disabled individual. Section 1414(b)(3)(i).
• limited what a pooled trust could retain of a deceased beneficiary’s account to 50 percent prior to Medicaid payback. Section 1414(b)(3)(iii).
• required that “any expenditure from the trust ... have a reasonable relationship to the [beneficiary’s] needs,” which the state agency indicated meant special needs arising from the individual’s disability. Section 1414(b)(3)(ii).
• limited the right to establish a PSNT account to those whose “special needs ... will not be met without the trust.” Section 1414(b)(2). Again, the needs had to be “related to the treatment of the beneficiary’s disability.” Section 1414(f).
• barred people age 65 and above from establishing pooled SNT accounts. Section 1414(b)(1).
• authorized enforcement by Medicaid “or other public agency [by] petition[ing] the court for an order terminating the trust.” Section 1414(c).

A complaint for declaratory and injunctive relief in the form of a putative class ac-

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1 Lewis v. Alexander, No. 11-3439 (3d Cir. June 20, 2012); also in 2012 WL 2334322.
4 Lewis, No. 11-3439, slip op. at 3.
tion was filed by two pooled trusts and 12 individuals, eight who had prestatute accounts and four who established their accounts after the statute was enacted. Lead counsel for the plaintiffs was Steven Feldman, a long-time Elder Law attorney and NAELA member.

Of the six contested requirements, the trial court invalidated all but the first, which it held permissible since it tracked federal law, and plaintiffs did not challenge that decision. On appeal by the Pennsylvania Medicaid agency, the Third Circuit affirmed the decision that states are required to honor special needs trusts and treat them and their funding as exempt, confirming the invalidity of all but the enforcement provision. In getting to that result, the court also had to address the status of federally authorized special needs trusts (SNTs), the nature of the right that arose from the statutory provisions, whether an injured party had standing under 42 U.S.C. § 1983 and under the Supremacy Clause, whether these plaintiffs had sufficient present injury to have standing, and whether the case was ripe. It answered all of those questions in plaintiffs’ favor.

The parties and the court all recognized that the central issue in the case was whether the special needs trust exclusions are mandatory. If not, then plaintiffs had no substantive right to enforce and they would lose the unambiguous imposition of a duty on the state that is a linchpin for Section 1983 relief under Blessing v. Freestone. Pennsylvania relied on the argument, which had prevailed in the Second and Tenth Circuits, that while the inclusion of most self-settled trusts as available is mandatory, the exclusion of special needs trusts in d-4-C did not, by itself, address how to treat them. Pennsylvania asserted that this created a gap in which the states could legislate; they were not required to count special needs trusts assets, but neither were they required not to count them. Under that reading, states were permitted, but not required, to treat SNTs as unavailable, and if they were not required to treat them as unavailable, they were perforce permitted to attach restrictions or conditions on their use. As the court noted, and all agreed, d-4-C plainly says “the States do not have to apply the trust-counting provisions to qualifying special needs trusts,” but it does not go further and expressly state that they “shall not be counted as available assets ....”

Plaintiffs made two arguments in response. First, relying on d-4-C and the correlative obligation to establish in its State Plan compliance “with respect to ... treatment of trusts,” the plaintiffs made a subtle argument drawn from the Medicaid statute on the nature of jural duties, following Hohfeld. Perhaps putting it far too simply, the key to

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5 Lewis, No. 2:06-cv-03963-JD, slip op. at 34–43, 44.
6 Although Pennsylvania challenged justifiability, its argument was largely based on the claim that d-4-C was not mandatory; it did not separately challenge, for example, whether the pooled trusts had standing in their own right, which is key to the holding with respect to retention.
8 Wong, 571 F.3d 247 and Keith, 212 F.3d 1190.
9 To call a trust “available” is shorthand for saying that the assets that it holds or the income that those assets generate is available for Medicaid purposes.
10 Lewis, No. 11-3439, slip op. at 31.
11 Id. at 31–32.
13 Citing and relying on Wesley Newcomb Hohfeld, Some Fundamental Legal Conceptions as Applied in Judicial Reasoning, 23 Yale L.J. 16 (1913); Brief for Appellee at 23, Lewis v. Alexander, No. 11-3439.
the argument is that d-4-A and -C affirmatively prohibit use of the mandatory availability rules of 42 U.S.C. § 1396p(d), analogous to the Supreme Court’s reasoning in *Arkansas Department of Health and Human Services v. Ahlborn*,¹⁴ which held that the parallel anti-lien provisions in 42 U.S.C. § 1396p(a) and (b) created express limits on state power.

Second, they argued artfully that all of the trust provisions must be viewed in the context of Medicaid and Supplemental Security Income (SSI) as a whole, where the basic law of Medicaid is the SSI income and resource standards. State Medicaid rules either are those for SSI beneficiaries, for those who are categorically eligible, or they must be comparable, and no more restrictive, for the medically needy.¹⁵ In that context, the mandatory inclusion of all trust assets and income as countable resources or income modifies that rule, to the extent it applies, and the exclusion of special needs trusts from the broad anti-trust provisions of d(1)-(3) leaves SNTs where they were beforehand — as measured under the SSI resource and income rules. The District Court agreed with that analysis and examined each of the specific provisions of Section 1414 to see which ones violated comparability.

The Third Circuit did not so much reject the comparability argument as decline to go through the analysis, saying its reliance on the Medicaid statute, alone, was adequate and more direct, and “given the complexity of Medicaid, we seek to simplify the analysis in any way we can.”¹⁶

The Court’s approach — not necessarily inconsistent with comparability — was to view the Medicaid provisions as a coherent whole to determine, through statutory analysis, whether Congress intended to require states to treat SNTs as detailed in the statute. The court said the focus on “[t]his subsection,” the opening clause of 42 U.S.C. § 1396p(d) (4)(C), misses the forest for the trees.¹⁷ OBRA 1993, the bill that implemented the new trust and anti-transfer provisions, “provided a comprehensive system for dealing with the relationship between trusts and Medicaid eligibility.” For the first time, it required compliance with “Section 1396p ... with respect to ... treatment of certain trusts ... ”¹⁸

No doubt, the court said, Congress’ primary object was to prevent wealthy people from using trusts to shelter their assets while getting means-tested public health care benefits, but its secondary purpose “was to shield special needs trusts from impacting Medicaid eligibility.”¹⁹ Congress was not sheltering SNTs from the broad anti-trust rule, but rather “shelter[ing] special needs trusts from having any impact on Medicaid eligibility.” It “rigorously dictates what assets shall count and what assets shall not count toward Medicaid eligibility... provid[ing] a comprehensive system of asset-counting rules [where] it has actually legislated on this precise class of asset.”²⁰ (Emphasis in original.)

The Court’s discussion of this holding is curiously devoid of further legal author-

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¹⁶ *Lewis*, No. 11-3439, slip op. at 43, note 21.
¹⁷ *Id.* at 32.
¹⁸ *Id.* at 33.
¹⁹ *Id.*
²⁰ *Id.* at 34.
ity. It relies on the exclusive nature of the trust rules in 42 U.S.C. § 1396p(d)(4) almost alone, adding only the provision that requires State Plans to incorporate those rules.\textsuperscript{21} It could have cited, but did not, the provisions in the same section that affirmatively require states to permit funding of d-4 special needs trusts by excluding them from the anti-transfer rules of 42 U.S.C. § 1396p(c). To be sure, transfer and resource exemptions are not entirely or necessarily coterminous, yet it would be strange indeed for Congress to say Medicaid agencies must allow individuals to fund d-4 special needs trusts without also requiring that such trusts be exempt.

The court’s choice of analysis is not without great significance, however. A decision based on comparability would have placed the locus of the federal standard in the SSI statute, further decision-making in the agency that determines SSI policy, and would have left the states free to be less restrictive under the comparability rule. The federal standard approach means that there is a statutory basis for mandatory rules — limiting what states can do both in expanding as well as limiting the use of trusts — with decision-making in the Center for Medicare & Medicaid Services rather than the unit that manages SSI.

As important as this holding was, the Court sliced a fine distinction in saying that this did not resolve whether there was necessarily the kind of conflict between federal law and Section 1414 that would entitle plaintiffs to judicial protection. The question that remained, in the Court’s view, was whether the federal special needs trust rules preempted state law and regulation in the area. In addition to requiring that states honor special needs trusts, this also required findings that Congress intended to displace state law, pro tanto, and that the states were not permitted to impose any additional burdens on SNTs.\textsuperscript{22}

Having found d-4 mandatory and that the federal statute occupied the field of special needs trusts, the court could give short shrift to whether any of the specific requirements of Section 1414 could stand:

- Section 1414(b)(3)(iii) — limiting retention prior to Medicaid payback to 50 per cent of the balance of the account at death — was struck down because it denied exempt status to trusts that might retain more and the individual’s right to use the trust of their choice that met federal requirements. The court relied in part on the trust’s standing,\textsuperscript{23} and dismissed out of hand the individual’s property interest in disposition of property after their death.”\textsuperscript{24}
- Section 1414(b)(3)(ii) — requiring that trust “expenditure[s] ... have a reasonable relationship to the [beneficiary’s] needs” — was struck down because the federal statute had no such limitation.\textsuperscript{25}
- Section 1414(f) — limiting the right to establish a pooled SNT account to those whose “special needs ... will not be met without the trust,” meaning needs “related

\begin{itemize}
\item \textsuperscript{21} 42 U.S.C. § 1396a(a)(18).
\item \textsuperscript{22} Lewis, No. 11-3439, slip op. at 41–43.
\item \textsuperscript{23} Id. at 46, note 22.
\item \textsuperscript{24} Id. The court apparently was not persuaded by the amicus’ argument that the state “failed to explain why the post-mortem disposition of one’s assets is not a morally and emotionally significant right that has real legal significance. It is not irrelevant to note that there is a whole financial-legal industry devoted to that concern only.”
\item \textsuperscript{25} Id. at 49.
\end{itemize}
to the treatment of the beneficiary’s disability” — was struck down because federal law required only that the person be disabled.

- Section 1414(b)(1) — barring anyone age 65 or older from establishing pooled SNT accounts — was also struck down as being more restrictive than federal law, which of course limits individual but not pooled accounts to individuals under age 65.26

The court reversed the district court and upheld Section 1414(c), the enforcement provision authorizing Medicaid “or other public agency [to] petition the court for an order terminating the trust.” The district court held it unenforceable because it would subject Medicaid beneficiaries to loss of the use of their pooled trust account not for anything they did, but because a problem existed with some other beneficiary.27 The court of appeals reversed, holding that this enforcement authority was a necessary element of Pennsylvania’s retained general authority to regulate trusts, like other provisions permitting termination of trusts whose trustees breach their duties.28

Throughout this discussion, the Court carefully noted, as all parties necessarily acknowledged or urged, as the case may be, that Congress did not abrogate state trust law generally or create its own general federal law of trusts.29 Congress did not intend to interfere with application of such traditional rules. “After all, Congress did not pass a federal body of trust law, estate law, or property law when enacting Medicaid. It relied and continues to rely on state laws governing such issues.”30 Rather, taking state trust law as a given, it established specific and precise rules for how trusts created under state law are to be treated.31

There is necessarily some tension between this conclusion and the bar on states adding requirements, the court noted. For example, even application of the trustee’s traditional duty of loyalty — to “administer the trust solely in the interests of the beneficiaries” — could be considered an extra requirement.32 Not having enacted a general federal law of trusts, Congress must of course intend its provisions to fit within that framework.

This interplay became especially important in the court’s treatment of, for example, the requirement that expenditures “have a reasonable relationship to the needs of the beneficiary.” In rejecting the imposition of this specific requirement on SNTs, and in the particular way the State did, the court responded to its “justifiable concern with the potential for fraud and abuse.” Putting aside that there is no history of particular problems with SNTs, the court said:

States are not without tools to prevent abuse. The trust-counting rules are built atop the States’ legal framework for trusts. Special needs trusts are therefore subject to supervision by the courts and legal actions to enforce trustees’ fiduciary duties.33

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27 Lewis, No. 2:06-cv-03963-JD, slip op. at 34–35.
30 Lewis, No. 11-3439, slip op. at 43.
31 Id. at 34, 43.
32 Id. at 43.
33 Id. at 49. See also slip op. at 52, dismissing the “reasonable relationship” provision purportedly designed to prevent fraud and abuse, given the availability of the state’s “full complement of general trust and non-profit laws to combat waste, fraud, and abuse.”
The fly in the ointment for PSNTs and their advocates is that in holding that denying over-65-year-olds access to pooled SNTs was not permissible, the Court assumed that the over-65 transfer penalty applied in funding such a trust is permissible.\textsuperscript{34} Whether the transfer penalty applied to pooled trust accounts was not an issue before the court and was not briefed by either party. Since the statute under attack broadly prohibited any use of pooled trusts by the elderly, the Plaintiffs logically focused on the lack of an age limitation in d-4-C, as compared to d-4-A. On the other hand, plaintiffs failed even to note the issue in relying on the district court’s favorable decision on this point,\textsuperscript{35} which also found logic in Congress’ choice to permit anyone to establish pooled trust accounts while limiting their use for older people, the ones more likely to seek long term care benefits, the kind subject to transfer penalties.

The Lewis court would almost certainly come to a different result than that in Hobbs v. Zenderman,\textsuperscript{36} the Tenth Circuit decision following Keith v. Rizzuto,\textsuperscript{37} which held that states were not required to permit the use of special needs trusts. To be sure, the lower court in Lewis allowed Pennsylvania to retain a “sole benefit” standard in its state law, like the one purportedly enforced in Hobbs, and the court of appeals recognized that conventional state trust law would always be available to police breaches of fiduciary duty. But the Third Circuit could hardly go so far afield as the Tenth did in allowing the state to put its financial interests ahead of beneficiaries based on, of all things, the “sole benefit” requirement. And the Third Circuit’s reasoning would have required the New Mexico Medicaid agency to return to the probate court, which had already approved most of the actions later attacked in a denial of Medicaid benefits.

It is of course not possible to know definitively what most moved the judges to decide as they did. But one of many wise choices made by Steve Feldman was to choose Zackery Lewis as lead plaintiff. It was Zackery’s parents’ wish to put his $1.8 million settlement into The Family Trust, one of the two pooled trust plaintiffs, that led to a probate court decision approving it to be in Zackery’s best interests to do so.\textsuperscript{38} By highlighting that Pennsylvania would require by legislation a result a court had already found not in the best interests of an individual beneficiary, Feldman framed the debate in a way that helped, if it did not assure, his ultimate victory.

\textsuperscript{34} Id. at 52–53.
\textsuperscript{35} Lewis, No. 2:06-cv-03963-JD, slip op. at 36–37.
\textsuperscript{36} Hobbs v. Zenderman, 579 F.3d 1171 (10th Cir. 2009).
\textsuperscript{37} Keith, 212 F.3d 1190.
Approximately 15,700 nursing homes receive payments from Medicare and/or Medicaid.1 Most, it is presumed, provide good care.2 Some do not.3 For more than a decade, nursing homes have used the Federal Arbitration Act,4 (FAA), as a sword, not a shield, to avoid or minimize accountability when they fail or refuse to provide the quality of care required under 42 U.S.C. § 1396r and 42 U.S.C. § 1395i-3.5 By ignoring the underlying facts, the United States Supreme Court, in Marmet Health Care Center v.

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2 In this author’s experience, Elder Law attorneys and other elder advocates generally hear from families when care is deficient. This author is pleased to report that nursing homes, generally speaking, receive high marks from families. In his opening remarks during a June 18, 2008, hearing on S. 2838, The Fairness in Nursing Home Arbitration Act, the Hon. Herb Kohl, stated: “It is important to note that we believe the vast majority of nursing homes are doing a very good job and working hard to deliver quality care. But we must protect the rights of those who receive inadequate care to hold poor-performing facilities publicly accountable.” http://www.gpo.gov/fdsys/pkg/CHRG-110shrg44741/pdf/CHRG-110shrg44741.pdf [hereinafter Fairness Transcript].
4 9 U.S.C. § 1-16. The Fed. Arb. Act (FAA) provides “A written provision in . . . a contract evidencing a transaction involving commerce to settle by arbitration a controversy thereafter arising out of such contract or transaction, or the refusal to perform the whole or any part thereof, . . . shall be valid, irrevocable, and enforceable, save upon such grounds as exist at law or in equity for the revocation of any contract.” 9 U.S.C. § 2.
5 “The adoption of arbitration agreements by the nursing home industry has been fueled … by its efforts to minimize damages awarded against nursing homes … .” Ann E. Krasuski, Comment: Mandatory Arbitration Agreements Do Not Belong in Nursing Home Contracts with Residents, 8 DePaul J. Health Care L. 263, 270 (2004). “Arbitration agreements benefit providers because the total cost of an arbitrated settlement tends to be about 37 percent lower than a litigated award, according to a 2009 report by Aon Global Risk Consulting.” Kathleen Lourde, Lawyers Baiting the Hook with Nursing Hours, 37 Provider 22 (Nov. 2010), http://www.providermagazine.com/archives/archives-2010/Pages/1110/Lawyers-Baiting-The-With-Nursing-Hours.aspx.
Brown, has now placed its official stamp of approval on arbitration agreements specifically drawn to avoid or minimize accountability for nursing home negligence. Mandatory pre-dispute arbitration agreements are permitted even when foisted upon a vulnerable population. Ironically, one federal law, the Federal Arbitration Act, now shields corporate miscreants from judicial accountability when they ignore federal (and state) quality of care standards applicable to nursing homes.

I. BACKGROUND

Marmet began as three consolidated cases in West Virginia. In each case, a person who was ill or incapacitated and who needed extensive, ongoing care was admitted to a nursing home. In each case, a family member signed an admission agreement that included an arbitration agreement buried within the text. The clauses generally provided that all future disputes would be submitted to arbitration, although Marmet recognized that the nursing homes had excluded themselves from this agreement by exempting claims to collect late payments owed by the patient. The Genesis court further noted that the nursing home exempted itself from arbitrating discharge actions.

The case of Clarence Brown, one of the Genesis plaintiffs, is illustrative. Clarence was born with severe cerebral palsy and other disabling conditions. In 1996, he was admitted to Marmet Health Care Center. Soon after his admission, his brother was appointed as his guardian. Eight years later, on March 24, 2004, the facility presented Clarence’s brother with a new admissions agreement. On page 12 of the 13-page document, the following clause appears:

MANDATORY ARBITRATION:
Except for Facility’s efforts to collect monies due from Resident and Facility’s option to discharge Resident for such failure, which the parties agree may be heard by a Court of competent jurisdiction in the city

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8 The tension between competing policies was mentioned in Estate of Ruszala ex rel. Mizerak v. Brookdale Living Communities, Inc., 415 N.J. Super. App. Div. 272 (2010). For example, 42 U.S.C. § 1396p(b)(2) provides that a nursing facility must provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care. Failure to abide by the federal quality of care statute and regulations, 42 C.F.R. §§ 483.1–483.75, is well documented. See e.g. GAO, Nursing Homes: Federal Monitoring Surveys Demonstrate Continued Understatement of Serious Care Problems and CMS Oversight Weaknesses, GAO-08-517 (May 2008), http://www.gao.gov/assets/280/275154.pdf.
11 The other nursing home residents were Leo Taylor and Pauline Virginia Willett.
12 One might ask what consideration was given for the new agreement, but apparently the issue was not raised.
or county where the Facility is located, all disputes and disagreements between Facility and Resident (or their respective successors, assigns or representatives) arising out of the enforcement or interpretation [*134] of this Agreement or related hereto or the services provided by Facility hereunder including, without limitation, allegations by Resident of neglect, abuse or negligence which the Resident and Facility are unable to resolve between themselves shall be submitted to binding arbitration in accordance with the Commercial Arbitration Rules of the American Arbitration Association then in effect. The party filing the arbitration (making a claim) shall be solely responsible for payment of the initial arbitration filing fee in accordance with the Rules of the American Arbitration Association fee schedules. The arbitrator or arbitrators shall be entitled to award recovery of the arbitration fees, attorney’s fees and out-of-pocket expenses incurred by the prevailing party up to a maximum award of $5000. The arbitrator shall also have the authority to issue interlocutory and final injunctive relief. The arbitrator’s decision shall be binding on the parties and conclusive as to the issues addressed, and may be entered as a judgment in a court of competent jurisdiction and not subject to further attack or appeal except in instances of fraud, coercion or manifest error. During the pendency of any [*135] arbitration proceeding, Facility and Resident shall continue to perform their respective obligations under this Agreement subject, however, to the right of either party to terminate this Agreement as established herein. The obligation of Facility and Resident to arbitrate their disputes or disagreements shall survive termination of this Agreement.13

While Clarence was at Marmet Health Care Center, he suffered from pressure sores, dehydration, malnutrition, contractures, aspiration pneumonia, and infections. Each of these conditions is generally preventable in the absence of an uncontrollable failure to thrive. For example, pressure ulcers occur at “pressure points” where blood flow is cut off because a resident is not moved; the solution (and the federally required standard) is to move the patient regularly to prevent blood flow from being cut off with the resulting development of a pressure ulcer.14 Malnutrition occurs when a resident fails to receive proper nutrition, and dehydration occurs when there is insufficient hydration. In most cases, proper monitoring would alert the health team that intervention is necessary well before a life-threatening condition occurs; without proper monitoring, residents die.15

13 The arbitration clause appears in Appendix 1 of Brown, 724 S.E.2d at 297-298. The nursing home’s brief alleged that the arbitration clause was added because it “lost its liability insurance coverage due to the well-chronicled medical malpractice maelstrom of that time.” Genesis, supra n. 9, at 15. As an aside, Pauline Willett’s arbitration clause appeared on pages 35 and 36 of a 73-page admissions agreement.
15 Regarding malnutrition and dehydration, in Sarah Greene Burger et al., Malnutrition and Dehydration in Nursing Homes: Key Issues in Prevention and Treatment (June 2000), http://www.globalaging.org/
Clarence left the nursing home in May 2007. Clarence died on June 10, 2008. His family filed a lawsuit claiming that his death resulted from injuries sustained at the nursing home.

Clarence’s case was consolidated with two others on appeal. The lawsuits alleged various acts and omissions, which constituted negligence. In each case, the defendant nursing home sought an order from the circuit court dismissing the lawsuit and compelling arbitration.

The Plaintiffs in each case argued that the arbitration provisions were void because they violated Section 15(c) of the West Virginia Nursing Home Act, W. Va. Code, 16-5C-1 to 20, by requiring that residents agree to arbitration prior to the occurrence of injury-related claims. As a secondary argument, the plaintiffs contended that the agreements were unconscionable under common law principles. Clarence Brown, for instance, argued that the agreement was a contract of adhesion, in part because it allows the nursing home to prohibit a plaintiff from gaining judicial relief, while leaving itself access to the courthouse doors. The family of Leo Taylor argued that the agreement was presented as a “take-it-or-leave-it” document; they also argued that the person signing had no authority to waive Taylor’s jury rights.

Each plaintiff’s claims were dismissed. On June 2, 2010, the Supreme Court of Appeals of West Virginia granted a petition to review the cases. The focus of the review, as recounted in Marmet, centered on whether the FAA pre-empted a judicial remedy for negligence. The West Virginia Court began its analysis with a review (or its view) of Congressional intent in enacting the FAA. The Genesis Court ultimately found that “Congress did not intend for the FAA to apply to arbitration clauses in pre-injury contracts, where a personal injury or wrongful death occurs after signing of the contract.”

II. THE NURSING HOME ADMISSIONS PROCESS

Clarence Brown’s brother obviously never thought Clarence would be harmed or he would not have placed his brother at Marmet Health Care Center. The Center, on the other hand, knew that it might be held accountable if it failed to provide quality care. With this in mind, the admission process likely went something like the process described in Gentry v. Beverly Enterprises-Georgia, Inc. In Gentry, a nursing home employee (Ms. Millsap)
testified that she “brought a stack of paperwork, including the arbitration agreement at issue, to Plaintiff’s room on the day Plaintiff was admitted to the nursing home, and told her that the paperwork had to be completed. … Ms. Millsap told Plaintiff that this was the “admission paperwork required for admission” and that someone would have to sign it.\textsuperscript{19}

Anyone who has ever admitted a loved one to a nursing home, or who has acted as guardian or agent for another, knows that the process is paperwork intensive. The process is chaotic and can induce panic.\textsuperscript{20} The \textit{Genesis} court observed “The process of signing paperwork for medical care — specifically, a contract for admission to a nursing home — is often fraught with urgency, confusion, and stress. People seek medical care in a nursing home for long-term treatment to heal; they rarely view the admission process as an interstate commercial transaction with far-reaching legal consequences.”\textsuperscript{21} Unfortunately, federal cases rarely show compassion (or, for that matter, any regard for the constitutional right to a jury trial)\textsuperscript{22} when considering the relative bargaining position between patients and health care providers. This is grossly demonstrated in \textit{Riverera v. Centro Medico de Turabo, Inc.}\textsuperscript{23} There, the First Circuit observed that the plaintiff’s “relationship with the hospital grew out of a grave medical condition. He was likely more focused on that medical condition than the significance of the documents that he was asked to sign. He was not thinking about possible lawsuits. Nevertheless, despite this regulatory initiative, the federal common law of overreaching as it presently stands convinces us that this is not a case where the presumption in favor of enforcing a forum selection clause is overcome.” In sum, as long as health care providers bury one-sided protective language well within an admission document, federal law gives patients two options: sign or reject treatment.

In fairness, there is another side to the arbitration argument. Nursing home operators argue that arbitration agreements are necessary to control runaway juries. Kelley Rice-Schild, an owner-operator who testified in 2008 before Congress, stated:

\begin{quote}
In the late 1990’s, the long-term care profession was subject to excessive liability costs, which were exacerbated by an increasingly litigious environment. As a result, operators of nursing facilities and assisted living residences were forced into making difficult decisions including potential closure or divestiture of facilities, and corporate restructuring…. In order to serve as a good steward of my family’s business and to continue to operate in such an environment, I turned to arbitration…. When legal concerns arise, we believe that fair and timely resolution — the kind that is often the product of arbitration — is in the best interest of both the consumers and their care providers.
\end{quote}

\textsuperscript{19} \textit{Id.} at 33, 52–53. “The experience of placing a family member in a long-term care facility is very emotion [sic]. Often the decision is the last resort after a medical emergency or when a family acknowledges that they cannot provide the level of care their loved one needs. The family’s sole focus is on finding the best facility, not studying technical legal clauses buried in the document.” \textit{Fairness Transcript, supra n. 2, at 1.}

\textsuperscript{20} \textit{Brown}, 724 S.E.2d at 269.

\textsuperscript{21} \textit{Brown}, 724 S.E.2d at 268.

\textsuperscript{22} U.S. Const. art. III, § 13.

\textsuperscript{23} \textit{Riverera v. Centro Medico de Turabo, Inc.}, 575 F.3d 10, 21–22 (1st Cir. 2009).
Without arbitration as an alternative dispute resolution process, I am afraid that I am only one jury verdict, or negotiated settlement from having to close the doors of The Floridean for good.24

Arbitration agreements may, therefore, be viewed as part of a larger public policy debate regarding medical malpractice reform. Reports indicate that each year 100,000 Americans die from preventable medical harm.25 The debate centers on whether judicial accountability or a systemic approach focused on education and improvement is the optimal strategy for eliminating preventable medical errors.

III. THE MARMET DECISION

Marmet, a four-and-one-half page decision, is emblematic of the disconnect between our current government and its people. Although decisions like Brown v. Board of Education26 remind us that lifetime appointments for the judiciary sometimes protect and preserve liberty, others, such as Marmet, cause advocates to wonder whether the current bench comprises corporate elitists: does this bench really understand the country it serves, or is it part of the 1 percent that has lost touch with the other 99 percent?

Marmet omits most of the facts recounted in the 99-page Genesis decision. Three broken families, alleging violations of state and federal law in the care of their loved ones, had the audacity of Oliver Twist as they approached the bench. They were given arbitration, which, for them, amounted to gruel.27 The families, like Oliver Twist, approached

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25 Consumers Union, To Err is Human — To Delay is Deadly (May 2009), http://safepatientproject.org/2009/05/to_err_is_human_to_delay_is_de.html. This article followed the Institute of Medicine report To Err is Human: Building a Safer Health System (Linda T. Kohn, Janet M. Corrigan & Molla S. Donaldson eds., National Academies Press 2000), http://www.nap.edu/catalog/9728.html, which suggests that 98,000 Americans die each year as a result of medical errors.


27 Frequently, families seek change so that no one else suffers what their loved ones endured. Unfortunately, utilitarianism seems to be the watchword on Wall Street; corporations respond best when their profits are impacted. Nursing home litigators argue that nursing home chains, armed with arbitration clauses, find it cheaper to let residents die than to provide quality care. Similarly, in the Ford Pinto case, a 1973 internal memorandum showed that it would cost Ford as little as $11 per car to recall and fix the Pinto but that it would be cheaper to allow drivers and passengers to die in the defective vehicles and for Ford to pay damages. See Amer. Assn. for Just., They Knew and Failed to ... 24, http://www.justice.org/clips/theyknewandfailedto.pdf. Arbitration awards are private, often subject to confidentiality agreements. As the Genesis court observed, the Constitution preserves inviolate the right of any person to air his or her grievances in a public courtroom. Genesis, supra n. 9, at 76. An additional concern often overlooked is that individuals who, arguably, have a conflict of interest generally administer arbitration proceedings.
trembling with their plea, “Please sir, I want some more.” In this instance, they wanted judicial accountability in the form of a jury trial. The U.S. Supreme Court, like the well-fed administrators of Twist’s workhouse, was outraged by that request. “You want more?!” How dare you ask for a jury of peers to review whether Marmet Health Care Center’s negligence killed Clarence?!

The second line of the decision reads: “Here, the Supreme Court of Appeals of West Virginia, by misreading and disregarding the precedents of this Court interpreting the FAA, did not follow controlling federal law implementing that basic principle.”

The Marmet court gave short shrift to West Virginia’s analysis of the FAA, rejecting its conclusion that Congress never intended the FAA as a shield for negligence in personal injury cases. The Court rejected the conclusion that an arbitration agreement adopted prior to the occurrence of negligence cannot be enforced. “The statute’s text includes no exception for personal injury or wrongful death claims.”

Marmet concludes, “When state law prohibits outright the arbitration of a particular type of claim [regardless of the facts, circumstances, or justice for doing so], the analysis is straightforward. The conflicting law is displaced by the FAA.”

The Supreme Court remanded the case, but not for arbitration. Marmet acknowledges that Genesis also found the arbitration agreement unconscionable, a second reason for refusing to enforce the arbitration agreement. The Genesis decision reviewed case law from other jurisdictions, finding that “numerous cases reveal that the enforceability of such an arbitration clause usually turns upon the authority of the signor of the admissions agreement, the formatting of the agreement, the admissions process and the fairness of the terms.”

Because Genesis did not clearly strike the arbitration clause on contract grounds, the Supreme Court remanded the case because it was unclear “to what degree the state court’s alternative holding was influenced by the invalid, categorical rule discussed above, the rule against predispute arbitration agreements.”

IV. DECISIONS SINCE MARMET

In Sherrer v. Covenant Health & Rehab of Picayune, the federal court for the Southern District of Mississippi compelled arbitration. The plaintiff sought to avoid a separately signed arbitration agreement arguing: 1) the resident lacked the requisite men-

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28 The truly odd result here is that, if the defendant is an individual appealing his or her death penalty sentence for murdering a nursing home resident, the defendant would find no sympathy from the current bench. But corporations are given license to commit preventable negligence without any real sense of accountability, knowing that their arbitration clauses will be enforced.

29 Marmet, 132 S. Ct. 1201 at 1203.


31 Marmet, 132 S. Ct. 1201 at 1204.

tal capacity to sign it; 2) the designated arbitrator did not exist at the time the arbitration agreement was executed, making the contract illusory; and 3) there was a lack of consideration. Each argument was rejected in favor of a two-step process for determining whether arbitration should be compelled: “First, the court must determine whether the parties agreed to arbitrate the dispute. Once the court finds that the parties agreed to arbitrate, it must consider whether any federal statute or policy renders the claims non-arbitrable.” The lack of capacity defense was rejected because the plaintiff failed to provide clear and convincing evidence of incompetency at the time the agreement was signed. The court gave the other two defenses no significant consideration before compelling arbitration.

In THI of N.M. v. Lovato, an arbitration agreement was signed by an agent under a power of attorney. A principal argument was that the agreement designated that arbitration would be conducted pursuant to the rules of the National Arbitration Forum (NAF), which had since discontinued accepting arbitration cases premised on a pre-injury agreement. The court found that, if NAF had been designated in the agreement as the arbiter, then its designation might be integral to the agreement; however, because the agreement only provided that its rules would apply, the unavailability of the NAF did not render the agreement unenforceable. An unconscionability defense was similarly rejected: “while the circumstances surrounding Ms. Atencio’s execution of the Arbitration Agreement reflect the inherently stressful nature of admitting a loved one into a nursing home, they do not establish procedural unconscionability. … Ms. Atencio’s “mere subjective feeling of not being free to decline arbitration terms [is not] enough to demonstrate procedural unconscionability.”

In Brewer v. Missouri Title Loans (not a nursing home case), the court found that arbitration agreements used by a Title Company were unconscionable and, therefore, unenforceable. In reaching this conclusion, the Brewer Court relied on a Supreme Court plurality decision, AT&T Mobility LLC v. Concepcion, in which the Supreme Court similarly had held that an absolute state law bar to arbitration violates the FAA; but that other generally applicable contract defenses, such as fraud, duress, or unconscionability may render the agreement to arbitrate unenforceable. Citing Marmet, the Brewer Court held that, although absolute bars to arbitration based on policy or statute are prohibited, the courts may consider and apply state law defenses to the formation of the particular contract at issue.

In finding the contract at issue to be unconscionable, the court found the agreement was one-sided, non-negotiable, and difficult to understand. There was no evidence that anyone had ever successfully negotiated a modification of the terms. The contract called for each party to bear his or her own costs and did not waive the company’s right to

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33 Id. at *5.
37 Id. at 1746. Nonetheless, Justice Scalia’s majority opinion indicates that the state contract rule applied to invalidate an arbitration agreement cannot be that arbitration itself is unconscionable in a given case; the FAA provisions permitting traditional contract defenses cannot be allowed to destroy the FAA. Id. at 1748.
38 Brewer, 364 S.W.3d at 492.
recover attorney’s fees in defending the claim. Further, three consumer lawyers offered testimony that the recovery provisions were so one-sided that it was unlikely a consumer could retain counsel to pursue an individual claim. Finally, although consumers were required to use arbitration in pursuing claims against the Title Company, the Title Company retained its right to use the judicial process. The Brewer court concluded the agreement was one that “no person in his senses and not under delusion would make.”

V. LESSONS FROM TENNESSEE

The State of Tennessee has been particularly gracious in providing insight regarding how to serve as an advocate in reviewing arbitration agreements. In Buraczynski v. Eyring, the Supreme Court of Tennessee found that pre-injury agreements between physicians and patients are not unenforceable per se; they should be closely scrutinized to determine if unconscionable or oppressive terms are imposed on the patient. The arbitration agreements in this case were presented on a “take it or leave it basis.” The agreement required arbitration of any and all medical malpractice claims by the patient against the doctor. Its provisions bound all potential parties, including the patient’s spouse and heirs, on all claims for medical negligence; and the physician, likewise, was bound by the arbitrators’ malpractice decision, including any fee claims involved in the disputed treatment. Finally, the patient had an unconditional right to revoke the agreement by providing written notice to the physician within 30 days of signing.

Initially, the Court found there is no public policy prohibiting arbitration agreements between physicians and patients. Similarly, the breadth of the agreement, which covered virtually all controversies, did not offend public policy. The contracts were, however, deemed adhesive. They were standardized forms prepared by a contracting party with superior knowledge of the subject matter — medical services. That conclusion, however, did not end the analysis or determine the enforceability of the agreement. The agreements in Buraczynski were not buried inside another agreement; the arbitration agreement was a separate one-page agreement, which included an explanation and a warning that the party signing would be giving up his or her right to a jury if a dispute arose. The agreement provided that each party would select an arbitrator, who in turn would select the arbiter of any dispute. Both sides would be bound. “Finally, and perhaps most importantly, the agreements did not change the doctor’s duty to use reasonable care in treating patients, nor limit liability for breach of that duty, but merely shifted the disputes to a different forum.”

In Howell v. NHC Healthcare-Fort Sanders, Inc., Buraczynski was applied to invalidate a nursing home arbitration agreement. In Howell, the resident’s husband, a roofer who could not read, signed an admissions agreement that included an arbitration clause; the relevant clause was on page 10 of an 11-page agreement. Residents or their representatives were required to sign the agreement upon admission. The agreement was not read to Mr. Howell; rather, it was paraphrased. Ms. Howell was too sick to return home and her husband was told she would not be admitted unless he signed the agreement. He was not told that he was giving up the right to a jury trial. Mr. Howell testified that he had never

39 Id. at 496.
40 Buraczynski v. Eyring, 919 S.W.2d 314 (Tenn. 1996).
heard of arbitration, did not know what it was and that it was not explained to him. The
court found it unnecessary to reach the issue of whether Mr. Howell had legal authority
to sign the agreement because, applying the Buraczynski principles, the agreement was
unenforceable. The clause was buried in a lengthy agreement rather than a stand-alone
agreement. It was written in the same font as the rest of the agreement and it did not ade-
quately explain how arbitration would work or who would administer it. The court also
found it relevant that, while there is no excuse for signing a document one cannot read,
when the defendant’s representative took it upon herself to explain the document, she
failed to do so adequately; thus, the facility failed to meet its burden that the agreement
was actually bargained for.

In Raiteri v. NHC Healthcare/Knoxville, Inc., a similar 11-page admission agree-
ment was reviewed subsequent to Howell. In addition to finding the contract unenforce-
able for the same reasons given in Howell, the court found no evidence that the person
signing the agreement had authority to do so. There was no evidence of express author-
ity and the nursing home could not rely on apparent authority as a basis for enforcing
the agreement. The issue of authority to sign was further explored in Owens v. National
Health Corporation, in which the Tennessee Supreme Court held that a durable power
of attorney for health care did, indeed, authorize an agent to sign an arbitration agreement.
Authority to agree, or lack thereof, remains an issue and recent cases in other jurisdic-
tions indicate authority might spring from default health care decision-making statutes.
More recently, in Duke v. Kindred Healthcare Operating, Inc., the court found clear and
convincing evidence that the agent had been appointed during a time when the principal was
incompetent; therefore, a motion to compel arbitration was denied because the agent had
no authority to agree to arbitration.

VI. HOW SHOULD THE ELDER LAW BAR RESPOND TO MARMET?

Initially, practitioners must determine where they stand on arbitration. Some will
reject the strong opinions against pre-injury arbitration agreements in this article. The
views expressed (and implied) in this article, however, are shared by traditionally “de-
fense-oriented” services such as the American Health Lawyers Association. Effective
June 2006, the American Health Lawyers Association’s Alternative Dispute Resolution
Service amended its rules for consumer health care liability claims filed with the Service
after January 1, 2004. It will administer a “consumer health care liability claim” on or
after January 1, 2004, only if 1) all of the parties have agreed in writing to arbitrate the
claim after the injury has occurred and a copy of the agreement is received by the Service
at the time the parties make a request for a list of arbitrators; or 2) a judge orders that
the Service administer an arbitration under the terms of a pre-injury agreement. Similar
statements have been made by the American Arbitration Association and the National
Arbitration Forum. Essentially this author is not “for” or “against” arbitration; instead,

ADR/Pages/RulesAmendment.aspx.
this author is against the waiver of a constitutional right without informed consent. The question, then, is whether the prospective resident (or his or her representative) truly understands what he or she is agreeing to, or is the resident being forced to sign away rights without first receiving competent legal advice?

For Elder Law attorneys, the principal issue is education and advocacy. NAELA members must understand the rules governing the formation of arbitration agreements where they practice. NAELA members should understand the benefits and limitations associated with arbitration and explain them to families well in advance of a nursing home placement. If possible, NAELA members should review admission agreements before they are signed and educate families regarding the bargain they are making.

Advice should also be given at the time agency documents are prepared. For example, the prudent Elder Law attorney should, after explaining what arbitration is, ask his or her client “would you want your agent to have authority to sign an arbitration agreement?” If the answer is “no,” then a limiting clause such as the following should be placed in the agency document:

Although I have given my Agent broad power under this general and durable power of attorney, I specifically withhold from my Agent the power to agree or consent to binding arbitration, or to agree to any other process that would preclude the right to have a jury decide any issue in controversy concerning my person or my property; this does not, however, preclude non-binding alternative dispute resolution processes such as mediation.

Limiting clauses such as this should prevent an agent from unknowingly bargaining away the right to judicial remedies. Although Estate of Ruszala v. Brookdale Living Communities, Inc.,\textsuperscript{46} addresses the absence of a power of attorney rather than a limited one, it illustrates how different facts result in different consequences; one of the consolidated cases was remanded for arbitration (with certain offensive terms stricken), while the other was remanded to determine whether the representative had authority to consent to arbitration.

The bottom line is that Marmet does not change the law. Marmet makes it clear that no per se rule or public policy will do our job for us. Protecting our clients remains our job.

Case Note

FOURTH CIRCUIT IN E.M.A. v. CANSLER REJECTS STATE AND DISTRICT COURT TREND AND HOLDS THAT AHLBORN REQUIRES HEARINGS TO DETERMINE MEDICAID SUBROGATION CLAIMS

By Ron M. Landsman, Esq., CAP

In a case note in 8 NAELA Journal 113 (2012), NAELA Journal reported on the decision against plaintiffs in Special Needs Trust for K.C.S. v. Folkemer,1 which misapplied the unanimous Supreme Court decision in Ahlborn.2 In Ahlborn, the Supreme Court said that Medicaid’s statutory right to subrogation of a beneficiary’s claim against a tort defendant for medical payments was limited by the Medicaid anti-lien rule to only the amount the plaintiff actually received from the defendant for medical expenses. The court in K.C.S. rejected plaintiff’s attack on the Maryland statute but never seemed to understand the issue: it conflated what Medicaid paid with what the plaintiff recovered for medical expenses and thus failed to see the need for a hearing to flesh out the latter as the limit on Medicaid’s recovery. Plaintiffs appealed but then subsequently settled with the state.

In attempting to apply Ahlborn, the case note pointed out that what the K.C.S. court and others overlooked was that in discussing the question of assessing what plaintiffs recovered, the U.S. Supreme Court accepted the ATLA amicus argument that there were plenty of trial procedures available for conducting such mini-trials within trials.3

In a more recent case, E.M.A. v. Cansler,4 the Fourth Circuit has correctly applied that portion of Ahlborn by rejecting as inconsistent with federal Medicaid law a statute of North Carolina that allowed it to recover its full expenditures up to one-third of the entire personal injury recovery. A similar Pennsylvania statute was limited for the same reasons in Tristiani ex rel. Karnes v. Richman.5 The Fourth Circuit neatly summarized its holding:

As the unanimous Ahlborn Court’s decision makes clear, federal Medicaid law limits North Carolina’s recovery to settlement proceeds representing payment for medical expenses. In the event of a lump-sum settlement, as in this case, the sum certain allocable to medical

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3 Id. 126 S. Ct. at 1765, n. 18. A substantially similar discussion was published in Ron M. Landsman, Case Note: Arkansas Department of Health and Human Services v. Ahlborn, Fall Tr. Rptr. 9 (2011), http://content.yudu.com/Library/A1u2ks/TrialReporterFall201/resources/content/11.swf.
5 Tristiani ex rel. Karnes v. Richman, 652 F.3d 360 (3d Cir. 2011).
expenses must be determined, in the absence of a stipulation by the affected parties, by judicial determination or some similar adversarial process, before the state may recoup its Medicaid outlays.\(^6\) (emphasis in original).

*Ahlborn*, the court noted, said the subrogation right was an exception — to be strictly construed — to the general Medicaid rule that prohibits liens against a beneficiary’s property. “[T]he Supreme Court has emphasized that ... a state cannot force assignment of, or place a lien on, any property that does not constitute reimbursement for medical expenses. ... ‘Beyond that, the anti-lien provision applies.’”\(^7\)

The North Carolina statute was based on the state’s view of “how attorneys and insurance adjusters typically value tort cases,” quoting the state’s brief, as three times special damages.\(^8\) The court said, however, the state’s interest in “efficiency” (the court’s use of air quotes) does not satisfy the anti-lien law. The state statute was the subject of extensive litigation in state courts, including two state supreme court decisions. While one dissenter insisted that *Ahlborn* required a trial court determination, the majority upheld the state statute on the grounds that “*Ahlborn* does not mandate a specific method for determining the medical expense portion of a plaintiff’s settlement,”\(^9\) and specifically does not require a judicial determination, even in the absence of a stipulation by the parties, as had been the case in *Ahlborn*. The state courts, and the federal trial court, limited *Ahlborn* to proscribing state recovery “in excess of the portion expressly stipulated as recovery for medical expenses in a Medicaid recipient’s settlement with a third party.”\(^10\) (emphasis in original).

That was not the Supreme Court’s holding, the Fourth Circuit observed. What the Court said in *Ahlborn* was that there were plenty of ways to avoid manipulation of settlements by the private parties to limit the state’s subrogation recovery:

Justice Stevens pointed out that the risk could be avoided either by obtaining a state’s advance consent to the allocation or by requiring that the allocation be submitted to the court. ... “[S]ome States have adopted special rules and procedures for allocating tort settlements. ... we leave open the possibility that such rules and procedures might be employed to meet concerns about settlement manipulation.”\(^11\)

The Fourth Circuit, consistent with the argument in the earlier case note, held that the reference to special procedures was to mini-hearings to allocate where the initial parties had not. Limiting recovery by statute to a portion of the full settlement does not satisfy the anti-lien provision, and nothing in *Ahlborn* supports the argument that it does. The

\(^{6}\) *E.M.A. v. Cansler*, supra n. 4, slip op. at 10.
\(^{8}\) *E.M.A. v. Cansler*, supra n. 4, slip op. at 15.
\(^{9}\) *E.M.A. v. Cansler*, supra n. 4, slip op. at 21.
\(^{10}\) *E.M.A. v. Cansler*, supra n. 4, slip op. at 23.
\(^{11}\) *E.M.A. v. Cansler*, supra n. 4, slip op. at 31 (internal citations omitted).
court went on to note a subsequent CMS memorandum on *Ahlborn* that listed a variety of ways for states to comply, none of which condoned across-the-board statutes like North Carolina’s.\(^\text{12}\) The court did not note, as it might have, that Justice Stevens said the courts had to be equally vigilant against “a rule of absolute priority [for Medicaid that would be] unfair to the recipient in other [cases].”\(^\text{13}\)

That is not to say that the states cannot put a thumb on the scales and tip the procedures in its own favor. The court cited with approval the Third Circuit decision in *Tristiani*,\(^\text{14}\) which upheld a Pennsylvania statute that established the state’s share as a rebuttable 50 percent but only because it was rebuttable at a hearing. More troubling, it cited without comment, and arguably with tacit approval, an Oklahoma statute\(^\text{15}\) that applies the state’s lien to the entire settlement subject to “a more limited allocation of damages to medical expenses ... shown by clear and convincing evidence.”\(^\text{16}\)

The upshot for trial attorneys is that they must find ways to force Medicaid into the process. At the least, plaintiffs should notify Medicaid’s recoveries office of settlement negotiations and settlement hearings and be prepared to provide a factual basis for settling. In *E.M.A.*, the Fourth Circuit noted plaintiff’s unrefuted contention that the Medicaid agency was given notice of the settlement negotiations and the mediation process, as well as of the trial court hearing to approve the settlement, but that no agency representative attended.\(^\text{17}\)

The apparently easier case to limit Medicaid’s recovery, from the plaintiff’s perspective, is when liability is at issue. Uncertainty about liability would prompt a plaintiff to reduce his claim for past medical expenses as much as he or she would reduce a claim for pain and suffering or future medical expenses. But a case settled for policy limits might well stand on similar footing. A plaintiff with a strong $20 million claim and past medicals of $3 million facing policy limits of $1 million might settle the future medicals for that $1 million, just as he would the claim for past medicals. Just because he could have settled the past medicals claim for $1 million is no reason to conclude he did so if he had an equally strong claim to settle future medicals for that same $1 million. The Fourth Circuit agreed with that reasoning.\(^\text{18}\)

Whatever the theory, Medicaid’s claim can only get resolved at settlement or trial if it is brought into the process by timely notice and opportunity to be heard. While the private parties’ allocation is not, *per se*, binding on Medicaid, a settlement stands on a different and much stronger footing when it is based on a factual presentation to the court and Medicaid has been provided notice and an opportunity to be heard.


\(^{13}\) *Ark. Dept. of Health and Human Servs. v. Ahlborn*, 547 U.S. at 288, 126 S.Ct. at 1765.


\(^{16}\) *Id.* slip op. at 33, 37.

\(^{17}\) *E.M.A. v. Cansler*, supra n. 4, slip op. at 5–6.

\(^{18}\) See *E.M.A. v. Cansler*, supra n. 4, slip op. at 35, n. 12, citing with approval *Price v. Welch*, 608 F.3d 698, 707–708 (10th Cir. 2010).
BOOK REVIEW

MOM ALWAYS LIKED YOU BEST: A GUIDE FOR RESOLVING FAMILY FEUDS, INHERITANCE BATTLES & ELDERCARE CRISSES

(Agreement Resources, LLC, 2011, 132 pp.)

By Arline Kardasis, Rikk Larsen, Crystal Thorpe, and Blair Trippe

Reviewed by Carol Cioe Klyman, Esq.

Effective argument can destroy relationships. Power coalitions within a family can result in battles won and wars lost. Building consensus is the smart way to negotiate when all parties are dug in, may not see issues rationally, and despite their differences must maintain contact when the battle is over. Even if you do not spend Christmas with mean Uncle Joe, you will probably see him at family weddings and funerals. How awkward and unpleasant if you lost your temper or felt bullied by him during a family dispute, no matter if you won the argument or were left with bruises.

This small volume written in conversational English by four experts in the field of conflict resolution should be required reading not just for Elder Law attorneys, but for anyone who may be involved in a dispute with layers of subtext, such as the typical family argument. Simmering beneath the overt problem are all of the unresolved feelings, slights, anger, and distrust that may have been passed down like inherited assets from one generation to the next. This book teaches how to get past all that and be more effective in a family dispute by focusing on the positive outcome rather than the process of the argument.

The authors are a bit Zen-like in their approach. They are not so naïve as to assume their readers are all rational, reasonable adults in touch with the better angels of their nature. They appeal to the pragmatic. Conflict resolution is not a capitulation, and resolution may or may not result in compromise. The authors understand the human need to win but contend that to have the negotiation end in the result you hoped for, with the other side feeling invested in your success is the true winning outcome.

The rational approach to “getting to yes” begins with identifying interests as opposed to positions. Positions and conclusions are established through our observations of the world. Our observations of the world are influenced by our experiences, biases, values, needs, and desires. For this reason a position may or may not be based in reality. Positions on a given issue often differ because individuals have their own individual perspectives. Arriving at a position rather than identifying one’s interests often ends in taking a stand, and it is from these disparate positions that family arguments ensue. If family members cannot get past these positions, there is impasse.

The key to breaking the stand-off is to separate positions from interests. While, according to the authors, positions are our biased conclusions, interests on the other hand represent our needs, desires, values, aspirations, fears, and concerns. For example, a posi-
tion would be: Mom needs to stop driving immediately. A competing position would be: Mom is fine; she will suffer more if she can’t drive. Behind the first stand is a concern for mom’s safety and the safety of others on the highway. Behind the second stand may be concern that mom will become depressed and lonely if she is deprived of her ability to drive. Interests tend to be more complex and layered than positions. The first sibling is likely also concerned about mom’s emotional well-being, and the second sibling likely also fears for mom’s safety. Both siblings may be reluctant to admit it, but they probably dread the logistical problem of arranging transportation for mother. They may differ on the “fact” of mom’s ability to drive, but in this example, their views of what is really important — mom’s physical and emotional well-being — intersect. This is the basis for collaborative decision-making. “[T]rue success is achieved only when you have determined what you need and why — and when you have created a resolution that satisfies your needs regardless of whether the resolution matches your initially stated position,” the authors write. This means putting aside positions and focusing on interests.

The next step to positive conflict resolution is to ask questions and gather information. The authors counsel that when an opponent digs into a position, the more enlightened party must try to understand the reason for the position taken. In the above example, it might mean questioning the sibling about the observations that led to the conclusion mom should not drive. She may have seen dents in mom’s car or a speeding ticket, and maybe she is afraid for mom but she does not dare ask mom about her observations. The siblings also need to gather more information about the risks to mom’s continuing to drive, perhaps involving professionals such as mom’s physician, as well as to investigate the availability and cost of alternate transportation. Through the process of information gathering the parties begin to move away from intractable positions.

The path to consensus essentially starts at the end and works backward. From the initial assessment of the goal one is trying to achieve and the identification of the parties’ common interests, the authors guide the reader in developing options toward reaching the goal, diffusing negativity through effective communication, and finally, on to consensus.

Each step is important. The authors contend that options should not be developed until the parties have fully explored their interests. It is clear that effective communication is key to resolution. “Active listening” — jargon that these authors deconstruct and illustrate — should enable opposing parties to feel that each of their views are being heard, respected, and understood. While expressions of anger and frustration are best avoided, it may be important to discuss those feelings in order to break an impasse. The authors provide an “Active Listening Kit” that includes examples of conversation boosters (open-ended questions that do not call for yes or no answers), acknowledgments of appreciation, bullet point summaries of discussion highlights, reframing of issues (to turn down the heat and illuminate), using optimism and transparency to generate trust, and stringing phrases together with “and” instead of “but,” which the authors call “the big eraser.” You have to read the book to find out why. Because each topic is explained with concrete examples, the list is a real toolkit rather than vague platitudes.

The Active Listening Kit enables the reader to develop consensus among different solutions that may develop during the communication process. For example, the authors encourage readers to deconstruct the elements of the various options and develop
a “zone of possible agreement” where the elements overlap and intersect. Elements outside the zone are non-negotiable, and elements inside the zone are negotiable. The most important negotiable elements will form the basis for an agreement.

The very best part of this book is how the authors apply theory to reality. For example, they discuss how the toolkit would apply to the issue of whether Dad should move to an assisted living facility, a very real issue in our clients’ lives. In this family discussion, Dad also gets a say. Readers are counseled to slow down. Developing a solid decision-making process takes patience and practice, but will stand a family in good stead through disagreements to come, particularly as parents and siblings age. The book also contains chapters on barriers to consensus, and how to unstick the negotiation process when it becomes stuck. The laundry list of barriers is a long one — starting with lack of trust and different concepts of fairness and ending with historical impasses and emotional responses (Mom always liked you best). They illuminate the forces giving rise to the barriers one at a time and provide helpful suggestions to overcome them to keep the conversation moving. The authors also give advice on how to include the elder in the negotiation process, how to conduct family meetings, and how to identify abuse and neglect of a loved one and confront and deal with the suspected wrongdoer.

The authors spend a whole chapter on the proper way to apologize, which is becoming a lost art. A proper apology must be an unconditional acceptance of responsibility with no “buts” attached. Timing is important — the apology must come at a time when the victim of the slight is able to choose whether or not to accept, not when it is convenient for the apologizer to apologize, and rarely in the heat of the moment in which offense is given. Expressing contrition is not empathizing. Empathy, “I know you’re upset,” may be helpful to break an impasse, the authors assert, but empathy can dilute an apology. After reading this chapter of the book, you will find yourself deconstructing the public mea culpas reported in the press and finding most of them wanting. As the authors note, a poor apology can be worse than no apology at all.

So much information and practical advice is packed into this little manual. Elder Law attorneys with litigation practices will find it particularly useful in that it focuses on issues confronted routinely. Because it is written in a very approachable and readable style, with short paragraphs and bullet points, the book would be a helpful instruction manual for clients facing difficult family situations and for the attorneys who counsel them.
BOOK REVIEW

SOMEDAY ALL THIS WILL BE YOURS:
A HISTORY OF INHERITANCE AND OLD AGE

(Harvard University Press, January 15, 2012, 368 pp.)
By Hendrik Hartog

Reviewed by E. Spencer Bates, Esq.

This book provides a unique insight into what is arguably the basis of modern Elder Law. In Someday All This Will Be Yours, Hendrik Hartog chronicles the history of legal actions to enforce promises of testamentary bequests made in exchange for care provided for an aging parent. Hartog documents the development, in a line of New Jersey cases, wherein children have brought suit against their parents or their parents’ estates for the enforcement of agreements to compensate them for providing care.

Hartog marks the late 19th century as the first instance of such a suit, with cases becoming more frequent into the early 20th century and beyond. In each case, an elder promises a child, or other family relative, property through his or her will in exchange for care services. Upon the death of the elder, the child then discovers that he or she was omitted from the elder’s will, or received less than promised, despite having performed the services.

Hartog marches through the development of the case law in this area with careful analysis. He suggests that in each of these cases the legal tension, from the court’s perspective, is between the desire of the court to recognize the labor of the child versus the right of the elder to freely distribute his or her property through a will. As reported by Hartog, the New Jersey courts have used a variety of methods to acknowledge that the labor of the child merited enforcement of the promise, from contrasting emancipated versus non-emancipated youth to contract theories of quantum meruit. For Hartog, the underlying trend is more important than the individual legal standards and so he narrates such case law from a cultural context. His narrative suggests that these cases document the shifting of elder-care from an entirely family-based system into a fully developed profession that requires payment for services, even when family members are providing the services.

Hartog provides a brief cultural background, which suggests that prior to the 20th century, elder care was simply an internal family function. He contends that as more and more people worked outside of the home society came to expect that children would break from their parental family, create their own new nuclear family, and accordingly have their own jobs and duties away from the extended family. He suggests that as this became the norm, family caregiving became the exception, and so the idea of compensating family for the care they provide gained acceptance. Hartog argues that this line of cases represents the recognition by the courts of changing societal values regarding the

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duty to care for the elderly.

Elder Law professionals will benefit from Hartog’s reminder that the Elder Law profession is not simply a set of legal standards to be enforced, but rather the management of interpersonal relationships. Elder Law, like the cases presented in Hartog’s book, comes into play once those relationships have failed and the individuals seek outside assistance with what has historically been considered to be a family issue.