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SPECIAL NEEDS TRUSTS: REFLECTIONS ON COMMON BOILERPLATE PROVISIONS

By Professor Jeffrey N. Pennell

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INTRODUCTION

The following article originated as a presentation at the 2009 Special Needs Trusts Annual Conference organized by Professor Rebecca Morgan at Stetson University College of Law. Offered as part of the “basics” curriculum of that program, the focus is on drafting the boilerplate — “fine print” trust administration1 provisions — in a third party special needs trust. The original concept was for a trust professor to bring a traditional trust law perspective to the endeavor, to help conjoin Elder Law, Medicaid, Social Security disability, and trust law knowledge that informs the creation and management of a special needs trust.

Various members of the faculty and organizers at the Stetson program were kind enough to provide samples from which the form itself was cobbled together. Some sam-

1 Note that many of the trust forms from the special needs trust specialists refer to “general administrative provisions” and trust lawyers refer to “trust administration provisions” — a difference that is more than just linguistic. The “administrative” provisions often deal with things like defining “survivorship” or “descendants,” specifying whether captions are part of the substance of a provision, selecting those who may act on behalf of an incapacitated beneficiary, stating the settlor’s primary intent, and other clauses that seem to have no logical “home” in the document. See Article 3 of this sample form. Trust lawyers regard trust “administration” provisions as those that deal with the core operation of the trust, ranging from facility-of-payment to trust investment to principal-and-income allocation rules. See the provisions that begin with Article 5 of this sample.
amples illustrate “best practice” or “preferred” approaches, but some provisions illustrate all-too-commonly-flawed drafting approaches. Together they highlight issues of particular or recurring concern but all are included purely for pedagogical purposes, and not as model or advisable language (as the annotations reveal). Caution therefore is required — these provisions are presented to spur reflection, and not necessarily for adoption.2

The annotations appear as if they were traditional footnotes, but they differ from those in a traditional article. These do not extract the distractions and bury them in the margin. Instead, they are the primary substance of the discussion and, as such, they warrant your full attention.

Note that the annotated sample is designed to ground a discussion about trust administration, not about dispositive provisions — the substantive provisions that are the bread-and-butter of special needs trust drafters. Nevertheless, there are some annotations to some dispositive provisions, simply because there are elements in them that also speak to trust administration.

The contributors who provided examples are not identified — solely to avoid casting aspersions as a result of any of the annotations to the form. Furthermore, this form is produced solely for educational purposes, and as such it may not be appropriate for any particular use. Added caution is necessary because the annotations were created by a trust law professor, not by a specialist Elder Law counselor. They have been reviewed by Elder Law specialists but they may ignore or overlook aspects of the endeavor that are informed by the substantive rules governing special needs trusts.

More critical is that the rules that govern this evolving endeavor are in a constant state of flux. Indeed, the state-by-state administration of many entitlements makes this a particularly difficult task, because interpretations and local procedures may vary significantly. Such that, even if correct upon publication, these comments and the provisions they annotate easily could become dysfunctional with the passage of time, or with a change of trust administration or beneficiary domicile. Thus, users must exercise restraint and discretion in considering these comments, so as not to defeat the original and overriding purposes of the trust. In addition, drafters are strongly encouraged to provide flexible mechanisms to adapt the trust to changing conditions, as for example with powers to amend, appoint, decant, migrate, or terminate the trust.

2 Few drafters create trusts from scratch. Most wisely draw on the experience and judgment of others, and favor provisions that have survived government or judicial review. Although publish forms are useful, there is danger in blind reliance on documents without considering a client’s circumstances and the need to make individuated choices among various alternatives.
THIRD PARTY SPECIAL NEEDS TRUST

This trust is established effective [Month] [date], [year], by [   ] (Grantor) for the benefit of [   ] (Beneficiary), on the following terms and conditions:

RECI Tumblr

A. Beneficiary is a resident of [city], [state], who was born on [      ]. Beneficiary is a disabled person, as defined in the Social Security Act § 1614(a)(3) (42 U.S.C. 1382c(a) (3)).

B. Grantor intends by this instrument to create a trust in accordance with the laws of the State of [state], by which the trust property shall be managed for the benefit of Beneficiary during Beneficiary’s life and distributed upon Beneficiary’s death.

ARTICLE 1. GENERAL PROVISIONS

A. Name.

This Trust shall be known as THE [   ] THIRD PARTY SPECIAL NEEDS TRUST for all purposes. This trust agreement is referred to herein as “the Trust” or “Agreement.”

B. Irrevocable Trust.

This trust is and shall remain irrevocable,⁴ except that the Trust may be amended or revoked, in whole or in part, by order of any Court of competent jurisdiction over the Trust, or by the [Trustee / Trust Advisor / Trust Protector] as set forth in Article 6 below, for the purposes of maintaining an effective trustee and allowing the Trust to continue to

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3 From a trust administration perspective neither recital is necessary — either to designate the beneficiary’s domicile or to state the settlor’s intent. It is not uncommon to state the settlor’s domicile (not that of the beneficiary, which may change during administration of the trust). Doing so may be helpful to establish which state’s law governs questions of interpretation or trust administration. Note that Article 7, Paragraph A contains a governing law provision, which makes a designation here less important. Occasionally a designation of the beneficiary’s domicile is harmful because it empowers more than one state to claim jurisdiction for state income tax purposes.

4 No drafter should leave the question to state law whether a trust is revocable or irrevocable, regardless of the state law rule at the time the trust is created. UNIFORM TRUST CODE § 602(a) changes the common law rule (which was that the trust is irrevocable if the document is silent) and its adoption may alter state law in a manner that is unanticipated and undesirable. Moreover, with “decanting” of trusts to make them subject to the law of another jurisdiction, it is conceivable that this aspect could be altered by a change of situs or by pouring an old trust into a new one. It is better to nail this down at the inception of the trust.
accomplish its stated purpose in the event that a change in the law, policy, interpretation of the law, or other circumstance will frustrate the Trust purpose.\(^5\)

OR

B. Revocability.

During the lifetime of the Grantor, or the survivor of the Grantors,\(^6\) the Grantor(s) shall have the right to alter, amend, revoke, or terminate this Trust at any time, and to designate the person(s) who shall possess or enjoy the trust property and the income therefrom, and to exercise any of the incidents of ownership in any property transferred to the Trust.

This trust shall become irrevocable upon the death of the Grantor, or the survivor of them, or upon initial trust funding by a third party\(^7\), and thereafter no person shall have the right (1) to alter, revoke, or terminate this Trust or any of the terms of this Agreement in whole or in part; (2) to designate the person who will possess or enjoy the Trust property, and the income therefrom; or (3) to exercise any of the incidents of ownership in any property transferred to the Trust. The Trust may be amended, in whole or in part, by further order of any Court of competent jurisdiction over the Trust, or by the [Trustee / Trust Advisor / Trust Protector] as set forth in Article 6 below, for the purposes of maintaining an effective trustee and allowing the Trust to continue to accomplish its stated purpose in

\(^5\) It is not common to give a trustee the power to amend a trust. Better that a trust advisor, trust protector, or other third party exercise this authority — either directly or through a power of appointment — to maintain checks and balances over the trustee.

A special provision is not needed to empower the trustee (or any other interested party) to petition a state court to reform a trust, as for example to adapt to changed circumstances. See note 32 and Uniform Trust Code §§ 411 through 416 (which are more robust than the law of many jurisdictions and likely provide all the authority needed to adapt to changed circumstances).

An important caveat to any grant of authority is that the trustee not be permitted to alter the fundamental fiduciary duties owed by the trustee that make this a trust. See text accompanying note 87.

\(^6\) Presumably this is a joint power, requiring the settlors to act unanimously while both are alive and competent, but it would be good to clarify that. Requiring both to act could prove problematic if (for example) one is incompetent, or following the divorce of married settlors. Note that even a joint power to alter, amend, or revoke the trust will cause its corpus to be includible in the settlor’s gross estate at death, under Internal Revenue Code § 2038.

\(^7\) From a trust law perspective it is not clear why this provision is included, nor why the drafter would permit a third party to make a contribution to the trust that would cause it to become irrevocable in its entirety (and not just to the extent of the third party’s funding).
the event that a change in the law, policy, interpretation of the law, or other circumstance will frustrate the Trust purpose.\textsuperscript{8}

C. Purpose of Trust.

The purpose of this Trust is to provide the greatest degree of security for Beneficiary and to preserve the assets of this Trust to provide for Beneficiary’s lifelong care. The term “security” includes consideration of Beneficiary’s overall circumstances and needs, including Beneficiary’s personal, emotional, spiritual, social, and financial well-being. The greatest degree of security can be provided for Beneficiary if this Trust is administered and managed to maximize and protect any insurance, public benefits for the disabled, or other assistance that Beneficiary is or may become eligible to receive. A number of needs other than support and maintenance are basic to a dignified life but may not be available to Beneficiary except through this Trust. This Trust is created expressly to benefit Beneficiary by providing for the special needs and supplemental care, maintenance, support, and education\textsuperscript{9} in addition to, and over and above, benefits that Beneficiary otherwise may be entitled to receive from any local, state, or federal government, or from any private or non-profit agencies that provide services or benefits to persons with disabilities similar to those of Beneficiary. It is the express purpose of this Trust that it be used to supplement any other benefits received by or on behalf of Beneficiary, and not to supplant any such benefits.

D. Intent of Trust.

Beneficiary will benefit from the protection and financial management provided by this Trust. It is the primary intent of this Trust to provide a system for handling funds, fiscal management, administration and disbursement, respite care, personal attendant services, advocacy, social development services, rehabilitation, care, education, training, and guidance for the sole benefit of Beneficiary to supplement all other financial and service benefits for which Beneficiary may be eligible from any local, state, or federal agency, or through any private or public profit or non-profit source. It is only an ancillary intent of this Trust to provide for the continued conservation and enhancement of the funds constituting the Trust Estate, or for the ultimate benefit of the remainder beneficiaries.

All actions of the Trustee shall be directed toward carrying out this intention. Beneficiary shall not be considered to have access to trust income or principal and may not, directly or through any legal representative of the Beneficiary, compel the Trustee to pay funds from the Trust for any particular purposes.\textsuperscript{10} This Trust shall not be construed as a support trust and is established as a pure discretionary trust.

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\textsuperscript{8} See note 5.
\textsuperscript{9} See note 13.
\textsuperscript{10} The intent of this provision is to preclude state Medicaid authorities from asserting that the beneficiary has greater rights than those meant to be granted by this supplemental needs trust. Nevertheless, the trust must be enforceable by someone.
E. Trust Funding.

Grantor and others may convey money or property to the Trustee on the same terms set forth herein, with the initial conveyance of trust principal to be known as the initial trust estate. The Trustee hereby agrees to hold that property and any other trust property on the terms set forth in this instrument. All property held by the Trustee, and all investments and reinvestments thereof, shall constitute the “Trust Estate.” No public assistance benefits received by or for Beneficiary shall be commingled with or become part of the Trust Estate.

F. Consideration.

In consideration of the mutual covenants contained herein, the Trustee hereby agrees to hold in trust those assets described as the Trust Estate for the uses and purposes and subject to the terms and conditions hereafter set forth.

ARTICLE 2. DISTRIBUTION AND ADMINISTRATION DURING BENEFICIARY’S LIFETIME

A. Distribution

1. In the Trustee’s sole and absolute discretion the Trustee shall distribute so much income and principal to or for the benefit of Beneficiary as the Trustee shall determine to provide special needs and supplemental benefits to Beneficiary that are not provided by or through private or governmental assistance programs. Any and all discretionary distributions shall be based primarily upon Beneficiary’s best interest. No Trust income or principal shall be paid or expended for Beneficiary so long as the Trustee determines that there are sufficient resources available for Beneficiary’s care, support, comfort, and welfare from any governmental or private programs. Although the intent of this trust is to preserve Beneficiary’s eligibility for public benefits, the overriding goal of the trust is to ensure Beneficiary’s good health, safety, and welfare.
In the Trustee’s discretion the Trustee may make distributions of trust assets to or for the benefit of Beneficiary to meet any need not fully met by public or private benefit programs. In its sole discretion the Trustee may pay to or for Beneficiary’s benefit any amount that does not exceed the state or federal regulations for maximum supplemental income. In the Trustee’s sole discretion the Trustee also may repay any part or all of any amounts owed to the Social Security Administration if an overpayment of benefits to Beneficiary has been made, either prior to or subsequent to establishment of this Trust, to prevent a loss of SSI or other related government assistance by Beneficiary.

2. The Trustee shall not be required to see to the application of any funds applied or paid, and the receipt of the payee shall be a full acquittal of the Trustee. The decision of the Trustee as to direct payments or application of funds as above prescribed shall be conclusive and binding upon all parties in interest if made in good faith.

B. Additions To Trust Estate; Environmental Compliance.

1. With the Trustee’s consent, any person may at any time or from time to time, whether by Court order, assignment, gift, transfer, beneficiary designation, deed, will, or otherwise, provide income or add to the principal of the Trust Estate, and any property so added shall be held, administered, and distributed under the terms of this Trust. The Trustee shall execute documents the Trustee may deem necessary to accept additional contributions to the Trust Estate and shall designate the additions on the business and accounting records of the Trust. At the end of a calendar year, the Trustee shall designate

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14 A common administration power is a “facility of payment” provision. The one in this trust (see text accompanying note 47) applies only with respect to a remainder beneficiary, and this is nearly “hidden” here with respect to Beneficiary.

15 In the same way that an insurance trust will relieve the insurance company from any obligation to see to the application of insurance proceeds paid to a trust (see text accompanying note 78), this document properly relieves the payor of any obligation to verify how distributed funds are used.
any accumulated and undistributed income as principal,\textsuperscript{16} and may so designate such additions on amended schedules to this Trust.

2. Regardless of any provision to the contrary, as a prerequisite to accepting property the Trustee may require that the transferor provide evidence satisfactory to the Trustee that (i) the property is not contaminated by any hazardous or toxic materials or substances; and (ii) the property is not being used and never has been used for any activities directly or indirectly involving the generation, use, treatment, storage, disposal, release, or discharge of any hazardous or toxic materials or substances.\textsuperscript{17}

C. Distribution Guidelines.

In making any distribution the Trustee shall:

1. Consider any other income or resources of Beneficiary known to the Trustee to be reasonably available;\textsuperscript{18}

\textsuperscript{16} This “add to principal” provision should not apply only to amounts added to the trust, and therefore might better be a separate, free standing provision. The rationale for it is to avoid the need to maintain a separate income accumulation fund that would require separate investment and accounting, generating its own separate fiduciary fee. This administration also need not be done “at year end”; it appropriately may be left to the trustee’s discretion. Compare text accompanying note 31, which refers to an annual (but not a calendar year) addition to principal.

\textsuperscript{17} Under City of Phoenix v. Garbage Services Co., 827 F. Supp. 600 (D. Ariz. 1993), a trustee that did not participate in an environmental tort is not personally liable for superfund cleanup costs, but the addition of contaminated property to a trust could generate trust liability that could exhaust the full corpus of a trust. Although the intent here is that the transferor incur the cost to verify that property is not tainted, this provision might authorize the use of trust funds to perform an independent environmental audit, incur legal or other fees (including to pay for a trustee’s extraordinary services), or to perform other appropriate due diligence before accepting potentially contaminated property.

\textsuperscript{18} Lacking this provision trust law may require the trustee to ignore the beneficiary’s other resources. See \textit{Restatement (Third) of Trusts} § 50, comment e “to the extent . . . the [beneficiary’s] discretionary interest is intended to provide for the support, education, or health care of a beneficiary . . . for periods during which a beneficiary probably was not expected to be self-supporting, the usual inference is that the trustee is \textit{not} to deny or reduce payments for these purposes because of a beneficiary’s personal resources.” A special needs trust is meant to supplement rather than provide for basic support, as appropriate to qualify for Medicaid, which might suggest that the trust is not for “support” (because the public entitlement instead provides for that care), but that refinement is intended only to preclude the trust from being a countable resource that would disqualify the beneficiary for the public benefit.
2. Consider Beneficiary’s entitlement to benefits from any government agency, such as federal SSDI, SSI, food stamps, Medicare, Medicaid, welfare, and any other special purpose benefits for which Beneficiary is or may be or become eligible;

3. Consider resource and income limitations of any such assistance program;

4. Consider making expenditures so that the standard of living of Beneficiary will be comfortable and enjoyable;\(^{19}\)

5. Not be obligated or compelled to make such payments;\(^{20}\)

6. Not be liable for any loss of benefits that may occur as a result of Trustee’s good faith actions in the administration of this trust;

7. Be entitled to rely on the representation of a trust advisor who is a competent professional that all other sources of income and benefits have been taken into consideration and the effect of trust disbursements on such benefits.\(^ {21}\)

D. Right of Trustee to Contest Demands Upon the Trust.

If the Trustee is requested by any department or agency to release trust income or principal to or on behalf of Beneficiary to pay for equipment, medical expenses, or other services that any governmental or private organizations or agencies are authorized to provide were it not for the existence of this Trust, or if the Trustee is requested by any department or agency administering such benefits to petition a court or administrative and does not alter the fundamental notion that this trust is a safety net that provides for the beneficiary’s needs (at least to the extent they exceed those provided for by the entitlement). As such, it is likely that the general principle noted is applicable. \textbf{Austin W. Scott, William F. Fratcher, & Mark L. Ascher, Scott and Ascher on Trusts} § 13.2.4 (5th ed. 2007) (hereafter referred to as \textit{Scott and Ascher}), is more pragmatic, stating: “When the terms of the trust require the trustee to pay to or apply for the beneficiary so much as is necessary for maintenance or support, but fail to provide whether the trustee is to take into account the beneficiary’s other resources, it is unclear what the usual inference ought to be.” As a general matter and here in particular that uncertainty is undesirable, which makes it essential to clarify the settlor’s intent. And it likely will not hurt to clarify the settlor’s intent, which absolutely is to consider the Medicaid resource before invading the trust.

\(^{19}\) See note 13.

\(^{20}\) See note 10.

\(^{21}\) Article 6 does not dovetail with this provision — no authority (or responsibility) is imposed on the Trust Advisor to advise the trustee, nor is any exculpation provided to an Advisor who provides advice. See text accompanying note 92, which would be the appropriate provision to expand for such purpose.
agency for the release of trust income or principal for this purpose, or if any department or agency terminates payment or eligibility for any benefits to Beneficiary based upon the existence of or payments from this Trust, the Trustee is authorized to deny and contest such request or termination through administrative or judicial action and to defend any contest or other attack of any nature on this Trust and the public assistance program eligibility of Beneficiary. Trustee also is authorized to settle or otherwise compromise any such claim or litigation in whole or in part. Any expenses of the Trustee in this regard, including reasonable attorney’s fees, shall be a proper charge to the Trust.  

E. Trust Estate Unavailable to Beneficiary.

Under no circumstances shall Beneficiary have the right to demand any distribution from the Trustee, who is under no obligation, implied or otherwise, to make any distributions to Beneficiary. Further, the Trustee may withhold distributions to Beneficiary if, in the Trustee’s sole discretion, such amounts would not be consistent with the intentions expressed in this Agreement. The Trustee shall use its best efforts to avoid distributions that may cause termination of public or private benefits that Beneficiary is or may be eligible to receive during the term of this Trust.

F. Administration Expenses.

The Trustee is authorized to pay or pre-pay out of trust income or principal any expenses of administration related to the Trust, including reasonable attorney’s fees, fees and expenses relating to the administration or termination of a guardianship or any legal

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22 Particularly because the trust corpus may be consumed if a challenge is not successful, this compensation for any extraordinary administration or legal and accounting fees incurred is essential to ensure that the trustee will mount an appropriate challenge.

23 See note 10, and see Article 7, Paragraph B (a standard spendthrift provision).

24 The critical element here is the authority to use income or principal. Lacking this the trustee might become embroiled in questions under the Principal and Income Act, particularly relating to the prepayment of expenses. This provision might be more helpful to the trustee if it also relieved the need to make any adjustments in income or principal to account for such use to make the initial payment — that is, adjustments to repay one set of beneficiaries for what otherwise could be regarded as only an advancement of the funds used to make payment. Because both income and principal are distributable from this trust, such a provision would not raise the concerns evoked by Doherty v. Director, 908 N.E.2d 390 (Mass. Ct. App. 2009) (trustee power to “determine all questions as between income and principal and to credit or charge to income or principal or to apportion between them” was deemed to allow indirect disqualifying invasions of principal in an income-only self-settled Medicaid trust). This provision only eases administration and principal and income accounting, which is irrelevant to the beneficiary’s entitlement.
action commenced by or on behalf of Beneficiary prior to Beneficiary’s death, and the Trustee should further consider purchasing a reasonable burial plan and paying the expenses relating to Beneficiary’s funeral and burial.

G. Acquisition and Maintenance of Residential Real Estate.

1. To the extent permitted by the laws, regulations, or policy provisions pertaining to any state or federal public benefit program for which Beneficiary may be eligible, the Trustee is authorized to purchase, maintain, improve, or replace a residence or any interest in a residence in which the Beneficiary may reside, whether by purchase, lease, or purchase of an interest in any such residence, including any portion of a residence that may be owned by a family member. If the Trust shall at any time own such realty, the Trustee may permit Beneficiary’s occupancy or use without charge in such manner as, in the opinion of the Trustee, best serves Beneficiary’s needs, without the necessity of turning such property into cash or generating an income therefrom.

2. To the extent permitted by the laws, regulations, or policy provisions pertaining to any state or federal public benefit program for which Beneficiary may be eligible, the Trustee is authorized to pay out of trust income or principal any taxes, insurance, and maintenance expenses needed to keep the residential or replacement property in suitable repair, or any portion thereof and to collect rent from other occupants of the property, as the Trustee deems proper. These powers may be exercised for the benefit of Beneficiary, even if Beneficiary is residing with any family member who also may be serving as a Trustee.

3. To the extent permitted by the laws, regulations, or policy provisions pertaining to any state or federal public benefit program for which Beneficiary may be eligible, the Trustee may acquire furnishings, make home improvements, and provide for regular household assistance to Beneficiary.

25 Here again the critical element is the authority to use income or principal. Lacking this the trustee could become embroiled in questions under the Principal and Income Act, particularly relating to the payment of maintenance expenses (which some might regard as improvements, which could alter their character). This provision also would be more helpful if it addressed the need to adjust. By way of example, if the trustee paid from principal to provide a new furnace or air conditioning system in the beneficiary’s dwelling, and paid extra for an extended warranty or maintenance agreement, the issue might be whether that added expense, also paid from principal, should be charged back against income during the years covered by the agreement. The effect of a prepayment and chargeback might be a wash, because payment from corpus would reduce the available investment fund, which might reduce the income subsequently produced, but that economic reality might not preclude controversy that a provision more easily could avert.

26 This provision permits a form of self-dealing by an individual trustee that likely would not be challenged, but there is no need to run the risk.
4. The Trustee is expressly authorized, in its absolute discretion, to permit any family member of Beneficiary, who is residing now or at any time in the future upon any real property forming a part of the Trust Estate to continue residing there on such terms as the Trustee shall deem proper, whether rent free or in consideration of payment of taxes, insurance, maintenance, and ordinary repairs, or otherwise, even if Beneficiary is residing with any family member who also may be serving as a Trustee.27

H. Emergency or Material Change of Circumstances.

In the event of an emergency or any other condition that the Trustee reasonably believes threatens the life, safety, or security of Beneficiary, or any material change of circumstances, the Trustee has full and unrestricted discretion to administer this Trust so as to alleviate the condition and address the change of circumstances in keeping with Beneficiary’s best interest, which is of primary importance in the administration of this Trust.

ARTICLE 3. ADMINISTRATIVE GUIDANCE TO THE TRUSTEE
A. Discretion of Trustee.

As used herein, “discretion” shall mean sole, exclusive, unrestricted and absolute discretion. Discretionary powers are exercisable in the sole and absolute discretion of the Trustee, and Beneficiary shall have no right or power to enforce or object to the lawful exercise of such powers.29

27 See note 26.

28 See note 29, and quaere whether “unrestricted” discretion is meant to differ from “absolute” discretion as used in the text accompanying that note. Then see note 12 regarding trust drafting in general.

29 No grant of sole, exclusive, absolute, unrestricted, unfettered, non-reviewable, or any other similar grant of authority is valid. Drafters regularly say this but presumably know that a fiduciary’s exercise of discretion must be subject to review. If it were otherwise there would be no enforceability, and that would mean that there would be no trust. See Restatement (Third) of Trusts § 50, comment c: “It is . . . a contradiction in terms, to permit the settlor to relieve a ‘trustee’ of all accountability. . . . Once it is determined that the authority over trust distributions is held in the role of trustee . . . words such as ‘absolute’ or ‘unlimited’ or ‘sole and uncontrolled’ are not interpreted literally.” Scott and Ascher, supra note 18, §§ 13.2.3, 18.2 (5th ed. 2007): “The terms of the trust may enlarge the trustee’s discretion by use of qualifying adjectives or phrases such as ‘absolute,’ ‘sole,’ ‘uncontrolled,’ or ‘unlimited.’ Such terms are not, however, interpreted literally; they do not confer on the trustee unlimited discretion,” citing Uniform Trust Code § 814(a): “Notwithstanding the breadth of discretion granted to a trustee in the terms of the trust, including the use of such terms as ‘absolute,’ ‘sole,’ or ‘uncontrolled,’ the trustee shall exercise a discretionary power in good faith and in accordance with the terms and purposes of the trust and the interests of the beneficiaries.” In this regard see also notes 10 and 86.
B. Maintain Eligibility for Public Benefits.

If Beneficiary is unable to do so independently, the Trustee shall exercise its best judgment and fiduciary duty to seek support and maintenance for Beneficiary from all available public and private resources, including but not limited to the Supplemental Security Income Program (“SSI”); Supplemental Income Program (“SIP”) of [state] or any other state; the Old Age Survivor and Disability Insurance Program (“OASDI”); the Medicaid Program, and any additional, similar, or successor program; and from any private support sources. The Trustee also shall request that any appointed guardian or conservator seek such support or maintenance. The Trustee shall take into consideration the applicable resources and income limitations of any public assistance program for which Beneficiary is eligible when determining whether to make any discretionary disbursements. In carrying out the provisions of this Trust, the Trustee shall be mindful of the present and probable future special needs of Beneficiary. With reasonable frequency the trustee shall reevaluate Beneficiary’s living conditions, treatment, and morale.

C. Restrictions on Trustee’s Discretion.

1. This provision is applicable only if any need of Beneficiary is not otherwise adequately provided for by private or governmental financial assistance and benefits or by the providers of services. Subject to this condition the Trustee may pay or apply for the benefit of Beneficiary any part or all of the trust income or principal as the Trustee in its sole discretion may from time to time deem necessary or advisable for any of Beneficiary’s special needs. Any income not distributed shall be added annually to principal.

2. In determining whether the existence of the Trust has the effect of rendering Beneficiary ineligible for any program of public benefit, the Trustee is hereby granted full discretion to initiate steps rendering Beneficiary eligible for any such program of public benefit and to initiate administrative or judicial proceedings to determine eligibility. All costs relating thereto, including but not limited to reasonable attorney’s fees, shall be a proper charge to the Trust.

3. If Beneficiary becomes ineligible for any program of public benefit the Trustee may obtain the authority of a court of competent jurisdiction to terminate this Trust, and distribute outright the balance of the Trust Estate in accordance with the ruling of such court.

Also note that “lawful exercise” in the last clause adds nothing because it begs the essential question.

30 See note 18. A similar provision would permit a trustee to consider a beneficiary’s tax liability in making or withholding distributions — which is a factor that likely is not important in this context but otherwise would require the grant of specific authority to resolve what likely is an absence of authority under state law.

31 See note 16.

32 See the second paragraph of note 5, here in regard to not needing authority to seek
D. Consultation with Advisors.

1. The Trustee shall, at least annually, and may at other times chosen by the Trustee, consult with an attorney or other consultant with appropriate knowledge and expertise in the area of public benefits and trust law to review applicable state and federal laws, regulations, and other requirements of the public benefit programs and to review the appropriateness of Trust distributions and expenditures so that the public benefits eligibility of Beneficiary is not jeopardized by inappropriate actions or distributions by the Trustee. The cost of such professional consultations may be paid by the Trustee from Trust assets.33

2. The Trustee may seek the counsel and assistance of Beneficiary’s advocate, guardian, or conservator, if any, and any state and local agencies that have been established to assist persons with similar disabilities and limitations. The Trustee may use the resources of the Trust Estate to aid Beneficiary’s advocate, guardian, or conservator as appropriate, in identifying programs that may be of social, financial, developmental, or other assistance to Beneficiary. However, the Trustee shall not in any event be liable to Beneficiary, the remainder beneficiaries of this Trust, or any other party for any acts as Trustee hereunder so long as the Trustee acts reasonably and in good faith. For example, the Trustee, as well as Beneficiary’s advocate, guardian, or conservator34 shall not be liable for the failure to identify each and every program or resource that might be available to Beneficiary on account of Beneficiary’s disabilities and limitations.

33 Approval to terminate a trust. Administratively it also might be appropriate to include a “small trust termination” provision, such as the following, and to incorporate added triggers relating to termination of any program of public benefits that made the trust appropriate in the first instance:

The trustee in its discretion may terminate and distribute any trust hereunder if the trustee determines that the costs of continuance thereof will substantially impair accomplishment of the purposes of the trust. Distribution under this provision shall be made to the persons then entitled to receive or have the benefit of the income from the trust in the proportions in which they are entitled thereto or, if their interests are indefinite, then in equal shares. In no event shall the trustee exercise this authority if doing so would cause termination of a beneficiary’s entitlement to public benefits, nor may the trustee be compelled to exercise this authority.

Some trust documents combine this provision with the Perpetuities Saving Clause because the distribution is the same. See, e.g., Article 7, Paragraph C.

34 This provision would be more helpful if it was crafted in the same manner and provided the same authority as the text accompanying notes 24 and 25.

34 Quaere whether the intent here is to exculpate these other advisors or fiduciaries. If not, this dependent clause may be inappropriate. If it is, quaere why this is an appropriate provision without more to guide a court regarding that intent.
3. The Trustee is authorized to employ investment counsel, financial advisors, corporate cotrustees, custodians of trust property, brokers, accountants, lawyers, realtors, rental agents, and other agents in those instances in which the Trustee, in the exercise of discretion, deems it necessary or advisable, and to pay reasonable fees in connection therewith from income or principal. The Trustee shall be free from liability for neglect or misconduct of any agent selected and retained with reasonable care. The Trustee may, at its discretion, obtain and compensate a correspondent trust fiduciary or other agent to hold, manage, or otherwise dispose of real property located in another jurisdiction.\(^\text{35}\)

4. It is a purpose of this Trust, which is precatory and not mandatory, that disbursements may be made from the Trust Estate for such advocates, both legal and non-legal, as may be necessary to protect any and all rights of Beneficiary, as well as to protect the integrity of this Trust. The Trustee is authorized, in its discretion, to take whatever administrative or judicial steps may be necessary to continue Beneficiary’s eligibility for benefits, including obtaining instructions from a court of competent jurisdiction ruling that the Trust corpus is not available to Beneficiary for eligibility purposes. Any expenses of the Trustee in this regard, including reasonable attorney’s fees, shall be a proper charge to the Trust estate.\(^\text{36}\)

E. Annual Evaluation of Beneficiary.

The Trustee is requested (but not required) to conduct or arrange for an annual evaluation of Beneficiary, addressing Beneficiary’s needs and circumstances such as: physical condition; educational, residential, vocational, and training opportunities; recreational, leisure, and social needs; appropriateness of existing program services; and the availability of governmental financial assistance and private contractual benefit programs. The Trustee or its agent(s) are requested to personally visit Beneficiary at Beneficiary’s resi-

\(^{35}\) Delegation is a critical function about which state law may be unclear, absent authority as found in this entire paragraph or specific state law. See Uniform Trust Code § 807; Restatement (Third) of Trusts § 80; Scott and Ascher, supra note 18, § 17.3 (5th ed. 2007). In addition to the authority to allocate fees to income or principal, the trustee should be relieved of any responsibility to adjust accounts, and it should be made clear that the trustee’s fee will not be reduced by the delegation of trustee functions to outsiders. The same delegation factors and relief of liability should apply to the out-of-state trustee provision in the last sentence (that is, if the selection and retention is prudent) — but notice that the order of these sentences suggests that it is not.

\(^{36}\) Given a fiduciary’s normal duty of loyalty, this authority — essentially to advocate against the beneficiary’s best interests under the trust — might appropriately grant exculpation to the fiduciary from any liabilities that may exist. Also quaere why the expense provision here does not authorize payment from income or principal, and whether it should be crafted in the same manner and provide the same authority as the text accompanying notes 24 and 25.
dence at periodic intervals determined appropriate by the Trustee, to assess Beneficiary’s living conditions, to assess the treatment given Beneficiary by caregivers, and to let Beneficiary know that Trustee is Beneficiary’s friend and advocate.  

F. Trustee Environmental Exculpation.

No Trustee shall be liable for any loss or depreciation in value sustained by the Trust as a result of the Trustee retaining any property upon which there is later discovered to be hazardous materials or substances requiring remedial action pursuant to any federal, state, or local environmental law, unless the Trustee contributed to the loss or depreciation in value through willful default, willful misconduct, or gross negligence.

G. Trustees’ Exemptions Regarding Bond, Inventoring, and Reporting.

No trustee shall be required to give bond or other security, or file any formal inventory, accounting, or appraisal with any court regarding the performance of Trustee’s duties hereunder, unless required to do so by a duly entered order of a court of competent jurisdiction over this Trust.

H. Annual Accounts.

The Trustee shall render and maintain an annual account of the administration of the Trust to Beneficiary or to the legal representative of Beneficiary. Such accounting shall include a schedule of receipts and disbursements of the Trust and a copy of any Federal fiduciary income tax return filed by the Trust. In addition, the Trustee shall furnish to Beneficiary at least annually documentation of the investment status of the Trust Estate.

37 Notwithstanding the reference to the trustee’s agent(s), this paragraph appears to suggest that a corporate fiduciary is less likely to serve than an individual, as to whom various protections, delegation authorities, and succession provisions will be appropriate, that otherwise would not be needed with respect to a corporate fiduciary. See, e.g., note 13 and accompanying text.

38 See note 17. This document seems obsessed with the environmental tort topic. Experience suggests that typical trusts are not so comprehensive about the issue. Quaere why this one is. In any event, quaer why the various references to this concern sprinkled throughout this document are not corralled into a single comprehensive provision.

39 This does not exempt the trustee from making accountings to beneficiaries, which is an essential function to permit enforcement of the trust. See Uniform Trust Code § 813(c); Restatement (Third) of Trusts § 83; Scott and Ascher, supra note 18, § 17.4 (5th ed. 2007). The more significant accounting function is addressed in note 62.

40 This provision is harmless but not common — because state law will determine what form of accountings are appropriate or required. And notice — why does the
I. Notices to Beneficiary.

Any time when Beneficiary is entitled to receive a notice, the Trustee may give such notice in writing by fax, regular mail, overnight courier, or hand delivery, in the Trustee’s discretion, to Beneficiary at Beneficiary’s last known address if Beneficiary is competent to receive such notice or, if not, to Beneficiary’s legally appointed guardian or conservator of the person or estate of Beneficiary or to any suitable person with whom Beneficiary resides or who regularly provides care for Beneficiary.

ARTICLE 4. TERMINATION OF TRUST

A. Termination Upon Death of Beneficiary.

This Trust shall terminate upon the death of Beneficiary, except that the title, powers, duties, immunities, and discretion herein conferred upon the Trustee shall continue after termination of the Trust and until final distribution. Upon Beneficiary’s death, or as soon as practical thereafter, the Trustee shall distribute the remaining trust principal and any accumulated income in accordance with the provisions for distribution set forth hereinbelow.

B. Payment of Final Expenses and Taxes.

The Trustee may pay or hold in reserve for payment an amount of money, which in Trustee’s opinion will be necessary, to pay the funeral and burial expenses of Beneficiary to the extent not covered by life insurance on Beneficiary’s life or any other funds set aside for such funeral or burial expenses. The Trustee also may withhold an amount in first sentence of this paragraph allow delivery to a beneficiary’s legal representative, but not the last? For that matter, why does the next paragraph not refer to the beneficiary’s “legal representative” simpliciter, instead of naming all of the various flavors thereof?

But not by e-mail attachment? Experience suggests that this provision also is not common. And quaere whether (or why) delivery to a caregiver — which might include an extended care facility — is adequate or appropriate.

Trust law permits a trustee to continue a trust for a reasonable period needed to wind up its affairs and make any required distributions. See Uniform Trust Code § 817(b); Restatement (Third) of Trusts § 89; Scott and Ascher, supra note 18, § 36.1 (5th ed. 2008).

First, why not just direct payment of these items and then termination of the trust, rather than the contorted provisions here and in paragraph A — is this a function of the requirements of a special needs trust, that it must terminate at Beneficiary’s death and the drafter does not want to raise any concerns about what that means as a practical matter?

This paragraph does not direct payment of any of these items, nor does it indicate how the trustee should exercise the discretion to pay (“may pay”) those items noted in the first sentence. Also quaere why the second sentence only authorizes withhold-
reserve to cover any estate, gift, generation-skipping transfer, or income taxes or final trust administration expenses that are or may be due upon or by reason of the death of Beneficiary. The decision as to the amount held in reserve shall be binding upon the remainder beneficiaries.

C. Remainder Beneficiaries.

After making or providing for the payments authorized in the prior paragraph the Trustee shall distribute the remaining trust principal and income to or for the benefit of one or more persons or organizations as Beneficiary may appoint by specific reference thereto in the last will and testament of Beneficiary, admitted to probate. Such appointment may be outright or in trust.44

To the extent Beneficiary fails to effectively exercise the power of appointment,45 then upon the death of Beneficiary the Trustee shall distribute any remaining principal and accumulated income to [ ] [Beneficiary’s spouse and children in equal shares per stirpes]46 [Beneficiary’s heirs at law].

44 This is a general (taxable) power to appoint. Quaere why it is appropriate to thereby make this trust taxable in the estate of the beneficiary for federal estate tax purposes. See Jeffrey N. Pennell, Transfer Tax Payment and Apportionment, 834-2 Estates, Gifts, and Trusts Portfolio (Tax Mgmt. 2010).

45 The following provision may be useful in determining whether Beneficiary effectively exercised the power:

In disposing of any trust property subject to a power to appoint by will, the trustee may rely upon an instrument admitted to probate in any jurisdiction as the will of Beneficiary or may assume that the power was not exercised if Trustee has no actual notice within three months of Beneficiary’s death of a will that exercises the power. The Trustee may rely on any document or other evidence in making payment under this will and shall not be liable for any payment made in good faith before the Trustee receives actual notice of a changed situation.

46 Numerous decisions indicate that “in equal shares per stirpes” doesn’t mean any-
During the minority or legal incapacity of any remainder beneficiary to or for whom income or principal is authorized or directed to be paid, the Trustee, in its sole discretion, may pay, transfer, or assign the income or principal in any one or more of the following ways: (a) directly to such beneficiary such amount as it may deem advisable; (b) to the guardian or custodian of the person or of the property of such beneficiary; (c) to a relative of such beneficiary upon the agreement of such relative to expend such income thing (because a per stirpital distribution does not necessarily produce equal shares) and thus invites a construction suit. See, e.g., RESTATEMENT (SECOND) OF PROPERTY, DONATIVE TRANSFERS § 28.2 Reporter’s Note 5.d. (1988). The likely intent of a drafter who uses this language is “in equal shares with the right of representation,” both components of which form the definition of a per stirpes distribution.

In this case does the “equal shares” provision mean that half goes to the spouse if living, and the other half goes to the class of children, each half subject to a right of representation? Or does the spouse receive an equal share as if the spouse was a child, also with the right of representation? Neither option makes much sense (unless the spouse’s descendants differ from Beneficiary’s descendants), but is there a third interpretation?

Text accompanying note 14 is a much less fulsome version of this “facility of payment” provision. The drafter’s concern is that state regulators might treat this provision as increasing Beneficiary’s entitlement and defeating the primary object of this third party special needs trust.

For that reason this provision should only provide payment alternatives, and apply only to amounts that are payable under other provisions. It should not alter the amount of payments otherwise allowed or directed by the dispositive provisions in the document. Thus, it might read: “if income or discretionary amounts of principal become payable to a minor or to a person under legal disability or to a person not adjudicated disabled but who, by reason of illness or mental or physical disability, is in the opinion of the trustee unable properly to manage his or her affairs . . . .” Then, this paragraph would omit “such amount as it may deem advisable” from option (a) and change the highlighted text in option (e) to “benefit.”

Drafters of marital deduction trusts fear that the government may regard the authority in (c) (to pay another person based on their promise) as allowing a diversion of the surviving spouse’s entitlement, so they would modify (c) to provide “to an adult relative or friend in reimbursement for amounts properly advanced for the benefit of the beneficiary.” That change would be proper here also. As a practical matter the administration of the two alternatives is not likely to differ.

These alterations would then allow modification of the text accompanying note 14 to avoid overlap or inconsistency and eliminate the split of this authority among multiple provisions in the document. Drafters whose traditional documents have been “blessed” by state regulators likely will hew to their tried and true versions, to avoid new battles over their meaning or scope.

See the last sentence of note 40. Lack of consistency in a document such as this increases the potential for a construction controversy.
or principal solely for the benefit of the beneficiary; (d) to any person or financial institution, including the Trustee, as custodian under the Uniform Transfers to Minors Act of any state, and in all other ways provided by any statute dealing with gifts or distributions to or for minors or persons under disability, or to any trust then in existence of which such minor or person is a beneficiary; or (e) by expending such income or principal directly for the education, support, and maintenance of such beneficiary. The Trustee shall have the power in its uncontrolled discretion to determine whether a beneficiary is incapacitated, and its determination shall be conclusive. Any such distribution by the Trustee shall be without continuing court supervision or the intervention of a guardian or other personal representative and without giving or requiring any bond, and any distribution so made shall be without obligation on the part of the Trustee to see to the further application thereof. A receipt for any such distribution by the recipient thereof shall fully discharge the Trustee.

Further, if any remainder beneficiary shall be a minor or be under any legal disability, his or her share shall be vested in him or her, but the Trustee, in its sole discretion, may hold such share in trust and distributions shall be postponed until the beneficiary attains such age or until such disability has been removed. The Trustee is authorized to pay to or for the benefit of such beneficiary such part of the income or principal of the retained share as the Trustee considers advisable for the beneficiary’s education and maintenance and may add to the principal any income not so expended, and shall, subject to the following paragraph of this Article, distribute to the beneficiary all remaining principal and income at the termination of the Beneficiary’s minority or legal disability.

If the Trustee determines that a remainder beneficiary (at any time such beneficiary otherwise would be entitled to receive a distribution of trust income or principal) does not have the ability to prudently use and conserve the trust income or principal, then the Trustee is authorized to withhold any part or all of such income or principal distribution until the Trustee shall deem such beneficiary to be qualified to prudently use and conserve the same; provided, however, such income or principal so retained shall continue to be administered as an integral part of such beneficiary’s trust estate and may thereafter, as the Trustee deems wise, be paid over and delivered to such beneficiary in whole or in part and from time to time as and when the Trustee has determined such beneficiary is qualified to prudently use and conserve the same.

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49 See note 13.
50 See note 29.
51 See note 15.
52 Why is this paragraph needed, given the existence of the prior paragraph? If it is needed, also quaere why it differs from the prior paragraph.
53 As a matter of fiduciary administration this paragraph raises the same questions as the prior two paragraphs. As a matter of fiduciary liability it is more troublesome than the prior two paragraphs because of the standard applied. If the standard for its application is thought to be needed, why not just meld the “inability to use and
ARTICLE 5. TRUSTEE(S)

A. Identity.

The initial Trustee of this Trust is [trustee]. If [trustee] fails to become or ceases to act as Trustee, then [trustee 2] shall be Trustee, and if [trustee 2] fails to become or ceases to act, then [trustee 3] shall be Trustee.

OR

The initial Trustee of this Trust shall be [cotrustees]. If either cotrustee fails to become or ceases to act, then the other cotrustee may continue to serve as sole trustee. If neither cotrustee is willing or able to act, then [trustee 2] shall be successor Trustee, and if [trustee 2] fails to become or ceases to act, then [trustee 3] shall be Trustee, in either case to serve alone.

54 Absent this provision the trust would require that a vacancy always be filled so as to always maintain two fiduciaries at all times. A careful reading of Restatement (Third) of Trusts §§ 34, comment d and § 39, comment a, along with the authorities cited therein (including Uniform Trust Code §§ 703 and 704(b)) reveals that they are a break from the traditional common law, which historically required that cotrustees must be unanimous and that a vacant cotrustee position must be filled. It is critical that the trust document address each question because the drafters of the Uniform Act and the Restatement (Third) are seeking to influence the law rather than reflect a development that already has occurred. As such, their position reveals that the law in this context is going to reflect turmoil.

Like these modern authorities, the provision in this document alters the traditional result, which raises the question why cotrustees were needed or appropriate in the first instance. In that regard see note 55, addressing the desirability of cotrustees.

55 Scott and Ascher, supra note 18, § 17.16 (5th ed. 2007), reveals that Uniform Trust Code § 703(f) and (g) modified the historic general rule (that still is the law in most jurisdictions) that cotrustees are jointly and severally liable for all mistakes that occur in the administration of a trust. The revised rule manifests cotrustee liability in a duty to “(1) prevent a cotrustee from committing a serious breach of trust; and (2) compel a cotrustee to redress a serious breach of trust.” Notwithstanding modification, this cofiduciary liability makes the use of multiple trustees disadvantageous. It is preferable for liability purposes to designate agents to perform special functions and name a single trustee to exercise overall responsibility for the trust, with authority to designate others to serve as advisors to the trustee or as agents — if, for example, the designated trustee is not the appropriate actor to exercise distribution discretion, or perform investments, or whatever other function a cotrustee otherwise would perform.

As drafted herein, these cofiduciaries essentially are exposed to the foibles of each
B. Successor or Substitute Trustees.

1. Any trustee may resign without court approval regardless of whether a successor trustee has been appointed or is willing and able to serve.\(^{56}\)

Any Trustee hereof is authorized, while serving as trustee, to appoint any person (excluding Beneficiary and Beneficiary’s spouse or child), financial institution, or trust company, as a successor Trustee to serve in such capacity if the Trustee becomes unable or unwilling to continue to serve; provided, however, that any successor Trustee named herein may be replaced by the initial Trustee only in the event the initial Trustee determines such replacement to be in the best interest of Beneficiary and the Trust Estate.\(^{57}\)

Any Trustee hereof is authorized, while serving as sole trustee, to appoint any person (excluding Beneficiary and Beneficiary’s spouse or child), financial institution, or trust company as a cotrustee; provided, however, that any such cotrustee shall be an “independent trustee” as defined in the Internal Revenue Code.\(^{58}\) If such a cotrustee shall be serv-

other and their collective liability is measured by the lowest common denominator as between them. Because of this exposure a knowledgeable cofiduciary will charge a higher fee to compensate for shared liability than it will charge to act alone.

In addition, this provision should specify whether the cofiduciaries must act by unanimous vote or whether one will trump the other in the event of a disagreement. Lacking express language to the contrary, the traditional rule reflected in note 54 is that unanimity is required, which gives either cofiduciary a veto power that can stymie any action. An express consent or veto provision is a preferable approach, combined with exoneration of the trustee whose actions are pre-empted.\(^{56}\)

Absent this provision the trustee would not be permitted to resign without prior approval of the court or the consent of all the beneficiaries. See Restatement (Third) of Trusts § 36. It is conceivable that the drafter of a trust would not grant this authority, as a means of locking a trustee into the function, but a knowledgeable trustee would more seriously consider whether to decline to serve in the first instance if the trustee could not resign after beginning to act.\(^{57}\)

Quaere the value (and thus the meaning) of this “best interest” requirement, given that a trustee always must act in the best interest of the trust and its beneficiaries.\(^{58}\)

An “independent trustee” is defined in Internal Revenue Code § 674(c) as not the grantor and “no more than half of whom are related or subordinate parties who are subservient to the grantor.” As such, no one person would ever be “independent” – this definition turns on the identity of several trustees. The apparent rationale here may be to prevent the trust from becoming a “defective grantor trust” for fiduciary income tax purposes, notwithstanding that grantor trust treatment during the settlor’s life likely would be a good thing (because it would allow the settlor to pay income tax on trust income that otherwise is available to the beneficiary, which increases the after-tax benefit to the beneficiary without incurring added gift tax). See note 80. None of that explains why the beneficiary or a spouse or child of the beneficiary must be excluded from serving and, for both income and wealth transfer tax purposes, it is possible for any of them to serve as the trustee or as a cotrustee if the
ing, Trustee shall have the authority to petition a court of competent jurisdiction over this trust for the removal or replacement of such cotrustee.\footnote{59} Any corporate cotrustee must be a bank or trust company or financial institution then qualified and licensed to do business in [state].\footnote{60}

2. If neither Trustee nor any successor trustee is currently willing and able to act as Trustee, then a successor Trustee shall be designated by Beneficiary’s guardian or appointed by a court of competent jurisdiction in keeping with the provisions of [state] Code (as amended).\footnote{61}

appropriate language is employed in establishing the standards for distribution. See note 13. From a trust administration perspective the primary point here is to consider the income and wealth transfer tax implications of any fiduciary designation.

Note that a \textit{self-settled} special needs trust would have grantor trust status under Internal Revenue Code § 677(a) by virtue of the settlor being the beneficiary. Subject to the “portion” rules in Treas. Reg. § 1.671-3, trust income, deductions, credits, and losses would pass through to the settlor’s income tax return, regardless of whether the trustee accumulated or distributed trust income. In this \textit{third party trust} the income tax status is as a “complex” trust, meaning that income not distributed currently is taxed to the trust at what amounts to the highest income tax rates under the Internal Revenue Code. See § 1(e). The third form of trust is a “simple” trust and it could be created in this context but the income tax consequences vary only because simple trusts must distribute all income annually (and the trust cannot make any corpus distributions during the year), which likely makes simple trusts not practical or appropriate for special needs purposes.

\footnote{59} Removal of a cotrustee also may be designed to engineer what is known as “toggle switch” defective grantor trust planning, allowing the trustee to turn on or off grantor trust status for federal income tax purposes.

\footnote{60} The in-state requirement is not necessary in jurisdictions that do not prohibit non-resident (foreign) corporations from service as trustee. The need (or even the desirability) for local actors is greatly reduced in this age of easy communication, and given the authority to employ agents.

\footnote{61} One of the most difficult aspects of trust design and administration is providing for trustee succession (and, under alternatives to Article 6 below, providing for succession of trust advisors or trust protectors). At some point the list of designated fiduciaries may be exhausted, but black letter law specifies that the trust will not fail for the lack of a trustee unless only particular trustees are allowable. \textit{See Restatement (Third) of Trusts} § 31. If not, the key to effective administration is to provide a viable means for selection of successors that will stand the test of time. This trust will not exist for multiple generations, making the challenge less difficult than in a perpetual dynasty trust. Common options for the selection include delegation to the local court with jurisdiction over the trust administration, or reliance on some other body or person (such as the trust advisor or protector, which just pushes the issue to selection of their successors), or the presiding judge of a local court or perhaps the
3. Any Trustee, upon ceasing to serve, shall pay over, deliver, assign, transfer, and convey to the successor Trustee (and to a successor cotrustee who qualifies and accepts appointment to serve in that role, if any) the trust estate as it shall then be constituted and that is under its control, and it shall make a full and proper accounting to the successor Trustee, whereupon the replaced Trustee, after such accounting is accepted and approved and the trust estate is fully received, shall be discharged and have no further responsibility. Upon the failure of a replaced Trustee to make such conveyance and accounting, the successor Trustee or Beneficiary may apply to any court having jurisdiction of this trust and such court may compel the conveyance and accounting by the replaced Trustee.62 The successor Trustee upon acceptance of this trust and the trust estate shall succeed to and possess all the rights, powers, duties, authority, and responsibility conferred upon the replaced Trustee.

C. Compensation of Trustees.

A Trustee other than a parent, spouse, or child of Beneficiary63 shall be entitled to such reasonable compensation as may be allowable under the laws of [state]. Any Trustee shall be entitled to be reimbursed for the reasonable expenses incurred in the administration of this Trust. Any corporate or independent Trustee or cotrustee hereof shall be entitled to compensation in accordance with the reasonable schedule of fees as from time to time maintained by trust institutions in the state for such trusts.64

lead lawyer in whatever amounts to the successor of the drafter’s law firm.

62 Most trusts exempt a successor trustee from the obligation to audit the accounts of a predecessor, and provide that a successor has no liability for failing to sue to recover for any losses attributable to a predecessor’s breach. That is not what this document provides, and it can cause a knowledgeable trustee to refuse to act as a successor. Or it can cause a successor to generate a significant fee to compensate the successor for engaging in that review. It would be wise to add such exculpation of the successor trustee from this liability unless there is a special reason to suspect that such a review is necessary (because, for example, accounts rendered to the beneficiary will not be studied carefully, or because it is expected that a trustee that is being replaced is likely to have breached the trust).

63 Portions of this document suggest that no spouse or child could serve as trustee. See, e.g., note 58 and accompanying text.

Trust administration is not a casual undertaking, and it exposes the trustee to liability for mistakes. Quaere the wisdom, then, of asking any trustee to serve without making a serious commitment to the role, and whether a serious commitment is realistic without compensation.

64 Quaere whether it is possible to determine the “average” compensation of trustees serving in a particular state, for trusts in general or for trusts of this variety in particular. In addition, why would a first-rate trustee be willing to serve for a jurisdictional-average compensation? It may be wrong-minded to include such a provision as this unless the notion is that good trustees will willingly reduce their fees, or that average
D. Powers of Trustees.

The Trustee shall have those powers, duties, and discretions listed in the following sections, in addition to those otherwise granted herein, and by the [state trustee powers provision] as amended, except as elsewhere herein specifically restricted.65

1. Exercise of Power.

Provided that the Trustee shall exercise such powers at all times in a fiduciary capacity in the best interest of Beneficiary, the Trustee may freely act under all or any of the powers given the Trustee by this Trust Agreement in all matters concerning the trust after exercising the Trustee’s best judgment in a good faith manner based upon all the circumstances of any particular situation known to the Trustee as to the best course to follow in the interest of this Trust and of Beneficiary, without the necessity of obtaining the consent or approval of any court and notwithstanding that the Trustee may also be acting individually or as trustee of other trusts.66

trustees are “good enough.” It probably is preferable to shop fees before selecting a fiduciary, and to negotiate a proper fee as part of the selection process. Unbeknownst to many consumers, corporate fiduciaries will discount their fees in the “right” circumstances (which includes a case in which there is family wealth in addition to the special needs trust).

A pervasive issue is whether to grant long form trustee powers (on the theory that no one knows what the state legislature might add or alter in the state law trust provisions) or to rely on state law trustee powers as sufficiently robust and generic. (A sample is appended to the end of this form and its annotations; it lacks certain provisions that are suggested in these annotations because it is based on a particular state law, which is not uncommon among state-provided powers provisions.) Professional trustees typically want their own form powers provision but will accept other trusts if the engagement is attractive and the powers provision is reasonably comprehensive. Lacking appropriate powers, however, good trustees may decline to act, which hardly serves the settlor’s purpose. At a minimum the drafter should consider asking designated trustees to review the document in advance of its execution, to determine whether changes or additions are needed to improve the chances that the trustee will accept that appointment.

This authority permits the trustee to engage in self-dealing or a conflict of interest, if the trustee is acting with respect to multiple trusts. For example, the trustee may be authorized to purchase shares in its own common trust funds, which provides better investment diversification at a lower cost than individually investing all assets of the trust, or the trustee may choose to purchase an asset from one trust or sell it to another, each under its administration.
2. Trust Property.

To manage, control, operate, invest, reinvest, sell, exchange, lease, mortgage, encumber, or deal with the property of this Trust for and on behalf of the trust and Beneficiary to the same extent and with the same powers that any individual would have in respect to his or her own property and funds.67

3. Maintenance of Investments.

To hold any or all of the trust estate in the form of investment in which it is received.68

4. Title of Investments.

To hold investments or any part of the trust estate in common or undivided interest with other persons.69

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67 This authority likely does not permit the trustee to make gratuitous transfers of trust funds to individuals not specifically named as beneficiaries, although an individual could make gifts with personal funds. See Casner and Pennell, supra note 13, § 3.10.4.3 (6th ed. 1999), regarding the need in a durable power of attorney to specifically authorize such transfers. In a similar vein, the trust document should be more specific if it is desirable for the trustee to engage in estate planning or other spend down transfers. Alternatively the settlor could grant a power of appointment to a powerholder that would permit transfers among a specified class of permissible appointees.

68 Normally a trustee must diversify trust assets. See Restatement (Third) of Trusts § 90(b) and comment g. Diversification may be undesirable if it requires sale of legacy assets, such as a family business or a farm/ranch that the family wishes to maintain. This provision is not an absolute grant of authority to hold assets that are in steady decline — without more specificity the trustee likely would not be regarded as exempt from the duty to review investments and act prudently in light of all the facts and circumstances. See id. § 91(b).

69 A corporate trustee also may want the authority to hold investments in nominee form as a means of insulating the trustee’s identity from public scrutiny. As written this provision only permits a trustee to continue to hold property as a tenant in common (which may be desirable because of valuation adjustments for fractional or minority interests) or as a joint tenant with the right of survivorship (for which no such adjustment is available). On the valuation differences compare John A. Bogdanski, Federal Tax Valuation ¶¶ 5.01 (coterminous interests) and 5.02 (survivorship interests) (2006)
5. Investments.

To invest and reinvest the trust estate without limitation in investments of any kind, real or personal, including without limitation stocks, bonds, notes, mortgages, real estate, mineral interests, royalties, leaseholds, and to participate in partnerships, joint ventures, and other business enterprises.\textsuperscript{70}

6. Participation In Corporate Activities.

To participate in any reorganization, consolidation, merger, or dissolution of any corporation, the stocks, bonds, or securities of which may be held at any time as part of the trust estate.\textsuperscript{71}

7. Voting on Trust Investments.

To vote in person or by proxy on shares of stock or other investments that may at any time be a part of the trust estate.\textsuperscript{72}

8. Disposal of Trust Property.

To sell at public or private sale, to mortgage, pledge, or hypothecate, or to exchange or lease any stocks, notes, securities, real estate, minerals, or any other trust property upon such terms, cash or credit or both, as the Trustee may deem advisable.\textsuperscript{73}

\textsuperscript{70} This grant of broad discretion may permit the trustee to consider a wider range of investment assets but it does not relieve the trustee of the overarching fiduciary duty to invest as would a reasonably prudent person, either in the investment of individual wealth or the wealth of others, depending on the state law prudent person/investor standard.

\textsuperscript{71} Particularly if the trustee is an individual who is employed in or as a director of a family business, this provision allows the trustee to engage in what otherwise might be regarded as self-dealing or conflict of interest activities vis-à-vis that investment. See \textit{Restatement (Third) of Trusts} § 78(2) and comment \textit{e}, and \textit{Scott and Ascher}, \textit{supra} note 18, § 17.2.8 (5th ed. 2007).

\textsuperscript{72} Proxy voting arguably violates the anti-delegation responsibility of a trustee, although \textit{Scott and Ascher}, \textit{supra} note 18, § 18.1.8.3 (5th ed. 2007), makes the practical case that it should not be deemed improper in circumstances in which an investment is not substantial. More useful here would be the authority to vote stock in a business in which the trustee is involved.

\textsuperscript{73} Particularly a private sale might generate criticism, even if it is clearly at arms’ length, because it entails self dealing and a conflict of interest. See \textit{Scott and Ascher}, \textit{supra} note 18, § 17.2.1 (5th ed. 2007). The power to borrow and pledge trust assets as security, or to enter into a lease or other transaction involving temporal interests, is more useful if the document specifies that the term of the loan or lease may exceed

To borrow funds for this Trust in such amounts and for such purposes as the Trustee may deem proper and to purchase property on the credit of this Trust and, in connection therewith, or in connection with such borrowing, to execute and deliver promissory notes or other evidence of indebtedness of this Trust, and to mortgage or pledge all or any part of the Trust to secure payment of such indebtedness and to repay such indebtedness out of the trust estate.

10. Settlement of Claims.

To demand, receive, provide receipt for, and collect any and all rights, money, properties, or claims to which this Trust may be entitled, and to compromise, settle, or abandon any claim in favor of or against this Trust.\textsuperscript{74}

11. Litigation.

To prosecute, defend, contest, or otherwise litigate legal actions or other proceedings for the protection or benefit of a trust or the Trustee; to pay, compromise, release, adjust, or submit to arbitration any debt, claim, or controversy; and to insure the trust against any risk, and the Trustee against liability, with respect to third persons.

12. Real Property; Investigation and Handling of Environmental Issues.\textsuperscript{75}

To construct, repair, improve, or demolish any improvements upon any real property held by the Trust; and to (i) conduct environmental assessments, audits, and site monitoring to determine compliance with any environmental law or regulation thereunder; (ii) take all appropriate remedial action to contain, clean up, or remove any environmental hazard including a spill, release, discharge, or contamination, either on its own accord or in response to an actual or threatened violation of any environmental law or regulation thereunder; (iii) institute legal proceedings concerning environmental hazards or contest or settle legal proceedings brought by any local, state, or federal agency concerned with environmental compliance, or by a private litigant; (iv) comply with any local, state, or

\textsuperscript{74} As articulated in \textit{Scott and Ascher}, \textit{supra} note 18, § 18.1.6 (5th ed. 2007), the pursuit of claims rather than the prudent settlement of them might be regarded as imprudent, and a trustee should consider the likely costs and possibility of success of litigation to collect. See the next power.

\textsuperscript{75} Again the environmental issues! See notes 17 and 38.
federal agency order or court order directing an assessment, abatement, or cleanup of any environmental hazards; and (v) employ agents, consultants, and legal counsel to assist or perform the above undertakings or actions. Any expenses incurred by the trustee under this subparagraph may be charged against income or principal as the Trustee shall determine.76

13. Insurance.

The Trustee has discretion to purchase whatever casualty insurance is deemed by the Trustee useful or advisable to protect the trust estate against any damage or loss and to protect the Trustee against liability with respect to third parties.77

14. Life Insurance.

To purchase, pay premiums, assessments, or other charges with respect to, cancel, convert, or modify, policies of life insurance on the life of Beneficiary and for the benefit of Beneficiary or the trust and to hold and to pay for the same as an investment and an asset of the estate, any time and upon successive occasions, the premiums to be charged against income or principal, as the Trustee shall determine, so long as the face amount of the life insurance policy does not exceed the maximum amount allowed by SSI or other applicable benefit programs. The Trustee may compromise, arbitrate, or otherwise adjust claims upon any policies and may, but shall not be required to, exercise any settlement options available under such policies. The receipt of the Trustee to the insurer shall be a full discharge, and the insurer is not required to see to the application of the proceeds.78

15. Preparation of Tax Returns and Elections.

(a) To prepare and file all types of tax returns, forms, and schedules and to arrange for payment with respect to all local, state, federal, and foreign taxes incident or

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76 This provision would be more helpful if it was crafted in the same manner and provided the same authority as the text accompanying notes 24 and 25.

77 Failure to insure likely would be regarded as a breach of fiduciary duty if a reasonably prudent individual would insure the subject property from the subject risk. See RESTATEMENT (THIRD) OF TRUSTS § 76(2)(b) and comment d; SCOTT AND ASCHER, supra note 18, § 17.8 (5th ed. 2007). As such, authority to insure is likely less important than would be a provision allowing the trustee not to insure.

78 See note 15 regarding the insurer’s duty to see to the application of insurance proceeds. The right to take and hold cash value life insurance is not fundamentally different than any other investment, which this provision recognizes. Quaere, then, why this paragraph does not allow investment in life insurance on the life of anyone other than Beneficiary in whom the trust has an insurable interest. For example, why not authorize the purchase of insurance on the life of the trust’s settlor, or Beneficiary’s parent(s)?
applicable to this Agreement; to prepare all necessary fiduciary income tax returns; and
to make all necessary and appropriate elections in connection therewith in its discretion.\textsuperscript{79}

(b) To pay any of Beneficiary’s income tax liability that results from income re-
ceived by the Trust but properly reported on Beneficiary’s income tax return. The funds
used to pay any such income tax liability shall be paid directly to the appropriate tax au-
thority and shall not be available to Beneficiary. Beneficiary shall not have any right to or
interest in any such funds paid by the Trustee.\textsuperscript{80}

(c) In the event of a tax refund, any amount refunded shall be paid directly to the
Trustee to the extent such refund is attributable to amounts previously paid by the Trustee.
Beneficiary or Beneficiary’s guardian or conservator shall execute any letters, powers of
attorney, or other documents required or requested by the taxing authority in order to al-
low payment of any refund to the Trustee.\textsuperscript{81}

\textsuperscript{79} A critical, missing authority is to make tax elections without regard to the impact they
may have on the relative interests of the beneficiaries and a direction not to make
equitable or “compensating” adjustments to account for or ameliorate the inequities
of those consequences. This is a very detailed and intricate concept that largely is
lost on casual observers and inexperienced trustees. Such a provision might read:
The Trustee shall make such elections and allocations under the tax laws
as the Trustee deems advisable, without regard to the relative interests
of the beneficiaries and without liability to any person. No adjustment
shall be made between income and principal or in the relative interests
of the beneficiaries to compensate for the effect of elections or alloca-
tions under the tax laws made by the Trustee.

For an excellent exegesis see Joel C. Dobris, *Equitable Adjustments in Postmortem
Income Tax Planning: An Unremitting Diet of Warms*, 66 Iowa L. Rev. 103 (1979),

\textsuperscript{80} Apropos the discussion in note 58, one reason for making the trust a defective grant-
or trust is to avoid the need recognized in this provision to pay income tax on trust
income that is deemed taxable to the beneficiary, and thus the need to wrestle with
whether an added distribution to pay that income tax is likely to cause disqualifica-
tion consequences for benefit calculation purposes. Also note that distributions of
trust funds to provide the beneficiary with funds to pay income tax will themselves
carry out income of the trust to the beneficiary to the extent the distributable net
income of the trust has not previously been exhausted, thus requiring a “gross up”
distribution of the original amounts needed by the beneficiary, followed by enough
added funds to cover the tax on those distributions and then the tax on the added
funds. See Internal Revenue Code § 662(a)(2). An algebraic calculation can be done
to make the determination of the proper amount of tax, and then tax on the tax, ad
nauseam, but it may be worth asking whether the benefit sought is worth all of this
complexity.

\textsuperscript{81} Quaere whether (or how) this document may direct a beneficiary’s personal repre-
16. Avoidance of Tax Liability.

To enter into agreements with any taxing agency, including but not limited to the Internal Revenue Service and any state taxing agency, to circumscribe the implementation of trust administration provisions to ensure that the Trust will not cause any unanticipated tax liability of any kind and to provide such taxing agency with any necessary disclaimer or agreements restricting the discretion of the Trustee in further transactions or any other matter that may be in the best interest of the Trust estate and the Beneficiary of the Trust. 82

17. Division of Trust Estate for Distribution.

When the Trustee must divide any of the trust estate into parts or shares for the purpose of distribution, or otherwise, the Trustee may, in its discretion, make the division and distribution in identical interest, in kind, or partly in kind and partly in money, pro rata or non-pro rata, and no adjustment shall be made to compensate for a disproportionate allocation of unrealized gain for federal income tax purposes. Also, the Trustee may make such sales of the property of the trust estate as the Trustee deems necessary to accommodate such distributions. 83 No action taken by the trustee pursuant to this paragraph shall be subject to question by any beneficiary.

ARTICLE 6. TRUSTEE — RIGHT TO AMEND TRUST

In furtherance of this trust, the Trustee shall have the power, which is hereby specifically given, to amend the terms of this Trust for the purpose of maintaining an effective trust and to comply with the requirements for Medicaid assistance under Title XIX of the Social Security Act and under the Medicaid laws of [state], and rules and regulations thereunder, and any other federal or state law that may impact this Trust or the payment of benefits to or on behalf of Beneficiary.

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82 Critical here is the authority to disclaim or renounce trustee powers if appropriate to limit or avoid future tax consequences. Lacking the authority in this provision it would be impossible under state law for one fiduciary to relinquish trustee powers in a manner that would bind the trust or future trustees. SCOTT AND ASCHER, supra note 18, § 18.1.7 (5th ed. 2007). See also the power accompanying note 85.

83 Lacking this authority the trustee might be required to distribute cash in satisfaction of pecuniary entitlements, or proportionate shares of assets distributed in kind, for example in a distribution to a group of individuals (such as “in equal shares to my children”). See SCOTT AND ASCHER, supra note 18, § 36.4 (5th ed. 2008). Note, however, that non pro rata division may be regarded by the government as an income tax sale or exchange event, notwithstanding this grant of authority to do so. See, e.g., Rev. Rul. 2008-41, 2008-2 C.B. 170.
A. The Trustee may modify or amend the following:

1. The trust administration provisions relating to the identity, qualifications, succession, removal, and appointment of the Trustee; provided, however, that no such amendment may provide that Beneficiary or Beneficiary’s spouse or child\textsuperscript{84} may be a Trustee hereof;

2. The financial powers enumerated in this instrument;

3. The terms of the Trust created in this instrument with respect to the purposes for which the Trustee may distribute trust income and principal, and the circumstances and factors that Trustee may take into account in making such distributions;

B. The Trustee acting from time to time, on his or her own behalf, or on behalf of any or all successor Trustee(s), may at any time irrevocably release, renounce, suspend, cut down, or modify to a lesser extent any or all powers and discretions conferred under this instrument by a written instrument delivered to the Trustee.\textsuperscript{85}

C. The Trustee shall exercise its powers under this provision as Trustee alone shall determine, and Trustee shall not be liable to Beneficiary or in any way for the exercise or non-exercise of these powers, or for the manner in which Trustee may exercise such powers, except for willful or deliberate malfeasance,\textsuperscript{86} and Trustee may, in addition and if Trustee chooses, rely absolutely on the opinion of counsel competent in the area of trust administra-

\textsuperscript{84} Notice that in the trust advisor counterpart to this provision no descendant of the beneficiary could be appointed either. See note 88 and accompanying text. Quaere what that inconsistency is about.

\textsuperscript{85} See note 82.

\textsuperscript{86} As discussed in note 29, trust law requires more from a trustee than that it not be willful or deliberate in any malfeasance. At a minimum a court likely would require good faith action, and perhaps more. See Restatement (Third) of Trusts § 63, comment j (the default standard regarding modification “against which the reasonableness of the trustee’s judgment can be measured . . . is whether the trustee has acted in bad faith or from an improper motive.”) Regarding consent to a termination of a trust, Scott and Ascher, supra note 18, § 35.1.4 (5th ed. 2007), says “if the terms of the trust neither expressly nor by implication limit the power of the trustee to consent to revocation, it would seem that the giving or withholding of consent ordinarily should be effective, as long as the trustee does not act dishonestly or from an improper motive.”

This provision seeks to be as effective as possible in empowering a trustee by exonerating the trustee from any liability for actions that might be found to be excessive, with the net result that a court might find the trustee to be in breach, and its actions (here, any amendment) invalid, but not impose personal liability on the trustee.
tion in Trustee’s exercise of the power to amend this instrument under this provision.  

[ALTERNATE ARTICLE 6]

ARTICLE 6. TRUST ADVISOR – RIGHT TO AMEND TRUST

In furtherance of this trust, the “Trust Advisor” shall have the power, which is hereby specifically given, to amend the terms of this Trust for the purpose of complying with the requirements for Medicaid assistance under Title XIX of the Social Security Act and under the Medicaid laws of [state], and rules and regulations thereunder, and any other federal or state law that may impact this Trust or the payment of benefits to or on behalf of Beneficiary.

A. Grantor hereby appoints [   ] as the Trust Advisor hereunder. If [   ] fails to become or ceases to act in such capacity, then [   ] may, but is not required to, appoint any one or more successor Trust Advisors as provided in the following subsection. No Trust created under this instrument is required to have a Trust Advisor acting with respect to such Trust.

B. Any Trust Advisor acting from time to time may appoint one or more individuals (other than Beneficiary or a descendant of Beneficiary) as successor Trust Advisor. Any appointment hereunder shall be in writing, may be made effective at any time or upon any event, and may be single or successive, all as specified in the instrument of appointment. The Trust Advisor may revoke any such appointment before it is accepted by the appointee, and may specify in the instrument of appointment whether it may be revoked by a subsequent Trust Advisor.

C. Any Trust Advisor may resign by giving prior written notice to the Trustee.

D. The Trust Advisor may, with respect to any Trust as to which the Trust Advisor is acting, modify or amend the following:

1. The trust administration provisions relating to the identity, qualifications, succession, removal, and appointment of the Trustee; provided, however, that no such amendment may provide that Beneficiary or Beneficiary’s spouse or child may be a Trustee hereof;

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87 The document should preclude any changes that diminish the trustee’s fiduciary duties to the trust. See note 5.

88 Quaere the intent of this exclusion of any lineal descendant of Beneficiary. It is not a function of any federal tax law. Also, why is Beneficiary’s spouse a permissible appointee here but not in the alternative provisions, and why does this provision make reference to “descendants” whereas the other alternatives only reference a “child”? See notes 84, 89, and 95 and accompanying text.

89 Notice that in paragraph B of this trust advisor counterpart no descendant of the beneficiary could be appointed either. See note 88 and accompanying text. Quaere what that inconsistency is about.
2. The financial powers enumerated in this instrument;

3. The terms of the Trust created in this instrument with respect to the purposes for which the Trustee may distribute trust income and principal, and the circumstances and factors that Trustee may take into account in making such distributions; or

4. The situs of the trust or the laws applicable to the trust.

E. The Trust Advisor may remove and replace any Trustee (other than any initial Trustee designated herein) if the Trust Advisor determines that the Trustee is not sufficiently responsive to the needs of the Beneficiary or that the Trustee’s actions in the administration of the Trust endanger Beneficiary’s eligibility for public benefits or otherwise are detrimental to the purposes of the Trust.

F. The rights and powers conferred on the Trust Advisor under this instrument, including without limitation the power to remove the Trustee, and all rights and powers granted to the Trust Advisor under Paragraphs D and E of this section shall be exercisable only in a fiduciary capacity.

90 Several aspects of this statement are notable. First, McLean Irrevocable Trust v. Patrick Davis, P.C., 283 S.W.3d 786 (Mo. Ct. App. 2009), wrestled with the question whether a Trust Protector is a fiduciary and must act in a fiduciary capacity. Notwithstanding the difference in “label” here, the trust advisor likely would be in the same situation. McLean did not decide the question but it reversed a grant of summary judgment in favor of the trust protector and remanded for a determination. In the course of the opinion the court noted that neither the document nor state law established the capacity in which a trust protector acts, nor the duties and liabilities involved. Further, it opined that minimum duties of good faith, undivided loyalty, confidentiality, and “some duty of care” were applicable.

Notable about the powers granted here is that they essentially amount to a power of appointment – allowing the trust advisor to make certain amendments to either administration or dispositive provisions. In that regard the requirement to act in a fiduciary capacity is more restrictive than a typical power to appoint, which might influence a court’s determination of the responsibility and liability that flows to the trust advisor in this capacity.

Also note that no well drafted trust lacks a trustee removal and replacement (a “revolving door”) provision, which allows the powerholder to exert some check-and-balance control over a fiduciary. This document reveals a clear bias in favor of individual fiduciaries, which is the trend over the past several decades, but the economic meltdown in 2008 revealed that corporate fiduciaries tend to be more defensive in their investment philosophy and many individual fiduciaries lost a larger percentage of trust net worth than did their corporate counterparts, which is just one of many reasons to reconsider the favor for individual fiduciaries. In addition, defalcation (theft) by individuals is a much bigger problem than it is for corporate fiduciaries.
G. Notwithstanding any other provision of this instrument, the Trust Advisor shall not participate in the exercise of a power or discretion conferred under this instrument that would cause the Trust Advisor to possess a general power of appointment within the meaning of Internal Revenue Code §§ 2041 or 2514.

H. The Trust Advisor acting from time to time, on his or her own behalf, or on behalf of any or all successor Trust Advisors, may at any time irrevocably release, renounce, suspend, cut down, or modify to a lesser extent any or all powers and discretions conferred under this instrument by a written instrument delivered to the Trustee.91

I. The Trust Advisor shall exercise the powers under this provision as he or she alone shall determine, and shall not be liable to Beneficiary or in any way for the exercise or non-exercise of these powers, or for the manner in which he or she may exercise such powers, except for willful or deliberate malfeasance, and he or she may, in addition and if he or she chooses, rely absolutely on the opinion of counsel competent in the area of trust administration in his or her exercise of the power to amend this instrument under this provision.92

[ALTERNATE ARTICLE 6]

ARTICLE 6. TRUST PROTECTOR93

This Trust shall have a Trust Protector. The purpose of the Trust Protector is to protect, modify, or otherwise exercise powers over the Trust as it currently exists or exists through amendment to carry out the intent of this Trust.

On the other hand, settlors routinely worry that a corporate fiduciary will not be as sensitive or as well informed about the personality and needs of the beneficiary, particularly if the corporate fiduciary is the subject of a merger or takeover and its operations are moved to a jurisdiction other than that of the trust’s original administration. All of these possibilities (and so many more considerations) inform the need to exert control over the fiduciary, whether that power is given to a beneficiary or to a third party, such as the trust advisor here or a trust protector, next below.

91 See note 82.
92 See note 86. If in fact these powers are exercisable in a fiduciary capacity (as stated in Paragraph F), then this Paragraph I almost certainly is no different.
93 A trust protector is likely no different than a trust advisor, in terms of the issues that arise with regard to the liability and duties imposed by trust law or the document itself. The term itself has a certain “aroma” from its original use in offshore asset protection trusts, and for that reason some drafters prefer to use a different term. The authorities granted in this provision are different from those in the trust advisor alternative, but there is nothing special about the label used and the same authorities could be granted and the same duties and liabilities created, regardless of the name used. Notice how the trust protector alternative is more robust, however; that is not a function of the office or title used.
The Trust Protector is to provide the ability to efficiently and more flexibly adjust the Trust to meet existing or changing statutory law or other rule of law that affects the Trust administration or the ability to carry out the intent of the Trust. Additionally, the Trust Protector is empowered to amend the Trust or act as otherwise authorized in this Article to ensure proper management of the Trust by the Trustee. The Trust Protector does not have a duty to act until such time as the matter or issue has been brought to the Trust Protector’s attention by written notice, following which the Trust Protector has the duty to either affirmatively act or to decline to serve as Trust Protector. In the event the Trust Protector declines to serve, the Trust Protector must notify the successor Trust Protector or otherwise establish his or her successor. The Trust Protector shall not in any event be liable to the Beneficiary, the remainder beneficiaries of the Trust, or any other party for its acts as Trust Protector hereunder so long as the Trust Protector acts reasonably and in good faith.

The Trust Protector is specifically relieved of any ongoing or continuous duties of supervision of the Trustee.

1. In its discretion the Trust Protector has the authority to remove any Trustee with or without cause.

2. The Trust Protector has the authority to appoint the Trustee (whether a listed successor Trustee or otherwise) if the position is vacant and must do so within 15 days of learning of the vacancy in the position of Trustee. The Trust Protector has the authority to name any qualified corporate or individual Trustee, but in no event can the lifetime Trust Beneficiary be named as Trustee.

3. The Trust Protector has the authority to amend the Trust under his or her own signature in compliance with statutory law on Trust amendments for purposes of validity. The amendments can be for the purpose of bringing the Trust in compliance with existing or changing laws governing government benefits that are received or potentially available to Beneficiary. The amendments can be made to bring the Trust in compliance or otherwise comply with any tax code provisions. The Trust Protector has the authority to amend the

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94 This was the fundamental issue in McLean, 283 S.W.3d 786 (Mo. Ct. App. 2009), whether the trust protector had merely the authority or more affirmatively a duty to exercise the authority in that case to remove a trustee that was misbehaving. Notice here that there is a duty, yet the exculpation in the last sentence of this paragraph is the same as in McLean, and as in that case likely is not as effective as the draft-er (who was the trust protector in McLean, which raises several interesting ethical questions in its own right) or perhaps the settlor intended.

95 Notice that in the trust advisor counterpart to this provision no spouse or descendant of the beneficiary could be appointed either. See note 88 and accompanying text. Quaere what that inconsistency is about.
Trust to otherwise effectuate the intent of this Article and the Trust purposes as a whole.96

4. The Trust Protector has the authority to appoint a Designated Representative to represent and bind a beneficiary and to receive notice, information, accountings, or reports in accordance with state law.

5. The Trust Protector may resign at any time by delivering written notice to the currently serving Trustee and, if no Trustee is serving, to the Beneficiary and any remainder beneficiaries as provided under this Trust.97

6. The initial Trust Protector is [   ]. If [   ] fails to become or ceases to serve, then [   ] shall serve as Trust Protector, and if [   ] fails to become or ceases to serve, then [   ] may, by written instrument executed by two witnesses and notarized, name the successor to this position. If a successor Trust Protector has not been named as provided herein, then a court of competent jurisdiction can appoint the successor Trust Protector.98 The alternate Trust Protectors shall serve in the original Trust Protector’s position with the same powers and authorities as provided under this Article.

7. The Trust Protector can be paid a reasonable fee for services rendered to the Trust or any beneficiary.

**ARTICLE 7. GENERAL PROVISIONS**

A. Governing Law; Severability.

All questions relating to the validity and construction of this Trust, the determination of the share of the Beneficiary, the dates, powers, authority, and discretion of the Trustee, and all other matters in connection therewith, shall be governed by, and the Trust shall be administered in accordance with, the laws of [state].99 If any provisions of this

96 Also quaere why this provision is worded differently than its counterpart in the alternative Article 6 for trust advisors. For example, what does “under his or her own signature in compliance with statutory law on Trust amendments for purposes of validity” add or alter? As a general tenet of document construction the notion is that if a drafter says something differently then the intent must be different as well, but here it is not apparent why this lingo should differ, or the significance thereof.

97 The remainder beneficiaries may not be determinable, or even yet in existence. Moreover, many settlors would prefer that the future interest beneficiaries not know about the existence of their potential inheritance – something that would be disclosed in some measure by this notice.

98 Notice that designating successor fiduciaries – here the trust protector – often constitutes the hardest element of trust drafting, particularly if a trust is expected to last for an extended duration. See the trustee succession provision discussed in note 61.

99 Trust law would recognize the selection of the law of any state with respect to which the trust has any reasonable connection. See Scott and Ascher, supra note 18, §
Trust shall be invalid or unenforceable, the remaining provisions hereof shall subsist and be carried into effect.

B. Spendthrift Clause.

No interest in the trust income or principal, or of any trust established for any remainder Beneficiary under the terms hereof, shall be anticipated, assigned, or encumbered, or shall be subject to any creditor’s claim or legal process, prior to its actual receipt by or for the Beneficiary thereof. Furthermore, because the Trust Estate is to be conserved and maintained for Beneficiary’s special needs throughout Beneficiary’s life, no part of the corpus thereof, neither principal nor undistributed income, shall, during Beneficiary’s lifetime, be construed as part of Beneficiary’s estate or be subject to the claims of voluntary or involuntary creditors.

C. Perpetuities.

If not sooner terminated pursuant to the terms of this Trust, any trust created hereunder shall terminate on the last date that would be in compliance with the Rule Against Perpetuities as the same may be in effect from time to time and, if a trust terminates pursuant to the terms of this paragraph, the principal thereof shall be paid over to the then current income Beneficiary thereof.

D. Interpretation; Headings.

Whenever used herein, and to the extent appropriate, the masculine, feminine, or neuter gender shall include the other two genders, the singular shall include the plural, and the plural shall include the singular. The headings and paragraph captions contained in this trust agreement are not a part of this trust agreement. They are only for the convenience of the parties and do not in any way modify or amplify this trust agreement. They do not give full notice of any of the terms, covenants, or conditions of any portion of this trust agreement and are not relevant to the interpretation of any provision of this trust agreement.

ARTICLE 8. DEFINITIONS

A. Trustee. “Trustee” shall include the initial Trustee hereof and any successor Trustee or cotrustee.

45.1 (5th ed. 2010). This need not be the state of trust administration or creation, although usually it is (so that the trustee is not obliged to learn or apply the law of another jurisdiction). Note, however, that the designation here could be the law of the state in which the trust currently is being administered, such that “decanting” the trust or moving the situs (a power that appears to be lacking) can alter the governing law (to acquire benefits or dodge detriments of a particular jurisdiction’s law).
B. **Death.** The death of Beneficiary or of a Trustee shall be evidenced by presentation of a certified copy of such person’s death certificate to the Trustee or successor Trustee or cotrustee as the case may be.

C. **Incapacity.** “Physical or mental incapacity,” as applied to disqualify a Trustee, shall include any physical or mental condition of such person that renders the trustee unable to conduct financial affairs and which condition is likely to extend for a period of greater than 60 days. A condition of incapacity as so defined shall be conclusively established by the written certificate or statement of the incapacitated Trustee’s regularly attending physician, or two doctors authorized to practice medicine in the Trustee’s state of residence, filed with and accepted by the successor Trustee or, in the case of an incapacitated cotrustee, filed with and accepted by the other cotrustee. Each individual Trustee, by accepting such role, for the sole purpose of determining his or her incapacity, (i) hereby authorizes any “covered entity” under the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) to disclose protected health information about such individual Trustee and further (ii) hereby voluntarily waives any physician-patient privilege or psychiatrist-patient privilege that may exist in such Trustee’s favor and hereby authorizes physicians to examine such Trustee and disclose the physical or mental condition of such Trustee to determine the incapacity or capacity of such person for purposes of acting in the role of Trustee according to the terms of this document. Refusal to permit such examination or disclosure shall be grounds for removal of such individual Trustee.

D. **Special needs.** As used in this trust, the term “special needs”:

1. Refers to the requisites for maintaining Beneficiary’s **good health, safety, comfort, and happiness** when, in the absolute discretion of the Trustee, and only when such requisites are not being provided by any public agency, office, or department of any state in which the Beneficiary may reside, or of the United States or by any private agency, or are not otherwise being provided by another source of income available to Beneficiary.

2. Shall include, but not be limited to, supplemental medical care and dental expenses, annual independent check-ups, assistive technology, programs of training, education, treatment, and rehabilitation, eye glasses, hearing aids, cosmetic surgery or other non-essential medical procedures, transportation (including vehicle purchase), maintenance, insurance, purchase or modification of housing, psychological support services, recreation, entertainment, payment of Beneficiary’s legal obligations, supplemental attendant and custodial care, and similar care or services that would enhance the quality of life of Beneficiary and that would not be paid for by private insurance or government entitlements.

3. Shall include, but not be limited to, the hiring of professionals to assist the

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100 See note 13. Lack of consistent terms may pose a significant issue in trust administration.
Beneficiary. It is contemplated that the types of professionals who may be needed to assist Beneficiary will be social workers, caretakers, medical professionals who would not otherwise accept government entitlements, legal counsel, accounting professionals, vocational counselors, educational counselors, tutors, feeders, therapists, any medical professionals or personnel, investment counsel, architects to advise on accessibility matters, rehabilitation technical engineers and technicians, and computer or augmentative communication technicians who would not otherwise accept or be paid for fully by government entitlements.

4. May include, by way of illustration and not by way of exclusion, money for discretionary spending (subject to the income limitations of any public benefit program); telephone, television, and telecommunications services; electronic equipment such as radios, televisions, audio and video recording and playback devices, and computer equipment; vacations, movies, trips, and recreational outings; payments for attendants to assist Beneficiary for travel, reading, driving, and cultural experiences, periodic outings, and vacations; and other items to enhance Beneficiary’s self-esteem or situation.

IN WITNESS WHEREOF, each Grantor and Trustee named below certifies that he or she has read the foregoing trust agreement and acknowledges that it correctly states the terms and conditions under which the trust estate is to be held, managed, and disposed of by the Trustee, and has executed this agreement, a true and correct photocopy of which may be used as effectively as the original, the day and year first above written, and each Trustee by his or her signature hereby accepts the appointment as Trustee and agrees to execute same in accordance with the terms and conditions thereof as such Trustee.

Executed and accepted this __________ day of __________________, 2010.

___________________________________
[      ], Grantor

___________________________________
[      ], Trustee
Sample Long-Form Trustees Powers

(a) To collect, hold, and retain trust assets received from a settlor until, in the judgment of the trustee, disposition of those assets should be made; the assets may be retained even though they include an asset in which the trustee is personally interested;
(b) To receive additions to the assets of the trust;
(c) To continue or participate in the operation of any business or other enterprise, and to effect incorporation, dissolution, or other change in the form of the organization of the business or enterprise;
(d) To acquire an undivided interest in a trust asset in which the trustee, in any trust capacity, holds an undivided interest;
(e) To invest and reinvest trust assets in accordance with the provisions of the trust or as provided by law;
(f) To deposit trust funds in a bank, including a bank operated by the trustee;
(g) To acquire or dispose of an asset, for cash or on credit, at public or private sale; to manage, develop, improve, exchange, partition, change the character of, or abandon a trust asset or any interest therein; and to encumber, mortgage, or pledge a trust asset for a term within or extending beyond the term of the trust, in connection with the exercise of any power vested in the trustee;
(h) To make ordinary or extraordinary repairs or alterations in buildings, improvements, or other structures; to demolish any improvements; to raze existing or erect new party walls, buildings, or improvements;
(i) To subdivide, develop, or dedicate land to public use; or to make or obtain the vacation or plats and adjust boundaries; to adjust differences in valuation on exchange or partition by giving or receiving consideration; and to dedicate easements to public use without consideration;
(j) To enter for any purpose into a lease as lessor or lessee with or without option to purchase or renew for a term within or extending beyond the term of the trust;
(k) To enter into a lease or arrangement for exploration and removal of minerals or other natural resources, or enter into a pooling or unitization agreement;
(l) To grant an option involving disposition of a trust asset, or to take an option for the acquisition of any asset;
(m) To vote a security, in person or by general or limited proxy;
(n) To pay calls, assessments, and any other sums chargeable or accruing against or on account of securities;
(o) To sell or exercise stock subscription or conversion rights; to consent, directly or through a committee or other agent, to the reorganization, consolidation, merger, dissolution, or liquidation of a corporation or other business enterprise;
(p) To hold a security in the name of a nominee or in other form without disclosure of the trust, so that title to the security may pass by delivery, but the trustee is liable for any act of the nominee in connection with the stock so held;
(q) To insure the assets of the trust against damage or loss, and the trustee against liability with respect to third persons;
(r) To borrow money to be repaid from trust assets or otherwise; to advance money for the protection of the trust and for all expenses, losses, and liability sustained in the
administration of the trust or because of the holding or ownership of any trust assets, for which advances with any interest the trustee has a lien on the trust assets as against the beneficiary;

(s) To pay or contest any claim; to settle a claim by or against the trust by compromise, arbitration, or otherwise; and to release, in whole or in part, any claim belonging to the trust to the extent that the claim is uncollectible;

(t) To pay taxes, assessments, compensation of the trustee, and other expenses incurred in the collection, care, administration, and protection of the trust;

(u) To allocate items of income or expense to either trust income or principal, as provided by law, including creation of reserves out of income for depreciation, obsolescence, or amortization, or for depletion in mineral or timber properties;

(v) To pay any sum distributable to a beneficiary under legal disability, without liability to the trustee, by paying the sum to the beneficiary or by using same for his benefit or by paying the sum for the use of the beneficiary either to a legal representative appointed by the court or, if none, to a relative or to an adult person with whom the beneficiary is residing, who is believed to be reliable by trustee;

(w) To effect distribution of property and money in divided or undivided interests and to adjust resulting differences in valuation;

(x) To employ persons, including attorneys, auditors, investment advisors, or agents, even if they are associated with the trustee, to advise or assist the trustee in the performance of his administrative duties; to act without independent investigation upon their recommendations; and instead of acting personally, to employ one or more agents to perform any act of administration, whether or not discretionary;

(y) To prosecute or defend actions, claims, or proceedings for the protection of trust assets and of the trustee in the performance of his duties;

(z) To execute and deliver all instruments which will accomplish or facilitate the exercise of the powers vested in the trustee.

CONCLUSION

This article examines the boilerplate (fine print) trust administration provisions in a third party special needs trust. Certain admonitions or recommendations may not be appropriate in other (albeit similar) contexts — such as a self-settled special needs trust. In addition, Elder Law, Medicaid, Social Security disability, and trust laws that underlie many of the concepts discussed are in a constant state of flux, requiring readers to verify whether any particular aspect has lost its currency. Coupled with striking differences in local interpretations and administration of many means-tested entitlements, drafting and managing these special needs trusts is a special challenge. Drafters must exercise restraint and discretion so as not to defeat the original and overriding purposes of the trust, and should provide flexible mechanisms to adapt these trusts to changing conditions, particularly with powers to amend or appoint, decant or migrate, or even to terminate the trust.
Dementia and Legal Capacity: What Lawyers Should Know When Dealing With Expert Witnesses

By Sharon B. Gardner, Esq.; Catharine Coble Armstrong, Esq., and Denise Rashti, MD

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I. INTRODUCTION

Doctors and lawyers view dementia from different perspectives. Doctors are concerned with the diagnosis and treatment of dementia. Lawyers are focused on how a dementia diagnosis may influence an individual’s capacity to function intellectually or that individual’s susceptibility to being unduly influenced due to diminished capacity. An understanding of the causes and effects of dementia is essential in determining how dementia will impact a client’s ability to function independently, to understand the nature of the attorney-client relationship, to sign documents, to consent to treatment, or to enter into binding contracts. Dementia may explain why an individual executed certain documents or deviated from a long-time estate plan. Dementia may also result in impaired judgment in the client so that a decision by the client would not be appropriate given the circumstances. A familiarity with the standard of care and the appropriate legal definition of capacity is also required when considering whether the client’s dementia interfered with his or her ability to transact business.

Lawyers who litigate cases dealing with guardianship, conservatorship, and estate planning will often use or cross-examine medical experts who will testify about the effect of an individual’s dementia on his or her legal capacity. Thus, it is important for lawyers to be aware of the known causes, the evaluation process, the manifestations, and the prognosis of dementia so that their cases will be properly prepared. Lawyers will never have the experience that physicians have in understanding the medical effects of dementia, but having a basic understanding of dementia from a medical perspective will help lawyers understand the extent of a client’s capacity. In addition, this understanding will give litigators the tools not only to determine the functional ability and legal capacity of an individual to engage in a particular transaction but also to effectively use or critique the testimony of a medical expert. Part II of this article explains the causes and effects of dementia from a medical perspective. Part III explores the use of medical expert witnesses in cases that involve the effect of dementia on an individual’s capacity.

II. DEMENTIA FROM A MEDICAL PERSPECTIVE

A. Definition, Etiology, and Importance of Dementia

The United States population is getting older and with it the prevalence of dementia is increasing. By the year 2030, the population of people age 65 and older is expected to double from 35 to 70 million. The National Institutes of Health-funded Aging, Demographics, and Memory Study (ADAMS) estimated that about 14 percent of people 71 years and older have a form of dementia, and that the prevalence of dementia increases with age from five percent in people aged 71 to 79 years, to 24.2 percent in people aged 80 to 89 years, to 37.4 percent in those aged 90 years and older.1

Dementia causes the loss of personal self, can overwhelm a family structure, and has an impact on health care costs in billions of dollars per year. Mistakenly, dementia is believed to be synonymous with memory loss. While memory loss is often the presenting complaint, dementia is defined as a condition involving two different cognitive deficits causing a progressive decline that impairs one’s ability to function. Memory is

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one domain; in the other domain are language disturbance (aphasia), not recognizing or identifying objects (agnosia), inability to perform motor activities although physically able (apraxia), and inability to plan/organize/abstract (executive functioning). Aphasia or language disturbance may manifest as word-finding difficulties, less involvement in conversation, or a decreased vocabulary. Examples of apraxia include difficulty dressing, using household items, or cooking. Not recognizing people and not naming objects demonstrate agnosia. Executive function impairment can manifest as difficulty with abstraction and problem solving, impairment in judgment, and trouble in making decisions. Finally, to make the diagnosis of dementia, as with any psychiatric diagnosis, the presenting symptoms cannot be due to another medical or psychiatric cause, and dementia cannot be initially diagnosed when a patient has delirium.

It is important to understand the meaning of a dementia diagnosis because dementia is not one illness but a condition with different causes, presentations, and prognoses. It can look like other medical or psychiatric conditions and vary in severity. Physicians take a clinical history, perform a physical exam, obtain lab work and imaging studies, and acquire, when necessary, neuropsychological testing to use when determining a patient’s diagnosis. As data are obtained with these tools, physicians use a technique called differential diagnosis in determining whether dementia is present, its severity, the probable cause, whether it is reversible, possible coexisting illnesses, treatment options, and prognosis.

Reversible conditions of dementia include, but are not limited to, hyper- or hypothyroidism, vitamin B12 deficiency, syphilis, normal pressure hydrocephalus, reaction to heavy metals, and HIV. Blood work, imaging studies, and lumbar punctures are used to help rule out these diagnoses. Once reversible causes have been eliminated, four irreversible causes account for 90 percent of dementia cases: Alzheimer’s Dementia (AD), Vascular Dementia (VaD), Dementia with Lewy Bodies (DLB), and Frontotemporal Dementia (FTD). Alzheimer’s and Vascular dementias alone account for 80 percent of all irreversible dementias.

B. Types of Irreversible Dementia

Alzheimer’s Dementia (AD) is the most common cause of dementia and can only be definitively diagnosed by brain biopsy. The pathogenesis is the formation of neurofibrillary tangles and amyloid plaques ultimately resulting in cell death. AD is a diagnosis of exclusion. Medical treatment either helps to slow its progression or treats behavioral and psychiatric symptoms. Loss of recent memory is its common early sign. As the illness progresses, distant memory and language deficits worsen and visuospatial dysfunction and executive dysfunction become more prominent.

3 Id. at 148.
6 Roy Yaari, M.D. & Jody Corey-Bloom, M.D., Ph.D., ALZHEIMER’S DISEASE: CLINICAL PRESENTATION, 27.1
Vascular Dementia (VaD) has a more varied presentation because it can have different causes (e.g., bleeding stroke, blood clot, or low oxygen).\(^7\) The presentation is based on where the brain injury occurs. These patients tend to have more physical impairments than AD, and their cognitive deficits tend to be more focal in presentation. Typically, they also have medical comorbidities: diabetes, high blood pressure, and cardiovascular disease.

Dementia with Lewy Bodies (DLB) is a degenerative\(^8\) dementia occurring in older individuals, which is often misdiagnosed as Parkinson’s Disease with Dementia (PDD). Patients with DLB often have a fluctuating mental status, Parkinsonian features, and visual hallucinations. Families report repeated falls, psychosis, blackouts, and fainting. Some distinguishing features between DLB and PDD exist to help clarify the diagnosis. In DLB, dementia usually presents within the first year of Parkinsonian symptoms and the patient exhibits more muscle rigidity, postural instability, and fewer tremors than PDD.\(^9\) Dementia normally occurs late in patients with Parkinson’s disease.\(^10\) 

Frontotemporal Dementia (FTD) is a set of neurodegenerative\(^11\) dementias of unknown cause with a possible genetic component. It can present with behavior and personality changes, and/or language deficits, but overall presents fewer memory difficulties. It is commonly misdiagnosed as a late-onset psychiatric illness, but a physical exam usually elicits prominent primitive reflexes early in the disease process. Three principal forms of FTD have been identified: behavioral variant of frontotemporal dementia, semantic dementia, and progressive nonfluent aphasia.\(^12\)

Patients with FTD with behavioral abnormalities present with both language and behavioral changes: disinhibition, impulsivity, loss of social awareness, neglect of personal hygiene, and language deficits. Patients with the progressive nonfluent aphasia form of FTD present with a broken speech pattern and a difficulty producing phonemes.\(^13\) Finally, FTD’s third form is Semantic Dementia, which is a fluent aphasia with both impaired naming and knowledge of word meanings.\(^14\)

Table 1 (page 141) summarizes and compares these four common irreversible causes of dementia.

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\(^{8}\) A degenerative condition is one causing or showing a gradual deterioration in the structure of a body part with a consequent loss of the part’s ability to function.


\(^{11}\) A neurodegenerative condition is one causing a loss of structure or function in nerve cells, their connections, or supportive tissue.


\(^{13}\) Phoneme is a speech sound that distinguishes one word from another, e.g., the sounds “d” and “t” in the words “bid” and “bit.” Tomas L. Clayton, *Taber’s Cyclopedic Medical Dictionary* (16th ed. 1989).

\(^{14}\) Kirshner, *supra* note 12.
C. Testing: Neuroimaging and Neuropsychological

After a comprehensive medical history, physical examination, psychiatric history, and mental status exam has been obtained, ancillary tests and procedures are performed. Blood work helps to rule out reversible causes of dementia. A lumbar puncture, although not always standard, may be performed to obtain cerebral spinal fluid (CSF) to help in the diagnostic process.

Computed tomography (CT) and magnetic resonance imaging (MRI) are neuroimaging tools that help, not only to rule out neurological diseases that may look like dementia, but also to differentiate the cause of dementia. In VaD, MRI/CT can validate a history of stroke by showing multiple infaricts, small vessel disease, and white matter lesions. MRI/CT also helps in eliminating the diagnosis of VaD when DLB is believed to be the diagnosis. These routine brain scans are of limited value in FTD; they usually find only cerebral atrophy in FTD. Finally, functional neuroimaging is becoming another radiologic tool. PET, positron emission tomography, which measures cerebral glucose metabolism, has been shown to have high specificity for AD and may be useful in confirming its diagnosis. Single-photon emission computed tomography (SPECT), which measures cerebral blood flow, is more widely available but has lower sensitivity and specificity.

A mental status exam is performed on the patient by the evaluating doctor. Much can be determined by appearance, orientation, mood, affect, thought content and process, insight, and judgment. Language, naming, the ability to perform motor activities, judgment, and abstracting can be further evaluated with scales and tests that have been standardized and peer reviewed. Both doctors and psychologists have a multitude of options, but the importance lies not in which test is chosen, but in what it evaluates. Some scales evaluate one domain of cognition; others are a composite to screen all five, as well as the patient’s functional status.

A physician’s comprehensive evaluation with appropriate scales can be enough to diagnosis a person with dementia and determine areas of incapacitation. However, when the diagnosis or severity of the condition is unclear, formal neuropsychological testing may be recommended. Testing has been shown to be effective for differentiating between early AD and normal patients.

Table 2 (page 144) lists some examples of tests and scales, the area of cognition being evaluated, and whether the tests are performed during the comprehensive evaluation or as part of a formal neuropsychological testing.

D. Confusing the Dementia Diagnosis

Though evaluating incapacity in dementia is the focus of this article, it is important

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15 Crystal, supra note 10.
16 Kirshner, supra note 12.
18 Utilizing peer-reviewed testing is important in order for the results of the exam to survive a Daubert challenge in a legal proceeding. See Daubert v. Merrell Dow Pharm., Inc., 509 U.S. 579, 593-94 (1993).
to note that many medical and psychiatric illnesses can cause a patient to be incapacitated temporarily or permanently. Some of these conditions are often misdiagnosed as dementia or worsen the severity of a demented patient’s condition. When treated for an underlying condition, a patient may be found not to have dementia, to be incapacitated in specific areas of function only, or to have total capacity.

E. Pseudodementia Equals Depression

Depression, especially in the elderly, can look like dementia, and subsequently, has been referred to as “pseudodementia.” It has been reported that 15 percent of the elderly who live in the community have signs of depression, 1-2 percent meet criteria for major depression, and the prevalence of depression in the nursing home population can be up to 25 percent. Depression is often under-diagnosed and under-treated in the elderly because they present to their primary care physician with increased somatic or physical complaints. They may exhibit agitation and/or anxiety with these complaints or may have decreased spontaneity in speech and behavior. They often complain they cannot do things like in the past and are getting old, and respond on mental status exams with “I don’t know” or “I don’t care.”

Again, a complicated relationship exists between depression and dementia. Late onset depression may double the risk of Mild Cognitive Impairment (MCI), as well as doubling the risk that MCI will develop into dementia. Treatment of depression can stop this progression. Dementia too can cause depression, whether as a direct result of the dementia cause (e.g., stroke or Parkinson’s disease) or secondarily from the patient’s awareness of the future or ongoing progressive loss in cognitive and functional abilities.

F. Delirium

Unlike dementia, delirium is not a diagnosis but a condition. Delirium is considered a medical emergency, which is acute in its presentation, transient in its course, and usually reversible. Delirium is defined as fluctuating consciousness, meaning a person is changing in his mental status over time. Delirium can present with any psychiatric symptom whether in cognition, behavior, mood, or thinking. It is often misdiagnosed as dementia, depression, schizophrenia, or old age. Delirium presents in 10-22 percent of the elderly when admitted into the hospital and develops in 10-30 percent after admission.

Delirium may be involved when there is a new onset or an acute change in behavior, cognition, or function. Almost anything can cause delirium: medical illness, medications, substance intoxication/withdrawal, or environmental change. Risk factors for delirium include malnutrition, a bladder catheter, physical restraints, multiple medications, and dementia itself.

23 Id.
The relationship between delirium and dementia is significant in many ways. The first starts with the two often being confused. Delirium is an acute change with a fluctuating course; dementia is insidious and progressive. Dementia increases the risk of delirium, and delirium can make a person appear demented or more severely so. Capacity can be an issue in both conditions, but notably, dementia cannot be diagnosed when a person is delirious.

G. Mild Cognitive Impairment

One final consideration is the condition of Mild Cognitive Impairment (MCI). It is a mild memory loss that does not impact function, but the memory loss is greater than expected for a patient’s age. MCI appears to precede AD around 50 percent of the time, and the AD medications may be of benefit in slowing its progress. MCI is a condition undergoing much research, its definition is evolving, and capacity tends not to be an issue.

III. USE OF MEDICAL EXPERTS WHEN DEMENTIA IS AN ISSUE IN PROBATE, GUARDIANSHIP/CONSERVATORSHIP, AND ESTATE MATTERS

Dementia is most commonly an issue in legal proceedings dealing with the ability of individuals to execute legal documents or to manage their personal or financial affairs. Medical experts will be called upon to testify as to the extent of the dementia.

An initial question that arises is whether to use the individual’s treating physician as an expert. There are both advantages and disadvantages to using the treating physician as a medical expert. Many times the treating physician has no real expertise in the area of dementia and has not conducted any peer-reviewed testing to support a diagnosis. The most obvious reason to use the treating physician is that in most instances he or she was chosen voluntarily by the individual whose capacity may subsequently be questioned. Thus, in a sense, the patient has endorsed the physician’s findings by the mere fact that the patient selected the physician. That physician may have a higher degree of credibility than a person who is hired to read medical records and come to a conclusion years after the questioned document or transaction is ripe for challenge.

A. Appropriate Legal Standard

The expert must be familiar with the legal test for capacity in the particular jurisdiction and for the particular matter. The expert testimony necessary in a capacity dispute differs depending on the exact nature of the legal proceeding. Similar testimony is required in both mental health commitments and guardianship proceedings; indeed the same type of expert is often used in both types of proceedings. It is not surprising that expert testimony would be required in capacity proceedings, because such proceedings often result in the restriction of liberties and basic civil rights of the proposed ward. Most jurisdictions require a reliable foundation for the admission of expert testimony and that it is relevant to the subject matter. This has been specifically applied to expert testi-

26 Daubert at 579, 589.
mony based on professional judgment, which includes most evidence offered by mental health experts.\textsuperscript{27}

The medical expert will have to determine whether there is senile- or age-related dementia, whether depression is present, or whether the individual suffers from alcoholism or other substance abuse problems, schizophrenia or bipolar disorders. In the past, a broad diagnosis, such as “advanced age,” would be sufficient to find the ward incapacitated. Today, judges tend to require a more specific diagnosis of the condition alleged to cause incapacity, and discussion of whether the condition is likely reversible. For example, short-term memory loss resulting from Alzheimer’s or multi-infarct dementia frequently results in the need for guardianship or conservatorship for elderly persons. Dealing with psychiatric issues and understanding the diagnosis and treatment of elderly patients is a must for an expert in estate planning.

B. Peer-Reviewed Testing

Frequently, experts can detail behaviors that tend to appear with those having capacity problems, such as “sundowning,”\textsuperscript{28} wandering\textsuperscript{29} or elopement.\textsuperscript{30} An expert will generally employ tests that have been peer-reviewed such as the mini-mental status exam,\textsuperscript{31} the Functional Assessment Staging Test (Table 3, page 146) and the clock-drawing test. A more recently used test, which is similar to the mini-mental status exam, is the SLUMS (St. Louis University Mental Status) examination (Table 4, page 147). It combines the mini-mental status exam with the clock test and portions of the Verbal Fluency – Category Retrieval exam. While a person subject to a guardianship may frequently be conversant, the ability to retain, comprehend, and provide appropriate insight and judgment may be impaired or even missing. All of the above-mentioned tests help the expert provide testimony to determine the level of capacity.\textsuperscript{32} Many times, courts will rely on expert testimony of a psychologist who has administered a battery of such tests over a sustained period of time.

An expert may request a brain scan to determine whether evidence of impairment is

\textsuperscript{27}Kumho Tire Co., Ltd. v. Carmichael, 526 U.S. 137, 152 (1999).

\textsuperscript{28}“Sundowning” is a syndrome in older people that usually occurs at night and is characterized by drowsiness, confusion, ataxia, and falling as the result of being overly sedated with medications. It can also be referred to as sundowner’s syndrome. See \textsc{Benjamin J. Kaplan, MD \& Virginia A. Sadock, MD, Kaplan \& Sadock’s Pocket Handbook of Clinical Psychiatry} (Lippincott Williams \& Wilkins, 4th ed., 2005).


\textsuperscript{30}A person who wanders is at risk for elopement — the act of leaving a safe area unsupervised and unnoticed and entering into harm’s way. \textit{Id.}

\textsuperscript{31}The Mini-Mental Status Exam (MMSE) is available through Psychological Assessment Resources (http://www.minimental.com/) and consists of 30 questions designed to test orientation to time and place, recall, attention, and calculation, for example.

Dementia and Legal Capacity: What Lawyers Should Know When Dealing With Expert Witnesses

present, such as brain atrophy. An expert who understands which medications may affect an individual’s ability to respond, remember, and to reason must consider what medications the individual may be taking when making a diagnosis. An expert may rely on other treating physician’s records in making the diagnosis and gerontologists and other physicians, nurses, social workers, psychologists, court investigators, therapists, and attorneys have qualified as experts in guardianship proceedings.

C. Topics of Testimony

The expert should be prepared to discuss his or her review of the proposed incapacitated person’s medical history, including the person’s memory loss, degree of disorientation, lack of insight or judgment, problem-solving abilities, outside influences, paranoia, compliance with taking medications, and successful completion of tasks. An expert should also be prepared to cover the ability to feed, clothe, and shelter oneself and to handle one’s estate. The proposed incapacitated person’s ability to drive may also be of concern to the court. The expert must be prepared to provide testimony about the examination itself, the length of the examination, the independence of his or her analysis, the diagnosis and how it was determined, the prognosis, and the degree of care and assistance the individual may need. The expert’s testimony can be based on hypothetical questions and even hearsay, but the opinions given must be based on reasonable medical probability and not all based on hearsay.

D. Limitations of Expert Testimony

It is interesting that on the issue of capacity most jurisdictions do not give a physician’s testimony any greater weight than a layperson’s opinion. Expert witness testimony as to capacity is not conclusive and must be evaluated by the jury or the trial court along with all the other evidence. Thus, the trier of fact may reject a physician’s report that contradicts a layperson’s observation. It is imperative that the expert maintain a file that contains the underlying data supporting those conclusions, including any tests administered and notes taken during the examination, and that the data be available to the opposing side.

IV. Conclusion

Dementia is often a key factor in determining the capacity of an individual, particularly in the elderly, and has far-reaching implications for both estate planners and litiga-
tors. An understanding of dementia and the level of capacity required in a transaction is critical for lawyers who practice in both of these areas. This understanding will greatly enhance the quality of the services provided and generally will help all lawyers who deal with aging clients. Litigators often use medical experts in cases in which capacity is an issue. Although no lawyer will ever have the full range of knowledge that is enjoyed by physicians who study and treat dementia, the lawyers will not be as effective as they can be without a working knowledge of dementia from a medical perspective.
Table 1: Comparison of the Four Common Irreversible Dementias

<table>
<thead>
<tr>
<th></th>
<th>Alzheimer’s Dementia (AD)</th>
<th>Vascular Dementia (VaD)</th>
<th>Dementia with Lewy Bodies (DLB)</th>
<th>Frontal Lobe Dementia (FLB)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Onset</strong></td>
<td>Insidious</td>
<td>Abrupt</td>
<td>Insidious</td>
<td>Gradual</td>
</tr>
<tr>
<td><strong>Age of Onset</strong></td>
<td>Increases with age</td>
<td>Variable</td>
<td>Late-middle and old age, increases with age</td>
<td>50s and 60s, rarely older than 75 years old</td>
</tr>
<tr>
<td><strong>Disease Course</strong></td>
<td>Gradual</td>
<td>Stepwise</td>
<td>Gradual</td>
<td>Fluctuating and progressive</td>
</tr>
<tr>
<td><strong>Prominent Features</strong></td>
<td>Early: short-term memory loss, difficulties with recall, and executive dysfunction</td>
<td>History of transient ischemic attacks, stroke, and vascular risk factors</td>
<td>Executive dysfunction</td>
<td>Word-finding difficulty, decreased fluency, difficulty with comprehending and/or producing language</td>
</tr>
<tr>
<td></td>
<td>Late: language and visuospatial difficulties</td>
<td>Executive dysfunction seen in performing complex tasks such as cooking, dressing, and housekeeping</td>
<td>Visuospatial impairment</td>
<td>Behavioral change: disinhibition or apathy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Fluctuating levels of alertness and attention</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Episodes of disorganized speech</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Visual hallucinations</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Parkinsonian motor features</td>
<td></td>
</tr>
<tr>
<td><strong>Other Common Symptoms</strong></td>
<td>Psychiatric and behavioral symptoms</td>
<td>Depression and apathy</td>
<td>Non-visual hallucinations, delusions</td>
<td>Neglect of personal hygiene, decreased insight on behavioral effect on others</td>
</tr>
<tr>
<td></td>
<td>Poor judgment</td>
<td>Difficulty with decision making, poor organizational skills, difficulty adjusting to change</td>
<td>Unexplained syncope</td>
<td>Reduced language output leading to muteness, stereotyped responses, and echolalia</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Rapid eye movement sleep disorder</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Antipsychotic sensitivity</td>
<td></td>
</tr>
</tbody>
</table>

Table 1, continued from previous page

<table>
<thead>
<tr>
<th>Mental Status Exam</th>
<th>Alzheimer's Dementia (AD)</th>
<th>Vascular Dementia (VaD)</th>
<th>Dementia with Lewy Bodies (DLB)</th>
<th>Frontal Lobe Dementia (FLB)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Difficulty with memory recall</td>
<td>Mild memory loss early</td>
<td>MMSE relatively preserved</td>
<td>MMSE often not helpful</td>
</tr>
<tr>
<td></td>
<td>Disorientation to time</td>
<td>Executive dysfunction</td>
<td>Fluctuating attention and alertness</td>
<td>Naming and word-finding difficulty</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Difficulty maintaining attention</td>
<td>Naming: good performance</td>
<td>Poor abstraction</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Apathy on appearance</td>
<td>Visuospatial skills: poor performance</td>
<td>Delayed shifting of cognitive sets</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Thought process slowed</td>
<td></td>
<td>Behavioral changes</td>
</tr>
<tr>
<td>Physical Exam</td>
<td>No focal signs</td>
<td>Gait is typically disturbed</td>
<td>Mild gait impairment</td>
<td>Memory preserved</td>
</tr>
<tr>
<td></td>
<td>Neurological exam relatively intact</td>
<td>Shuffling and with short steps</td>
<td>Myoclonus</td>
<td>Visuospatial intact</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hemiparesis</td>
<td>Orthostatic hypotension</td>
<td>命名 and word-finding difficulty</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Parkinsonian signs</td>
<td>Poor abstraction</td>
</tr>
<tr>
<td>Cause or Pathophysiology</td>
<td>Neurofibrillary tangles and neuritic plaques resulting in cell death</td>
<td>Bleed, stroke, vascular disease</td>
<td>Neurodegenerative Lewy Bodies seen on autopsy</td>
<td>Unknown cause of a family of neurodegenerative dementias</td>
</tr>
<tr>
<td></td>
<td>Often seen in combination with AD</td>
<td></td>
<td>Clinically difficult to diagnosis</td>
<td>Possible genetic component</td>
</tr>
</tbody>
</table>

Table 1 continued on next page
### Treatment

<table>
<thead>
<tr>
<th>Dementia Type</th>
<th>Alzheimer's Dementia (AD)</th>
<th>Vascular Dementia (VaD)</th>
<th>Dementia with Lewy Bodies (DLB)</th>
<th>Frontal Lobe Dementia (FLB)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social</strong></td>
<td>Memantine (Namenda) and Acetylcholinesterase inhibitors (Aricept, Excelon) to slow disease progression</td>
<td>Prevention of vascular disease, management of symptoms</td>
<td>Memantine (Namenda), Acetylcholinesterase inhibitors (Aricept, Excelon) unapproved</td>
<td>No medical interventions found to effective</td>
</tr>
<tr>
<td><strong>Interventions</strong></td>
<td>Antidepressants for depression</td>
<td>Memantine (Namenda) and Acetylcholinesterase inhibitors (Aricept, Excelon) found to be effective</td>
<td>Klonopin or Melatonin for sleep d/o</td>
<td>Speech/language/cognitive therapy to facilitate the use of spared functions</td>
</tr>
<tr>
<td><strong>Groups</strong></td>
<td>Antipsychotics for psychosis and agitation</td>
<td>Antidepressants for depression</td>
<td>Antidepressants for depression</td>
<td>SSRI for depression</td>
</tr>
<tr>
<td><strong>Counseling</strong></td>
<td></td>
<td></td>
<td></td>
<td>Trazodone for sleep</td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Caregiver</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Groups</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Memantine (Namenda), Acetylcholinesterase inhibitors (Aricept, Excelon) found to be effective.

Klonopin or Melatonin for sleep d/o.

Antidepressants for depression.

Atypical antipsychotics for psychosis and agitation.

Levodopa/Carbidopa (Sinemet) for motor features.

SSRI for depression.

Trazodone for sleep.
Table 2: Examples of Tests and Scales Performed for Dementia Work Up

<table>
<thead>
<tr>
<th>Test or Scale</th>
<th>Cognitive or Functional Domain Evaluated</th>
<th>Administration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Folstein Mini Mental Status Exam (MMSE)</td>
<td>Memory, language, apraxia, naming, reading, comprehension, repetition, sequencing, attention, constructional apraxia</td>
<td>Structured Interview</td>
</tr>
<tr>
<td>Montreal Cognitive Assessment (MoCA)</td>
<td>Memory, naming, abstraction, fluency, trails, construction, repetition</td>
<td>Structured Interview</td>
</tr>
<tr>
<td></td>
<td>Executive function, attention, language, attention, distant recall</td>
<td></td>
</tr>
<tr>
<td>The Executive Interview (EXIT25)</td>
<td>Executive dysfunction, constructional apraxia, aphasia, response inhibition, set shifting, primitive reflexes, neurological signs, naming, sequencing</td>
<td>Structured Interview</td>
</tr>
<tr>
<td>Boston Naming Test</td>
<td>Naming (agnosia)</td>
<td>Neuropsych Testing</td>
</tr>
<tr>
<td>Trail Making B</td>
<td>Executive function — sequencing, attention</td>
<td>Neuropsych Testing</td>
</tr>
<tr>
<td>Digit Span</td>
<td>Attention and concentration</td>
<td>Structured Interview or Neuropsych Testing</td>
</tr>
<tr>
<td>Stroop Color/Word Inter</td>
<td>Executive function — Response inhibition</td>
<td>Neuropsych Testing</td>
</tr>
<tr>
<td>Wisconsin Card Sorting Test</td>
<td>Executive function — set shifting</td>
<td>Neuropsych Testing</td>
</tr>
<tr>
<td>Wechsler Adult Intelligence Scale – Revised (WAIS-R)</td>
<td>Intellectual functioning</td>
<td>Neuropsych Testing</td>
</tr>
<tr>
<td>Wechsler Adult Intelligence Scale-III (WAIS-III)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rey-Osterrieth Complex Figure – Copy condition</td>
<td>Visuospatial assessment — construction apraxia</td>
<td>Neuropsych Testing</td>
</tr>
<tr>
<td>WAIS Block Design Subtest</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hooper Visual Organization Test</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 2 continued on next page

### Test or Scale

<table>
<thead>
<tr>
<th>Test or Scale</th>
<th>Cognitive or Functional Domain Evaluated</th>
<th>Administration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wechsler scales: Memory Scale (WMS)</td>
<td>Verbal learning and memory</td>
<td>Neuropsych Testing</td>
</tr>
<tr>
<td>Logical Memory I and II</td>
<td></td>
<td></td>
</tr>
<tr>
<td>WMS-III Verbal Memory Index</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rey Auditory Verbal Learning Test</td>
<td></td>
<td></td>
</tr>
<tr>
<td>California Verbal Learning Test</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instrumental Activities of Daily Living (IADL)</td>
<td>Verbal learning and memory</td>
<td>Structured Interview with caregiver</td>
</tr>
<tr>
<td>Physical Self-Maintenance Scale (PSMS)</td>
<td>Function, apraxia, self care, executive function</td>
<td>Structured Evaluation</td>
</tr>
<tr>
<td>Simpson-Angus Scale (SAS)</td>
<td>Behavior, dressing apraxia, self care</td>
<td></td>
</tr>
<tr>
<td>Frontal dysfunction (Behavior) FBI</td>
<td>Behavior: apathy, indifference, inflexibility, personal neglect, social inappropriateness, aggression,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>frontal lobe signs of hyperorality, hypersexuality</td>
<td></td>
</tr>
</tbody>
</table>
NOTE: The following tests are used and interpreted by qualified physicians only.

TABLE 3

Table 3 continued on next page
Dementia and Legal Capacity: What Lawyers Should Know When Dealing With Expert Witnesses

**Differential Diagnosis**

Use the FAST tool to determine if changes in a patient’s condition are due to Alzheimer’s disease or another condition. If the change is due to AD progression, then any changes on the FAST scale will be in sequence—**AD-related changes do not skip FAST stages**.

**Example:** a patient is mildly demented (FAST stage 4), and loses the ability to bathe (FAST 6b) but can still pick out their clothes (FAST 5) and dress themselves (FAST 6a), then they skipped FAST stages 5 and 6a and went directly to FAST stage 6b. These changes are not due to AD progression. It could be that the diagnosis of AD is wrong or that the patient has a second dementing disorder in addition to AD. Alternatively, the patient may have an exacerbation of an existing medical problem, developed a new medical problem, or had some other change in their care or living situation that caused the difficulty bathing.

**Measurement of delay in AD**

Use the FAST tool at each office visit to measure treatment effect in each patient. The longitudinal view of the FAST shows how long a patient has spent in each FAST stage, plus its average expected untreated duration. The difference, which appears in the column, “Actual minus Expected Untreated AD Duration”, indicates whether treatment has delayed AD progression.

**Example:** you have been treating an AD patient for four years and staging them at each office visit. The FAST longitudinal view shows that the patient has spent 46 months in stage 4 (e.g., difficulty managing finances). The average, expected untreated duration of stage 4 is 24 months, and the difference shown is 22 months. This indicates that treatment has delayed AD progression by approximately 22 months. Without treatment, they would have progressed to FAST stage 6b and would be unable to dress or bathe.

**References**


Medical Care Corporation
Simple and Accurate Memory Assessment
www.mccare.com • (888)655-5535
Table 4

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>What day of the week is it?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>What is the year?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>What state are we in?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Please remember these five objects, I will ask you what they are later.</td>
<td>Apple</td>
<td>Pen</td>
<td>Tie</td>
<td>House</td>
<td>Car</td>
</tr>
<tr>
<td>5.</td>
<td>You have $1000 and you go to the store and buy a dozen apples for $3 and a tricycle for $20.</td>
<td>How much did you spend?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>How much do you have left?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Please name as many animals as you can in one minute.</td>
<td>0-4 animals</td>
<td>5-9 animals</td>
<td>10-14 animals</td>
<td>15+ animals</td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>What were the five objects I asked you to remember? I point for each one correct.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I am going to give you a series of numbers and I would like you to give them to me backwards. For example, if I say 42, you would say 24.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Which of the above figures is largest?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>I am going to tell you a story. Please listen carefully because afterwards, I’m going to ask you some questions about it. Jill was a very successful stockbroker. She made a lot of money on the stock market. She then met Jack, a devastatingly handsome man. She married him and had three children. They lived in Chicago. She then stopped work and stayed at home to bring up her children. When they were teenagers, she went back to work. She and Jack lived happily ever after.</td>
<td>What was the female’s name?</td>
<td>What work did she do?</td>
<td>What state did she live in?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TOTAL SCORE


Table 5

<table>
<thead>
<tr>
<th>Table 5 Continued on next page</th>
<th>Table 5 Continued on next page</th>
</tr>
</thead>
</table>

Dementia and Legal Capacity: What Lawyers Should Know When Dealing With Expert Witnesses

---

Table 5, continued from previous page

<table>
<thead>
<tr>
<th>DOCTOR’S MEDICAL EVALUATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>INSTRUCTIONS TO THE DOCTOR: The Department of Motor Vehicles' records indicate your patient may have a condition that could affect the safe operation of a motor vehicle. (See Instructions to the Doctor, page 1 for the specific medical condition that is a concern to the department.) With your assistance, the department hopes to resolve the matter with a minimum of inconvenience to all concerned. The Health History and Medical Information Authorization sections on page 1 must be completed and signed by the patient before you complete this Driver Medical Evaluation form. Your experience and knowledge of the patient's condition, results of medical examinations and treatment plans, will be of great value in assisting the department to determine a proper licensing decision. PLEASE ANSWER ALL QUESTIONS on this form that are applicable to your patient's condition(s). You may furnish a narrative report if you prefer, but please include all information pertinent to your patient. The department has sole responsibility for any decision regarding the patient's driving qualifications and licensure. The department will also consider non-medical factors in reaching a decision.</td>
</tr>
</tbody>
</table>

| VISION |
|----------------------|---------|---------|---------|
| VISUAL ACUITY (without biopic telescope) | BOTH EYES | RIGHT EYE | LEFT EYE |
| Without Lenses | 20/ | 20/ | 20/ |
| With Present Lenses | 20/ | 20/ | 20/ |

<table>
<thead>
<tr>
<th>IS FURTHER EYE EXAMINATION SUGGESTED?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TREATMENT BY OTHER DOCTOR(S)</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CONDITION IN WHICH TREATED</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TREATMENT UNDER YOUR SUPERVISION</th>
</tr>
</thead>
<tbody>
<tr>
<td>DIAGNOSIS (IF THE DIAGNOSIS IS A DISORDER CHARACTERIZED BY LALPSES OF CONSCIOUSNESS, DEMENTIA, OR DIABETES, COMPLETE PG. 3, 4 OR 5.)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IS THE CONDITION</th>
<th>□ Stable □ Worsening or deteriorating □ Subject to change</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(IF MULTIPLE CONDITIONS, PLEASE DESCRIBE STATUS AND PROGNOSIS IN COMMENTS BELOW)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PRESENTED</th>
<th>□ Present □ Absent</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>HOW LONG HAS THIS PERSON BEEN YOUR PATIENT?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>IS YOUR PATIENT UNDER A CONTROLLED MEDICAL PROGRAM?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IS THE PATIENT ADHERING TO THE MEDICAL REGIMEN IF NO, PLEASE EXPLAIN:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LEFT THE MEDICATIONS PRESCRIBED PLEASE INCLUDE DOSAGE AND FREQUENCY OF USE</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>WHEN WAS THE LAST MEDICATION CHANGE MADE?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>WOULD THE SIDE EFFECTS FROM THE PRESCRIBED MEDICATIONS INTERFERE WITH THE SAFE OPERATION OF A MOTOR VEHICLE?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DO YOU CURRENTLY ADVISE AGAINST DRIVING?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DOCTOR'S COMMENT:</th>
</tr>
</thead>
</table>

---

Table 5 continued on next page
### LEVELS OF FUNCTIONAL IMPAIRMENTS

Functional impairments that may affect safe driving ability. Please check where applicable.

<table>
<thead>
<tr>
<th></th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual neglect</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Left side</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Right side</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Loss of upper extremity motor control</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Left side</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Right side</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Loss of lower extremity motor control</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Left side</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Right side</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

**WOULD ADAPTIVE DEVICES ASSIST YOUR PATIENT IN COMPENSATING FOR HIS/HER DISABILITY?**

- Yes ☐ No ☐ Uncertain ☐

**IF YES, PLEASE DESCRIBE.**

**WOULD YOU RECOMMEND A DRIVING TEST BE GIVEN TO THIS PATIENT?**

- Yes ☐ No ☐ Uncertain ☐

**DEMENTIA OR COGNITIVE IMPAIRMENTS**

- ☐ Alzheimer's Disease
- ☐ Other Dementia *(Please describe the type of dementia below, e.g., multi-infarct, metabolic, post-traumatic.)*

**HISTORY OF DISEASE, RESULTS OF TESTING, ETC.**

---

Using the definitions given below, please rate the severity of the following forms of cognitive impairments in this patient.

- **Mild:** Judgment is relatively intact but work or social activities are significantly impaired. Ability to safely operate a motor vehicle may or may not be impaired.
- **Moderate:** Independent living is hazardous and some degree of supervision is necessary. The individual is unable to cope with the environment and driving would be dangerous.
- **Severe:** Activities of daily living are so impaired that continual supervision is required. This person is incapable of driving a motor vehicle.

<table>
<thead>
<tr>
<th>Cognitive Impairment</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Uncertain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory Loss</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Depression, secondary to dementia</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Diminished Judgment</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Impaired Attention</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Impaired Language Skills</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Impaired Visual Spatial Skills</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Impulsive Behavior</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Problem Solving Deficits</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Loss of Awareness of Disability</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

**OVERALL DEGREE OF IMPAIRMENT**

- ☐ Yes ☐ No ☐ Uncertain ☐

---

*Table 5 continued on next page*
Table 5, continued from previous page

<table>
<thead>
<tr>
<th>LAPSE OF CONSCIOUSNESS DISORDER</th>
<th>DATE(S) OF EPISODE(S) IN THE PAST THREE YEARS</th>
</tr>
</thead>
<tbody>
<tr>
<td>SHOCKED</td>
<td></td>
</tr>
<tr>
<td>REACTED</td>
<td></td>
</tr>
<tr>
<td>AWARE</td>
<td></td>
</tr>
<tr>
<td>DATE OF ONSET, IF KNOWN</td>
<td></td>
</tr>
<tr>
<td>DATE AND TIME OF LAST EPISODE</td>
<td></td>
</tr>
</tbody>
</table>

Please indicate the impairments identified below that are presently shown by your patient.

- Sporadic loss of conscious awareness
- Loss of consciousness
- Impaired motor function
- Contusion
- Diminished concentration
- Diminished judgment
- Memory loss
- If medication is taken to control seizures, are the serum levels recorded?
- Are the serum levels medically acceptable?

<table>
<thead>
<tr>
<th>DIABETES</th>
<th>DATE OF DIAGNOSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>PLEASE INDICATE THE TYPE OF DIABETES THIS PATIENT HAS</td>
<td></td>
</tr>
<tr>
<td>☐ Type 1</td>
<td>☐ Type 2</td>
</tr>
<tr>
<td>☐ Gestational</td>
<td></td>
</tr>
<tr>
<td>WHAT METHOD OF TREATMENT IS REQUIRED?</td>
<td></td>
</tr>
<tr>
<td>☐ Controlled diet</td>
<td>☐ Oral diabetes medication</td>
</tr>
<tr>
<td>☐ Insulin injections</td>
<td>☐ Insulin pump</td>
</tr>
<tr>
<td>☐ Other:</td>
<td></td>
</tr>
<tr>
<td>DOES THIS PATIENT RECEIVE DIABETES EDUCATION FROM A HEALTH CARE PROFESSIONAL?</td>
<td></td>
</tr>
<tr>
<td>☐ Yes</td>
<td>☐ No</td>
</tr>
<tr>
<td>IF NO, PLEASE EXPLAIN</td>
<td></td>
</tr>
<tr>
<td>IS THE DIABETES MANAGED AT THIS TIME?</td>
<td></td>
</tr>
<tr>
<td>☐ Yes</td>
<td>☐ No</td>
</tr>
<tr>
<td>IF YES, HOW LONG HAS DIABETES BEEN MANAGED OR MAINTAINED?</td>
<td></td>
</tr>
<tr>
<td>IF NOT, PLEASE EXPLAIN</td>
<td></td>
</tr>
<tr>
<td>WHAT ARE THIS PATIENT'S FASTING BLOOD GLUCOSE LEVELS?</td>
<td></td>
</tr>
<tr>
<td>AFTER HOW MANY HOURS OF Fasting?</td>
<td></td>
</tr>
<tr>
<td>WHEN THE LAST THREE YEARS, HAS THIS PATIENT EXPERIENCED HYPEROGLYCEMIC EPISODES?</td>
<td></td>
</tr>
<tr>
<td>REASON FOR EPISODES (e.g., non-compliance with diet, change in condition, insulin unavailable, illness, etc.)</td>
<td></td>
</tr>
</tbody>
</table>

Please indicate the complications manifested by the hypoglycemic or hyperglycemic episodes and rate the severity of each.

Abdominal pain
Cognitive deficits
Confusion
Confusion or disorientation
Incoordination
Hypoglycemic unawareness
Lack of stamina
Loss of consciousness
Stupor
Visual changes
Ketoacidosis
Slowed reactions
Seizures
Weakness or fatigue
Other

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| DOES THIS PATIENT MANAGE HYPOGLYCEMIC OR HYPERGLYCEMIC EPISODES WITH OR WITHOUT HELP? |
|-----------------------------------|--------------------------------------------------|-----------------|----------------|-----------------|
| □ With □ Without                  |                                                  |                 |               |                 |

<table>
<thead>
<tr>
<th>HAS THIS PATIENT'S DIABETES CAUSED ANY OF THE FOLLOWING CHRONIC COMPLICATIONS?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Visual changes □ Kidney disease □ Nervous system disease □ Vascular disease</td>
</tr>
<tr>
<td>PLEASE DESCRIBE THE EXTENT OF THE COMPLICATIONS</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HAS THE PATIENT BEEN HOSPITALIZED WITHIN THE LAST THREE YEARS DUE TO DIABETIC COMPLICATIONS?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No. If yes, please give details:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HAS ANY URGENCY BEEN NECESSARY?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No. If yes, please explain</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ADDITIONAL COMMENTS BY DOCTOR</th>
</tr>
</thead>
<tbody>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>DOCTOR'S SIGNATURE</th>
</tr>
</thead>
<tbody>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>CLASSIFICATION OR SPECIALTY</th>
</tr>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>DOCTOR'S NAME (Printed)</th>
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<tbody>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>MEDICAL LICENSE NUMBER</th>
</tr>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>TELEPHONE NUMBER</th>
</tr>
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<tbody>
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<td>(                )</td>
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</tbody>
</table>
Health Care Surrogate Decision Making and Bioethics:
Case Studies from the Files of the
Office of the Cook County Public Guardian

By Charles Perez Golbert, Esq.

I esteem it the office of a physician not only to restore health, but to mitigate pain and dolours; and not only when such mitigation may conduce to recovery, but when it may serve to make a fair and easy passage.

—Francis Bacon, New Atlantis (1623)

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I. Introduction

The Office of the Cook County Public Guardian (Public Guardian’s Office) in Chicago is one of the largest guardianship offices in the country. It serves as guardian of the person and/or estate for more than 800 persons with disabilities.1 Most of its wards are elderly and have age-related dementia, such as Alzheimer’s disease, although it also serves some younger wards with disabilities.2 Many of the wards also have physical disabilities

Charles P. Golbert is the Deputy Public Guardian in charge of the adult guardianship division of the Office of the Cook County Public Guardian, in Chicago, Ill. He is responsible for overseeing the Office’s guardianship services for its more than 800 adult wards with disabilities, including legal and social services and management of nearly $100 million in collective ward assets. Mr. Golbert personally reviews all end-of-life decisions for the Office’s wards, including DNR orders and removal of life support orders, and other complex health care surrogate decisions. He has litigated numerous matters in these areas on behalf of the Office’s wards. The opinions expressed in this article are those of the author and not necessarily those of the Public Guardian’s Office. The author wishes to thank Professor Katie Watson of the Northwestern University Feinberg School of Medicine for her thoughtful suggestions for Section III of the article. The author also wishes to acknowledge Kristin Wood, Kristi Blankenberger, and Meghan Nemiroff, law student interns at the Public Guardian’s Office, for their research assistance for this article.

2 Id.
and are medically fragile. The wards come from all walks of life and from every corner of Cook County, which is one of the largest and most diverse counties in the country. The Public Guardian’s Office serves as the guardian of last resort, so its wards either have no family to act as guardian or have family members who are abusive, financially exploitative, or otherwise inappropriate. In its capacity as guardian, the Public Guardian’s Office has authority to make health care surrogate decisions for most of its wards.

Due to the number of wards served, their diverse backgrounds, the fact that the wards have no family at all or family members who are problematic decision makers, the wards’ cognitive disabilities, their advanced ages, and often medically frail conditions, the Public Guardian’s Office is frequently faced with complex and difficult health care surrogate decisions, especially in the area of end-of-life decisions, such as do not resuscitate (DNR) orders and removal of life support orders. As one state supreme court noted, this is a realm in which law, medicine, and religion intersect.

As another state supreme court observed:

[These cases] raise profoundly disturbing questions that do not lend themselves to easy answers or ideal solutions. To err either way — to keep a person alive under circumstances under which he would rather have been allowed to die, or to allow that person to die when he would have chosen to cling to life — would be deeply unfortunate. We thus approach this case with caution, conscious that life-and-death decisions like these are an awesome responsibility that can be undertaken only with a profound sense of humility and reserve. [These cases] raise moral, social, technological, philosophical, and legal questions involving the interplay of many disciplines. No one person or profession has all the answers.

This article will use three particularly complex case studies to illustrate some of the challenges and ethical dilemmas that arise when making health care surrogate decisions. The studies are based on actual health care surrogate decisions that the Public Guardian’s Office was called upon to make on behalf of its wards. The facts of the studies are true; only minor identifying information has been changed to preserve privacy.

Section II will provide legal context. The section will discuss the Uniform Health Care Decisions Act (UHCDA), which has been adopted by eight states and introduced

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4 Cook County Public Guardian, http://www.publicguardian.org/ag_4.htm (last visited Oct. 15, 2009); see generally Estate of Debevec, 552 N.E.2d 1043, 1046 (Ill. App. 1990) (explaining the preference for family members to serve as guardian because family members are presumed to be more solicitous of the ward’s welfare than a nonrelative).

5 755 Ill. Comp. Stat. 5/11a-17(a) and (d) (2010); 755 Ill. Comp. Stat. 40/25(a). Because, in Illinois, a plenary guardian has authority to make health care surrogate decisions for the ward, the issue of who should most appropriately serve as the surrogate decision maker usually does not arise in our cases and is not implicated in the case studies discussed in this article.

6 In re Estate of Longway, 549 N.E.2d 292, 294 (Ill. 1990).

7 In re Conroy, 486 A.2d 1209, 1220 (N.J. 1985).

in the General Assembly of a ninth state. This section will also discuss the health care surrogacy laws of Illinois, New York, Oregon and Texas. Finally, the section will discuss the influential case of In re Conroy, decided by the Supreme Court of New Jersey, which provides a thoughtful discussion of the factors that a surrogate decision maker should consider when making a substituted judgment or best interest determination.

As a general matter, the law of most jurisdictions entails a three-step analysis. First, does the person have decisional capacity to make the health care decision at issue and the ability to communicate the decision? If so, the person’s decision will be followed.

If the person lacks decisional capacity, the analysis will continue to the second inquiry: What would the person have wanted if able to make and communicate a decision? This is known as substituted judgment. This step entails searching for advance directives, attempting to ascertain the person’s religious convictions and ethical values, interviewing family members and significant others, and the like. This inquiry can be fraught with all kinds of challenges. For example, what if two sons give conflicting accounts of their mother’s views about end-of-life decisions? What if one of the sons abused and financially exploited the parent, appears overly eager to enjoy his inheritance, and is advocating withdrawal of life support? What weight should be given to an advance directive signed when the person was beginning to lose capacity, or under circumstances suggesting that a family member may have been exerting undue influence? What weight should be given an advance directive signed many years earlier under different circumstances? What if the person’s views changed frequently and widely over her lifetime? How should the surrogate decision maker take into account the person’s religious values? When are consults with clergy appropriate?

If the person’s wishes cannot be ascertained, the analysis will continue to the third step, which is determining what is in the person’s best interest. Again, this can be a difficult inquiry. Medical care providers sometimes disagree about what is best for a patient. Likewise, family members acting in the best of faith can passionately disagree about what is best for a loved one.

With this legal framework in place, Sections III – V will discuss the actual case histories of three wards of the Public Guardian’s Office: Bonnie T., Sarah W., and Eula W. In the process of discussing these wards’ cases, the article will highlight and analyze some of the difficult dilemmas that arise in making health care surrogate decisions.

In Section VI, the author offers some concluding thoughts. This section will discuss the importance of counseling clients to sign thoughtful and detailed advance directives in order to avoid the difficult dilemmas discussed in this article. This section will also emphasize the importance of seeking consults with interdisciplinary professionals in working through these hard issues. Finally, the section will discuss the need to put aside per-

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10 755 ILL. COMP. STAT. 40/1 et seq. (2010).
11 N.Y. PUB. HEALTH LAW §§ 2980 et seq. (Consol. 2010).
13 TEX. HEALTH & SAFETY CODE §§ 166.001 et seq. (2009).
14 In re Conroy, 486 A.2d 1209 (N.J. 1985).
sonal values when making a substituted judgment decision on behalf of another, in order to preserve that person’s fundamental rights to personal autonomy and bodily integrity.

II. LEGAL FRAMEWORK

A. Uniform Health Care Decisions Act

The Uniform Health Care Decisions Act (UHCD)\textsuperscript{15} was approved by the Uniform Law Commission in 1993 and has been adopted by eight states: Alabama, Alaska, Delaware, Hawaii, Maine, Mississippi, New Mexico, and Wyoming.\textsuperscript{16} It also has been introduced in the General Assembly of Kansas.\textsuperscript{17}

The UHCD allows the surrogate to make health care decisions for a patient when it has been determined by the primary physician that the patient lacks capacity.\textsuperscript{18} “Health care” is defined as any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect an individual’s physical or mental condition.\textsuperscript{19} “Health care decision” is defined as a decision regarding health care, including selection and discharge of health care providers and institutions; approval or disapproval of diagnostic tests, surgical procedures, programs of medication, and orders not to resuscitate; and directions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care.\textsuperscript{20} “Capacity” is defined as the ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision.\textsuperscript{21}

If the patient lacks capacity as defined above, the surrogate is to make health care decisions in accordance with the patient’s instructions, if any, and other wishes to the extent known to the surrogate.\textsuperscript{22} Otherwise, the surrogate shall make the decision in accordance with the surrogate’s determination of the patient’s best interest.\textsuperscript{23} In determining best interest, the surrogate shall consider the patient’s personal values to the extent known.\textsuperscript{24} The UHCD does not attempt to define “best interest.”\textsuperscript{25}

The Preamble to the UHCD states that it is built around several concepts, including the right of a competent individual to decide all aspects of his or her own health care in all circumstances, which includes the right to decline health care or to direct that health care be discontinued, even if death ensues.\textsuperscript{26} The UHCD also seeks to ensure, to the

\begin{itemize}
\item[17] Id.
\item[18] UHCD § 5(a); see also § 2(c).
\item[19] UHCD § 1(5).
\item[20] UHCD § 1(6).
\item[21] UHCD § 1(3).
\item[22] UHCD § 5(f); see also § 2(e).
\item[23] Id.
\item[24] Id.
\item[25] See UHCD § 1, the definitional section, which does not define “best interest.”
\item[26] UHCD Preamble.
\end{itemize}
extent possible, that decisions about an individual’s health care are governed by the individual’s own desires.\textsuperscript{27} The Comments to UHDCA § 1, which is the definitional section, state that the definition of “health care” is to be given the broadest possible construction.\textsuperscript{28}

\textbf{B. Illinois}

The Illinois Health Care Surrogate Act (Illinois Act)\textsuperscript{29} was enacted in 1991. The Illinois Act applies only to patients who lack decisional capacity, which must be determined by the attending physician to a reasonable degree of medical certainty.\textsuperscript{30} “Decisional capacity” is defined as the ability to understand and appreciate the nature and consequences of a decision regarding medical treatment or the forgoing of life-sustaining treatment, and the ability to reach and communicate an informed decision.\textsuperscript{31} A patient is presumed to have decisional capacity in the absence of actual notice to the contrary, without regard to advanced age.\textsuperscript{32} Moreover, a diagnosis of mental illness or mental retardation, of itself, is not a bar to a determination of decisional capacity.\textsuperscript{33} The determination that a patient lacks decisional capacity must be in writing and placed in the patient’s medical record.\textsuperscript{34}

If the patient lacks decisional capacity, the surrogate shall make decisions for the patient as closely as possible to what the patient would have done or intended under the circumstances.\textsuperscript{35} In making this determination, the surrogate must take into account evidence that includes, but is not limited to, the patient’s personal, philosophical, religious and moral beliefs, and ethical values.\textsuperscript{36}

If the patient’s wishes are unknown and remain unknown after reasonable efforts to discern them, the decision shall be made on the basis of the patient’s best interests as determined by the surrogate decision maker.\textsuperscript{37} In determining the patient’s best interests, the surrogate shall weigh the burdens on and benefits to the patient of the treatment against the burdens and benefits of that treatment.\textsuperscript{38} The surrogate shall take into account any other information, including the views of family and friends, that the surrogate believes the patient would have considered if able to act for himself or herself.\textsuperscript{39}

If the decision at issue is whether to forgo life-sustaining treatment, the Illinois Act provides two additional protections for the patient. To “forgo life-sustaining treatment” is defined as to withhold, withdraw, or terminate all or any portion of life-sustaining treatment with knowledge that death is likely to result.\textsuperscript{40} “Life-sustaining treatment” is defined

\begin{itemize}
\item \textsuperscript{27} Id.
\item \textsuperscript{28} UHCDA § 1, Comments.
\item \textsuperscript{29} 755 ILL. COMP. STAT. 40/1 et seq. (2010).
\item \textsuperscript{30} 755 ILL. COMP. STAT. 40/15, 40/20(c).
\item \textsuperscript{31} 755 ILL. COMP. STAT. 40/10. The term “forgo life sustaining treatment” is discussed below.
\item \textsuperscript{32} 755 ILL. COMP. STAT. 40/20(c).
\item \textsuperscript{33} Id.
\item \textsuperscript{34} Id.
\item \textsuperscript{35} 755 ILL. COMP. STAT. 40/20(b-5)(1).
\item \textsuperscript{36} Id.
\item \textsuperscript{37} Id.
\item \textsuperscript{38} Id.
\item \textsuperscript{39} Id.
\item \textsuperscript{40} 755 ILL. COMP. STAT. 40/10.
\end{itemize}
as any medical treatment, procedure or intervention that, in the judgment of the attending physician, when applied to a patient with a qualifying condition, would not be effective to remove the qualifying condition or would serve only to prolong the dying process.\textsuperscript{41} Such procedures can include, but are not limited to, assisted ventilation, renal dialysis, surgical procedures, blood transfusion, and the administration of drugs, antibiotics, and artificial nutrition and hydration.\textsuperscript{42}

The first extra protection is that the patient’s lack of decisional capacity must be certified in writing by a concurring physician and placed in the patient’s medical record.\textsuperscript{43} The second additional protection is that the patient must have a qualifying condition, documented in writing in the medical record by the patient’s attending physician and a concurring physician.\textsuperscript{44} A qualifying condition is one or more of the following three conditions:

1. \textit{Terminal condition}, which is defined as an illness or injury for which there is no reasonable prospect of cure or recovery, death is imminent,\textsuperscript{45} and the application of life-sustaining treatment would only prolong the dying process;

2. \textit{Permanent unconsciousness}, which is defined as a condition that, to a high degree of medical certainty, (1) will last permanently, without improvement, (2) in which thought, sensation, purposeful action, social interaction, and awareness of self and environment are absent, and (3) for which initiating or continuing life-sustaining treatment, in light of the patient’s medical condition, provides only minimal medical benefit; or

3. \textit{Incurable or irreversible condition}, which is defined as an illness or injury (1) for which there is no reasonable prospect of cure or recovery, (2) that ultimately will cause the patient’s death even if life-sustaining treatment is initiated or continued, (3) that imposes severe pain or otherwise imposes an inhumane burden on the patient, and (4) for which initiating or continuing life-sustaining treatment, in light of the patient’s medical condition, provides only minimal medical benefit.\textsuperscript{46}

Under the Illinois Act, all health care decisions made by the surrogate must be in consultation with the patient’s attending physician.\textsuperscript{47}

The Illinois Act enumerates a number of legislative findings. First, the legislature recognizes that all persons have a fundamental right to make decisions relating to their own medical treatment, including the right to forgo life-sustaining treatment.\textsuperscript{48} Moreover, lack of decisional capacity, alone, should not prevent decisions to forgo life-sustaining treatment from being made on behalf of persons who lack decisional capacity.\textsuperscript{49} Finally, statutory guidelines for decision making will bring improved clarity and certainty to the

\textsuperscript{41} Id. “Qualifying condition” is discussed below.

\textsuperscript{42} Id.

\textsuperscript{43} 755 ILL. COMP. STAT. 40/20(c).

\textsuperscript{44} 755 ILL. COMP. STAT. 40/20(b) and (e).

\textsuperscript{45} “Imminent” is defined as a determination made by the attending physician according to accepted medical standards that death will occur in a relatively short period of time, even if life-sustaining treatment is initiated or continued. 755 ILL. COMP. STAT. 40/10.

\textsuperscript{46} Id.

\textsuperscript{47} 755 ILL. COMP. STAT. 40/20(b)(1), 40/20(b-5)(1).

\textsuperscript{48} 755 ILL. COMP. STAT. 40/5(a).

\textsuperscript{49} Id.
process of implementing decisions concerning medical treatment and to forgo life-sustaining treatment and will reduce the associated emotional distress for involved parties.\textsuperscript{50}

The Illinois Act states its intent that health care surrogate decisions be made, whenever possible, without the need for judicial involvement.\textsuperscript{51}

C. New York

New York’s health care surrogacy laws\textsuperscript{52} became effective in 1991. A surrogate decision maker’s authority commences upon a determination that the patient lacks capacity to make health care decisions.\textsuperscript{53} “Capacity to make health care decisions” is defined as the ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of and alternatives to any proposed health care, and to reach an informed decision.\textsuperscript{54} “Health care” is defined as any treatment, service, or procedure to diagnose or treat an individual’s physical or mental condition.\textsuperscript{55} “Health care decision” is defined as any decision to consent or refuse to consent to health care.\textsuperscript{56}

The patient’s attending physician must make the determination of lack of decisional capacity to a reasonable degree of medical certainty and put it in writing.\textsuperscript{57} The determination must include the attending physician’s opinion regarding the cause and nature of the patient’s incapacity, as well as its extent and probable duration, and must be placed in the patient’s medical record.\textsuperscript{58} If the decision is to withdraw or withhold life-sustaining treatment, the attending physician must consult with another physician to confirm the determination of lack of decisional capacity, and the consultation is also included in the medical record.\textsuperscript{59} If the basis for the determination of lack of decisional capacity is mental illness, the attending physician must consult with a qualified psychiatrist and documentation of the consultation must be included in the medical record.\textsuperscript{60} If the basis for the determination of lack of decisional capacity is developmental disability, the attending physician must consult with a physician or clinical psychologist with qualifications as set forth in the statute and a record of the consultation included in the medical record.\textsuperscript{61}

The attending physician is under a continuing obligation to confirm the patient’s continued incapacity before complying with an agent’s health care decisions, other than

\begin{itemize}
\item \textsuperscript{50} Id.
\item \textsuperscript{51} 755 ILL. COMP. STAT. 40/5(b).
\item \textsuperscript{52} N.Y. PUB. HEALTH LAW §§ 2980 et seq. (Consol. 2010).
\item \textsuperscript{53} N.Y. PUB. HEALTH LAW § 2981(4).
\item \textsuperscript{54} N.Y. PUB. HEALTH LAW § 2980(3).
\item \textsuperscript{55} N.Y. PUB. HEALTH LAW § 2980(4).
\item \textsuperscript{56} N.Y. PUB. HEALTH LAW § 2980(6).
\item \textsuperscript{57} N.Y. PUB. HEALTH LAW § 2983(1)(a).
\item \textsuperscript{58} Id.
\item \textsuperscript{59} Id.
\item \textsuperscript{60} N.Y. PUB. HEALTH LAW § 2983(1)(b).
\item \textsuperscript{61} N.Y. PUB. HEALTH LAW § 2983(1)(c). The consulting physician or clinical psychologist must either be employed by a school delineated by statute, or have a minimum of two years’ employment rendering care and service in a facility operated or licensed by the office of mental retardation and developmental disabilities, or be approved by the commissioner of mental retardation and developmental disabilities in accordance with regulations promulgated by the commissioner. Id.
\end{itemize}
those made at or about the time of the initial determination. 62 The confirmation must be in writing and included in the patient’s medical record. 63 Notwithstanding a determination of lack of decisional capacity, when a patient objects to the determination of incapacity or to a health care decision made by a surrogate, the patient’s objection or decision shall prevail unless the patient is determined by a court of competent jurisdiction to lack capacity to make health care decisions. 64

If lack of decisional capacity has been established as set forth above, the surrogate shall make health care decisions in accordance with the patient’s wishes, including his or her religious beliefs. 65 If the patient’s wishes are not reasonably known and cannot with reasonable diligence be ascertained, the decision shall be made in accordance with the patient’s best interests. 66 However, when the patient’s wishes regarding administration of artificial nutrition and hydration are not reasonably known and cannot with reasonable diligence be ascertained, the surrogate decision maker shall have no authority to make decisions regarding these measures. 67

New York allows family members and others to initiate a judicial proceeding to address disputes that arise under the health care surrogacy laws. 68 Such proceedings may be initiated, among other purposes, (1) to determine the validity of a health care proxy; (2) to remove an agent for bad faith or due to unavailability, unwillingness or incompetence to fulfill his or her obligations; and (3) to override the agent’s decisions made in bad faith or contrary to the standards set forth in the health care surrogacy statute. 69

D. Oregon

Oregon enacted its Health Care Decisions Act (Oregon Act) 70 in 1993. Under the Oregon Act, a surrogate decision maker has authority to make a health care decision for a patient only when the patient is incapable. 71 “Health care decision” is defined as consent, refusal of consent, or withholding or withdrawal of consent to health care. 72 “Health care” is defined as the diagnosis, treatment or care of disease, injury and congenital or degenerative conditions, including the use, maintenance, withdrawal or withholding of life-sustaining procedures and the use, maintenance, withdrawal or withholding of artificially administered nutrition and hydration. 73 “Incapable” is defined as (in the opinion of the court in a proceeding to appoint or confirm authority of a health care representative, or in the opinion of the patient’s attending physician) the patient’s lack of the ability to

62 N.Y. PUB. HEALTH LAW § 2983(6).
63 Id.
64 N.Y. PUB. HEALTH LAW § 2983(5).
65 N.Y. PUB. HEALTH LAW § 2982(2).
66 Id.
67 Id.
68 N.Y. PUB. HEALTH LAW § 2992.
69 Id.
71 OR. REV. STAT. §127.535(1).
72 OR. REV. STAT. § 127.505(8).
73 OR. REV. STAT. § 127.505(7). The terms “life-sustaining procedure” and “artificially administered nutrition and hydration” are discussed below.
make and communicate health care decisions to health care providers, including communication through persons familiar with the patient’s manner of communicating if those persons are available.\footnote{74 Or. Rev. Stat. § 127.505(13). “Health care provider” is defined as a person licensed, certified or otherwise authorized or permitted by the laws of Oregon to administer health care in the ordinary course of business or practice of a profession. Or. Rev. Stat. § 127.505(11).}

In making health care decisions, the surrogate has the duty to act consistently with the desires of the patient as expressed in an advance directive, or as otherwise made known by the patient to the surrogate at any time.\footnote{75 Id.} If the patient’s desires are unknown, the surrogate has a duty to act in what the surrogate in good faith believes to be in the patient’s best interests.\footnote{76 Id.}

A surrogate does not have authority to make a health care decision on behalf of the principal with respect to admission to or retention in a health care facility for care or treatment of mental illness, convulsive treatment, psychosurgery, sterilization, or abortion.\footnote{77 Or. Rev. Stat. § 127.540.}

The Oregon Act provides extra protections if the decision involves withholding or withdrawing a life-sustaining procedure. “Life-sustaining procedure” is defined as any medical procedure, pharmaceutical, medical device or medical intervention that maintains life by sustaining, restoring or supplanting a vital function.\footnote{78 Id.} “Life-sustaining procedure” does not include routine care necessary to sustain patient cleanliness and comfort.\footnote{79 Id.}

The first extra protection is that the health care surrogate is not authorized to withhold or withdraw life-sustaining procedures if the patient manifests an objection.\footnote{80 Or. Rev. Stat. §§ 127.540(6)(b)(A), 127.505(22).} In addition, the surrogate may not consent to withholding or withdrawing of a life-sustaining procedure unless the surrogate has been given authority to make such a decision, or the patient has one of the following conditions:

1. \textit{Terminal condition}, which is defined as a health condition in which death is imminent irrespective of treatment, and when the application of life-sustaining procedures or the artificial administration of nutrition and hydration serves only to postpone the moment of death;\footnote{81 Or. Rev. Stat. §§ 127.540(6)(b)(A), 127.505(22).}

2. \textit{Permanently unconscious}, which is defined as completely lacking an awareness of self and external environment, with no reasonable possibility of a return to a conscious state, and that condition has been medically confirmed by a neurological specialist who is an expert in the examination of unresponsive individuals;\footnote{82 Or. Rev. Stat. §§ 127.540(6)(b)(B), 127.505(18).}

3. A condition in which the administration of life-sustaining procedures would not benefit the patient’s medical condition and would cause permanent and severe pain;\footnote{83 Or. Rev. Stat. §§ 127.540(6)(b)(C).}

4. A progressive, debilitating illness that will be fatal and is in its advanced stages, and the patient is consistently and permanently unable to communicate, swallow food...
and water safely, care for himself or herself, recognize his or her family and other people, and there is no reasonable chance that the patient’s underlying condition will improve.\(^\text{84}\)

Oregon’s Act also provides additional protections if the decision is to withhold or withdraw artificially administered nutrition and hydration, other than hyperalimentation, necessary to sustain life. “Artificially administered nutrition and hydration” is defined as a medical intervention to provide food and water by tube, mechanical device or other medically assisted method.\(^\text{85}\) The term does not include the usual and typical provision of nutrition and hydration, such as the provision of nutrition and hydration by cup, hand, bottle, drinking straw, or eating utensil.\(^\text{86}\) The first extra protection is that the health care surrogate is not authorized to withhold or withdraw artificially administered nutrition and hydration if the patient manifests an objection.\(^\text{87}\) In addition, it is presumed that the patient has consented to artificially administered nutrition and hydration, other than hyperalimentation, necessary to sustain life, except in one or more of the following circumstances:

1. The patient while a capable adult clearly and specifically stated that he or she would have refused artificially administered nutrition and hydration;
2. Administration of such nutrition and hydration is not medically feasible or would itself cause severe, intractable, or long-lasting pain;
3. An appointed surrogate has been given authority to make decisions on the use, maintenance, withholding or withdrawing of artificially administered nutrition and hydration;
4. The patient does not have an appointed surrogate or an advance directive that clearly states that the person did not want artificially administered nutrition and hydration, and the patient is permanently unconscious;
5. The patient does not have an appointed surrogate or an advance directive that clearly states that the person did not want artificially administered nutrition and hydration, and the patient has a terminal condition;
6. The patient has a progressive illness that will be fatal and is in an advanced stage, the patient is consistently and permanently unable to communicate by any means, swallow food and water safely, care for himself or herself, and recognize his or her family and other people, and it is very unlikely that the patient’s condition will substantially improve.\(^\text{88}\)

The conditions specified in paragraphs 2, 4, 5, and 6 must be medically confirmed to overcome the presumption that the patient has consented to artificially administered nutrition and hydration.\(^\text{89}\) When life-sustaining procedures or artificially administered nutrition and hydration are withheld, care must be provided to insure comfort and cleanliness, including but not limited to oral and body hygiene; reasonable efforts to offer food and fluids orally; medication, positioning, warmth, appropriate lighting, and other measures to relieve pain and suffering; and privacy and respect for the patient’s dignity and hu-

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\(^{85}\) Or. Rev. Stat. § 127.505(4).
\(^{86}\) Id.
\(^{87}\) Or. Rev. Stat. § 127.535(5).
\(^{88}\) Or. Rev. Stat. § 127.580(1).
\(^{89}\) Or. Rev. Stat. § 127.580(3).
manity. The Oregon Act provides for judicial review of a surrogate decision pursuant to petition filed by an interested person.

E. Texas: A Different Approach — No Best Interest Analysis

Texas enacted its Advance Directives Act (Texas Act) in 1999. Under the Texas Act, a surrogate is authorized to make decisions for the patient only when the patient is incompetent or incapable of communication. “Incompetent” is defined as lacking the ability, based on reasonable medical judgment, to understand and appreciate the nature and consequences of a treatment decision, including the significant benefits and harms of and reasonable alternatives to a proposed treatment decision.

If the patient is a qualified patient who is incompetent or incapable of communication, and the patient has executed an advance directive, the health care surrogate shall make a treatment decision in accordance with the patient’s directions. “Qualified patient” is defined as a patient with a terminal or irreversible condition that has been diagnosed and certified in writing by the attending physician. “Terminal condition” is defined as an incurable condition caused by injury, disease, or illness that according to reasonable medical judgment will produce death within six months, even with available life-sustaining treatment provided in accordance with the prevailing standard of medical care. A patient in a qualified hospice program is presumed to have a terminal condition.

A patient in a qualified hospice program is presumed to have a terminal condition. “Irreversible condition” is defined as a condition, injury, or illness that may be treated but is never cured or eliminated; that leaves a person unable to care for or make decisions for the person’s own self; and that, without life-sustaining treatment provided in accordance with the prevailing standard of medical care, is fatal. The attending physician must certify that a patient is a “qualified patient,” based on a diagnosis of a terminal or irreversible condition. “Treatment decision or health care” is defined as consent, refusal to consent, or withdrawal of consent to health care, treatment, service, or a procedure to maintain, diagnose, or treat an individual’s physical or mental condition.

When a qualified patient who is incompetent or incapable of communication has not executed an advance directive, the attending physician and the surrogate decision maker may make a treatment decision on behalf of the patient that includes a decision to withhold or withdraw life-sustaining treatment. “Life-sustaining treatment” is defined as treatment that, based on reasonable medical judgment, sustains the life of a patient.

93 Tex. Health & Safety Code §§ 166.038(a), 166.039(a).
94 Tex. Health & Safety Code § 166.002(8). The term “treatment decision” is discussed below.
95 Tex. Health & Safety Code § 166.038(b).
96 Tex. Health & Safety Code § 166.031(2).
98 Id.
100 Tex. Health & Safety Code § 166.040(a).
and without which the patient will die. The term includes both life-sustaining medications and artificial life support, such as mechanical breathing machines, kidney dialysis treatment, and artificial nutrition and hydration. The term does not include the administration of pain management medication or the performance of a medical procedure considered to be necessary to provide comfort care, or any other medical care provided to alleviate pain.

The Texas statute provides that the fact that an adult qualified patient has not executed an advance directive does not create a presumption that the patient does not want a treatment decision to be made to withhold or withdraw life-sustaining treatment. However, the Texas statute also requires that surrogate treatment decisions made when the patient has not executed an advance directive must be based on knowledge of what the patient would desire, if known. Moreover, before withholding or withdrawing life-sustaining treatment, the attending physician must determine that the steps proposed are in accord with the patient’s desires. Texas has no provision for decision making based on the patient’s best interests, or pursuant to any other standard, when there is no advance directive and the patient’s wishes are unknown.

Another peculiarity of the Texas statute is its handling of judicial challenges to surrogate decisions. Under the Texas statute, an interested person who wishes to challenge a treatment decision must petition for temporary guardianship under the Texas Probate Code.

The Texas statute explicitly recognizes the validity of advance directives executed in other states, and provides that such directives shall be given the same effect as a directive validly executed under Texas law. Under Texas law, life-sustaining treatment may not be withheld or withdrawn from a pregnant patient.

F. In re Conroy

As shown above, most states employ a three-step inquiry, or a variation thereof, in their health care surrogacy laws:

1. Does the person have capacity to make and communicate the health care decision? If so, the person’s decision will control.
2. If the person does not have decisional capacity, the second inquiry is substituted judgment: What would the person have wanted?
3. If the person’s wishes cannot be determined, the analysis will continue to the third inquiry: What is in the person’s best interest?

As the case studies below will show, these inquiries can be difficult. An influential

103 TEX. HEALTH & SAFETY CODE § 166.002(10).
104 Id.
105 Id.
106 TEX. HEALTH & SAFETY CODE § 166.039(f).
107 TEX. HEALTH & SAFETY CODE § 166.039(c).
108 TEX. HEALTH & SAFETY CODE § 166.040(b).
109 TEX. HEALTH & SAFETY CODE § 166.039(g).
110 TEX. HEALTH & SAFETY CODE § 166.005.
111 TEX. HEALTH & SAFETY CODE § 166.049.
case from the Supreme Court of New Jersey, In re Conroy, provides valuable discussion of the factors that a surrogate decision maker should consider when making a substituted judgment or best interest determination.

Clair Conroy was adjudicated disabled and her only living relative, her nephew, was appointed her guardian. Ms. Conroy, who resided in a nursing home, had organic brain syndrome, was severely demented, and was unable to speak or respond to verbal stimuli. She was non-ambulatory and confined to her bed, unable to move from a semi-fetal position. She was unable to swallow and had a nasogastric tube to provide food and medicine. She had a urinary catheter and could not control her bowels. Ms. Conroy had necrotic gangrenous ulcers on her left foot and necrotic decubitus ulcers on her legs and hip. She suffered from arteriosclerotic heart disease, hypertension, and diabetes mellitus.

In re Conroy was decided in 1985, before New Jersey enacted its health care surrogacy law. The nephew therefore moved the court in the guardianship case to remove his aunt’s feeding tube. After an evidentiary hearing, the trial court granted the nephew’s motion, but the appellate court reversed. In affirming the trial court and reversing the appellate court, the New Jersey Supreme Court found that Ms. Conway had constitutional and common law rights to privacy and bodily integrity that encompassed the right to refuse treatment, including artificial nutrition and hydration, through a substitute decision maker.

The Court’s decision has a thoughtful and substantive discussion of factors the surrogate decision maker should consider when engaged in an analysis of substituted judgment and best interest. Regarding substituted judgment, the Court emphasized that the inquiry is not what a reasonable or average person would have chosen under the circumstances, but what the particular patient would have done if able to choose for himself. To answer this question, the surrogate decision maker should investigate the existence of written documents such as a living will, power of attorney, or other advance directive. The decision maker should also investigate whether the patient gave an oral directive to a family member, friend, or health care provider, or whether the patient voiced a reaction regarding medical treatment administered to others. Evidence might also be deduced from the person’s religious beliefs and the tenets of that religion, or from a pattern of conduct with respect to prior decisions about his or her own medical care.

112 In re Conroy, 486 A.2d 1209 (N.J. 1985).
113 In re Conroy, 486 A.2d at 1216-17.
114 Id.
115 Id.
116 Id. at 1217.
117 Id. at 1220-21.
118 Id. at 1218-19.
119 Id. at 1221-23, 1226-29.
120 Id. at 1229.
121 Id. at 1229-30.
122 Id. at 1229.
123 Id. at 1230.
124 Id.
The Court then discussed the relative probative value of various pieces of evidence. Although all evidence tending to demonstrate a person’s intent should be considered by a surrogate decision maker, the probative value may vary depending on factors such as the remoteness, consistency, and thoughtfulness of the prior statements and actions and the maturity of the person at the time of the statements or acts.\textsuperscript{125} For example, the Court explained, an offhand remark about not wanting to live under certain circumstances made by a person when young and in the peak of health would not, in itself, constitute proof 20 years later that he or she would want life-sustaining treatment withheld under those circumstances. In contrast, a carefully considered position, especially if written, that a person maintained over a number of years or that he had acted upon in comparable circumstances might be strong evidence of intent.\textsuperscript{126} Another factor impacting the probative value of prior statements is their specificity. While one cannot accurately predict the precise medical circumstances he may face in the future, any details about the level of impaired functioning and the forms of medical treatment that one would find tolerable are of value.\textsuperscript{127}

The Court emphasized that, since the goal is to effectuate the patient’s right of informed consent, the surrogate decision maker must have at least as much medical information upon which to base a decision as one would expect a competent patient to have before consenting to or rejecting treatment.\textsuperscript{128} Depending on the case, such information might include evidence about the patient’s level of physical, sensory, emotional, and cognitive functioning; the degree of physical pain resulting from the medical condition, treatment, and termination of treatment; the degree of humiliation, dependence, and loss of dignity likely resulting from the condition and treatment; the life expectancy and prognosis for recovery with and without treatment; the various treatment options; and the risks, side effects, and benefits of each of those options.\textsuperscript{129} Care should be taken not to base a decision on a premature diagnosis or prognosis.\textsuperscript{130}

In the event that the patient’s wishes cannot be ascertained, the Conroy Court discussed factors that the surrogate decision maker should take into account when determining what is in the patient’s best interest. These include whether the burdens of the patient’s continued life outweigh the benefits of that life. The Court explained that this means that the patient is suffering and will continue to suffer throughout the expected duration of his or her life, and the net burdens of his or her prolonged life outweigh any physical pleasure, emotional enjoyment, or intellectual satisfaction that the patient may still be able to derive from life.\textsuperscript{131} As with the substituted judgment inquiry, medical evidence must be considered when determining what is in the patient’s best interest.\textsuperscript{132} Medical information is particularly important with respect to the degree, expected duration, and constancy of pain with and without treatment, and the possibility that the pain could be reduced by

\begin{itemize}
\item \textsuperscript{125} Id.
\item \textsuperscript{126} Id.
\item \textsuperscript{127} Id. at 1230-31.
\item \textsuperscript{128} Id. at 1231.
\item \textsuperscript{129} Id.
\item \textsuperscript{130} Id.
\item \textsuperscript{131} Id. at 1232.
\item \textsuperscript{132} Id.
\end{itemize}
drugs or other means short of terminating the life-sustaining treatment. Medical information about the patient’s life expectancy, prognosis, level of functioning, degree of humiliation and dependency, and treatment options, should also be considered.\footnote{Id. at 1232-33.}

Finally, the Court emphasized that although the surrogate decision maker should consider factors such as pain, suffering, and enjoyment of life, the inquiry is \textit{not} based on an assessment of personal worth or social utility of the person’s life or the value of that life to others.\footnote{Id. at 1233.} The mere fact that a person’s functioning is limited or the prognosis is dim does not mean that it is in his or her best interests to die.\footnote{See \S IIB, supra; 755 ILL. COMP. STAT. 40/10, 40/20(b).}

\section*{III. Bonnie T.}

Bonnie T., who was 57 years old when the Public Guardian’s Office was called upon to make an end-of-life decision on her behalf, was one of the Office’s younger wards. Nonetheless, she was extremely medically fragile and complex.

Ms. T. worked as a registered nurse until her health deteriorated when she was in her 40s. She had a history of brain cancer, having had a tumor removed when she was 45. In her late 40s and early 50s, Ms. T. had a series of strokes and resultant seizure disorder, which caused a cognitive decline. When she was 54, Ms. T.’s left leg was amputated above the knee due to gangrenous decubitus ulcers that she developed at a nursing home. She had other decubitus ulcers, including a Stage IV sacral wound. In addition, Ms. T. had chronic encephalopathy and sepsis, as well as hypertension, hypothyroidism, diabetes, degenerative joint disease, and peripheral vascular disease. She was on 16 different medications.

Ms. T. was completely unresponsive to both verbal and tactile stimuli. She suffered from respiratory failure and was on a ventilator. She was unable to eat, and was being supplied nourishment and medicine through a nasogastric tube. Nonetheless, her health care providers were having difficulty administering sufficient nutrition due to malabsorption syndrome and poor circulation.

The Public Guardian’s Office obtained a written certification from Ms. T.’s attending physician and a concurring physician documenting the above medical conditions. The doctors also certified Ms. T.’s lack of decisional capacity. In addition, the doctors certified all three qualifying conditions, any one of which is required under Illinois law to forgo life-sustaining treatment: terminal condition, permanent unconsciousness, and an incurable or irreversible condition.\footnote{See \S IIB, supra; 755 ILL. COMP. STAT. 40/10, 40/20(b).} The doctors also certified that Ms. T.’s condition was poor, chronic, and guarded. She had multi-system failure with no hope of recovery. They likewise certified that Ms. T. was in a chronic debilitative state with no quality of life. No alternative treatments were available to improve her condition; to the contrary, she would only suffer more with more medical intervention. As a result, both physicians strongly recommended a DNR order and withdrawal of life support with only the provision of comfort care.

Interviews were conducted with Ms. T.’s family, consisting of her mother, sister, two
brothers, and a daughter. Ms. T.’s mother and her brothers reported that they had no specific discussions with Ms. T. about end-of-life issues. However, they emphasized that Ms. T. was a nurse by profession and believed that she would not want to remain alive under the circumstances. They strongly urged the Public Guardian’s Office to withdraw the life support. The sister said that she had a specific discussion with Ms. T. approximately 12 years earlier, shortly before the surgery to remove the brain tumor, about life-sustaining treatment including specifically remaining on a ventilator. During the discussion, Ms. T. was clear that she would not want to be on life support if she had only minimal prospects for recovery. The sister, like the other family members, urged that life support be removed. Ms. T.’s daughter could not be interviewed because her whereabouts were unknown. Moreover, it is alleged that seven years earlier the daughter had used a power of attorney for property to help herself to $35,000 of her mother’s funds.

On occasion I lecture on surrogate decision making to attorneys and health care providers, and I use this case study. I typically stop at this point, and ask the attendees if they would be comfortable ordering withdrawal of life support based on the above information. The overwhelming consensus is “yes.” Applying the three-step analysis, the necessary certifications showed that Ms. T. lacked decisional capacity, being able to neither make nor communicate a decision about her care. Therefore, one can move on to the second step, substituted judgment. The available evidence suggests that Ms. T. would want life support withdrawn. This evidence consists of the generalized beliefs of Ms. T.’s mother and brothers, the specific discussion about life support with her sister, and the lack of contrary evidence. Even if one were to deem this evidence insufficiently strong to make a substituted judgment decision with confidence, the same outcome — withdrawal of life support — results under step three, best interest.

But then I tell the audience about Ms. T.’s husband. He is alleged to have been physically and verbally abusive to Ms. T. during their marriage. He had a criminal history that included a felony conviction for bank robbery. Much of the time he did not work, relying on Ms. T.’s income as a nurse. Instead, he would be gone from the house for extended periods. It was reported that he had a drinking problem. He resented that the Court selected the Public Guardian’s Office over him to be Ms. T.’s guardian and was verbally abusive and threatening to our staff. As just one of many examples, the attorney from the Public Guardian’s Office assigned to this case was a quadriplegic in a wheelchair. The husband once left this attorney a threatening voice mail message to the effect that when he (the husband) was done with the attorney, the attorney would wish that being in a wheelchair was the worst of his problems. The husband was also verbally abusive and threatening to the staff at Ms. T.’s nursing home.

When I present this case study, I stop again at this point and ask whether the husband should be contacted. A few people in the audience opine that there is no reason to contact him, that whatever information he has to offer would be suspect and could not overcome the evidence above. Some go so far as to opine that, due to his behavior, the husband has no “right” to have input in the decision. However, the majority state that all possible evidence should be considered. They also point out that the inquiry has nothing to do with

137 The daughter allegedly used the money for breast augmentation surgery and cosmetic dental work.
the husband’s rights; instead it must focus on Ms. T.: what she would have wanted and what is in her best interest. There is no way of knowing whether the husband has information probative on these points without talking with him.

The Public Guardian’s Office typically takes the latter approach. It wants to err in favor of obtaining all possible evidence even if it might be of limited evidentiary value. Therefore, the Office attempted to contact the husband. Because he did not have a telephone, the Office sent letters to him explaining the situation, and stating that it was going to be making a decision about withdrawal of life support and that it was urgent that he call if he had input to provide. The letters were sent by mail and by messenger, and a letter was also posted on his door. The husband responded with several expletive-laden voice mails to the effect that the Public Guardian’s Office had better not kill his wife.

When I present this case study, I stop here and ask whether this changes anyone’s decision about withdrawal of life support. The overwhelming response is “no.” Regarding step one of the inquiry, the husband’s messages did not change the fact that Ms. T. lacks decisional capacity. Regarding step two, substituted judgment, the husband’s messages shed no light on what Ms. T. would want. In fact, his messages were about himself, and what he wanted, and provided no evidence about what Ms. T. would want. Likewise, regarding step three, the husband’s messages had no relevance as to what was in Ms. T.’s best interest.

Then I relate a final fact. Recall that Ms. T. had a daughter, whereabouts unknown, who had abused a power of attorney for property approximately seven years earlier to help herself to $35,000 of her mother’s funds. At approximately the same time that Ms. T. signed the power of attorney for property, she also signed a power of attorney for health care naming her daughter as agent. In the power of attorney for health care, Ms. T. initialed a box stating that she wanted her life to be prolonged to the greatest extent possible without regard to her condition, the chances for recovery, or the cost of the procedure. Although the court in the guardianship case had revoked both powers of attorney when it appointed the Public Guardian’s Office as Ms. T.’s guardian, this is obviously an important piece of evidence of Ms. T.’s wishes.

Ms. T. signed this power of attorney seven years earlier, when she was 50 years old. This was around the time that she was suffering the series of strokes with resultant seizure disorder causing her cognitive decline. Therefore, there were questions about her capacity at that time. The Public Guardian’s Office was able to track down and interview the attorney who prepared the document and who was present when Ms. T. signed it. The attorney did not recall his discussions with Ms. T. about the power of attorney. However, he said that it is his practice to determine the client’s competence before the client signs such a document. It is his routine to ask questions to confirm that the person is oriented as to time and current events, such as the name of the President, the year, and home address. It is also his practice to review the power of attorney with the client, focusing on the choice regarding life-sustaining treatment.

When we interviewed Ms. T.’s family, none of them had any idea about this power of attorney. They were highly surprised that Ms. T. would sign such a statement, and were also surprised that she would sign a health care directive and not tell anyone about it. They also questioned whether Ms. T. would have had cognitive capacity when she signed the document.
Here I again stop, and ask the audience what they would do. At this point most people are unsure about what to do. The overwhelming consensus is that it would be in Ms. T.’s best interest to remove support, but her best interest comes into play only if her wishes cannot be ascertained, and there is a written instrument that purports to express her wishes. Yet this instrument is inconsistent with her expressed wishes as reported by a close family member, the instrument is also inconsistent with what others in the family believe she would have wanted, and there are multiple red flags about the circumstances under which the instrument was executed.

So what did the Public Guardian’s Office do? It filed an emergency report to the court that set forth the facts, including the doctors’ certifications and affidavits, and asked the court for direction. The court, however, declined to provide direction, and entered an order directing the Public Guardian’s Office to make an end-of-life decision for the ward in accordance with the Health Care Surrogate Act.

At that point, the Public Guardian’s Office arranged a consult with Professor Katie Watson, a bioethicist at the Northwestern University Feinberg School of Medicine. Professor Watson agreed that there was little question about lack of decisional capacity. She also agreed that, under a best interest determination, life support should be withdrawn, but this inquiry comes into play only if Ms. T.’s wishes cannot be ascertained. As far as the substituted judgment inquiry, the question is what respective weight to give the written and more recent power of attorney versus the discussion with the sister, and the other family members’ beliefs as to what Ms. T. would have wanted.

Professor Watson offered an insight that the Office had not thought of with regard to the evidentiary value of the power of attorney. The professor suggested that the context of Ms. T.’s relationship with her abusive husband should be included in the interpretation of the power of attorney. Specifically, given the abusive and dysfunctional relationship with the husband, it is possible Ms. T. believed that such an advance directive might be necessary to ensure that she received the medical care she might need in the future.

Professor Watson opined that the power of attorney was not dispositive and constituted but one piece of evidence to be considered with all of the other evidence, which included that:

1. The power of attorney for health care named the daughter as agent, was signed around the same time as the power of attorney for property that also named the daughter as agent, and the daughter was alleged to have used the latter power of attorney to steal her mother’s funds;
2. The power of attorney for health care was inconsistent with Ms. T.’s oral directive to her sister that she did not want to be on life support, including specifically a ventilator if she had only minimal prospects for recovery;
3. Ms. T.’s mother, sister, and brothers believed that Ms. T. would not want to continue to be kept alive on a ventilator under the circumstances;
4. Ms. T. did not tell her mother, sister, or brothers about the power of attorney;
5. The power of attorney was signed years earlier and under circumstances that

138 In re Estate of Bonnie T., No. 04 P 6901 (Cir. Ct. Cook County), Emergency Report to Court and Request for Direction, filed December 13, 2007.
139 Id., Order, filed December 13, 2007.
were very different than Ms. T.’s current medical situation; and

6. There are at least some questions about Ms. T.’s capacity when she signed the document.

When all of the conflicting evidence is considered together, Ms. T.’s wishes are unclear and cannot be reasonably ascertained. Therefore, it was appropriate to move on to the third inquiry, best interest. The professor agreed with the Public Guardian’s Office, the medical providers, and the family members that it would be in Ms. T.’s best interest to remove life support.

The Public Guardian’s Office authorized withdrawal of the ventilator and put in place a DNR order. Ms. T. died shortly after the ventilator was removed. Her health care providers reported that she died peacefully and in comfort, surrounded by family members.

The following week the Public Guardian’s Office received beautiful, thoughtful cards from Ms. T.’s family members expressing their appreciation for the care provided to Ms. T. during the time the Public Guardian’s Office was her guardian and thanking the Office for reaching the decision to allow her to die peacefully and in comfort.

When I present this case study, I am sometimes asked why the Public Guardian’s Office, which is limited to serving as guardian of last resort, was appointed guardian over the various family members. The court was uncomfortable appointing the husband due to his criminal history, including a felony conviction for bank robbery, as well as his abusive history. Ms. T.’s mother, while loving and concerned, was elderly and lived out of state. As for the siblings, they feared that the husband would oppose anything they would attempt to do for Ms. T. as guardian, and also expressed fear of his violent and abusive background. Under the circumstances, the court felt that the Public Guardian’s Office was the most appropriate guardian for Ms. T., and the Office accepted appointment.

IV. SARAH W.

Immediately upon being appointed as Sarah W.’s guardian, the Public Guardian’s Office was called upon to make a decision about withdrawal of life support and a DNR order. Another public guardianship office, the Office of the State Guardian (OSG), had been Ms. W.’s guardian for approximately three weeks when it was discovered that she had more than $25,000 in assets, and guardianship was transferred to the Public Guardian’s Office.

A hospital referred Ms. W. for guardianship when its ethics committee concluded that she was appropriate for a DNR order and withdrawal of life support, but she had no

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140 See §1, supra; Cook County Public Guardian, http://www.publicguardian.org/ag_4.htm (last visited Oct. 15, 2009); see generally Estate of Debevec, 552 N.E.2d 1043, 1046 (Ill. App. 1990) (explaining the preference for family members to serve as guardian).

141 The husband’s felony conviction, while not an absolute bar, is a factor the court must consider when determining who should most appropriately serve as guardian, taking into account the ward’s best interests. See 755 ILL. COMP. STAT. 5/11a-5(5).

142 The Office of the Cook County Public Guardian is appointed as guardian of last resort for Cook County residents who have more than $25,000 in assets. The Office of the State Guardian is appointed statewide as guardian of last resort and in Cook County for persons with less than $25,000 in assets. 755 ILL. COMP. STAT. 5/13-5.
known family or significant others to provide consent. Ms. W. was hospitalized when concerned neighbors found her on the floor of her apartment after not being seen or heard from for several days. Ms. W. was 82 years old.

The hospital determined that Ms. W. had suffered a stroke causing left-side hemiplegia and significant brain damage. She also had advanced congestive heart failure and acute renal failure. The hospital diagnosed end-stage renal disease and implemented dialysis three times weekly. Dialysis had to be discontinued when Ms. W. developed respiratory distress and was placed on a ventilator. Ms. W. also had stage II decubitus ulcers on her sacrum, mid-back and left hip. She had a Foley urinary catheter and a gastrostomy tube. Ms. W. was totally unresponsive, unable to communicate even in non-verbal ways.

The hospital and the predecessor guardian, OSG, had searched for family members and significant others and found none. When she was able to communicate, Ms. W. had indicated that she had no family or friends. Her neighbors and landlord were unaware of any family or friends, and reported that Ms. W. kept to herself and had no visitors. Upon its appointment as guardian, OSG searched Ms. W.’s apartment for clues as to family and friends, but found no leads. Nor did OSG discover any advance directives or evidence as to Ms. W.’s wishes regarding end-of-life decisions. Upon its appointment, the Public Guardian’s Office searched the apartment for a second time and investigated for family members, but also could find no living family members or significant others.

Ms. W.’s physicians recommended a DNR order and withdrawal of life support. She clearly lacked decisional capacity, her wishes were unknown after diligent inquiry and investigation by the hospital and by two public guardianship offices, and it was in Ms. W.’s best interest to withdraw life support. She had no quality of life and was suffering as toxins developed in her body without the possibility of dialysis due to her respiratory distress.

The Public Guardian’s Office was appointed on a Thursday, and had already completed much of its investigation and due diligence during the process of transferring the guardianship from the OSG. The Public Guardian’s Office was therefore prepared to consent to withdrawal of support and a DNR order as of the next afternoon, a Friday. It wanted to implement these measures before the weekend. However, as it was about to do so, the Office received a voice mail message from a caller who identified himself as a rabbi. The caller stated that Ms. W. was a religious Jew, and that withdrawal of life support is contrary to Jewish law. He left a cell phone number and requested that we call him as soon as possible before sunset, when the Jewish Sabbath begins.

At the outset, there are many red flags and questions raised by this message. Who is the rabbi? How does he know Ms. W.? How long has he known her? What is the basis of his belief that she is religious? From our investigation we knew that Ms. W. was Jewish, but there was no evidence that she was observant. There was no evidence that she belonged to a synagogue. Her apartment was devoid of religious articles such as a Passover plate, menorah, or mezuzah. Moreover, the statement that withdrawal of life support is contrary to Jewish law is, at best, simplistic and lacking in nuance. In fact, our office has consented to withdrawal of life support on behalf of wards who were observant Jews, after consultation with orthodox rabbincial authorities on bioethics.

We called the rabbi. He had first met Ms. W. a few weeks earlier at the hospital. When he has spare time, this rabbi makes the rounds of the local hospitals to minister to
Jewish patients. When I asked the rabbi the basis of his belief that Ms. W. was religious, he stated that he sensed that Ms. W. had religious conviction, even though she was unable to communicate. I then explained that there were no religious items in Ms. W.’s home. The rabbi replied that many people who are not religious during their lives become religious when they are near death. The rabbi advocated that we not withdraw life support until a Beit Din, or Jewish Council of Law, could be assembled. This likely could not occur, at the earliest, until after the Jewish Sabbath ended on Saturday night.

The role of religion can be critical in step two of the analysis: substituted judgment. In cases in which the evidence shows that a ward would have wanted to abide by the tenets of their faith, the Public Guardian’s Office does so. In such cases, the Office often consults with clergy, in particular clergy who have a relationship with the ward and his or her family as well as clergy in the faith who are knowledgeable of bioethics issues. However, when the evidence shows that the person was uninvolved in their religion or lived a secular life, and their wishes cannot be determined, the Office moves on to the best interest determination. This was explained to the rabbi, and he was appreciative of the need to follow the requirements of the guardianship and health care surrogacy laws.

The Office consented to withdrawal of life support and a DNR order late in the day that Friday. Ms. W. died peacefully in her sleep the next day.

In addition to the role of religion, this case implicates the tension between the sometimes competing objectives of making medical decisions in a timely manner for the comfort and dignity of the patient, versus obtaining all possible relevant information. Because Ms. W. was suffering from renal failure but could not continue dialysis, especially when considered in combination with her other medical conditions, her doctors considered keeping Ms. W. alive as a form of suffering. They urged the Public Guardian’s Office not to go into the weekend without appropriate orders. At the same time, however, the Office had only been Ms. W.’s guardian for a short time, and did not want to make an irreversible decision without the benefit of as much information as possible. While the rabbi’s information ultimately did not change its position, the Office would have viewed it as irresponsible not to have tried to reach him. But what if it was unable to reach the rabbi before the Sabbath started at sunset? Should the Office have delayed a decision by at least 24 hours when there was no evidence that Ms. W. was religious or would want religious law to guide the decision? When there was such limited time to gather information and little was known about the ward? Fortunately it did not come to that.

As a postscript, as a courtesy the Public Guardian’s Office called the rabbi on Saturday night to inform him that Ms. W. had passed away earlier in the day. The rabbi stated that he felt a connection to her, and offered to perform the burial service without compensation. He even arranged to have members of his congregation bussed to the service and burial so that Ms. W. would not leave this world alone. The assigned attorney from the Public Guardian’s Office and I also attended the service and burial, at which the rabbi officiated.

V. EULA W.

Eula W., age 84, was extremely medically fragile. She had advanced Alzheimer’s disease, infective endocarditis (infection to the lining of her heart), encephalopathy, and
Ms. W. had multiple additional diagnoses, including coronary artery disease, congestive heart failure, diabetes, seizure disorder, renal insufficiency, hypertension, multiple non-healing decubitus ulcers, anemia, and latent syphilis. She suffered from respiratory failure and was on a ventilator. Ms. W. also had a gastrostomy tube because she was unable to swallow. Her doctors certified lack of decisional capacity, and were strongly advocating for withdrawal of life support and a DNR order.

Ms. W.’s only family was a stepdaughter who lived out of state and had limited involvement. The stepdaughter and Ms. W. were estranged and did not get along. Their differences became exacerbated when Ms. W.’s husband (the stepdaughter’s father) died, and the stepdaughter believed that Ms. W. had wrongfully received the inheritance.

Nonetheless, the Public Guardian’s Office called the stepdaughter to determine whether she had any relevant information. As discussed above, when in doubt the Office would rather err on the side of obtaining all possible information, and then determine its appropriate weight.

When the Public Guardian’s Office called, the stepdaughter said that she needed to speak with her husband and would call back. When she did not call back, the Office called her again. The stepdaughter stated that she did not want life support withdrawn or a DNR order put in place for Ms. W. When asked whether she ever had any specific conversations with Ms. W. about a DNR order or withdrawal of life support, the stepdaughter stated that “she wouldn’t want that.” When again asked whether she ever had any specific discussions with Ms. W., the stepdaughter said that they had discussed these issues many times, and Ms. W. would not want a DNR order. The attorney and case manager who interviewed the stepdaughter were unsure whether the stepdaughter had actually discussed end-of-life issues with Ms. W. The attorney and case manager believed that the stepdaughter was reporting her own desires, rather than Ms. W.’s.

Ms. W. had two friends, although neither had seen her for several years. For several decades Ms. W. had owned and operated a tavern in Chicago, and she knew these friends because they frequented the tavern. The first friend reported that the issue of a DNR order came up during a conversation with Ms. W. some 20 years earlier. The discussion took place at the bar. During this conversation, Ms. W. said that she would not want a DNR order, and that she needed to get papers to reflect this. In Ms. W.’s personal effects, no such papers were located. The Public Guardian’s Office then asked the friend a series of questions about Ms. W.’s condition, and whether Ms. W. would want to be hooked up to machines keeping her alive in these circumstances. The friend did not waiver in her position that Ms. W. would not want withdrawal of life support or a DNR order. Because the discussion took place at a tavern, the Office asked the friend whether she or Ms. W. had been drinking when the conversation occurred. The friend replied that Ms. W. did not drink when she was working at the bar. Regarding her own condition, the friend stated to the effect that she was not inebriated at the time.

The second friend had not seen Ms. W. for about five years. She reported never having a conversation with Ms. W. about end-of-life issues. However, based on her knowing Ms. W. for many years, the friend opined that Ms. W. was “vibrant, a fighter, and would fight to live.” When Ms. W.’s condition, the doctors’ recommendations, and the reasons
for their recommendations were explained more explicitly, the friend remained firm in her belief that Ms. W. was a fighter and would not want withdrawal of life support or a DNR order. This friend was also aware that Ms. W.’s stepdaughter did not want a DNR order, but did state her belief that the stepdaughter did not fully comprehend all the circumstances of Ms. W.’s illness because she lived so far away and had not seen her stepmother in some time.

The Public Guardian’s Office felt conflicted about its decision. The Office strongly agreed with Ms. W.’s physicians that it would be in her best interest to withdraw life support and authorize a DNR order, but you only get to the best interest inquiry if the patient’s wishes cannot be determined. There was a stepdaughter and two friends reporting that Ms. W. would want to be kept artificially alive, but their information was suspect.

The Public Guardian’s Office decided to file a motion in court seeking direction. After a hearing, the court concluded that, regarding the substituted judgment analysis, all of the available evidence showed that Ms. W. would want to remain on life support, and there was no contrary evidence. The court found the evidence sufficient to support a determination that this is what Ms. W. would want. The court therefore directed the Public Guardian’s Office not to withdraw life support or enter a DNR order.

Ms. W. lived for another 14 months. Based on the court’s order, Ms. W. had a full code status that entire period. She never recovered more than minimal brain activity or the ability to speak or communicate. During this time Ms. W. suffered illnesses including fevers, pneumonia, episodes of vomiting, fungal infections, and abnormal labs. On the day she died, Ms. W. went into cardiac arrest. Because she had a full code status, hospital staff attempted to revive her for approximately 40 minutes before she was declared dead.

VI. Conclusion

Of all the decisions the Public Guardian’s Office is called upon to make on behalf of its wards, health care surrogate issues are among the hardest. Such decisions implicate many disciplines, and go to the essence of the meaning and dignity of life. Moreover, end-of-life decisions such as DNR orders and removal of life support orders can be irreversible.

One lesson from the case studies discussed above is the need for attorneys to counsel clients to sign detailed and thoughtful advance directives. Attorneys should also counsel clients to have open and frank conversations with family members about health care surrogate issues, and especially end-of-life issues, even though such discussions might be uncomfortable for some clients. The advance directives should be reviewed and updated on a regular basis — at least every few years. Copies of up-to-date advance directives should be provided to family members, significant others, health care providers, and maintained in the client’s home with other important personal and legal papers.

Although the existence of a purported advance directive did not result in an easy decision in Bonnie T.’s case, a clear and detailed advance directive would likely have simplified the decisions in Sarah W. and Eula W.’s cases. In fact, in the majority of cases

143 In re Estate of Eula W., No. 06 P 4628 (Cir. Ct. Cook County), Emergency Report to Court and Request for Direction, filed July 1, 2008.
144 Id., Order, filed July 1, 2008.
in which the Public Guardian’s Office has to make an unusually difficult health care surrogate decision, there is no advance directive in place and the existence of an advance directive would likely have resulted in a more straightforward decision. A clear advance directive not only makes an already difficult situation easier for loved ones and surrogate decision makers in the event that a health care decision must be made on behalf of the client, but the existence of the directive makes it more likely that the ultimate decision will accurately reflect the desires and values of the client.

In general, powers of attorney are preferable to living wills. Unlike most living wills, a power of attorney delineates whom the client trusts and desires to make the decision, as opposed to merely articulating the client’s wishes if certain conditions arise. This not only allows for more expeditious decision making, but also serves to reduce disagreements within the family and the need for a guardian or court to become involved. However, for a variety of reasons some clients may not want to select certain family members over others and may prefer a living will. In the experience of our office, a carefully crafted and detailed living will can also provide valuable guidance in the event a surrogate decision has to be made.

The case studies above also demonstrate the importance of interdisciplinary consults when making health care surrogate decisions. In all cases, consults with the treating doctor are essential. Indeed, most state health care surrogacy statutes explicitly require consultation with the treating doctors.145 It is often valuable for the surrogate decision maker to seek out second opinions and the views of specialists. This is explicitly required under the statutes of some states.146 As the Supreme Court of New Jersey emphasized in the case of In re Conroy, the surrogate decision maker must have at least as much medical information upon which to base a decision as one would expect a competent patient to have before consenting to or rejecting treatment.147 Discussions with the treating professionals played an important role in the Public Guardian Office’s decisions in all three of the case studies.

In cases where the evidence shows that the patient would want a decision made consistent with the dictates of his or her religion, consults with clergy are important. At a minimum, the decision maker should consult with clergy who have a relationship with the patient and his or her family. In some circumstances, there should also be consults with clergy in the given faith who have special expertise in bioethics issues.

In unusually hard cases, consultations with bioethicists can be invaluable. Just having a fresh set of eyes review a difficult set of facts can be insightful, and this is particularly true when the eyes belong to a professional with specialized training and experience working through bioethics dilemmas. In Bonnie T.’s case, the consult with the bioethics professor at Northwestern Medical School proved to be of great assistance.

The Public Guardian’s Office has found most bioethicists to be generous and giv-

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145 UHCDA § 5; 755 ILL. COMP. STAT. 40/10, 40/20(b)(1), 40/20(b-5)(1), 40/20(c); N.Y. PUB. HEALTH LAW §§ 2983(1)(a), 2983(1)(b), 2983(1)(c), 2983(6); OR. REV. STAT. §§ 127.505(13), 127.580(3); TEX. HEALTH & SAFETY CODE §§ 166.002(8), 166.002(9), 166.002(10), 166.002(13), 166.031(2), 166.039(a), 166.040(a), 166.040(b).
146 ILL. COMP. STAT. 40/20(b)(c) and (e); N.Y. PUB. HEALTH LAW §§ 2983(1)(a), (b) and (c).
147 In re Conroy, 486 A.2d at 1231-32.
ing of their time. The Office asks for consults with treating doctors, and sometimes seeks second opinions from doctors and specialists who are not connected to the case. The Office seeks consultations with bioethicists at universities and hospitals. It also has called on religious authorities of different faiths. These professionals typically are willing and even eager to help analyze the decisions the Office is called upon to make on behalf of its wards. In fact, I cannot recall a time that an outside bioethics expert asked for a fee or compensation for a consult.

The case studies also point to the importance of obtaining all information about what the patient would want. In most states, the surrogate decision maker is mandated to do what the patient would have wanted, if that can be ascertained.\textsuperscript{148} This mandate cannot be fulfilled unless all sources of potential information are explored.

It might be tempting not to interview a relative or significant other whose information may be suspect. This is especially true if the person is unlikeable and unpleasant to deal with — for example, Bonnie T.’s abusive husband. But that person might have knowledge of an indisputable advance directive that unambiguously articulates the patient’s desires. It is important to collect all information and then assign the appropriate evidentiary weight. Although challenging, this is the only way to ensure that you have undertaken all efforts to ascertain and fulfill the person’s wishes.

Finally, when making a substituted judgment decision, the surrogate must put aside his or her own views and values and focus like a laser on what the patient would want. This is difficult, but critical. For example, in Eula W.’s case, her doctors opined that it would be in her best interest to order a DNR and withdrawal of life support. That might also be what at least some of the persons involved in making the decision would want for themselves or their loved ones under the circumstances. However, as the Supreme Court of New Jersey emphasized in the case of \textit{In re Conroy}, a substituted judgment inquiry is not what a reasonable or average person would have chosen under the circumstances, but what the particular patient would have done if able to choose for himself or herself.\textsuperscript{149} The available evidence pointed to Ms. W.’s desire, as her friend from the tavern put it, to fight to live, and the judge supervising the guardianship made a finding that this is what Ms. W. would want. Under such circumstances, the surrogate decision maker is required to respect the wishes of the individual. This is the essence of personal autonomy and bodily integrity in a free society.
TERMINATING TREATMENT FOR INCOMPETENT PERSONS:  
THE NEED FOR OBJECTIVE STANDARDS

By Caroline Klosko, Esq. and William J. Brisk, CELA

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I. INTRODUCTION

Courts in the United States decide whether to terminate treatment for incompetent patients on the basis of either a subjective test or an objective test. Under the subjective test (often labeled substituted judgment) the incompetent patient’s own previously expressed wishes about undergoing or forgoing treatment are applied to the present situation. The objective test, on the other hand, purports to determine whether the patient would be better off if treatment were terminated, regardless of the patient’s hypothetical preferences.

Most decisions to terminate treatment of incompetents are made when physicians and close family members reach a consensus. The cases that reach court involve disputes over patients who will die shortly after treatment is terminated. When a court decides, applying the objective test, to authorize the withdrawal of treatment, it has decided that

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2 Id. Court differs on the standard of proof to establish the patient’s wishes to forego treatment under the substitute judgment test. While the U.S. Supreme Court permitted Missouri to require “clear and Convincing” evidence of the patient’s wishes, it did not require that standard as a constitutional matter. Cruzan v. Director, Missouri Department of Health, 497 U.S. 261, at 289 (1990). Most states are silent as to whether “clear and convincing” evidence is required.
3 Id.
the patient would be better off dead than alive. This article contends that while the subjective test is preferable (because it preserves autonomy), deference to substitute judgment masks the need for elaborating objective standards to be used when the now-incompetent patient never clearly expressed his or her preferences.

Section II reviews the precedents for the two tests developed in leading cases. The subject test, it notes, is based on the American value of personal “autonomy” that favors reliance on the well-documented, clearly expressed views of the person on the issues at hand; it relies on, or is an extension of, the Supreme Court decisions finding a right to privacy to decide about birth control. The objective, test, by contrast, is an extension of the best interests tests for deciding custody of minor children to decide, in essence, that a person is better off dead; the leap from one to the other is far greater than the privacy interest undergirding both birth control and termination of medical care.

Section III of this article observes that there are many cases — more cases than the courts have been willing to acknowledge — in which it is impossible to determine what the patient’s wishes would have been. This is likely to remain true in the future, even if Living Wills and surrogate decision makers are used with greater frequency. Since the subjective test is useless if the patient’s wishes are ambiguous or unknown, there is an extent to which we are stuck with the objective test. Therefore, it is important to formulate the best possible version of the objective test — and this is a matter about which existing authorities disagree.4

Section IV recognizes that there are indeed precedents for objectively determining the “best interests” of patients facing life-and-death decisions. Accordingly, Section IV considers the critical factors required to determine that a patient is better off with or without treatment.

Section V explores the extent to which courts need to enunciate their own standards for the end-of-life care of incompetents, explaining that in a far greater number of cases than is evident from reading the oft-quoted cases on these issues, incompetents at death’s door did not appoint a surrogate and are likely not to have anticipated the specific decisions that are now required.

Section V also argues that courts must develop objectives tests that go beyond simply comparing pain to pleasure by considering “subjective critical interests, a more comprehensive sense of what it is to be a person.

Section VI attempts to articulate an objective test based on bodily integrity, independence, and the ability to pursue subjective critical interests. It argues, further, that courts are already applying such standards under the guise of applying “substituted judgment” but that rather than rely on dubious presentations on the patient’s prior expressed intent, they should develop carefully articulated public policy.

We conclude, in Section VII, by recognizing the need for a “best interests” standard to determine what lives should not be artificially prolonged now that physicians just because physicians can do so.

II. SUBSTITUTED JUDGMENT: STRAINING TO IMPLEMENT “AUTONOMY”

When they apply substituted judgment, courts pretend that the patient himself is making the decision. This is consistent with the march toward “patient autonomy,” which has been a hallmark of American medical practice for only a century.\(^5\)

Until the 20th century, in the absence of organized medicine and with the paucity of hospitals, few patients could afford doctors and, if they could, most they chose were pre-scientific.\(^6\) Yet, physicians in the 19th and even into the 20th century made most medical decisions for their patients.\(^7\) Given their experience (in matters which may occur only once in a lifetime to a layman), expertise, and objectivity, doctors’ decisions on life-or-death issues were granted great respect and deference.\(^8\) Even when their monopoly was breached, American physicians dictated the terms of discourse over which controversies were fought.\(^9\) The more their wisdom was celebrated, the less they needed to disclose to families and patients.\(^10\)

On the other hand, courts that apply “best interests” are perforce making a value judgment that there is some empirical, universal standard to be applied that is less ambiguous than searching the patient’s history to define what she would have chosen had she confronted the situation with her faculties intact.\(^11\) American courts have been reluctant to decide such cases according to an objective standard because of the nature of the deci-

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\(^5\) Schloendorff v. Society of New York Hospital, 211 N.Y. 125 (1914), built upon Pratt v. Davis, 118 Ill. App. 161, 165 (1905), aff’d, 224 Ill. 30 (1906). (“Under a free government at least, the free citizen’s first and greatest right which underlies all others — the right to the inviolability of his person … is the subject of universal acquiescence, and this right necessarily forbids a physician … to violate without permission the bodily integrity of his patient by a major or capital operation.”)


\(^8\) Id.

\(^9\) “Justice was originally not seen to apply to clinical medicine; now it is opposite because we no longer understand the medical act as that of an individual clinician caring for an individual patient within a relationship, but as a commodity or a resource within a marketplace.” Id at 20.

\(^10\) In fact, in the United Kingdom today, the attending physician is the “final arbiter” of treatment for a mentally incompetent patient. Stephen Luttrell, Making Decisions About Medical Treatment for Mentally Incapable Adults in the UK, 350 Lancet 950 (1997), cited in Garrison, supra note 7, at 513. The text continues that, in England and Wales, court involvement in such cases is limited to declaratory judgments on the legality of steps taken by the treating physician not to invoke the patient’s authority to consent to or reject particular therapies.

\(^11\) “Under a best interests approach, the factors to be considered by a surrogate — physical and mental suffering, chances of recovery, nature of patient interaction with his or her environment, regaining of function, indignity, and so on — are drawn from what most people consider to be critical factors in shaping post-competence decision-making.” Norman L. Cantor, The Bane of Surrogate Decision-Making: Defining the Best Interests of Never-Competent Persons 26 J. Legal Med. at 158-159 (2005), citing Curran v. Bosze, 566 N.E.2d 1319, 1326 (Ill. 1990).
sion (“playing God”) and the absence of universally accepted principles to guide them.\footnote{12}{Courts have uniformly failed to discuss adequately how to evaluate the benefits of a particular patient’s life to that patient, thereby avoiding problematic quality of life considerations.” Kevin P. Quinn, \textit{The Best Interests of Incompetent Patients: The Capacity for Interpersonal Relationships as a Standard for Decisionmaking}. 76 Cal. L. Rev. at 897-900 (1998).}\footnote{13}{“Every jurisdiction that has spoken to end-of-life surrogate decision-making has upheld a formerly competent patient’s prerogative to shape post-competence care either by an advance medical directive or other prior expressions.” Cantor, \textit{supra} note 11, at 157.}\footnote{14}{\textit{In re Quinlan}, 70 N.J. 10 (1976).}\footnote{15}{Eisenstadt v. Baird, 405 U.S. 438 (1972).}\footnote{16}{Griswold v. Connecticut, 381 U.S. 479 (1965).}\footnote{17}{Griswold, 381 U.S. at 484.}\footnote{18}{\textit{In re Quinlan}, 70 N.J. 10 at 40.}\footnote{19}{Id.}\footnote{20}{Id.}\footnote{21}{\textit{Superintendent of Belchertown School v. Saikewicz}, 373 Mass. 728, 739 (1977).}\footnote{22}{\textit{Cruzan} simply upheld Missouri’s right to require “clear and convincing” evidence of the patient’s wishes. The decision, however, did not impose that standard on other states and, in fact, most states do not require that level of proof. Justice O’Connor, in her concurring opinion in \textit{Cruzan}, wrote that the courts must honor the decisions of surrogate decision makers to refuse medical treatment because, “In my view, such a duty may well be constitutionally required to protect the patient’s liberty interest. . . .” Cruzan v. Director, Missouri Department of Health, 497 U.S. at 289. “The right of an adult, who, like Claire Conroy, was once competent to determine the course of her medical treatment, remains intact even when she is no longer able to assert that right or to appreciate its effectuation.” John F. Kennedy Memorial Hospital, Inc. v. Bludworth, 452 So.2d 921, 924 (Fla. 1984).}

Instead, most courts opt to apply substituted judgment, not only for the right reason (because it tailors a reaction to illness which is inherently that of the patient), but also out of fear (of enunciating an unlegislated but universal principle when, in fact, no such legislation or consensus exists).\footnote{13} The seminal case dealing with the termination of treatment for incompetent patients is \textit{In re Quinlan}, decided by the New Jersey Supreme Court in 1976.\footnote{14} Before \textit{Quinlan}, the United States Supreme Court pronounced the existence of a Constitutional right to privacy in cases such as \textit{Eisenstadt v. Baird}\footnote{15} and \textit{Griswold v. Connecticut}.\footnote{16} These cases dealt specifically with questions about the availability of birth control, but the right that they established was broad. Particularly significant was the “penumbras and emanations” language from \textit{Griswold},\footnote{17} quoted in \textit{Quinlan},\footnote{18} which is sufficiently nebulous to allow courts to define the right to privacy virtually however they wish. The \textit{Quinlan} court interpreted this right as a general protection for individuals to determine the course of their own lives,\footnote{19} and held that it encompassed a right to “decline medical treatment under certain circumstances.”\footnote{20} Other cases followed suit.\footnote{21} At first blush, the rationale behind the subjective test appears to be plausibly grounded on jurisprudential precedent: The patient \textit{himself} (not physicians, insurers, contentious family members, or even the courts) has the right to decide whether and when to terminate his own medical treatment. If that constitutional principle grants authority to competent individuals it must also be granted to incompetents even if, indeed especially if, they cannot directly assert them.\footnote{22} A concern then arises in developing a standard for those
who, when competent, did not make their wishes known and never-competent persons. These circumstances result in a unique area of law in which the existing jurisprudence articulating the subjective test simply cannot apply, leaving the objective test as the only safeguard of patient autonomy. Moreover, should a patient’s previously enunciated position about whether or not to be treated be considered irrevocable and immutable?

A. Objective Test

The jurisprudential rationale behind the objective test is not nearly as clear as that of the subjective test. This can be seen in the Conroy opinion, in which the New Jersey Supreme Court attempted to connect the objective test with other legal principles, and found itself on shaky ground.

An incompetent, like a minor child, is a ward of the state, and the state’s parens patriae power supports the authority of its courts to allow decisions to be made for an incompetent that serves the incompetent’s best interests, even if the person’s wishes cannot be clearly established. This authority permits the state to authorize guardians to withhold or withdraw life-sustaining treatment from an incompetent patient if it is manifest that such action would further the patient’s best interest.

The Conroy court invoked the power of the state to decide the best interests of minor children in order to bolster the legitimacy of the objective test, according to which the state has the power to authorize the termination of medical treatment on the basis of its determination of an incompetent patient’s best interests. The problem is that there is a gap between the notion of “best interests” embodied in decisions regarding minor children and decisions regarding the termination of medical treatment.

Take, for example, decisions about child custody, for which many courts apply the “best interests of the child” test. While the details of this test vary somewhat from state to state, there are many constants. Courts almost always consider it to be in the “best interests of the child” to live with a parent with a stable address, with whom the child has developed a close relationship, and who does not have substance abuse problems. Each of these factors suggests a single theory of what the child’s “best interests” are: to have a physically and emotionally stable existence, to be nurtured, to thrive — in short, to have a good life. In rendering a decision to terminate medical treatment for an incompetent

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23 “The medical fate of never-competent persons cannot be resolved according to the approach governing previously competent persons. For never-competent medical patients, the commonly stated approach to surrogate decision-making is the best interests of the incapacitated ward.” Cantor, supra note 11, at 204-205.

24 “Courts have explicitly recognized that ‘substituted judgment’ is a fiction when evidence of the patient’s wishes is unavailable. For example, in In re Storar … [s]ince Mr. Storar ‘was always totally incapable of making a reasoned decision about medical treatment,’ the court recognized the futility of attempting to determine his wishes … Instead, it reasoned that its decision must rest on principles different from those applicable to patients who had once been competent. Unfortunately, the court never specified what these principles were.” Quinn, supra note 12, at 913-914.


26 Katheryn D. Katz With Dawn Gray, Child Custody and Visitation. §1.05.

27 But see Quinn, supra note 12, at 184 citing Reno v. Flores, 507 U.S. 22, 304 (1993). “Numerous deci-
patient, however, adopting an objective test may result in deciding that it is in the patient’s best interests to *die*. While such a decision is defensible, it clearly represents a dramatic departure from prior applications of a best interests test.

**B. Subjective Test**

There is a similar disjunction between the application of the subjective test and previous applications of the right to privacy. As already mentioned, *Eisenstadt* and *Griswold* established the right of individuals to decide privately whether to use birth control. This is altogether different from positing their right to make private decisions that will almost certainly result in death — which is what the subjective test often justifies. But the legitimacy of the right to privacy does not depend on the results of any particular application of it. This is best illustrated in some florid language used by the Supreme Court in *Planned Parenthood v. Casey*:

> These matters, involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one’s own concept of existence, of meaning, of the universe, and of the mystery of human life.

Whatever one thinks of the soundness of this declaration, the language makes it clear that the subjective test used by the *Quinlan* court flows from the same right to privacy that the Supreme Court enunciated in cases that dealt with family planning issues. This is because the right to privacy holds that in certain matters, the good thing to do is *whatever the individual thinks it is*. For this reason, it does not matter if the results of the application of the right to privacy in cases such as *Quinlan* diverge from the results in the family planning cases. The subjective test (when it is grounded on the right to privacy) is *not* about results at all but about process. In other words, the subjective test is not about where the line is to be drawn, but only about who draws the line.

### III. Conditions That Limit Use of the Subjective Test

By contrast, when the objective test is employed, results are the *only* thing that matters. When a court decides on an incompetent patient’s medical care using the objective test, the court is making an independent judgment about what is good for the patient.

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sions confirm that natural parents are entitled to custody even when their children’s interests would be better served by remaining with foster parents or with aspiring adoptive parents.” *Id.*

28 "The question is whether the particular patient would be better off dead than alive in the circumstances facing the patient, not whether the surrogate (or even the average incapacitated person) would want to live in those circumstances.” Cantor, *supra* note 11, at 162.

29 *Id.*


31 “The typical understanding is that a best interests judgment requires maximizing the helpless ward’s interest or determining ‘the highest benefit [for the ward] among available options.” Cantor, *supra* note 11, at 168.

32 “In 1983, the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research listed ‘quality as well as the extent of the life sustained’ as an element within a
The objective test does not make reference to the patient’s own probable choices. While the subjective test strives to mandate what the patient would have wanted, the objective test aims to do the right thing. The objective test is useless if it rests on a mistaken idea of what the right thing is.

Thus, it is natural that courts deciding on whether to terminate treatment for incompetent patients tend to prefer the subjective test to the objective test. Simply put, the subjective test is assumed to be better law than the objective test because it enhances autonomy. Prominent philosophers disagree. The best known rebuttal to the subjective test was set forth in two articles by Rebecca Dresser and John Robertson, who contend that the subjective test irrationally favors the wishes that the incompetent patient expressed when she was competent over her current interests. They illustrate their view with a vignette (the “sociology professor” example), which can be paraphrased as follows:

At time t1, A is a professor of sociology who has published prolifically, reads voraciously, and whose primary source of pleasure, as well as her sense of self-worth, is derived from intellectual pursuits, executes a Living Will which states that should she ever lose her intellectual capacities, she does not wish to receive life-saving medical care. At time t2, A suffers a massive stroke, which results in severe dementia. A is no longer able to read anything more complex than a comic strip and is certainly unable to publish an article. However, A does derive a fair amount of pleasure from her life: For example, she enjoys watching television and sharing her meals with fellow nursing home residents. At time t3, A comes down with pneumonia.

A is incompetent at time t3. The question is whether she should be treated for the pneumonia. If we apply the subjective test (which, as we have seen, is what courts normally do), we would follow the directions expressed in A’s Living Will and declare to treat the pneumonia, because it clearly expresses (much more clearly than can usually be hoped for) what A’s wishes would have been if she were competent.

The same individual faced, at different times, with the same choices, is not certain to make them consistently. Emotions, new information, and added experience are some of the factors that change our minds over time. The psyche is a “moving target,” rapidly shifting positions and perspectives. Using other words, Dresser and Robertson claim that...
the subjective test fails to account for something important — specifically, the patient’s interests at the time at which treatment is being considered.\(^3\)\(^8\) To Dresser and Robertson, it is a mistake to apply a test that gives less weight to the patient’s present interests than to the wishes that she has expressed in the past, because the patient’s interests have changed.

“[T]he desires competent persons have concerning their future medical care reflect the activities and goals that make life worthwhile for them as competent, choosing individuals. To most competent persons, work, family, friendships, exercise, hobbies, and related pursuits seem integral to a life worth living. Many competent persons would refuse life-sustaining treatment that severely compromised those interests.”\(^3\)\(^9\)

However,

[W]hen people become incompetent and seriously ill…their interests may radically change. With their reduced mental and physical capacities, what was once of extreme importance to them no longer matters, while things that were previously of little moment assume much greater significance. An existence that seems demeaning and unacceptable to the competent person may still be of value to the incompetent patient, whose abilities, desires and interests have so greatly narrowed.\(^4\)\(^0\)

The obvious response to the Dresser-Robertson critique of the subjective test is that there is a good reason to prefer the wishes that the patient expressed while he was competent over his present interests as predetermined by some generalized principles. Nancy Rhoden argues to this effect in a series of law review articles, most notably “Litigating Life and Death.”\(^4\)\(^1\) Rhoden’s argument is that applying the sort of objective test for which Dresser and Robertson advocate is dehumanizing. Rhoden writes that “[A]n ‘objective’ test that looks at an unconscious or barely conscious person and focuses too heavily on her present condition forgets that, morally speaking, she is still a person, not just some largely [non-sentient] thing totally divorced from her former values.”\(^4\)\(^2\)

Ronald Dworkin offers an explicit account of this point in his book, Life’s Dominion.\(^4\)\(^3\) He distinguishes from what he calls an individual’s experiential interests and his critical interests.\(^4\)\(^4\) Roughly, an individual’s experiential interests are those whose satisfaction would give him immediate pleasure, while his critical interests are those whose satisfaction would give his life coherence and meaning.\(^4\)\(^5\) In Dresser’s sociology professor example, A has an experiential interest in watching television, and a critical interest in living a life in which she is able to make full use of her intellectual capacities. For Dworkin,

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\(^3\)\(^8\) Dresser & Robertson, supra note 34, at 248; Dresser, supra note 34, at 248.

\(^3\)\(^9\) Id.

\(^4\)\(^0\) Id.

\(^4\)\(^1\) Rhoden, supra note 1, at 376.

\(^4\)\(^2\) Id. at 410.

\(^4\)\(^3\) Ronald Dworkin, Life’s Dominion (1993).

\(^4\)\(^4\) Id. at 202.

\(^4\)\(^5\) Id.
the development and satisfaction of critical interests is a central human activity. Furthermore, clearly defined critical interests are a necessary feature of an integrated human life — that is, of a life with integrity.

People think it important not just that their life contain a variety of the right experiences, achievements, and connections, but that it have a structure that expresses a coherent choice among these — for some, that it display a steady, self-defining commitment to a vision of character or achievement that a life as a whole, seen as an integral creative narrative, illustrates and expresses.

A person’s critical interests are concerned with something deeper than pleasure or pain; they are concerned with whether and under what circumstances an individual believes his life to be good. Thus, they are qualitatively different, and in a sense more important than his experiential interests.

Dworkin’s distinction between experiential and critical interests explains why the subjective test is superior philosophically as well as jurisprudentially to the objective test. The subjective test holds that we should follow wishes that a patient expressed concerning the termination of medical treatment while he was competent. These wishes generally pertain to the patient’s critical interests — that is, they pertain to the values that he wants his life to express. In the sociology professor example, A drafts her Living Will in a particular way because her intellectual abilities give her life integrity. We should follow A’s previously expressed wishes concerning the cessation of her treatment because these wishes relate to her deepest feelings concerning the course and meaning of her life. We should follow A’s previous wishes even if they conflict with A’s present interest in watching television. After all, the latter is only an experiential interest, and thus pertains only to A’s momentary pleasure. As Dworkin points out, “People do not make momentous decisions like these by trying to predict how much pleasure each choice might bring them.”

Dworkin’s and Rhoden’s argument that a person’s interests are ordered (in the sense that some of them are “deeper” than others) derives support from contemporary philosophy. Dresser and Robertson make no attempt to challenge this framework — they make no attempt, for example, to advance a utilitarian account of human life, according to which pleasure is the sole good. Rather, Dresser and Robertson’s response to the Dworkin-Rhoden argument is based on an idiosyncratic theory of personal identity developed by Derek Parfit, who writes that an individual’s identity is not necessarily stable through time. An individual’s continuing to be the same person at time t2 as he was at

46 Id.
47 Id. at 205.
48 Id.
49 See also Quinn, supra note 12, at 901. “The meaning and substance of life … is found in personal relationships. As ethicists have contended, this emphasis on the capacity to relate to another human being is demonstrably objective, adequately captures the dignity of personhood, and avoids a subjective evaluation of a person’s self-worth by another.” Id.
50 Id.
time t1 depends on whether he possesses *psychological continuity* from t1 to t2 — which in many cases he does not. As a person accumulates different life experiences, his memories of long-past events gradually fade, and his personality gradually shifts. Through this process, an individual becomes (in a radical, as opposed to a merely colloquial sense) a different person.

Dresser and Robertson assert that the incompetent patient whose continued treatment is at issue is not the same person as the competent individual who expressed a wish to have his treatment discontinued under certain circumstances. In the sociology professor example, there is little if any psychological continuity between A when she is competent and A when she is incompetent. The incompetent A is incapable of understanding the intellectual pursuits that absorbed the competent A — she does not even remember that “she” once had such interests. Therefore, Dresser and Robertson argue, even if we grant that the previous wishes express critical interests, and that the patient’s present interests are “merely” experiential, it would be a mistake to base our decision about the incompetent patient’s medical treatment on the competent patient’s wishes. This is because the competent patient’s wishes concern only herself. At the time at which the decision must be made, the person who expressed the wishes no longer exists.

An analysis of the metaphysics that underlie Parfit’s theory is beyond the scope of this article (indeed, Dresser and Robertson present the theory without metaphysical argument), but Nancy Rhoden’s commentary on Dresser and Robertson’s reference to Parfit alludes to such analysis. Simply put, a theory that depends on a fragmented account of personal identity has no place in a discussion of legal policy. Once we accept the notion that A is a different person when she is incompetent than when she was competent, we will indeed have a good reason not to carry out the wishes that A had expressed when she was competent. To make society work, however, requires enforcing commitments made earlier even if they clash with later intent. For example, the law requires a mortgagor to continue making monthly payments even if, 10 years later, he decides that the mortgage was not convenient or appropriate. The metaphysical justification for the ordinary conception of personal identity — that one is the same person from birth until death, irrespective of psychological changes — may indeed be wrong — although Dresser and Robertson do not make a serious attempt to argue that this is so. The ideas about obligation and liability imbedded in our laws depend on it, and we cannot entertain a theory that contravenes it.

If we accept the ordinary, unified theory of personal identity, then we are committed to the notion that an individual’s critical interests do not alter when she becomes incompetent. The salience of one’s critical interests does not depend on her awareness of them in the same way that the salience of her experiential interests does; for example,

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53 Dresser & Robertson, supra note 34; Dresser, supra note 34.
54 Rhoden, supra note 1, at 413.
55 See also Lebit, supra note 33, at 128-29 (1993). “In order to alleviate the confusion surrounding the application of the substituted judgment doctrine to cases involving minors and incompetents, a new standard must be developed to apply to these particular circumstances … This new standard begins with the proposition that substituted judgment can never be used in cases involving minors and the mentally deficient.” Id.
56 Note that Dresser insists that her theory does not depend on Parfit’s conception of identity. Dresser & Robertson, supra note 34, at 248.
a desire for a massage may be tied to wanting relief from neck pain. Critical interests, by definition, are interests that pertain to the whole of a person’s life. If I have an interest in leading a dignified life, then I have an interest in my entire life being dignified. If a person is the same person from birth to death, then a person has critical interests when he is incompetent to the same extent he had them when he was competent. Contrary to Dresser and Robertson’s assertion, it makes perfect sense to talk about an incompetent patient’s interest in (for example) privacy and dignity.57

Since the Dresser/Robertson argument against the subjective test seems to depend upon an unacceptable notion of personal identity, the objection fails. The rest of this article is based on an assumption that while the subjective test is, in principle, the best way to make decisions about terminating medical treatment for incompetent patients, it often serves as a “cop-out,” allowing courts to exaggerate the patient’s past commitments in order to avoid confronting the real question of the patient’s “best interests.” Its virtue lies in the features that Dworkin points out: the subjective test considers the patient’s critical interests — it reflects the patient’s most deeply held desires about what his life should mean, and what course it should take. Given that this is so, and given that the subjective test is more strongly rooted in legal precedent than the objective test, courts correctly apply the subjective test when the patient has made his wishes clear. But that does not mean that all cases can be resolved by reference to the patient’s past expressions.

IV. Why a Clear Objective Test Is Necessary

Most cases that reach the courts involve patients who have not made their wishes clear or, at the very least, there are opposing interpretations of what they wanted. In fact, studies indicate that only between 18 percent and 30 percent of Americans have completed an Advance Directive.58 Furthermore, 24 percent of the United States population is under the age of 18, according to the U.S. Census Bureau.59 While there is no accurate estimate of non-competent adults, the most widely cited statistic, from an Associated Press study in 1987, said that between 300,000 and 400,000 adults were under guardianship in the United States.60 These numbers indicate that, broadly speaking, half of the United States population has not made its wishes known, and another quarter of the population is incapable of doing so.

It should be emphasized that there will always be a need for the objective test, even if people come to use mechanisms such as Living Wills and surrogate decision makers with greater frequency in the future. Such measures are worth encouraging, since they make it possible to apply the subjective test more often. But we can never expect all incompetent patients to have previously executed a Living Will, designated a surrogate, or otherwise made their wishes concerning the termination of medical treatment discern-

57 Id. at 248.
60 See ERICA F. WOOD, STATE-LEVEL ADULT GUARDIANSHIP DATA: AN EXPLORATORY SURVEY (ABA COMM’N ON LAW AND AGING FOR THE NAT’L CTR. ON ELDER ABUSE, 2006).
ible and applicable. Even if we could achieve 100 percent compliance among formerly competent patients (who at one point had the capacity to form and express the relevant wishes), there would remain a question of what to do about never-competent patients. In short, an objective test will almost certainly be necessary in some cases. Thus, it is important to get a clear grasp of exactly which factors the objective test should weigh.

The absence of a clear formulation of the objective test in our law has resulted in cases that are problematic in at least two distinct ways. First, there is a group of cases in which courts engage in “doublethink.”61 In such cases, the evidence concerning the patient’s wishes is slim to nonexistent, but the courts purport to apply the subjective test anyway. The courts in these cases in fact conduct objective analyses, without acknowledging that they are doing so, and without explicitly laying out their terms. In a second group of cases, the courts acknowledge that the objective test is warranted, but formulate the test in an unsatisfactory way.62

Ideally, legislatures ought to set forth a statutory framework that would make it easier for courts to apply the objective test overtly, consistently, and correctly. We will draw on our previous discussion of the merits of the subjective test to outline a positive account of what the objective test should look like.

The first group of problematic cases has its genesis in Quinlan, which involved a 22-year-old woman in a persistent vegetative state. Interestingly, the Quinlan court declined to consider some statements that the patient had made to her friends while she was competent concerning heroic medical treatment: The court found these statements “remote and impersonal,” and therefore they “lacked sufficient probative weight.”63 The court then discussed in gruesome detail Ms. Quinlan’s physical condition, making reference to Ms. Quinlan’s 40-pound weight loss, her “fetal-like and grotesque” posture,” and found that “as nearly as may be determined…[Ms. Quinlan] can never be restored to cognitive or sapient life.”64 But as discussed above, the court went on to find that the termination of Ms. Quinlan’s treatment could be justified by the constitutional right to self-determination:

We have no doubt, in these unhappy circumstances, that if Karen were herself miraculously lucid for an interval (not altering the existing prognosis of the condition to which she would soon return) and perceptive of her irreversible condition, she could effectively decide upon discontinuance of the life-support apparatus, even if it meant the prospect of natural death.65

It is not clear how the court could be so certain of Ms. Quinlan’s preferences, especially given its dismissal of the only evidence on this score available to it — i.e., Ms. Quinlan’s casual conversations with her friends. It seems that the Quinlan court per-

61 “In most jurisdictions, the formerly competent patient’s values and preferences, even if not explicitly directed toward end-of-life choices, are also deemed relevant to surrogate decision-making.” Cantor, supra note 11, at 157.
62 “The courts applying this objective balancing test have focused solely on physical pain as experienced by the incompetent patient.” Quinn, supra note 12, at 900.
63 In re Quinlan, 70 N.J. at 21 (1976).
64 Id. at 26.
65 Id. at 39.
formed a sleight of hand — the court said that it was interested in honoring Ms. Quinlan’s preferences, but it was really interested in the objective hopelessness of her situation. In other words, the court claimed to be applying the subjective test under circumstances in which the subjective test was impossible in principle to apply. The Quinlan court actually arrived at its decision by using objective criteria.66

The various Florida courts that considered Terry Schiavo’s case engaged in a similar sort of reasoning. By the time that case reached the courts, Ms. Schiavo had been in what appeared to be a persistent vegetative state for 10 years. One of the intermediate appeals opinions described Ms. Schiavo’s condition as follows:

Over the span of this last decade, Theresa’s brain has deteriorated because of the lack of oxygen it suffered at the time of the heart attack. By mid 1996, the CAT scans of her brain showed a severely abnormal structure. At this point, much of her cerebral cortex is simply gone and has been replaced by cerebral spinal fluid. Medicine cannot cure this condition. Unless an act of God, a true miracle, were to recreate her brain, Theresa will always remain in an unconscious, reflexive state, totally dependant on others to feed her and care for her.67

But again, none of the courts that ruled in the Schiavo case explicitly justified its decision by reference to Ms. Schiavo’s physical condition. Rather, each of the courts purported to accept the validity of a Florida common law rule that a surrogate’s decision to terminate treatment for an incompetent patient must be supported by “clear and convincing evidence” that the incompetent patient would have wanted it this way.68 Each court found that the facts of the Schiavo case met this standard.69 Ms. Schiavo, who was 27 years old when she first lapsed into a coma, had left no relevant written instructions, but she had made some statements to her friends and family through the years, which (according to the various courts) suggested that she would want treatment terminated. Ms. Schiavo had made these statements, respectively, in reference to her grandmother’s being in intensive care at the hospital, to her husband’s grandmother’s protracted death, and to a television show about people on life support.70

These are the sort of statements that the Quinlan court disregarded as “insufficiently probative,” and it is strange that the Schiavo courts accepted them as “clear and convincing” evidence of Ms. Schiavo’s wishes. Indeed, it seems that from the available evidence, it is impossible to “know,” in any responsible sense of the word, what Ms. Schiavo’s wishes concerning her situation would have been. In an article for the New York Review of Books, Joan Didion succinctly stated the difficulty:

Imagine it. You are in your early twenties. You are watching a movie, say on Lifetime, in which someone has a feeding tube. You pick up the empty chip bowl. “No tubes for me,” you say as you get up to fill it. What are the chances you have given this even a passing thought?71

66 Rhoden makes this point. See Rhoden, supra note 1, at 383.
68 In re Schiavo, No. 90-290, slip op. at 8 (G.D. Fla. Feb. 11, 2000).
69 Id. at 9; In re Schiavo, 780 So. 2d 180.
70 In re Schiavo, No. 90-290, at 9.
71 Joan Didion, The Case of Theresa Schiavo, 52 N.Y. REV. OF BOOKS 10 (June 9, 2005).
As is the case with Quinlan, one gets the sense that Schiavo opinions paid lip service to the subjective test, while actually relying on medical evidence to discern Ms. Schiavo’s “best interests.” A passage from the District Court of Appeals opinion is telling on this point:

Theresa was very young and very healthy when this tragedy struck. Like many young people without children, she had not prepared a will, much less a living will. She had been raised in the Catholic faith, but did not regularly attend mass or have a religious advisor who could assist the court in weighing her religious attitudes about life-support methods. Her statements to her friends and family about the dying process were few and they were oral. Nevertheless, those statements…gave the trial court a sufficient basis to make this decision for her.72

Here, the court is using impressionistic facts about Ms. Schiavo — her youth, her good health, her childlessness — to create a notion of what she had thought about the particular dilemma. Under the circumstances, it is reasonable to believe that Ms. Schiavo never expressed unambiguous thoughts about how she would want physicians to treat her if she fell into a persistent vegetative state. The courts consistently held that “substituted judgment” justified cession of life-extending treatment, while they might more credibly have declared that preserving her life was not in her interest based on abundant medical evidence. Courts should be prepared to admit when they have insufficient evidence to determine “substituted judgment” and move on to declaring the patient’s best interest. At the very most, the Schiavo courts applied a hybrid of the subjective and the objective tests. They started with an assumption that Ms. Schiavo’s medical condition was objectively horrendous and that anyone in such a condition would want her treatment terminated. The courts then bolstered this assumption with the meager subjective evidence that they had. But this “hybrid” test is a far cry from the test that the Schiavo courts claimed to adhere to — that is, it is a far cry from a test which takes the patient’s own wishes as the only relevant factor and which requires clear and convincing evidence to prove those wishes.

This “doublethink” is even more blatant in the Massachusetts case of Superintendent of Belchertown State School v. Saikewicz.73 That case involved a 67-year-old man, Joseph Saikewicz, who had an IQ of 10, a mental age of two years and eight months, and had lived most of his life in an institution.74 He had recently been diagnosed with leukemia, and there was a question of whether to administer chemotherapy — a course of treatment that would be painful, produce many undesirable side effects, and have only a 30 percent to 50 percent chance of inducing a temporary remission.75 Mr. Saikewicz’s guardian ad litem had filed a report recommending that chemotherapy not be administered, and it is worth noting that the trial court upheld this report on purely objective grounds.76

The Massachusetts Supreme Judicial Court, however, used this case as an opportunity to create the doctrine of “substituted judgment.” After acknowledging that Mr.

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72 In re Schiavo, 780 So. 2d 179-80.
74 Id. at 731.
75 Id.
76 Id. at 734-35.
Saikewicz’s mental retardation created a special situation, insofar as Mr. Saikewicz had never possessed the capacity to express preferences concerning his medical treatment, the court proceeded to find that:

[T]he decision in cases such as this should be that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision making process of the competent person.\(^{77}\)

Accordingly, the court found that if Mr. Saikewicz were competent, he would decline to undergo the pain that chemotherapy entailed, given that he would not be able to understand the treatment’s purpose.\(^{78}\)

Problems with this reasoning have been widely noted.\(^{79}\) The question of what Mr. Saikewicz would do if he were competent is not coherent. We can acknowledge that this question makes sense when it is applied to Karen Quinlan and Terry Schiavo, even if we think that there was insufficient evidence available to answer it in their cases. Both Ms. Quinlan and Ms. Schiavo had once been competent. At some point in time, both of them had possessed the capacity to form thoughts and feelings concerning the relevant issues. Given a unified theory of personal identity, according to which an individual is the same person from birth to death irrespective of psychological and cognitive changes, it would be perfectly reasonable to honor the wishes that Ms. Quinlan and Ms. Schiavo had formed while competent. (This assumes that these wishes were discernible, which is highly questionable.)

But the problem in Mr. Saikewicz’s case goes beyond the epistemic problem displayed in Quinlan and Schiavo. Mr. Saikewicz had never been competent. It is not merely that we cannot ascertain his wishes, it is that he never had any wishes to ascertain — indeed, he had always been incapable of forming such wishes. The notion of what Mr. Saikewicz would do “if he were competent” makes no sense, because there never was a competent Mr. Saikewicz. Put another way, if Mr. Saikewicz were competent, he would not be Mr. Saikewicz. Thus, it would be impossible in principle to decide the Saikewicz case on the basis of Mr. Saikewicz’ own likely choice — even though this is what the court claimed to be doing. In reality, the court reached the decision that it did based on what it thought would be best for Mr. Saikewicz — and this is an objective inquiry.

The Saikewicz, Quinlan, and Schiavo courts employed the same sort of reasoning to reach their results. The courts were, it appears, extremely wary of making decisions on the basis of “quality of life.” Indeed, the Nuremberg Trials had made it clear to American jurists that life-and-death decisions on the basis of the “quality of one’s life” were abhorrent and tantamount to “Nazi science” and the worst form of racism.\(^{80}\) The fact remains

\(^{77}\) Id.
\(^{78}\) Id. at 754-55.
\(^{79}\) See RHODEN, supra note 1, at 286.
\(^{80}\) “If we look closely at contemporary American invocations of the self-determination ideal in doctor-patient relations, we can see the same underlying sense of betrayal and helpless vulnerability that framed the Nuremberg judgment … The shadow of the Nazi experiments hovers in the background of the cases in the image of predatory doctors subjecting vulnerable people to inhumane scientific procedures in order to benefit some dogmatic social policy unrelated to the individual welfare of their
that some lives are of such low quality and the likelihood of recovery is so unfavorable that it simply does not make sense to continue to provide them with medical care. Our existing legal framework makes it difficult for courts to enunciate the sentiment that some people are better off dead than alive.

It should be emphasized that the results in these cases are not necessarily wrong. Setting aside ideas about the intrinsic sacredness of life, it made sense in each of the aforementioned cases, for various reasons, to allow the termination of treatment for Ms. Quinlan, Ms. Schiavo, and Mr. Saikewicz. It is the reasoning in these cases that is problematic, what Rhoden calls the “disjunction between the result and the rationale.” This disjunction does not amount to a harmless bit of hypocrisy, from which we can avert our eyes. When courts apply the objective test while claiming to apply the subjective test, they hide the ball. Since they do not acknowledge that they are applying the objective test, they do not reveal how they are formulating that test. They do not disclose which factors they are actually weighing when deciding what is in a patient’s best interest. And as we shall see, there are many different factors that could go into a formulation of the objective test.

Courts applying the objective test have formulated it narrowly, so that the question of the patient’s best interests is reduced to the question of whether the patient is in an unacceptable amount of physical pain. In Conroy, the New Jersey Supreme Court formulated one such test. After asserting that the subjective test should be applied whenever possible, but acknowledged that there would be cases in which evidence of the patient’s wishes was inconclusive or nonexistent. For those cases, the court outlined two possible tests: a limited objective test, and a pure objective test. The limited objective test requires that a decision to terminate treatment for an incompetent patient be supported by medical evidence, that

make[s] it clear that the treatment would merely prolong the patient’s suffering and not provide him with any net benefit. Information is particularly important with respect to the degree, expected duration, and constancy of pain with and without treatment, and the possibility that the pain could be reduced by drugs or other means short of terminating life-sustaining treatment.


81 Id. at 387.
82 “An Illinois court was similarly disparaging of the substituted judgment standard in the context of three-and-one-half-year-old twins, one of whose parents was hoping to use the twins as bone marrow donors to rescue the twins’ dying half brother. In finding substituted judgment irrelevant to the children’s situation, the court remarked: ‘[I]t is not possible to discover the child’s likely treatment/ non-treatment preferences by examining the child’s philosophy, religion and moral views, life goals, values about the purpose of life and the way it should be lived.’” Cantor, supra note 11, at 158-59, citing Curran v. Bosze, 566 M/E.2d 1319, 1326 (Ill.1990).
83 See Quinn, supra note 12, at 900.
85 As the dissent noted, the Conroy court seems to have engaged in some doublethink. The court found that the limited objective test was applicable to Ms. Conroy’s situation, even though it was not clear that there was any evidence at all of what her wishes would have been. Id. at 391.
86 Id. at 366.
The Conroy court chose to apply the limited objective test when there is some, but not quite sufficient, evidence that the patient would want her treatment terminated, reserving the pure objective test for when there is no evidence whatsoever concerning the patient’s wishes. Like the limited objective test, the pure objective test consists in weighing the pleasure that the patient is experiencing against his pain, but the standard is set higher, so that “the recurring, unavoidable, and severe pain of the patient’s life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane.”

The Conroy court explicitly declined to consider factors other than the patient’s pleasure and pain in formulating its objective test, finding that “[t]he mere fact that a patient’s functioning is limited or his prognosis dim does not mean that he is not enjoying what remains of his life or that it is in his best interests to die.” The court also found that “[m]ore wide-ranging powers to make decisions about other people’s lives…would create an intolerable risk for socially isolated and defenseless people suffering from physical or mental handicaps.” Thus, the Conroy court attempted to create a universal criterion that is relatively immune to manipulation. Pain is unquestionably a bad thing for everyone, and pleasure is unquestionably a good thing. This means that a pleasure/pain analysis will always track the patient’s interests. A more expansive inquiry into whether the patient’s life is “worth living” could conceal a eugenics regime, under which incompetent individuals are denied medical care because society does not value them.

Limiting the objective test to comparing pain versus pleasure is over-simplistic. One problem is that pain is not an issue for many incompetent patients. As Rhoden points out, patients in persistent vegetative states — such as Karen Quinlan and Terry Schiavo — have no physical sensations of any kind; neither pleasure nor pain. And as the dissent in the Conroy case points out, the pain that conscious incompetent patients experience is almost always controllable with medication. A deeper problem with the pleasure-pain formulation of the objective test is that it does not capture the nature of the tragedy of the cases that we have considered. The horror of Ms. Quinlan, Ms. Schiavo, Mr. Saikewicz, and Ms. Conroy’s situations is not exhausted by their physical pain. A good account of exactly what is horrifying about these situations will point us to a better formulation of the objective test.

This inquiry is reminiscent of our earlier examination of the Dresser-Robertson thesis. There, our conclusion was that the subjective test reflects desires that are deeper and more important than any desires which the incompetent patient has in his incompetent state. Then, as now, our inquiry concerned what is “really” good for a human being, and we made use of Dworkin’s notion of critical interests. We concluded that human beings have interests that are more important than pleasure and pain. But there, we had an easy way of determining what the patient’s critical interests are: the patient’s own idea of what

87 Id.
88 Id. at 367.
89 Id.
90 See Burt, supra note 80.
91 Rhoden, supra note 1, at 399.
they are. For clarity’s sake, we will depart from Dworkin’s lexicon and call the critical interests that are determined in this way subjective critical interests. A person’s subjective critical interests are whatever he says they are.

V. COURTS NEED TO ENUNCIATE “BEST INTERESTS” IN A GREAT NUMBER OF CASES

Can courts develop an objective account of critical interests when a patient has left no indication of what he thinks his critical interests are beyond measuring pleasure and pain? We submit that courts should begin by defining the critical interests that pertain to an individual’s objective quality of life as his objective critical interests; and these may be independent of his subjective critical interests. In other words, it is possible to assess the former without making reference to what the patient wants.

The dissent in Conroy took a step toward laying out a comprehensive version of the objective test. The dissent would hold that terminating treatment should be permissible for patients who are terminally ill and “facing imminent death,” who had permanently lost consciousness, and who had suffered the “irreparable failure of at least one major and essential bodily organ or system.”93 Furthermore, the dissent found that the patient’s general physical condition ought to be taken into account, so that “[t]he presence of progressive, irreversible, extensive, and extreme physical deterioration, such as ulcers, lesions, gangrene, infection and the like…should be considered in the formulation of the appropriate standard.”94

This is an improvement over the standard set forth by the Conroy majority, but it has at least one major flaw. The first part of the dissent’s proposed test has the effect of making it impossible to terminate treatment for two important classes of incompetent patients — those in persistent vegetative states and those who retain a degree of conscious awareness. Patients in persistent vegetative states are not terminally ill in the usual sense of the phrase; given treatment, such patients could go on living almost indefinitely. Likewise, the question of terminating treatment often arises with respect to patients who are not unconscious, such as Ms. Conroy. It seems unwise to adopt a version of the objective test that forecloses the possibility of terminating treatment for these two categories of patients.

The Conroy dissent deserves more consideration than it has received, particularly the second part of its test, that refers to the patient’s physical condition. It seems that the deterioration of one’s body is a bad thing, whether or not one is in a position to experience pain from this deterioration. Likewise, as the Conroy dissent suggests,95 it seems that being in a constant state of physical dependence on others is a bad thing, whether or not one is in a position to know that one is dependent. The situations we have been considering are tragic because they involve individuals whose bodies are deteriorating (recall the Quinlan court’s grisly description of Ms. Quinlan’s physical condition) and are dependent on others for their “most private needs.”96 Both of these factors need to be recognized in any comprehensive formulation of the objective test.

93 Id. at 398.
94 Id.
95 Id. at 396.
96 In re Schiavo, 780 So. 2d at 177 citing “most private needs.”
The Conroy dissent uses subjective language when setting forth these criteria, suggesting that people such as Ms. Conroy might “value personal privacy and dignity, and prize independence” and that “pervasive bodily intrusions...will arouse feelings akin to humiliation and mortification for the helpless.” Such discussion suggests a reluctance to give up on “substituted judgment.” Discussing patients’ wishes and values is, of course, relevant to the subjective test. But as far as the objective test is concerned, these things are beside the point. The inquiry here is what is good for the patient.

As demonstrated, the subjective test involves discerning the patient’s subjective critical interests and acting according to them. It seems that the ability to form subjective critical interests, and to live according to them once they are formed, is also an important characteristic of a good human life. It seems, indeed, that choosing the values that we want to live by, and then acting accordingly, is an essential human activity. None of the patients in the cases that we have considered had the capacity to form subjective critical interests. Furthermore, none of these patients had the capacity to live out any subjective critical interests that they may have formed prior to becoming incompetent. The capacity to form subjective critical interests, and to act upon subjective critical interests that one has previously formed, is an important feature of a good human life. To put it another way, we believe that all people have an objective critical interest in being able to form subjective critical interests.

A comprehensive formulation of the objective test will consider whether or not the patient is able to form or act upon such interests. Courts need not, however, take into account what an individual patient’s subjective critical interests are. Rather, courts should focus on whether the individual possesses the capacity in question, not on whether a certain course of action would further a particular subjective critical interest of the patient. The latter inquiry is indistinguishable in practice from the subjective test.

VI. HOW AN OBJECTIVE TEST MIGHT BE CONSTRUCTED

To sum up, American law is in need of objective tests which acknowledge that the quality of a person’s life is determined by factors other than the ratio of pain to pleasure that he experiences at a given moment. A person’s bodily integrity influences the qual-

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98 Id. at 399.
99 This is a popular notion in contemporary moral philosophy. See Williams, supra note 51; Christine Korsgaard, The Sources of Normativity (1996).
100 Note the counterintuitive results reached by the court in Strunk. Strunk v. Strunk, 445 S.W. 2d 145 (Ky. Ct. App. 1969). That court found that it would be in an incompetent man’s best interest to donate a kidney to his competent brother, because the incompetent man’s relationship with his brother was central to his life.
101 “Advance directives have been treated with greater caution in England, where the physician usually is allowed to determine the treatment to be provided to an incompetent patient based on professional judgment. Very likely, this system is acceptable because English physicians have been statistically far less likely to be sued and are therefore more willing to accept the responsibility that accompanies the power to choose for a patient .... [T]he patient’s right to dictate the course of treatment through informed consent is quite limited in England, compared with the extent of the right in the United States .... [In England] the best interest standard has more often been applied in medical decision-making.” Alison Patrucco Barnes, Beyond Guardianship Reform: A Reevaluation of Autonomy and Beneficence
ity of his life. A person whose physical condition has deteriorated suffers a corresponding deterioration in his quality of life, whether or not the deterioration is associated with physical pain. Likewise, it is an objectively good thing for a human being to be able to live more or less independently from others, and his quality of life suffers to the extent that he cannot. Also, the ability to form subjective critical interests, and to live according to the critical interests that one has already formed, is an objectively good thing. Courts that purport to apply the subjective test actually employ one or more of the objective criteria under the guise of “autonomy.” Our version of the objective test would have the effect of bringing this sort of reasoning out in the open, so that the result matches the rationale.

Two additional points are worth making. First, the objective test we propose would be useful even if surrogate decision making, such as the one proposed by Rhoden, becomes widespread. Even if family choices regarding the care of incompetent patients were to be presumed valid, these choices would not go unchallenged 100 percent of the time. No matter what, some cases regarding medical treatment for incompetent patients will reach the courts, and the courts will need a rule of decision.

The second point is more complicated. The three criteria set forth — bodily integrity, independence, and the ability to form subjective critical interests — are all criteria that count against continuing life-saving treatment. To be dependent on others, and to have a diminished or nonexistent ability to form subjective critical interests, are simply part of what it means to be incompetent. In addition, many conditions that render people incompetent also compromise their bodily integrity. For these reasons, it is worth emphasizing that we are not advocating a “meat axe” approach to the objective test. Courts, in our opinion, should not authorize the termination of medical treatment for anybody to whom any of these criteria apply. All three criteria are matters of degree. For example, an individual with mild retardation is probably able to form subjective critical interests to some extent. Such an individual may be capable of deciding that he wants to live in such a way as to express (for instance) his love for his family. This individual’s subjective critical interests will be simpler and less than a normal person’s, but his capacity will still be considerably greater than that of an individual in a persistent vegetative state.

In sum, we propose a standard, and not a rule. Others have contended that such rulemaking concerns not where you draw the line but how you draw the line. Courts should determine the degree to which each of these criteria apply to each individual, and render judgment on a case-by-case basis. By this process, a patient in the early stages of Alzheimer’s disease, who has a moderate level of subjective interest capacity, a moderate level of independence, and high level of bodily integrity, will probably not be a candidate for terminating treatment, notwithstanding the fact that medicine has not yet found a way to reverse mental and organic decline. On the other hand, a patient in a persistent vegetative state, who has low levels of all three criteria, will be the perfect candidate for termination of treatment. These are the results that our intuitions would suggest, and these


102 Rhoden, supra note 1, at 437.

103 See Cantor, supra note 11, at 157-58 (discussing how factors that make up an “objective test” can be used by surrogate decision makers to determine the incapacitated person’s non-expressed wishes to satisfy the “subjective test”).
are the results that the test we are proposing would achieve.

The “eugenics” objection remains to be addressed. Is the formulation of the objective test vulnerable to abuse and could courts apply such criteria as a pretext to secure the deaths of people who have a real interest in remaining alive, but whose families want them out of the way for one reason or another? The answer is that, of course, such standards could be perverted. The challenge is to devise criteria that are truly objective, i.e., that can be relatively easy to measure. The question of whether and to what degree a person enjoys bodily integrity depends upon objective medical facts. A person’s independence is similarly quantifiable. The capacity to form subjective critical interests is a little bit less “firm” a criterion, but it still lends itself to empirical investigation (perhaps by expert psychologists). If anything, the subjective test is more open to abuse than this version of the objective test. In a legal context in which it is normal for courts to make findings about a patient’s wishes on slim or nonexistent evidence, it is all too easy to claim what the patient “would have wanted” without having real evidence that the patient consistently and unambiguously expressed precisely that need. A similar problem arises when courts impute specific subjective critical interests to patients and make decisions about their care accordingly.104

The proposed objective test does not, in fact, ask courts to do anything that they are not already doing. Courts already make judgments about the quality of a person’s life that go beyond pain-pleasure analyses — the Quinlan court did it, the Schiavo court did it, and the Saikewicz court did it. What they did not do is say that they were doing it. The regime we propose might be viewed as a transparent version of the old regime. Under the old regime, courts purported to apply the subjective test while actually applying an objective test. Since they pretended that they were not applying it, courts never enumerated the criteria of the test that they were applying. Under the regime that we are proposing, courts would have to say exactly what they are doing. This would ensure consistency and would surely serve to prevent abuse.

VII. CONCLUSION

This article began with observations about the reluctance of courts to apply the objective test, noting that applying “best interests” in the context of life-and-death decisions is quite different from its use in deciding, for example, custodial issues involving children. In the latter case, courts enumerate someone’s “best interest” by considering which course of action (living with one parent or another, receiving spiritual education at one place rather than the other, attending what school, and, primarily, being subject to the parenting of one parent) would be most conducive to living well.105 But when the issue is whether to treat or not treat, courts have to consider whether it is in somebody’s best interest to die. This is indeed a radical notion, but we have been dealing with radical circumstances. As the Quinlan court noted, the problem of terminating treatment for incompetent patients is a problem of the modern age: if they had been born 200 years ago, Karen Quinlan, Terry Schiavo, and Joseph Saikewicz would have died naturally, without

104 See Strunk, 445 S.W. 2d 145.
requiring someone to decide to terminate their treatment.\textsuperscript{106} If we lack a legal principle that permits courts to say it is sometimes better for a person to die than to live, it is because we have not needed such a principle until recently.

Bodily integrity, independence, and a capacity for subjective critical thought are necessary for a good human life; a life that does not include them (to some degree) is not \textit{worth living}. This is a proposition with which many people are deeply uncomfortable.\textsuperscript{107} Judges must bite the bullet, i.e., they must decide cases in which “autonomy” is ambiguous and consider objective standards that can be concretely measured. To do that requires a consensus, manifested in a statute that provides clear guidelines.\textsuperscript{108}

The subjective test is superior in principle to the objective test, but in a great many cases, when there is no compelling and consistent evidence of what the patient wanted and when such expressions did not fully anticipate the current circumstances, the subjective test is too often applied with a heavy dose of intellectual dishonesty. For the sake of transparency, courts should tell us what they are really doing.

\textsuperscript{106} \textit{In re Quinlan}, 70 N.J. at 27 (1976).
\textsuperscript{107} See Didion, \textit{supra} note 71.
\textsuperscript{108} Courts have taken the lead in determining the standards over which life-death treatment decisions are made. Charles H. Baron, \textit{Life and Death Decision Making: Judges v. Legislators as Sources of Law in Bioethics}, 1 \textit{J. Health & Biomedical Law} 107, 123 (2004). He concludes “In the end, legislatures and courts both play important roles in the process of developing principles governing bioethics in the United States. In many instances, courts will take the initiative, making new law on the basis of new problems that are brought to them for resolution. The legislature may then supplement the common law or it may modify or overrule it.”
It’s All About the Money: Denying Disabled Veterans the Right to an Attorney

By Benjamin W. Wright

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I. INTRODUCTION

Twenty years ago, Congress passed the Veterans’ Judicial Review Act (VJRA), due in large part to the efforts of Vietnam Era veterans frustrated by the perceived inability of the Department of Veterans’ Affairs (VA) to process claims for disability compensation benefits fairly and accurately.1 The VJRA provided previously unheard-of judicial review of VA determinations.2 Unfortunately, after two decades of judicial review, the veterans’ benefits adjudication system has not improved in any substantive way.3 The VA disabil-

2 Id.
3 See Veterans’ Disability Benefits, Claims Processing Challenges Persist, while VA Continues to Take Steps to Address Them: Testimony Before the H. Subcomm. on Disability Assistance and Memorial Affairs, Comm. on Veterans’ Affairs, 110th Cong. (2008) [hereinafter GAO Testimony] (statement of
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In some ways, the fact that the VA is struggling is a testament to the abilities and resources of the medical professionals in the military. Combat medics, surgeons, and nurses in field hospitals are saving the lives of service members whose wounds would have been fatal a generation ago. For example, in 1945 (and probably 1968 as well), an infantryman with a traumatic brain injury probably would have died from his wounds; but through the Herculean efforts and resources of the military’s Medical Service Corps, a soldier who suffers such a wound today has a good chance at survival. Once the soldier leaves the service, however, the VA is unprepared to cope with such an injury. In fact, only recently has the VA recognized traumatic brain injury as a compensable injury. Thus, although problems with the VA place tremendous burdens on veterans, in a sense, these problems are a blessing.

For over a century, advocates have asserted (with only modest success) constitutional and public policy arguments in favor of legal representation for veterans from the initiation of a disability compensation claim. Therefore, constitutional and public policy arguments will not be recapitulated in this article, except to provide a backdrop to the


5 See Walters v. Nat’l Ass’n of Radiation Survivors, 473 U.S. 305, 323 (1985) (claimant died before the case was resolved); see also Bayabos v. Gober, No. 96-374, 1997 WL 580605, at *3 (Vet. App. Sept. 10, 1997) (holding that a regional office failed to fulfill its duty to assist a World War I veteran by failing to attach documents that would have made appellant eligible for benefits); see also Dambach v. Gober, 223 F.3d 1376, 1381 (Fed. Cir. 2000) (recognizing mishandling of the file by the VA, and the long delays in reaching a decision); see also Hayre v. West, 188 F.3d 1327 (Fed. Cir. 1999) (VA lied to the veteran and said the records showed no mental illness had been treated); see also Whorton v. West, 1998 WL 199789, at *2 (again, claimant died before the VA resolved the claim, despite the court ordering the VA to give “expeditious treatment” to a nearly decade-old claim with two prior remands by the Court of Appeals for Veterans Claims and a lack of responsiveness by the agency staff to the court’s remands).


objective argument.\textsuperscript{8} Also, while streamlining the bureaucratic process would likely reduce the problems of slow and inaccurate disability compensation determinations, the difficulties in implementing such a solution are prohibitive. Therefore, this article does not propose a solution that is unlikely to materialize.\textsuperscript{9}

Instead, this article focuses on the objective monetary impact of inaccurate disability compensation determinations. Refusing veterans the freedom to retain attorneys at the outset of a claim may cost a single veteran millions of dollars. This is demonstrated by examining the probability of an attorney achieving a positive outcome for a veteran, and the potential magnitude of that outcome in terms of larger disability benefits for the veteran and the financial effect of those larger benefits over time.

This article will first describe the veteran population, disability benefits, and the disability determination process. Second, the article will describe the legal proscriptions on a veteran’s ability to hire an attorney. Third, the combined effect of the legal proscriptions and the claims process will be analyzed. Fourth, the article will calculate the potential financial effects of inaccurate disability compensation determinations on the younger and older veterans. Finally, this article will recommend: (1) giving veterans the freedom to hire an attorney at the initiation of a disability compensation claim and (2) studying the effectiveness of different forms of representation.

II. THE VETERAN POPULATION, DISABILITY BENEFITS, AND THE CLAIMS PROCESS

Since 1636, Americans have cared for their veterans in one form or another.\textsuperscript{10} Since 1930, the VA has been responsible for the determination and administration of veterans’ disability compensation benefits.\textsuperscript{11} This section lays the foundation for understanding how attorneys can help disabled veterans by establishing (A) who is in the veteran population, (B) what benefits are at stake, (C) how the disability compensation claim process works, and (D) how accurate that process is.

A. The Veteran Population

The current veteran population is about 24 million, approximately three million of whom receive disability compensation.\textsuperscript{12} The very old veterans, those of the World War II (WWII) era, comprise about seven percent of the total veteran population, which trans-
lates to over 2.5 million people.13 The WWII cohort is dying at a rate of 900 per day.14 Veterans over the age of 60 comprise 45 percent of the veteran population, or over 11 million veterans.15 As an indication of the future veteran population who may someday require disability compensation, nearly 34,000 service members have been wounded in Operation Iraqi Freedom and Operation Enduring Freedom.16 However, these figures do not capture the soon-to-be veterans who have suffered latent injuries, such as post-traumatic stress disorder and Gulf War Illness.

B. Disability Compensation Benefits

The VA assigns disabled veterans a disability “rating,” based upon the degree of impairment to the veteran’s earning capacity. Compensation is based upon that disability rating. As Table 1 illustrates, a single veteran receives benefits ranging from $123 per month for a 10 percent disability rating to $2,673 per month for a 100 percent disability rating.17 The VA offers additional compensation for veterans with spouses and/or dependent children.18

<table>
<thead>
<tr>
<th>Disability Rating</th>
<th>Monthly Benefit</th>
<th>Approximate Annual Benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>10%</td>
<td>$123</td>
<td>$1,476</td>
</tr>
<tr>
<td>20%</td>
<td>$243</td>
<td>$2,916</td>
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<tr>
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<td>40%</td>
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<tr>
<td>50%</td>
<td>$770</td>
<td>$9,240</td>
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<tr>
<td>60%</td>
<td>$974</td>
<td>$11,688</td>
</tr>
<tr>
<td>70%</td>
<td>$1,228</td>
<td>$14,736</td>
</tr>
<tr>
<td>80%</td>
<td>$1,427</td>
<td>$17,124</td>
</tr>
<tr>
<td>90%</td>
<td>$1,604</td>
<td>$19,248</td>
</tr>
<tr>
<td>100%</td>
<td>$2,673</td>
<td>$32,076</td>
</tr>
</tbody>
</table>

Table 1: Disability Compensation Benefits for a Single Veteran with No Dependents


14 See NSV, supra note 13, at 3-2; see also O’Reilly, supra note 4, at 229.

15 See NSV, supra note 13, at 3-2.


18 Id. A detailed description of the disability compensation available to veterans is available on the VA website. Because the payments are made on a monthly basis, the annual benefit is an approximation; given the complexity of calculating the exact amount, for the purposes of this article, the inaccuracy of this approximation is considered insignificant.
C. The VA Disability Compensation Determination Process

This article is not a primer on the disability compensation determination framework, but the following summary of the process illustrates how attorneys might assist veterans. For brevity, decisions and alternative courses of action at each step in the process are omitted.

First, a veteran has to file a claim with the VA Regional Office (VARO) requesting disability benefits. Generally, there is no deadline by which a veteran must prepare a claim; although the claim should be filed as soon as possible because the filing date determines when benefits begin. Second, the VARO decides whether to grant benefits based on the claims, the evidence that the veteran provides, and the evidence that is produced through VA-ordered medical examinations. The VARO decision takes an average of 179 days from the time the VARO receives the claim. It is important to note that during the first two steps, the record is being created for appeal. The VARO can also require additional evidence, and if the veteran cannot produce the evidence within 60 days, the claim is disallowed. Third, if the veteran believes that the VARO’s determination is incorrect, he or she can file a Notice of Disagreement (NOD) within 365 days of the VARO mailing its decision.

Under current law, a veteran can hire an attorney only after the NOD is filed and most of the record for appeal has been created. Then, the VARO prepares a Statement of the Case to explain its decision. The veteran can then elect to have the NOD go directly to the Board of Veterans’ Appeals (BVA) or to a Decision Review Officer (DRO). A DRO is a VARO officer who can revise the findings of the VARO. The veteran can further elect to meet with the DRO in person, or rely on the NOD to accurately express the veteran’s position. Once the NOD is filed with the VARO, the DRO takes an average of 645 days (about two years) to reach a decision. Because veterans need not opt for DRO review, this time is not included in the total time calculation below.

If the veteran elects to skip DRO review, or disagrees with the DRO’s findings, the claim goes to the BVA. The BVA then reviews the veteran’s claims and the record. From receipt of the appeal, it takes an average of 1,215 days, or over three years, for the BVA to

19 For an excellent primer on the disability compensation determination process see Frolick & Kaplan, supra note 11, at 352; for a more elementary illustration see also Understanding the Appeal Process “How do I Appeal?”, http://www.va.gov/vbs/bva/010202A.pdf (last visited May 29, 2009).
20 See Frolick & Kaplan, supra note 11, at 352.
21 See VA Performance, supra note 4, at 8.
22 See David R. DiMatteo, Walters Revisited: Of Fairness, Due Process, and The Future of Veterans’ Fight for the Right to Hire an Attorney, 80 Tul. L. Rev. 975, 997 (2006) (Veterans “are prohibited from hiring counsel prior to . . . when the record for review that will be the sole basis for appeal is being created.” While the law now allows that additional evidence can be presented to the BVA, the majority of the record comes from the initial steps in the process).
23 See Frolick & Kaplan, supra note 11, at 353.
24 Id.
27 See O’Reilly, supra note 4, at 226.
28 See VA Performance, supra note 4, at 240.
reach a decision. The BVA adjudicates the merits of a veteran’s claim and may: (1) deny the claim, leaving the veteran the option to appeal to the United States Court of Appeals for Veterans Claims (CAVC); (2) allow the claim and grant the veteran deserved benefits; (3) remand the claim to the VARO for further development of the case or findings consistent with the BVA’s instructions; or (4) otherwise determine the claim.

After the BVA has made a determination, the veteran has 120 days to file an appeal to the CAVC. From receipt of the appeal, it takes an average of 446 days, or about a year and a half, for the CAVC to make a decision. Finally, under limited circumstances, the veteran can appeal to the United States Court of Appeals for the Federal Circuit.

In summary, assuming a veteran can immediately answer the VA’s denial of a claim at each level, the soonest a veteran can fully adjudicate a claim is, on average, approximately five years. A more realistic estimate is that the veteran will require time to prepare an appeal by seeing doctors, developing evidence, retrieving documents, and documenting the disabling condition. As a result, claims can take six to seven years to resolve.

D. Accuracy of the VA Disability Compensation Determination

The VA disability compensation determination framework is elegantly and accurately described as “a carousel consisting of remand, mishandling, rehearing, remand, and so on.” In terms of making timely and accurate compensation determinations, the VA sets low standards, and consistently fails to meet them.

Of the 838,000 disability benefit claims filed in fiscal year 2007, approximately 114,451 NODs were filed. Therefore, the VA touts an estimated 86 percent accuracy rate in its disability compensation process. However, this braggadocio is misleading, because it fails to identify erroneous decisions that were not appealed due to unawareness of the right to appeal, a sense of futility, or some other reason. A more informative metric of the VA’s accuracy would be to examine the claims that are appealed to the BVA. Of these appeals, only 38.9 percent of the VARO decisions were correct. Also significant

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30 See Understanding the Appeal Process “How do I Appeal?”, supra note 19, at 11-12 (note that in this handbook for veterans, the only suggestion offered that does not imply some legal question is to “do nothing;” the other options are to appeal to the CAVC, file a motion for reconsideration due to clear and unmistakable error, or “go back to your local VA and try to reopen your claim”).
32 See GAO Testimony, supra note 3.
33 See O’Reilly, supra note 4, at 229.
34 See VA Performance, supra note 4, at 8 (indicating a failure to meet VA-set standards in all dimensions relating to disability compensation and a failure to improve from the previous year in many of the same dimensions).
35 See GAO Testimony, supra note 3, at ii and 5; See also BVA Chairman Report, supra note 29, at 21.
36 See BVA Chairman Report, supra note 29, at 22 (22.4 percent of the claims were allowed, 37.2 percent were remanded, and 2.3 percent had another disposition); see also VA Performance supra note 21, at 8, 121, 228.
is the fact that of the claims made to the BVA, 94.4 percent were disability compensation claims, demonstrating that disability compensation is a significant area of contention between veterans and the VA.\footnote{is the fact that of the claims made to the BVA, 94.4 percent were disability compensation claims, demonstrating that disability compensation is a significant area of contention between veterans and the VA.\footnote{See BVA CHAIRMAN REPORT, supra note 29, at 22.}}

VA employees have a poor record for competence. On an open-book job-skill certification test, only 25 percent of the “best and brightest adjudicators” passed.\footnote{VA employees have a poor record for competence. On an open-book job-skill certification test, only 25 percent of the “best and brightest adjudicators” passed.} The VA’s poor performance in making timely and accurate disability compensation determinations is certainly due, in part, to VA employee ineptitude. However, to be fair, incomplete or unclear claims may also lead to slow and inaccurate disability compensation determinations.

Using the claims appealed to the BVA to analyze the accuracy of VA decisions may appear to have a selection bias, but that bias is mitigated by understanding a veteran’s mentality. First, dealing with the VA gives veterans a justifiable sense of futility due to the time involved, the bureaucracy, and the ineptitude of VA personnel.\footnote{Using the claims appealed to the BVA to analyze the accuracy of VA decisions may appear to have a selection bias, but that bias is mitigated by understanding a veteran’s mentality. First, dealing with the VA gives veterans a justifiable sense of futility due to the time involved, the bureaucracy, and the ineptitude of VA personnel.} Second, the veteran may not understand the VARO’s decision and the supporting medical and legal reasons for the decision, and thus not know how to proceed.\footnote{Second, the veteran may not understand the VARO’s decision and the supporting medical and legal reasons for the decision, and thus not know how to proceed.} Third, the veteran may not understand that he/she has rights in this process and can appeal.\footnote{Third, the veteran may not understand that he/she has rights in this process and can appeal.} Finally, although the existence of veterans’ rights may seem intuitive to a legal reader, a veteran, especially one recently discharged, may have a mentality of following orders. After all, the chance for appeal for a private when ordered to do something by a sergeant is nil. When the VARO decision comes down from “higher-up,” the veteran may believe that this is just another occasion when he/she must “suck it up and drive on” as the veteran was told to do in the service.\footnote{Finally, although the existence of veterans’ rights may seem intuitive to a legal reader, a veteran, especially one recently discharged, may have a mentality of following orders. After all, the chance for appeal for a private when ordered to do something by a sergeant is nil. When the VARO decision comes down from “higher-up,” the veteran may believe that this is just another occasion when he/she must “suck it up and drive on” as the veteran was told to do in the service.}

III. LEGAL PROSCRIPTIONS ON, AND ARGUMENTS AGAINST, THE FREEDOM OF VETERANS TO HIRE ATTORNEYS

A law dating back to the Civil War prohibited a claimant from paying an attorney more than $10 for representation in a VA benefits claim.\footnote{A law dating back to the Civil War prohibited a claimant from paying an attorney more than $10 for representation in a VA benefits claim. The spirit of this archaic clause is embodied in an act dating back to the Civil War.} The spirit of this archaic clause

\footnote{37 See BVA CHAIRMAN REPORT, supra note 29, at 22.} \footnote{38 See Melinda F. Podgor, The Inability of World War II Atomic Veterans To Obtain Disability Benefits: Time Is Running Out On Our Chance To Fix The System, 13 ELDER L.J. 519, 530 (2005); see also U.S. GOV’T ACCOUNTABILITY OFFICE, VETERANS BENEFITS ADMINISTRATION: BETTER COLLECTION AND ANALYSIS OF ATTRITION DATA NEEDED TO ENHANCE WORKFORCE PLANNING 3 (2003) available at http://www.gao.gov/cgi-bin/getrpt?GAO-03-491).} \footnote{39 See William F. Fox, Jr., Deconstructing and Reconstructing the Veterans Benefits System, 13 KAN. J.L. & PUB. POL’Y 339, 342-43 (2004) ("It appears clear that many veterans simply give up after a . . . negative BVA decision.").} \footnote{40 See Dowd, supra note 8, at 79-80 (discussing one 20-year Army veteran who said “They wouldn’t look at my medical records, but kept telling me I had to submit additional evidence, and I would say, what the hell additional evidence? . . . I would start reading these letters with five pages of legal garbage and just give up. It was, like, I’m not reading this crap.” Another, a Vietnam-era infantryman who lost his hand and was denied his claim stated “ . . . the VA refuses to respond to my letters. I guess they don’t respond because they know I have pending claims and, if they do so, they’ll have to back up to 1970 and pay me retroactive benefits.”).} \footnote{41 Id.} \footnote{42 “Suck it up and drive on” is a common Army aphorism; see also Jared Brokaw, Editorial, It’s a soldier’s job is to ‘suck it up and drive on’ when called, WESTERN COURIER, September 22, 2004, http://media.www.westerncourier.com/media/storage/paper650/news/2004/09/22/Opinion/Its-A.Soldiers.Job.Is.To.suck.It.Up.And.Drive.On.When.Called-726885.shtml.} \footnote{43 See Act of July 14, 1862, ch. 166, § 6, 12 Stat. 566, 568; amended by Act of July 4, 1864, ch. 247, § 12,
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haunted the Veterans Judicial Review Act (VJRA), passed in November 1988. The current version of the law does not allow for even the $10 fee. The law states: “a fee may not be charged, allowed, or paid for services of agents and attorneys with respect to services provided before the date on which a notice of disagreement is filed with respect to the case.” Notably, this law allows an attorney to be hired only after most of the record for appeal has been created. Thus, an attorney does not have the opportunity to correct errors as they occur, preserve the record for appeal, or counsel the veteran client; and therefore must take the case as it is. The law further states that attorney’s fees are subject to the approval of the VA.

The constitutionality of the fee limitation in a nearly identical preceding law was examined in Walters v. National Association of Radiation Survivors. In Walters, a Veterans Service Organization (VSO), veterans, and a veteran’s widow challenged the $10 attorney’s fee limitation for representation in VA disability compensation claims. Specifically, the United States Supreme Court addressed the question of whether veterans had a right to counsel in the VA disability compensation process. The Court held that the proscription on fees was constitutional, citing the United States Government’s interest in protecting veterans from dividing disability benefits with attorneys, keeping the cost of the claims process low, and thereby having more money available for disabled veterans. The Court observed that the fee limitation would deny claimants due process of law only with an extraordinarily strong showing that there is a probability of error in the VA’s present benefits claim procedures and that attorneys would sharply diminish that error.

The rationale for proscribing attorney involvement was that if veterans had attorneys then so would the VA, and costs and time would increase. However, an equally strong argument can be made that lawyers would draft clear, complete, accurate claims with the legal framework in mind, and would thus assist VARO officials in reaching the correct disability compensation determination the first time. In doing so, attorneys would help reduce the overall cost of the process and the amount of time it takes to adjudicate a claim. Moreover, attorneys have a pecuniary interest in the claim. While attorneys and their veteran clients can arrange fee payments either through “fixed fee, hourly rate, a percentage of benefits recovered” or some combination thereof, attorneys would likely base the fee, at least in part, on a contingent basis, because fees exceeding one-third of past due

13 Stat. 387, 389; for a discussion of these laws, see also Walters, 473 U.S., at 323.
44 See VJRA, supra note 1, at § 104.
46 Id. (emphasis added). To give some context, the statute makes exceptions to this rule for proceedings before a court and regarding a loan; and the statute has robust requirements for how the fee is to be paid and subjected to the scrutiny of the VA.
48 See Walters, 473 U.S., at 321.
49 Id.
50 Id.
51 Id.
52 Id. at 326-34 (1985) (more succinctly stated in the syllabus at 305).
53 Id. at 321, 324-25.
benefits are presumptively unreasonable.\textsuperscript{54} Further, due to ethical obligations, attorneys could act as a filter, eliminating or discouraging frivolous or weak claims.\textsuperscript{55} Therefore, since an attorney’s pecuniary interest in winning cases is tempered by professional responsibility and ethical obligations, he or she would not file frivolous or weak claims.\textsuperscript{56}

When the VJRA was being passed, United States Senator Lisa Murkowski (R.-Alaska) expressed concern that unscrupulous lawyers would cheat their veteran clients. Senator Murkowski’s statements are contrary to the evidence, which reveals no endemic ethical violations by attorneys representing veterans.\textsuperscript{57} Other arguments that attorneys are unnecessary include the VA’s position that the disability compensation determination is not adversarial.\textsuperscript{58} Former CAVC Chief Judge Kenneth B. Kramer recognized, however, that the non-adversarial argument is “illusory once you have said ‘no’ to a claimant.”\textsuperscript{59}

A final argument is that attorney involvement is unnecessary because the VA has a duty to assist the veteran in filing the disability claim.\textsuperscript{60} However, the fact that fewer than 60 percent of veterans are satisfied with the assistance received from the VA could indicate that the VA is failing in this duty.\textsuperscript{61} Moreover, the fact that the VA Congressional Liaison Service receives “nearly 600 inquiries per week from House and Senate members on behalf of constituents” further indicates that the assistance that the VA provides is not satisfactory.\textsuperscript{62}

IV. THE COMBINED EFFECT OF THE CLAIMS PROCESS AND LEGAL PROSCRIPTIONS ON THE RIGHT OF VETERANS TO HIRE ATTORNEYS

When failures of the VA disability compensation determination process combine with the ban on veterans hiring attorneys set forth in Title 38 United States Code §5904(c), veterans, VSOs, and attorneys are detrimentally affected.

\textsuperscript{55} See \textsc{Model Rules of Prof’l Conduct} R. 3.1 (1983) (“A lawyer shall not bring or defend a proceeding, or assert or controvert an issue therein, unless there is a basis in law and fact for doing so that is not frivolous ...”).
\textsuperscript{57} See Bill Russo, \textit{Ten Years After the Battle for Veterans Judicial Review: An Assessment}, 46-June Fed. Law. 26, 28 (1999) (CAVC decisions have not revealed any widespread ethics violations by attorneys; “Likewise, a 1996 study by professor William Fox . . . did not reveal any negative impact of attorney representation of veterans. To the contrary, his data indicated that attorney representation greatly improved a claimant’s chances of winning his case.”).
\textsuperscript{58} See Forshey v. Principi, 284 F.3d 1335, 1355 (Fed. Cir. 2002) (en banc) (the veterans’ benefits system is non-adversarial while claims are pending before the VA; however, CAVC proceedings are adversarial).
\textsuperscript{59} See \textit{Hearing Before the S. Comm. on Veterans’ Affairs}, 109th Cong. 45 (2005).
\textsuperscript{60} See 38 C.F.R. §3.103(a) (2008).
\textsuperscript{61} See VA PERFORMANCE \textit{supra} note 4, at 123.
A. Effect on Veterans

Applying the process set forth above, a veteran who does not agree with an initial VARO decision and wants to appeal to the BVA must take six steps. First, the veteran must draft an application for benefits, with supporting medical documentation. Second, the veteran must answer any VA requests for additional information which, if not adequately answered, will result in the veteran’s claim being disallowed. Third, as discussed earlier, the veteran must understand the VARO’s decision and the fact that the veteran has the right to an appeal.

Fourth, the veteran must compile the evidence that the VA did not take into account in the initial decision, including: (1) having additional medical examinations, which the veteran may have to pay for; (2) accounting for any medical or service records lost in the service or by the VA; (3) requesting records that may be available only through the Freedom of Information Act; and (4) producing any other information that the VARO requires from the veteran. Fifth, the veteran must draft an NOD (explaining in clear, concise, complete, and precise language why the VARO’s decision is incorrect and how the evidence that the veteran has compiled proves the VARO decision to be incorrect) and request that the VARO reconsider its decision. Sixth, the veteran must decide whether to have the NOD sent directly to a DRO and, if so, whether to request a meeting with a DRO or go directly to the BVA. The decisions made at each of these steps will have a significant impact on the amount of time and level of complexity involved in having the claim decided.

B. Effect on Veterans Service Organizations

Because of the attorney’s fee limitation, the burden for assisting veterans has fallen onto the shoulders of VSOs. There can be no argument that VSOs provide an invaluable service in the area of veterans’ affairs. In fact, their services have been called “first rate.” Arguing that VSO representation is “first rate” is inaccurate, however, since attorneys have a higher rate of positive outcomes before the BVA.

If attorneys and VSOs would combine their skills and work collaboratively, veterans’ interests would be better served. As Federal District Judge Ronald Spears stated, attorneys should be leveraged by the VSOs as a “force multiplier.” A number of VSOs agree with that position; for example, the Vietnam Veterans of America recognizes the value of attorney representation. Moreover, most VSOs regularly “hired attorneys, who work alongside their non-attorney service representatives, to represent claimants at the CAVC.” The National Organization of Veterans Advocates (NOVA) best illustrates the ways that VSOs and attorneys can better serve veterans:

63 See Dowd, supra note 8, at 79-80.
64 See 134 CONG. REC. S9191 (1988) (emphasis added) (statement of Sen. Murkowski – “The Veterans’ Affairs claims process, although flawed in some individual cases . . . veterans’ service organizations already represent any claimant for free, and their work is absolutely first rate ...”).
65 See BVA CHAIRMAN REPORT, supra note 29, at 22.
67 See Russo, supra note 57, at 29.
68 Id.
NOVA believes that the most effective means of ensuring that the VA provides all benefits which can be supported in law, is to permit all claimants the right to hire an attorney at the initial claims process. The current system merely reinforces the adjudicatory errors of the VA and compounds needless delay of these claims. NOVA submits that legal representation at the initial claim level is necessary.

C. Effect on Attorneys

There are a number of factors that limit attorneys’ involvement in VA disability compensation claims, but the fact that representing a veteran in an initial claim must be done pro bono certainly discourages attorneys from engaging in VA disability compensation work.

The opportunity cost of representing a veteran pro bono for approximately one year is tremendous. For example, even if an attorney has a choice between taking a court-appointed case, in which the financial rewards may be minimal, and representing a veteran pro bono, the opportunity costs are significant. The opportunity cost between representing a veteran pro bono and representing a paying client is even more severe.

In addition to the opportunity cost, attorneys who might otherwise assist veterans are discouraged by the fact that the average time from the date of filing a claim to filing an NOD is about one year (not including any time that a veteran spends preparing to file a disability claim to the VA), and also the litany of tasks described in Parts II (c) and IV (a) of this article. For these reasons, fewer than 10 percent of veterans are represented by attorneys before the BVA, and of the approximately 400,000 attorneys in the United States, only about 700 are approved by the Secretary of Veterans’ Affairs to assist veterans before the CAVC.

Altruistic notions notwithstanding, the vast majority of attorneys are business people. Consequently, while assisting veterans may be good for public relations, it is a poor business decision when viewed from a purely financial perspective.

V. EFFECTS OF INACCURATE DISABILITY COMPENSATION DETERMINATIONS ON VETERANS

It is more probable that claims by veterans with representation from VSOs or attorneys will be successful; and the magnitude of that success, in terms of the disability rating, is significant. Previous discussions and litigation on this topic have addressed the probability issue, but have failed to complete the analysis by considering the possible magnitude of the increase in benefits. This factor is significant, as will be shown in the following discussion.

69 See The Board of Veterans’ Appeals and Appeals Management Center: Hearing Before the Subcomm. on Disability Assistance and Memorial Affairs of the H. Comm. on Veterans’ Affairs, 109th Cong. 61-62 (2005) (statement of Robert Vincent Chisholm, Past President, NOVA); Not all VSOs support a veteran’s freedom to hire an attorney. See Battling the Backlog: Challenges Facing the VA Claims Adjudication and Appeal Process: Hearing Before the S. Comm. on Veterans’ Affairs, 109th Cong. 45 (2005) at 79 (testimony of Rick Surratt, Deputy Nat’l Legislative Dir., Disabled Am. Veterans, stating the Disabled Am. Veterans’ opposition to veterans having the freedom to hire an attorney).

70 See BVA CHAIRMAN REPORT supra note 29, at 22; see also http://www.abanet.org/about/ (membership of the American Bar Association is over 400,000); see also http://www.uscourts.cavc.gov/ (publicly listing approximately 700 attorneys approved to practice before the CAVC).
Consider a loose parallel to the B<PL legal principle of tort law espoused by Justice Learned Hand. In the case of disability compensation claims, the probability \( P \) of inaccurate disability compensation is higher for veterans without an attorney, and the amount of the loss \( L \) to the unrepresented disabled veteran is very large. Thus, when the United States Supreme Court in \textit{Walters} determined that the veterans had not met the burden \( B \) of showing that banning veterans from hiring attorneys denied veterans due process, the Court examined only the probability \( P \) of inaccurate disability compensation. The Court’s analysis was incomplete because, due to an incomplete record, it did not examine the magnitude of the loss \( L \) that a disabled veteran would suffer.

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A. The Younger Veteran

Conservatively estimated (as demonstrated below), denying a younger veteran the freedom to hire an attorney may cost that veteran tens of thousands to millions of dollars.

1. The Probability of a Positive Outcome for the Disabled Veteran with Different Types of Representation

One measure of the effectiveness of different types of representation of veterans seeking disability compensation benefits is the outcome of disability compensation hearings before the BVA. Although approximately 12 percent of veterans choose to proceed before the BVA pro se, nearly 60 percent of veterans rely on VSO representation, approximately eight percent of veterans have attorney representation, and the remaining veterans rely on other forms of representation.73 There is some inherent inaccuracy in the numbers, because these statistics are determined at the time of filing the appeal even though many veterans retain attorneys after filing their appeal.74 The effect of this inaccuracy is to understate the effectiveness of attorneys, as some of the attorneys’ successes will be counted as successes of other organizations or pro se claimants. The relevant probability statistics on which this analysis relies are adapted from the 2008 BVA Chairman Report in Table 2.75

While these percentages are informative, they fail to capture the magnitude of the success because claims “allowed” refers to any case in which the BVA grants benefits. For example, a veteran who receives a 10 percent increase in benefits and a veteran who receives a 90 percent increase in benefits both would be considered “allowed.” For the purposes of this analysis, positive outcomes for the veteran include when the BVA allows a claim and when the BVA remands the claim to the VARO. While remand is not a dispositive holding, it is progress towards a fair determination of benefits for the veteran, and is certainly better than a denial.

With regard to the effectiveness of attorneys as compared to the other representation options available, attorneys achieve a positive outcome for their disabled veteran clients more than any other form of representation. Attorneys achieve a positive outcome for their disabled veteran clients 66.5 percent of the time, as opposed to an average 60.9 percent of the time for VSOs. The 5.6 percent difference in success rates may appear insignificant, but is indeed significant when that percentage is multiplied by the amount of additional benefits (discussed herein). A notable exception to the generalization about the effectiveness of VSOs is the Paralyzed Veterans of America (PVA), which obtains a positive outcome for veterans more often than any other organization and has the lowest level of denials; however, the total number of disabled veterans represented by the PVA is relatively low. While VSOs have the highest percentage of “allowed” claims before the BVA, the percentage of VSO-represented claims denied (36.6 percent) is significantly higher than attorney-represented claims denied (29.9 percent), which is the lowest percentage of denied claims. For context, a veteran proceeding pro se has about a 50 percent chance of a positive outcome.

73 See BVA CHAIRMAN REPORT supra note 29, at 22.
74 See Gary E. O’Connor, Rendering to Caesar: A Response to Professor O’Reilly, 53 ADMIN. L. REV. 343, 356 (Spring 2001).
75 Adapted from BVA CHAIRMAN REPORT supra note 29, at 22.
Of course, it could be that attorneys carefully select those claims that have the best chance of being allowed before the BVA, and it is for this reason that attorneys have the highest percentage of positive outcomes. While there is no data available that would directly disprove this possible selection bias, several factors suggest that selection bias is not a major issue. First, the fact that VSOs have the highest level of cases allowed would indicate that VSOs represent those cases that have the best chance of being allowed outright. Second, it seems likely that a veteran with a more complicated claim would be more likely to retain an attorney. Third, historically, attorneys were not paid to represent veterans before the BVA; therefore, any distinction in selection by attorneys would be moot. In any case, any selection bias cuts both ways. If those opposed to veterans having the freedom to hire an attorney argue that the higher attorney success rate is a result of attorneys skimming the cream, then they also must concede that attorneys weed out frivolous claims, thereby streamlining the VA disability compensation process.

2. Possible Magnitude of the Lost Benefits for an Unrepresented Veteran

Unfortunately, there is no reliable information available contrasting the magnitude of the increase in the disability rating when a veteran is represented by an attorney versus other forms of representation, such as a VSO. However, a 2005 report by the VA Office of the Inspector General stated that “the average annual disability payments for veterans with . . . representation were $6,225 higher than the payments for those without representation.”76 In 2005, a $6,225 increase in benefits was approximately a 40 percent increase in a veteran’s disability rating.77 If a similar disparity in the magnitude of the increase of benefits exists for a veteran who is represented by an attorney versus any other form of representation, then the argument for veterans having the freedom to hire an attorney would be much stronger. As discussed above, while the difference in probability of claims having a positive outcome whether represented by an attorney or a VSO is small, when that probability is multiplied by the possible magnitude of the increase of benefits, the effect of the lost benefits is staggering—from tens of thousands to millions of dollars.

a. Potential Effects of Increased Benefits Resulting from Attorney Representation

If veterans do achieve higher disability ratings through attorney representation than through other forms of representation, the effect of that increase in benefits can be significant. Moreover, if attorneys can achieve an increase in benefits, hiring an attorney is always cost-effective, assuming the veteran lives long enough to collect the benefits. To illustrate the potential financial effect of an increase in benefits resulting from attorney representation, a rudimentary financial analysis follows. Before launching into the financial analysis, an explanation of the conservative assumptions and financial principles

77 See Compensation and Pension Benefits Rate Tables, supra note 17.
78 The calculations upon which this analysis relies are on file with the author. The author would like to thank Professor Charles M. Kahn of the University of Illinois, College of Business, for his assistance and verification of these financial calculations. See http://www.business.uiuc.edu/FacultyProfile/faculty_profile.aspx?id=222.
The first assumption is that Congress will never increase the amount of benefits for a veteran, or if it does increase benefits, those benefits will increase at the same average rate as they have since 1988 (see Table 3). Second, if a veteran chooses to invest the benefits, then for the purpose of determining the Future Value (FV) of that investment, it is assumed that the veteran will invest very conservatively in Treasury Bills, earning a very modest interest rate of 3.8 percent (the current 30-year Treasury Bill rate). On the other hand, if the veteran chooses not to invest the benefits, and chooses to pay expenses instead, then a discount rate of 15 percent will be used to determine the Present Value (PV). Third, the veteran in this analysis is single, and remains so throughout his or her lifetime. Fourth, the veteran receives benefits for 40 years, and any back pay from benefits will not be invested. For example, the veteran leaves the service and files a claim at age 23, benefits begin at age 30, and the veteran dies or cashes in the investment at age 70. Fifth, benefits begin in 2009. Sixth, attorney’s fees are the maximum that is presumed reasonable — namely, one-third of the past-due benefits — and are paid when the increased benefits commence. In order to maximize the attorney’s fee calculation, it is assumed that the claim took seven years to process (see Table 4). The assumptions are designed to: (1) understate the financial effect of a veteran’s representation by an attorney, (2) illustrate that even a high attorney’s fee is inconsequential, and (3) understate the potential loss to the veteran, if the veteran is not represented by an attorney.

There are two financial principles that are essential to understanding the potential loss to the veteran resulting from lack of attorney representation. The first is PV or net present value (NPV), which is a measure of whether an investment is worthwhile. NPV and PV are mathematical formulae that calculate the value of a stream of income to occur in the future in today’s dollars. For example, if a rational veteran had a choice between

### Table 3: Average Rates of Increase of Benefits from 1988-2009

<table>
<thead>
<tr>
<th>Disability Rating</th>
<th>Average Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>10%</td>
<td>2.658%</td>
</tr>
<tr>
<td>20%</td>
<td>2.918%</td>
</tr>
<tr>
<td>30%</td>
<td>3.009%</td>
</tr>
<tr>
<td>40%</td>
<td>3.037%</td>
</tr>
<tr>
<td>50%</td>
<td>3.053%</td>
</tr>
<tr>
<td>60%</td>
<td>3.078%</td>
</tr>
<tr>
<td>70%</td>
<td>3.067%</td>
</tr>
<tr>
<td>80%</td>
<td>3.091%</td>
</tr>
<tr>
<td>90%</td>
<td>3.082%</td>
</tr>
<tr>
<td>100%</td>
<td>3.096%</td>
</tr>
</tbody>
</table>

involved will help the reader to understand the significance of the results derived.

79 Calculated from the historical rates in Benefits Rate Tables available at http://www.vba.va.gov/bln/21/rates/index.htm (click “Prior” for the rating tables) (on file with author).

80 The reasoning for the choice of interest and discount rates is to understate the value to the veteran; it is related to the adage, “a dollar today is worth more than a dollar tomorrow.” How much more that dollar is worth depends on the veteran’s situation. For example, the high discount rate for the PV calculation illustrates the situation in which a veteran has expenses that must be paid. In a situation in which expenses are immediate, a dollar tomorrow is worth a lot less than a dollar today. The other hand, if there are no immediate expenses, then the money can be invested and interest can be earned. Of course, how much more the dollar is worth tomorrow depends on the interest rate. The 30-year Treasury Bill, chosen as the standard to calculate FV, is a very low and very secure interest rate, and is chosen to understate the value of the dollars available tomorrow from the investment. For examples of the Treasury Bill rate, see http://www.irs.gov/retirement/article/0,,id=96450,00.html.

81 Id.


83 See supra text accompanying notes 78, 80; the term NPV is used for a growing annuity, and PV is used...
taking an annual benefit of $1,476 for 40 years (that had a PV of $9,803) and an immediate lump-sum payment, in order for the veteran to choose the lump-sum payment, the payment would need to be more than $9,803. The second fundamental principle is FV, which takes a stream of income and calculates what that stream of income will be worth in the future. For example, if a person deposits $100 in an interest-bearing savings account every year for five years, and never withdraws the money, at the end of five years, that person would have more than $500, due to the interest that the money would earn.

\[ FV = A \times \frac{(1+i)^n - (1+g)^n}{i-g} \]

**Table 4: Estimated Attorney’s Fees**

<table>
<thead>
<tr>
<th>Disability Rating</th>
<th>Attorney’s Fees</th>
</tr>
</thead>
<tbody>
<tr>
<td>10%</td>
<td>$3,444</td>
</tr>
<tr>
<td>20%</td>
<td>$6,804</td>
</tr>
<tr>
<td>30%</td>
<td>$10,528</td>
</tr>
<tr>
<td>40%</td>
<td>$15,148</td>
</tr>
<tr>
<td>50%</td>
<td>$21,560</td>
</tr>
<tr>
<td>60%</td>
<td>$27,272</td>
</tr>
<tr>
<td>70%</td>
<td>$34,384</td>
</tr>
<tr>
<td>80%</td>
<td>$39,956</td>
</tr>
<tr>
<td>90%</td>
<td>$44,912</td>
</tr>
<tr>
<td>100%</td>
<td>$74,844</td>
</tr>
</tbody>
</table>

\[ PV = \frac{A}{i-g} \times (1-((1+g)/(1+i))^n) \]

\[ FV = A \times (1+i)^n - (1+g)^n \]

i. Example of the effect of an increase in benefits, if benefits do not increase at the historical rate and the veteran chooses to use the funds to pay immediate expenses

If a veteran chooses to pay immediate expenses with the disability compensation benefits, and Congress never increases the benefits, then the stream of payments to a veteran rated 10 percent disabled has a present value of $9,803.

If an attorney could achieve a 10 percent higher rating for the veteran than the veteran could have achieved pro se or with another form of representation, then that 10 percent increase would have an additional PV of $9,564, for a total PV of $19,367. This is significant, because the veteran is spending $3,360 in attorneys fees (i.e., one-third of the back pay would be $6,804-$3,444=$3,360, per Table 3) for an increase in PV benefit of $9,564. In other words, the veteran spends $3,360 for a return of $9,564. Repeating the calculations for an initially 80 percent-disabled veteran; a 10 percent increase would cost $4,956 in attorney’s fees and have an additional PV of $14,107. These examples demonstrate that if attorneys can achieve even a 10 percent higher rating than other forms of representation, then by hiring an attorney, the veteran spends $1 to make about $3. Table 5 illustrates the PV for different disability ratings and different increases in those ratings if there is no increase in benefits and the veteran uses the benefits to pay immediate expenses.

ii. Example of the effect of an increase in benefits, if benefits do not increase at the historical rate and the veteran chooses to invest the benefits

If a veteran chooses to invest the disability compensation benefits, and Congress never increases the benefits, then the stream of payments to a veteran initially rated 10 percent-disabled would have a FV of $133,820; the increase in value is the result of the interest earned on the disability compensation payments.

\[ PV = \frac{A}{i-g} \times (1-((1+g)/(1+i))^n) \]

\[ FV = A \times (1+i)^n - (1+g)^n \]

84 See supra text accompanying notes 78, 80; The formula for future value is: \[ FV(A) = A \times \frac{(1+i)^n - (1+g)^n}{i-g} \]

\[ PV = \frac{A}{i-g} \times (1-((1+g)/(1+i))^n) \]

\[ FV = A \times (1+i)^n - (1+g)^n \]
If an attorney could achieve a 10 percent higher rating for the veteran than if the veteran had proceeded pro se or with another form of representation, then that 10 percent increase would have an additional FV of $130,556, for a total PV of $264,376. If an attorney could achieve a 10 percent higher rating, and the veteran invests, then the veteran spends $3,360 for a return of $130,556. Repeating the calculations for an initially 80 percent-disabled veteran; a 10 percent increase would cost $4,956 in attorney’s fees and have an additional PV of $192,570.

Therefore, by hiring an attorney, the veteran spends $1 to make about $40. Table 6 illustrates the FV for different disability ratings and different increases in those ratings if there is no increase in benefits and the veteran invests the benefits.

### iii. Example of the effect of an increase in benefits, if benefits increase at the historical rate and the veteran chooses to use the funds to pay immediate expenses

If a veteran chooses to pay immediate expenses with the disability compensation benefits, and Congress increases the benefits, as it has historically, then the stream of payments to a veteran initially rated 10 percent-disabled would have an NPV (net present value) of $11,832.

If an attorney could achieve a 10 percent higher rating for the same veteran than if the veteran had proceeded pro se or with another form of representation, then that 10 percent increase would have an additional PV of $12,018, for a total NPV of $23,850. The veteran spends $3,360 for a return of $12,018. Repeating the calculations for an initially 80 percent-disabled veteran; a 10 percent increase would cost $4,956 in attorney’s fees and have an additional PV of $17,501. These examples demonstrate that if attorneys can...
It’s All About the Money:  Denying Disabled Veterans the Right to an Attorney

Table 6: Future Value for the Younger Veteran if There Is No Increase in Benefits and the Veteran Invests the Benefits

<table>
<thead>
<tr>
<th>Disability Rating</th>
<th>FV</th>
<th>FV of a 10% Increase</th>
<th>FV of a 20% Increase</th>
<th>FV of a 30% Increase</th>
<th>FV of a 40% Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>10%</td>
<td>$133,820</td>
<td>$130,556</td>
<td>$275,256</td>
<td>$454,770</td>
<td>$703,915</td>
</tr>
<tr>
<td>20%</td>
<td>$264,376</td>
<td>$144,700</td>
<td>$324,214</td>
<td>$573,359</td>
<td>$795,304</td>
</tr>
<tr>
<td>30%</td>
<td>$409,076</td>
<td>$179,515</td>
<td>$428,659</td>
<td>$650,604</td>
<td>$926,948</td>
</tr>
<tr>
<td>40%</td>
<td>$588,590</td>
<td>$249,144</td>
<td>$471,090</td>
<td>$747,433</td>
<td>$963,939</td>
</tr>
<tr>
<td>50%</td>
<td>$837,735</td>
<td>$221,945</td>
<td>$498,289</td>
<td>$714,794</td>
<td>$907,365</td>
</tr>
<tr>
<td>60%</td>
<td>$1,059,680</td>
<td>$276,344</td>
<td>$492,849</td>
<td>$685,419</td>
<td>$1,848,456</td>
</tr>
<tr>
<td>70%</td>
<td>$1,336,024</td>
<td>$216,505</td>
<td>$409,076</td>
<td>$1,572,112</td>
<td>$1,572,112</td>
</tr>
<tr>
<td>80%</td>
<td>$1,552,529</td>
<td>$192,570</td>
<td>$1,355,607</td>
<td>$1,355,607</td>
<td>$1,355,607</td>
</tr>
<tr>
<td>90%</td>
<td>$1,745,099</td>
<td>$1,163,037</td>
<td>$1,163,037</td>
<td>$1,163,037</td>
<td>$1,163,037</td>
</tr>
<tr>
<td>100%</td>
<td>$2,908,136</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
</tbody>
</table>

achieve even a 10 percent higher rating than other forms of representation, then by hiring an attorney, the veteran spends $1 to make about $3.50.

Table 7 illustrates the NPV for different disability ratings and different increases in those ratings if there is an increase in benefits and the veteran uses the benefits to pay immediate expenses.

iv. Example of the effect of an increase in benefits, if benefits increase at the historical rate and the veteran chooses to invest the benefits

If a veteran chooses to invest the disability compensation benefits, and Congress increases the benefits, as it has historically, then the stream of payments to a veteran initially rated 10 percent-disabled would have an FV of $205,549.

If an attorney could achieve a 10 percent higher rating for the same veteran than if the veteran proceeded pro se or with another form of representation, then that 10 percent increase would have an additional FV of $219,536, for a total PV of $424,995. Thus, the veteran spends $3,360 for a return of $219,536. Repeating the calculations for an initially 80 percent-disabled veteran; a 10 percent increase would cost $4,956 in attorney’s fees and have an additional FV of $314,793.

These examples demonstrate that the veteran spends $1 to make about $65.

Table 8 illustrates the FV for different disability ratings and different increases in those ratings if there is an increase in benefits and the veteran uses the benefits to invest.

B. The Elder Veteran

Given the glacial pace of the VA in deciding claims, denying an older veteran the
freedom to hire an attorney may cost the elder veteran, and that veteran’s dependents, all of the benefits due the veteran.

While five to seven years to adjudicate a claim may seem to be a pittance, and is arguably fast for a government bureaucracy, it is literally a lifetime for 2.5 million WWII veterans. There may be thousands of riders on the VA disability compensation carousel from the WWII era. In the approximately five to seven years it takes to fully adjudicate a claim, at least 1.94 million, or more than 75 percent of all WWII veterans alive today will die, and their claims will die with them. This means that not only will older veterans be denied the compensation they deserve, but their spouses and other beneficiaries will be disadvantaged as well. To be fair, the VA has put its proverbial thumb in the dam with “teams to process disability claims for veterans 70 years and older.” It only took the VA about 60 years to identify this problem.

Moreover, the same financial issues exist for older veterans that exist for younger veterans. The distinction is that, as compared to a younger veteran, both the PV and FV of any payments will be lower, because the lifetime of the payments is presumably shorter. For the sake of brevity, the calculations will not be explained once again. However, for the sake of completeness, Tables 9 and 10 show the financial effects on an

<table>
<thead>
<tr>
<th>Disability Rating</th>
<th>NPV</th>
<th>NPV of a 10% Increase</th>
<th>NPV of a 20% Increase</th>
<th>NPV of a 30% Increase</th>
<th>NPV of a 40% Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>10%</td>
<td>$11,832</td>
<td>$12,018</td>
<td>$25,338</td>
<td>$41,764</td>
<td>$64,549</td>
</tr>
<tr>
<td>20%</td>
<td>$23,850</td>
<td>$13,319</td>
<td>$29,745</td>
<td>$52,531</td>
<td>$72,956</td>
</tr>
<tr>
<td>30%</td>
<td>$37,170</td>
<td>$16,426</td>
<td>$39,212</td>
<td>$59,636</td>
<td>$84,779</td>
</tr>
<tr>
<td>40%</td>
<td>$53,596</td>
<td>$22,785</td>
<td>$43,210</td>
<td>$68,353</td>
<td>$88,379</td>
</tr>
<tr>
<td>50%</td>
<td>$76,381</td>
<td>$20,425</td>
<td>$45,567</td>
<td>$65,594</td>
<td>$83,094</td>
</tr>
<tr>
<td>60%</td>
<td>$96,806</td>
<td>$25,142</td>
<td>$45,169</td>
<td>$62,670</td>
<td>$169,235</td>
</tr>
<tr>
<td>70%</td>
<td>$121,948</td>
<td>$20,027</td>
<td>$37,527</td>
<td>$144,093</td>
<td>$144,093</td>
</tr>
<tr>
<td>80%</td>
<td>$141,975</td>
<td>$17,501</td>
<td>$124,066</td>
<td>$124,066</td>
<td>$124,066</td>
</tr>
<tr>
<td>90%</td>
<td>$159,476</td>
<td>$106,566</td>
<td>$106,566</td>
<td>$106,566</td>
<td>$106,566</td>
</tr>
<tr>
<td>100%</td>
<td>$266,041</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
</tbody>
</table>

Table 7: Net Present Value for the Younger Veteran if There Is an Increase in Benefits and the Veteran Uses the Benefits to Pay Expenses

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85 See O’Reilly, supra note 4, at 229.
86 See O’Reilly, supra note 4, at 224, 225 (“If a veteran dies while the claim is pending, the disability claim dies and the federal government does not pay the claim. . . . However, rights of a deceased appellant’s survivors are not affected by this action. Survivors may still file a claim at the regional office for any benefits to which they may be entitled.”).
87 See GAO Testimony, supra note 3, at 5.
Table 8: Future Value for the Younger Veteran if There Is an Increase in Benefits and the Veteran Invests the Benefits

<table>
<thead>
<tr>
<th>Disability Rating</th>
<th>FV</th>
<th>FV of a 10% Increase</th>
<th>FV of a 20% Increase</th>
<th>FV of a 30% Increase</th>
<th>FV of a 40% Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>10%</td>
<td>$205,459</td>
<td>$219,536</td>
<td>$462,992</td>
<td>$41,764</td>
<td>$64,549</td>
</tr>
<tr>
<td>20%</td>
<td>$424,995</td>
<td>$243,457</td>
<td>$541,519</td>
<td>$52,531</td>
<td>$72,956</td>
</tr>
<tr>
<td>30%</td>
<td>$668,451</td>
<td>$298,063</td>
<td>$711,253</td>
<td>$59,636</td>
<td>$84,779</td>
</tr>
<tr>
<td>40%</td>
<td>$966,514</td>
<td>$413,190</td>
<td>$786,515</td>
<td>$1,239,420</td>
<td>$1,607,831</td>
</tr>
<tr>
<td>50%</td>
<td>$1,379,704</td>
<td>$373,325</td>
<td>$826,229</td>
<td>$1,194,641</td>
<td>$1,509,433</td>
</tr>
<tr>
<td>60%</td>
<td>$1,753,029</td>
<td>$452,905</td>
<td>$821,316</td>
<td>$1,136,109</td>
<td>$3,073,249</td>
</tr>
<tr>
<td>70%</td>
<td>$2,205,934</td>
<td>$368,411</td>
<td>$683,204</td>
<td>$2,620,344</td>
<td>$2,620,344</td>
</tr>
<tr>
<td>80%</td>
<td>$2,574,345</td>
<td>$314,793</td>
<td>$2,251,933</td>
<td>$2,251,933</td>
<td>$2,251,933</td>
</tr>
<tr>
<td>90%</td>
<td>$2,889,137</td>
<td>$1,937,141</td>
<td>$1,937,141</td>
<td>$1,937,141</td>
<td>$1,937,141</td>
</tr>
<tr>
<td>100%</td>
<td>$4,826,278</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
</tbody>
</table>

older veteran if benefits increase at the historic rate. The assumptions remain the same, except that the lifetime of the benefits is reduced to ten years and the Treasury Bill rate is reduced to 3.3 percent. The significance of these numbers is that it is always in the veteran’s best interests to hire an attorney if attorneys achieve a larger magnitude of disability benefits.

VI. RECOMMENDATIONS

Four former chief judges of the CAVC support attorney assistance of veterans at a greater level. Chief Judge Nebeker asserted that “there should be legislation that would permit attorneys’ fees for work at [the initial hearing and administrative appeal] levels. . . . Such legislation would do much to avoid errors and speed the adjudication process, which today is tragically slow and fraught with avoidable error.”

The American Bar Association House of Delegates unanimously approved a resolu-

89 See Russo, supra note 57, at 28 (citing In re Fee Agreement of Kenneth B. Mason, Jr., in Case Number 90-920, U.S. Vet. App. No. 96-1663 (Jan. 22, 1999), the chief judge stated, “The Court’s experience in other cases over the past nine years convinces me that the time is ripe for a re-examination of the role of attorneys in the benefits adjudication process.”); see also Dowd, supra note 8, at 79-80 (citing statements by the Honorable Kenneth B. Kramer, the Honorable Donald L. Ivers, and the Honorable Frank Q. Nebeker).
90 See DiMatteo, supra note 22, at 977-78 (citing Frank Q. Nebeker, Chief Judge, United States Court of Appeals for Veterans Claims, Address at the Sixth Judicial Conference of the United States Court of Appeals for Veterans Claims (Sept. 18, 2000)).
tion supporting legislation to repeal the prohibition of attorney’s fees for attorneys who represent veterans.91

A. The Benefits Allowed for Veterans Represented by Attorneys and Veterans Represented by Others Should be Compared

Given the higher percentage of positive outcomes achieved by veterans represented by attorneys at the BVA, it cannot be definitively argued that VSOs are as effective as attorneys. Therefore, Congress, the General Accounting Office, or the VA should examine whether veterans represented by attorneys receive a higher disability rating than veterans represented by another organization. If veterans represented by attorneys do receive a higher disability rating, then the argument for attorney representation of veterans at the outset of filing a claim is that much stronger from a financial point of view.

B. Veterans Should Be Allowed to Hire Attorneys Because of the Efficiencies Attorneys Bring to the VA Disability Claims Process

First, the idea that attorneys will “cause delay and sow confusion”92 in the disability

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92 See Walters, 473 U.S., at 325.
claims process is overly cynical and contrary to the attorney’s ethical obligations and pecuniary interest in seeing a case resolved in the veteran’s favor for the maximum amount possible. Second, given the increasing complexity of disability claims and of the underlying medical conditions, such as post-traumatic stress disorder and traumatic brain injury, allowing veterans the freedom to hire an attorney will result in clear and cohesive arguments, better supported by well-developed facts necessary to support a claim. Third, because the “law governing veterans’ benefits has grown increasingly complex,” attorneys are best suited to navigate and understand the bureaucratic rules and regulations and draft claims that are written within the framework of the law and with the support of the law. Poorly prepared claims are a problem, as demonstrated by the fact that in a survey reviewing Veterans Service Representatives, “[f]orty-one percent of the respondents estimated that 30 percent or more of the claims were not ready to rate when presented for rating.” Fourth, attorneys can identify and preserve issues for appeal while that record is being created, reducing or eliminating the need for the veteran to further develop the record later. Fifth, fewer claims will be dismissed due to failing to follow procedural rules that attorneys are trained to follow. For example, “a veteran appealing a denial of a claim to the CAVC must present all issues and arguments in the opening brief. Any issue not presented in the opening brief will be deemed abandoned. . . .”

93 See DiMatteo, supra note 22, at 997.
94 See Dowd, supra note 8, at 55.
about 25 percent of all appeals for procedural reasons." Sixth, attorneys are better able to decide whether appealing an adverse VA decision is justifiable, and will make a more measured decision rather than a decision based on a sense of futility.

Eliminating the proscription of attorney’s fees is not a new idea. In 2006, Senate Bill 2694, the Veterans’ Choice of Representation Act of 2006, and its companion bill in the House, House Bill 5549, sought to eliminate any proscription on a veteran’s ability to hire an attorney for representation during the claims process.

VII. CONCLUSION

Political platitudes will not solve the problem of inaccurate disability compensation determinations. Nor can judges solve the problem, as they only see a small fraction of the VA’s determinations. Certainly, academic discussion will not create an effective system.

The solution lies in the capable hands of attorneys who are trained to advocate for their clients, write clear and cohesive arguments, understand bureaucratic rules and regulations, and preserve issues for judicial review. These qualities come at a premium, however, and attorneys should not have to choose between going out of business and providing services to those who served our country. Therefore, eliminating the proscription on attorney’s fees will provide immeasurable benefits to America’s veterans.

96 Id. at 75-76.
97 See Fox, supra note 39, at 55.
98 See Dowd, supra note 8, at 87-88.
BOOK REVIEW

THEY’RE YOUR PARENTS, TOO!
HOW SIBLINGS CAN SURVIVE THEIR PARENTS’ AGING
WITHOUT DRIVING EACH OTHER CRAZY

(Bantam Books, 2010)
Author: Francine Russo

Reviewed by Barbara J. Gilchrist, JD, PhD

Remember “Ask Francine” in Time magazine? Beginning in April 2004, and continuing for almost 10 years, Francine Russo shared stories from baby boomers and responded to their dilemmas with wit and wisdom. Now she has written a book using the same technique of sharing a real story and offering ideas for how to cope. The book, They’re Your Parents, Too!: How Siblings Can Survive Their Parents’ Aging without Driving Each Other Crazy, grew out of her own experience with her sister and their mother’s last illness and death.

Every Elder Law attorney will recognize the behaviors of the adult siblings who populate Russo’s book — the butting of heads over who will make medical decisions for Mom or Dad or who will control the money. We are also familiar with the gambit of adult children’s reactions to a parent’s decline — from the child who steps in to provide care, to the one who flies in for a weekend only to challenge or up-end the structures that have been put in place. We talk about how these situations are similar to divorces in which control over minor children can become the focal point for all the parents’ emotional pain. Emotional baggage from childhood can cause current conflict as now-adult children struggle to figure out what to do with and for the person who used to be in charge. Some of us have experienced this in our own lives and may not have known how to accomplish the common goal of caring for an elderly parent without damaging sibling relationships.

Russo describes this circumstance — siblings dealing with ill and dying parents — as an “existential crisis” and as the “Twilight” stage in the life of our first family. Specifically she notes:

This transition unfolds over several years, even decades, as we and our siblings reunite around our aging parents and their new needs. Over time we share or resist responsibilities for their health, well-being, and property, making decisions from the mundane to the literally life-and-death. But the twilight is not only a matter of solving practical problems and meeting practical needs. It is an existential crisis through which we will be transformed from the children of our parents to the elders of our family.

The theme of the book is that the experience for siblings of parents becoming frail

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and dying is a major break from what has been. It requires a redefinition of roles and a change in perception of one’s place. The first chapter of the book is aptly titled: “The Last Transition of Our First Family.” The 10 chapters that follow take the reader through a process: from acknowledging the new reality to adapting to new roles, from resolving old conflicts to adjusting to new decision makers, and finally, gathering at the deathbed and dealing with the aftermath of death. Throughout, Russo provides real stories and suggests strategies for dealing with issues and coping with change. For example, Russo describes the three Kristal sisters in the “Dad Still Loves You More” chapter. Two sisters stayed near home and one went away, causing the two to feel abandoned. Now the three must work together in caring for Dad. Russo suggests ways to “tame” the old rivalries. For instance, recognize that old feelings may erupt in this time of crisis, but, as an adult, you have the ability to understand things differently. She also suggests that, if the parent is contributing by fanning the flames of old issues, the conflict may be diffused by a discussion between the siblings so that they are not pitted against each other.

Russo is a journalist who, in addition to her regular column in Time magazine, has also written for the New York Times Magazine, the Village Voice, Family Circle, and the Atlantic. Her experience studying the current generation of adult children with elderly parents and her own life-experience is apparent in this book. It is not a one-dimensional self-help book that claims to have the solution for all families. Rather, Russo recognizes that family dynamics are complex and unique: “Every family is a separate country with its own laws, governing powers, and assumptions.” And she recognizes that, no matter what, not everything can be fixed in family relationships. Speaking about her own experience, she says “understanding [family dynamics] better could have helped me do more of what was possible and reduce my distress over what was not.”

Elder Law attorneys will find this book helpful. Often, the lawyer is introduced to a family crisis by one sibling, or possibly two siblings, at his or her wit’s end because of a sister or brother who disagrees about who should be in charge, with the type of care needed, or just won’t help. Perhaps decisions about care or the use of money have already been made without input from all the siblings and those decisions are now being questioned. Emotions are likely high and every family member believes in the “rightness” of his or her perspective. In addition, if the siblings cannot resolve their differences, legal actions such as a contested guardianship or a challenge to a power of attorney may cause further emotional damage. The insights in Russo’s book may help the attorney in understanding the emotional dynamics within a particular family and, thus, be better prepared to suggest non-legal options for resolving differences. This may also be a book attorneys will want to recommend to clients who are in the midst of a crisis so that they may find better ways of coping with family strife.

While Russo is no longer writing her “Ask Francine” column, she is available on her blog. For those boomers who want to share a story or ask for more advice, Francine can be reached at: http://yourparentstoo.squarespace.com/blog-dispatches-from-the-front.
BOOK REVIEW

ORGANIZING THE CHAOS, DISPELLING THE MYTHS, ELEVATING THE DEBATE: CCH’S SUCCESSFUL ANALYSIS OF HEALTH CARE REFORM

(Wolters Kluwer Law and Business, 2010)

Reviewed by Claire DeMarco, Esq.

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I. INTRODUCTION

Rarely in our country’s history has a single legislative issue spawned over half a century of debate; those that have are among the most intimate to our delicate balance of federalism and individualism — judicial review, slavery, women’s suffrage, the right to privacy. Including health care reform in this list of iconic battles cements its place in our collective understanding of what constitutes our basic civil rights as Americans. The media’s coverage of this tortured legislative effort was replete with accusations that the framers of the law, our elected representatives, were unfamiliar with its content. The average American could reasonably believe that the law violated the Constitution in favor of socialized medicine or that the law would produce a utopian society of happier, healthier Americans.

With over 2,100 pages, organized into two volumes, Commerce Clearing House’s Law, Explanation and Analysis of the Patient Protection and Affordable Care Act (CCH’s Analysis) takes the text of the Patient Protection and Affordable Care Act with Recon-

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conciliation Act and expands it to include easy-to-understand explanations and background information, compiling it into digestible summaries by topic. CCH has, in record time, produced an analysis that rewards the reader with an organized, comprehensible account of the outcome of this most recent health care reform battle. *CCH's Analysis* begins, appropriately, with a summary of the “more than 70 years of attempts by the federal government to expand health care access and coverage,” highlighting the impact of the Social Security Act of 1965, which established Medicare and Medicaid. The text then turns to the specific legislative history of the Patient Protection and Affordable Care Act, as well as the Health Care and Education Reconciliation Act. Readers unfamiliar with federal legislative process will appreciate this high-level summary, which includes the turning point in January 2010, when the seating of newly elected Senator Scott Brown from Massachusetts ended the possibility of a filibuster-proof majority. Since, under Senate Rules, the budget reconciliation process requires only a 51-vote majority, rather than the 60-vote filibuster-proof majority, the Democratic majority was able to pass both the Patient Protection and Affordable Care Act, as well as the Health Care and Education Reconciliation Act without a single Republican vote.

*CCH's Analysis* breaks the Patient Protection and Affordable Care Act, including the subsequent Reconciliation Act, into digestible topic summaries, and cross-references them to the original text of the statute. Elder Law attorneys will find the manual’s organization by topic to be particularly helpful in singling out issues of interest to older clients, while providing a broad overview of the law’s impact on the general population. Given the high profile of the law in mass market media, clients are likely to be concerned about its potential impact on health care issues beyond the scope of Elder Law.

This review is intended to provide an overview of *CCH's Analysis* and to direct Elder Law attorneys to specific topics of interest, providing critical analysis of the way in which the authors and editors address these topics. Although *CCH's Analysis* is the first comprehensive reference text for the Patient Protection and Affordable Care Act, many other independent analyses of the law have been proffered from highly regarded sources such as the Kaiser Family Foundation and the Commonwealth Fund, as well as reports by the Congressional Budget Office, House and Senate Committees, and coverage from media outlets. Unlike a traditional book review, which critiques the author’s hypothesis,

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1. *CCH's Law, Explanation and Analysis of the Patient Protection and Affordable Care Act*, Introduction (Paul Gibson pub., Commerce Clearing House, 2010).
2. *Id.*
argument, and reasoning, this review examines the authenticity, usability, and appropriateness of *CCH’s Analysis* as a practical guide for Elder Law attorneys.

II. FOCUS POINTS

*CCH’s Analysis* includes both general and detailed tables of contents. The first provides a quick listing including chapter headings such as: “Public Programs: Medicaid & Children’s Health Insurance Program,” “Medicare Part D Improvements,” “Elder Justice Act,” “CLASS Act,” and the corresponding paragraph number.² The second, more detailed table breaks the chapters into subchapters and subheadings, again with corresponding paragraph numbers. For example, “Chapter 5 Public Programs: Medicaid & Children’s Health Insurance Program” is broken down into eight subchapters, such as: “Medicaid Coverage and Eligibility,” “Expansion of Medicaid Services,” and “Options for States to Provide Long-Term Services and Supports.” Each of those subchapters includes a listing of subheadings by topic with corresponding paragraph numbers. Under “Options for States to Provide Long-Term Services and Supports” there are eight subheadings including: “Removal of Barriers to Home- and Community-Based Services,” Protection of Home- and Community-Based Services Recipients from Spousal Impoverishment,” and “Sense of the Senate Regarding Long-Term Care.” These tables of contents are followed by a “Highlights” section, which provides a brief synopsis of each topic subheading, over 100 in total. On page 55 the analysis begins, taking each chapter, subchapter, and subheading in turn.

In order to determine the applicability of *CCH’s Analysis* to the work of Elder Law attorneys, there are several key areas that must be addressed: changes to Medicaid, specifically around long-term services and supports; changes to existing Medicare provisions, including Part D Prescription Drug Coverage; attempts to address quality of care issues in Medicare; Medicare and Medicaid Transparency, including Nursing Home transparency; the Elder Justice Act; and the CLASS Act. In addition, a general overview of insurance market reforms and increasing access to care, while not directly applicable to elders, are positioned to have a dramatic effect on the population at large, and cannot be overlooked by Elder Law attorneys.

A. Changes to Medicaid

The most significant reform is expansion of Medicaid to most of the nation’s uninsured and underinsured population. Beginning January 1, 2014, states will be required to provide Medicaid benefits to individuals with household incomes up to 133 percent of the federal poverty level who are: under the age of 65, not pregnant, and not entitled to or enrolled in Medicare or Medicaid under any other category.³ While the age restriction makes this clearly a non-issue for the elderly population, *CCH’s Analysis* points out that

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² *CCH’s Law, Explanation and Analysis of the Patient Protection and Affordable Care Act* uses paragraph numbers at the bottom of each page, which are referenced in both the tables of contents and the index, rather than relying on the page numbers listed at the top of each page. While it may be confusing upon first glance, this distinction allows the practitioner to progress seamlessly from Volume 1 to Volume 2 without relying solely upon duplicative page numbers.

³ *Id.* at 259.
“the likely inclusion of many millions of new Medicaid recipients will strain local social services districts that are charged with determining eligibility by considering income and other resources … [and] portend a shift in the number of patients who remain ‘Self-Pay,’ as they move to the Medicaid rolls.”6 States will be required to use modified adjusted gross income to determine Medicaid eligibility, and asset tests will no longer apply except for long-term services.7 Placing such strain on the system may result in decreasing benefits for long-term care. Among the potential cutbacks are: reducing coverage, tightening eligibility standards for the program, and expanding recovery from currently non-countable assets. Clients younger than 65 who are in need of rehabilitative care may benefit tremendously from the new law’s prohibition on asset or resource-based tests for Medicaid eligibility. Elder Law attorneys should be prepared to deal with these consequences as we approach 2014.

For community care clients, the law establishes a new program known as the Community First Choice Option, which allows state Medicaid programs to offer community-based personal care attendant services and supports to Medicaid beneficiaries who would otherwise require long-term care.8 The program will have an income limit of 150 percent of the federal poverty level, and states that choose to participate will be eligible for an enhanced federal match rate of an additional six percent for reimbursable expenses in the program.9 Furthermore, the law expands home- and community-based services (HCBS) systems that have previously been available only to states that obtain a federal waiver.10 The Secretary of Health and Human Services (HHS) is directed to promulgate regulations to ensure that all states develop HCBS systems for non-institutional long-term care services and supports in order to maximize the independence of beneficiaries receiving such services.11 The law also has extended a little-known project entitled the “Money Follows the Person Rebalancing Demonstration,” which awards competitive grants to states to help transition Medicaid-eligible individuals from long-term institutional care to community-based long-term care. The law also expands the definition of “institutionalized spouse” beyond that of a spouse in a skilled nursing facility to include a spouse who is eligible for HCBS or Community First Choice Option. This will enable a married couple to obtain Medicaid benefits, even for home-based care, without becoming completely impoverished.12 The limits for assets retained by a “community spouse” are still based entirely on a state-by-state resource determination.13

CCH’s Analysis summarizes Section 2406 of the Act, which provides “the sense of the Senate” — the intent of the law’s drafters — that “Congress should address long-term services and supports in a comprehensive way that guarantees elderly and disabled individuals the care they need, in the community as well as in institutions.”14 The Senate also

6 Id. at 260.
7 Id. at 263.
8 Id. at 279.
9 Id. at 279-280.
10 Id. at 281.
11 Id. at 282.
12 Id. at 290.
13 Id.
14 Id. at 292.
expressed displeasure that “long-term care provided to elderly and disabled individuals has not improved [in the past 20 years] and, in many instances has worsened.”15 In 2007, 69 percent of Medicaid long-term care spending for elderly and disabled individuals were for institutional services, according to CCH’s Analysis.16 Only six states spent 50 percent or more of their Medicaid long-term care dollars on HCBS, while half of states spent less than 25 percent on those non-institutional services.17 The Act’s home-based care provisions cannot single-handedly turn the tide on the provision of non-institutional services, but the inclusion of this “sense of the Senate” demonstrates intent to move toward community and home-based services.

B. Changes to Medicare

CCH’s Analysis categorizes the changes to Medicare under the Act into several general sections: Medicare Payment Accuracy Improvements, Changes to Part C, Changes to Part D, and Medicare Sustainability. While these groupings are not unique to CCH’s Analysis, the subject-matter organization allows for clear explanations of incredibly complex issues, rather than listing hot-button issues out of context or relying on the jumbled order of the law’s original text.18 Placing legislative changes in context is critical to an understanding of Medicare reimbursement issues, where a tumultuous history of debate among private insurers, providers, and health policy experts has left significant misinformation in the public.19 CCH’s Analysis does an excellent job of explaining not only the changes to home health care reimbursements, for example, but the original legislation that mandated the development of the home health prospective payment system, and in a separate section with expert guidance, detailing the eligibility criteria for the Medicare Home Health benefit.20

Another example of how vital the context provided by CCH’s Analysis is for Elder Law practitioners, who may be unfamiliar with Medicare reimbursement rules, can be found in the discussion of the Skilled Nursing Facility Prospective Payment System. CCH’s Analysis discusses a 2006–2007 study known as the Staff Time and Resource Intensity Verification (STRIVE) study, which aimed to identify the level of staffing resources needed to provide quality care to nursing home patients.21 As a result of information learned from the study, CMS was set to implement a revised classification system that would allocate reimbursements more accurately based on patient types, medical practice and updated staff resources.22 Section 10325 of the Act delays the implementation of the

15 Id.
16 Id.
17 Id.
20 CCH’S LAW, EXPLANATION AND ANALYSIS OF THE PATIENT PROTECTION AND AFFORDABLE CARE ACT at 481-482.
21 Id. at 489.
22 Id.
STRIVE system, that would have produced lower overall payments than the existing classification system.

One area of particular interest to Elder Law attorneys, an example of the comprehensiveness of CCH’s Analysis, can be found in the discussion of the Programs of All-inclusive Care for the Elderly (PACE). PACE was created in 1990 as a demonstration project to help community-based organizations provide health and long-term care services to elderly persons at risk of being institutionalized. In 1997, PACE became a permanent program and a state option for the Medicaid program to “provide pre-paid, capitated, comprehensive health care services designed to enhance the quality of life and autonomy for frail, older adults; maximize the dignity of, and respect for, older adults; enable frail, older adults to live in the community as long as medically and socially feasible; and preserve and support the older adult’s family unit.” The Patient Protection and Affordable Care Act would have maintained payments for PACE programs on a capitated or per-member basis, but under the Reconciliation Act, the programs will now be subject to competitive bidding and pay-for-performance bonuses based on Medicare Advantage benchmarks. While an analysis of the previous capitated payment system may seem superfluous in light of the repeal, Elder Law practitioners may be called on to correct client misunderstandings on the topic and, in states where the PACE program option is exercised, to understand the shift from capitation to competitive bidding. CCH’s Analysis outlines what changes would have occurred had the section not been repealed, which allows the reader a broader understanding of the pre-reform PACE program. Patty Te-lenger, a Senior Director of Reimbursement at Emerson Consultants, Inc. reflecting on the shift to competitive bidding as an expert for CCH’s Analysis, laments that there is now “a certain level of uncertainty for the PACE programs.”

Additional topics of interest to Elder Law practitioners and their clients include an earlier, extended annual enrollment period for Medicare Advantage and Part D plans, a permanent senior housing facility demonstration project, and the development of new standards for Medigap plans. The most talked about provision related to Medicare, however, is the elimination of the so-called “Donut Hole” in Medicare Part D Prescription Drug Plans. According to CCH’s Analysis:

“In order for prescription drugs, dispensed on or after January 1, 2011, to be covered under Medicare Part D, a drug manufacturer must participate in a new coverage gap discount program that provides a 50 percent discount on applicable drugs provided to applicable beneficiaries that fall into the coverage gap know[n] [sic] as the ‘donut hole.’”

23 Id. at 523.
24 Id. at 524.
25 Id.
26 Id.
27 Id.
28 Id.
29 Id. at 528, 533, and 535.
30 Id. at 540.
31 Id.
CCH’s Analysis includes a reference to the role of the Pharmaceutical Research and Manufacturers of America (PhRMA) in developing this plan, which should not go unnoticed by the reader. Unlike previous attempts to enact health care reform, where the pharmaceutical companies were vilified by political rhetoric, this most recent reform effort relied heavily on the participation of industry representatives, most notably in changes to the Part D program. President Obama has consistently referenced the inclusion of all interested parties at the table when developing the various health care reform proposals that led to the passage of the final bill. Many political pundits hailed the President’s inclusion of industry leaders as a departure from failed attempts in the past to fight against the influence of insurers, pharmaceutical companies, and providers. PhRMA estimated that its proposal to provide 50 percent discounts will save Medicare patients $34 billion over 10 years, while the Congressional Budget Office estimated that the proposal will save them $30 billion in the same period.

In addition to the donut hole discount provided by the pharmaceutical industry, the new law partially closes the coverage gap in 2010 by providing a $250 rebate for individuals enrolled in a Part D plan (or Medicare Advantage drug plan) who have incurred costs for covered drugs exceeding the initial coverage limit — in other words, those who fall into the donut hole. CCH’s Analysis does an excellent job of walking the reader through the changes to the original reform legislation resulting from passage of the Reconciliation Act. The Reconciliation Act builds on the pharmaceutical industry’s 50 percent discount on brand-name drug discount, by providing a 75 percent discount on generic as well as brand-name drugs by the year 2020.

C. Transparency

Although there are several sections of the new law aimed at increasing transparency in terms of physician referrals and hospital ownership, of significant interest to Elder Law practitioners is the section dealing with Nursing Home Transparency, which is highlighted prominently in CCH’s Analysis. As a result of health care reform, nursing facilities will be required to disclose new information regarding the ownership and organizational structure of their facilities to the Secretary of HHS, who will then make the information available to the public. In addition to the information such facilities were required to

32 Id. at 541.
35 See infra note 28.
36 CCH’S LAW, EXPLANATION AND ANALYSIS OF THE PATIENT PROTECTION AND AFFORDABLE CARE ACT at 541.
37 Id. at 546.
38 Id.
39 Id.
40 Id. at 820.
41 Id.
disclose under existing law, these facilities must also provide information on (1) each member of the governing body of the facility, (2) each person or entity who is an officer, director, member, partner, trustee, or managing employee, and (3) any other person or entity who exercises operational, financial, or managerial control over the facility, leases or subleases real property to the facility, or provides management or administrative services, consulting services, or financial services to the facility. Such facilities are also now required to implement a compliance and ethics program for all employees and agents.\footnote{Id. at 822.}

These compliance and ethics programs “will need to be reasonably designed, implemented, and enforced to be generally effective in preventing and detecting civil, criminal, and administrative violations, as well as promoting quality of care.”\footnote{Id. at 823.} Required components include: standards and procedures, resources and authority to assure compliance, monitoring for individuals at risk, effective communication through training programs, auditing systems, disciplinary mechanisms, as well as plans for periodic reassessment. Such programs must be in place within three years of enactment of the Act, with specific regulations from the Office of Inspector General and HHS established within two years.\footnote{Id.}

As most Elder Law attorneys are likely aware, one key element to choosing an appropriate skilled nursing facility is staffing information, and unlike any regulation existing in current law, under the Patient Protection and Affordable Care Act, skilled nursing facilities will now be required to submit direct care staffing information, including agency and contract staff, based on payroll and other auditable data to the Secretary of HHS.\footnote{Id. at 829.} The information to be reported includes: (1) work performed by a certified employee; (2) resident census data; (3) an established reporting schedule; and (4) employee tenure and turnover, as well as hours of care provided by each certified employee category, per resident, per day.\footnote{Id. at 830.} This requirement, coupled with the inclusion of this information on CMS’ Nursing Home Compare website, mandated expenditure reporting, complaint standardization, and dementia and abuse prevention training should not only increase the quality of care for residents in facilities, but also provide peace of mind to their families in making a decision to institutionalize a loved one in need.\footnote{Id. at 824-832.}

\section{Elder Justice Act}

\textit{CCH’s Analysis} begins its discussion of the Elder Justice Act with a compelling statement of need: “More than 500,000 adults over age 60 are victims of elder abuse. They are subjected to physical, sexual, and psychological abuse, as well as neglect, self-neglect, abandonment, and financial exploitation.”\footnote{Id. at 916.} In order to address this growing problem, the Patient Protection and Affordable Care Act establishes an Elder Justice Coordination Council and an Advisory Board on Elder Abuse, Neglect and Exploitation, made up of experts in the field to develop innovative approaches to improve the quality of long-term care.
care, including preventing abuse, neglect, and exploitation.\textsuperscript{49} The Elder Justice Coordination Council will oversee several grant programs, whose results will be reported to Congress, with a combined funding of more than $600,000,000 for fiscal years 2011-2014.\textsuperscript{50}

The law does not create this Council in a vacuum however; the Elder Justice Act employs a “multi-pronged” approach to combat these types of abuses.\textsuperscript{51} The Act includes training for those who investigate allegations of abuse, as well as grants to state agencies to develop complaint investigation systems.\textsuperscript{52} Additionally, the law requires that owners, employees, and contractors of federally funded long-term care facilities report crimes occurring in such facilities; failure to report will subject individuals to monetary civil penalties and exclusion from federal health care programs.\textsuperscript{53} No such law currently exists to mandate the reporting of elder abuse, and as CCH’s Analysis points out, the National Institute of Justice estimates that 11 percent of people age 60 and above suffer some kind of abuse each year. The reporting requirements should not be taken lightly, for example, if a suspected crime results in serious bodily injury, the individual—owner, employer, or contractor—must report the suspicion immediately, and not later than two hours after forming the suspicion.\textsuperscript{54} Failure to report will result in a civil monetary penalty of as much as $200,000 or exclusion from federal programs for up to two years.\textsuperscript{55} There are also increased penalties if failure to report the crime in a timely manner exacerbates the harm.\textsuperscript{56} The inclusion of this Act in the larger health care reform package was heralded by the 622 member non-partisan Elder Justice Coalition as “a new day in the fight against elder abuse, neglect and exploitation.”\textsuperscript{57} Robert Blancato, National Coordinator of the Coalition, said about the Elder Justice Act, “with one stroke of a pen, President Obama ended a more than a seven year legislative journey to make elder justice the law of the land.”\textsuperscript{58} While there is no new private right of action created under this law, practitioners who litigate on behalf of elders and their families will now have the support of the federal government in holding facilities and medical professionals accountable for reporting abuse, neglect, and exploitation.

\section*{E. CLASS Act}

Finally, and perhaps of most interest to Elder Law practitioners is the Community Living Assistance Services and Supports (CLASS) program. This consumer-funded and voluntary long-term care insurance program provides a benefit that is not less than $50 per day, with a five-year vesting period for eligibility. Premiums will be paid through payroll deduction from wages or self-employment income, and for the unemployed, HHS

\begin{thebibliography}{99}
\bibitem{49} Id.
\bibitem{50} Id.
\bibitem{51} Id.
\bibitem{52} Id. at 918-919.
\bibitem{53} Id. at 920. Note that prior to enactment of health care reform there was no federal law requiring the reporting of elder abuse. Id.
\bibitem{54} Id. at 921.
\bibitem{55} Id.
\bibitem{56} Id.
\bibitem{58} Id.
\end{thebibliography}
will devise a method of premium payment.\textsuperscript{59} \textit{CCH’s Analysis} includes a well-written summary of the need for such a program, highlighting that there are presently 10 million Americans in need of long-term care services and supports, and as the baby boomers age into retirement, these numbers will more than double.\textsuperscript{60} As all Elder Law attorneys know, most individuals who have or develop functional impairments come to depend on Medicaid to pay long-term care costs once assets are spent down to $2,000.\textsuperscript{61}

The law establishes a trust fund consisting of enrollees’ premiums and interest earned on accumulated fund balances to pay claims, and the law explicitly states that no taxpayer funds can be used for payment of benefits.\textsuperscript{62} According to the Kaiser Family Foundation, monthly premium amounts will be determined by the HHS Secretary. The goal is to maintain a 75-year program solvency, with younger participants paying less than older participants.\textsuperscript{63} Those with incomes below the federal poverty level and full-time students who are actively employed will pay nominal premiums, starting at $5 per month.\textsuperscript{64} The Congressional Budget Office (CBO) estimated that average premiums would be $123/month.\textsuperscript{65}

\textit{CCH’s Analysis} provides a comprehensive overview of the CLASS Act’s requirements, and identifies areas where the rules for this new program will differ from Social Security benefits and Medicaid. For example, unlike Social Security, which will provide benefits retroactively from as long as one year prior to the application filing date, a claimant applying for a CLASS benefit will not be able to receive retroactive benefits regardless of the length of time it might take for a claim to be approved.\textsuperscript{66}

Eligibility for CLASS program benefits is intended to have no effect on eligibility for other public benefits such as Medicaid, Medicare, Social Security, or disability benefits.\textsuperscript{67} If an individual is eligible for both CLASS program benefits and long-term services and supports under Medicaid, CLASS benefits will be used to offset the costs of Medicaid.\textsuperscript{68} For example, a Medicaid beneficiary who resides in an institution will be able to keep five percent of the daily or weekly cash benefit amount.\textsuperscript{69} That amount will be added to their personal needs allowance with the remainder of the benefit being applied to the facility’s cost of providing the patient’s care.\textsuperscript{70}

The CBO estimates that the CLASS Act will reduce the federal deficit by $70.2 bil-

\begin{itemize}
\item \textsuperscript{59} C\textsc{ch}’\textsc{s} \textsc{l}\textsc{aw}, \textsc{e}x\textsc{planation} \textsc{a}nd \textsc{a}n\textsc{alysis} \textsc{of} \textsc{t}he \textsc{p}atient \textsc{p}rote\textsc{ction} \textsc{a}nd \textsc{a}ffordable \textsc{c}are \textsc{a}ct at 941.
\item \textsuperscript{60} \textit{Id.} at 948.
\item \textsuperscript{61} \textit{Id.}
\item \textsuperscript{62} \textit{Id.} at 955; \textit{see also} Kaiser Family Foundation, Focus on Health Reform: Health Care Reform and the CLASS Act \textit{available at} http://www.kff.org/healthreform/upload/8069.pdf.
\item \textsuperscript{63} Kaiser Family Foundation, Focus on Health Reform: Health Care Reform and the CLASS Act \textit{available at} http://www.kff.org/healthreform/upload/8069.pdf.
\item \textsuperscript{64} \textit{Id.}
\item \textsuperscript{65} American Association of Homes and Services for the Aging, CLASS Act Summary \textit{available at} http://www.aahsa.org/classact.aspx.
\item \textsuperscript{66} C\textsc{ch}’\textsc{s} \textsc{l}\textsc{aw}, \textsc{e}x\textsc{planation} \textsc{a}nd \textsc{a}n\textsc{alysis} \textsc{of} \textsc{t}he \textsc{p}atient \textsc{p}rote\textsc{ction} \textsc{a}nd \textsc{a}ffordable \textsc{c}are \textsc{a}ct at 952.
\item \textsuperscript{67} Kaiser Family Foundation, Focus on Health Reform: Health Care Reform and the CLASS Act \textit{available at} http://www.kff.org/healthreform/upload/8069.pdf.
\item \textsuperscript{68} \textit{Id.}
\item \textsuperscript{69} C\textsc{ch}’\textsc{s} \textsc{l}\textsc{aw}, \textsc{e}x\textsc{planation} \textsc{a}nd \textsc{a}n\textsc{alysis} \textsc{of} \textsc{t}he \textsc{p}atient \textsc{p}rote\textsc{ction} \textsc{a}nd \textsc{a}ffordable \textsc{c}are \textsc{a}ct at 951.
\item \textsuperscript{70} \textit{Id.}
\end{itemize}
lion over the course of a 10-year period, in addition to reducing Medicaid spending by serving individuals in community-based settings rather than institutional settings.\textsuperscript{71} The HHS Secretary retains some discretion as to the implementation of this program, but it is fair to say that it is the broadest reaching effort since the creation of the Medicare program to provide care for our aging population.

III. EDITORS AND CONTRIBUTORS

The contributors to \textit{CCH's Analysis} range from employment law practitioners, health care finance and policy experts, and experts in both public and employee benefits, to coding and billing specialists. While most of the contributors have legal backgrounds, many have additional degrees in business, public health, or health law. Two of the more widely published health law and policy experts are Attorney Timothy Blanchard of Blanchard Manning LLP and Professor Leighton Ku of the George Washington University School of Public Health and Health Sciences.

Attorney Blanchard practiced for 20 years at McDermott, Will & Emery before embarking on his own practice, which comprises health care regulatory issues, including Medicare and Medicaid coverage, billing, and payment; fraud and abuse audits and investigations; and health care compliance programs; clinical trials billing and compliance; electronic health records and HIPAA privacy; certification, licensing, and enrollment; and medical necessity and utilization review.\textsuperscript{72} He has testified before the House Committee on Small Business regarding Medicare coverage and payment policy issues and has addressed Government Accountability Office staff regarding Medicare and Medicaid medical necessity policy issues.\textsuperscript{73}

Professor Ku joined the George Washington University School of Public Health and Health Services as a full-time faculty member in 2008, but held adjunct positions at the School of Public Policy and Public Administration since the early 1990s, as an expert on Medicaid, the State Children’s Health Insurance Program (SCHIP), immigrant health, state health reform, and health care financing and budgets, with an emphasis on strengthening the health care safety net.\textsuperscript{74} During that time, he also served as a senior fellow at the Washington-based Center on Budget and Policy Priorities, which focuses on improving policies for low- and moderate-income Americans; as principal researcher at the Urban Institute; and as a policy and budget analyst for the federal Women, Infants and Children (WIC) nutrition program.\textsuperscript{75} Professor Ku is widely published as the author or co-author of more than 200 articles and reports about health policy and public health focused on health care access and insurance coverage for low-income and vulnerable populations.\textsuperscript{76} Including these two experts among such a diverse panel demonstrates a balanced approach to the analysis of this dense and multi-faceted legislation.

\begin{itemize}
\item [73] Id.
\item [74] Leighton Ku, Biography available at http://www.gwumc.edu/sphhs/faculty/index.cfm?employeeID=301.
\item [75] Id.
\item [76] Id.
\end{itemize}
Elder Law attorneys should note, however, that although the board includes experts in Medicare and Medicaid, none of the contributors have a specific background in Elder Law. Mirroring the broad focus of the law on increasing access to the uninsured and underinsured working populations, the board of contributors appears focused on the impact of health care reform from an employee benefits perspective, which obviously has much less of an interplay with the elderly. The book does, however, highlight the significant reforms in both Medicare and Medicaid that will likely have a lasting impact on the health care system at large.

IV. CONCLUSION

In this author’s view, CCH’s Analysis is a must-read for those attorneys seeking a well-organized, explanatory outline of the Patient Protection and Affordable Care Act including the Reconciliation Act impact. While practitioners with knowledge of health care reform efforts over the years might appreciate more comparative background, those looking for a comprehensive reference text to address client issues will find it well-documented and free of jargon. In addition to the five major initiatives detailed here, which will be addressed in greater detail in the NAELA Journal’s next issue, practitioners can use the index to quickly find explanations of some of the more miscellaneous provisions related to care for the elderly. This objective text will also help to dispel the myths promulgated by radical members of both political parties that dominated the debate surrounding the law’s passage. It is with a deep reverence for the effort that went into taking on the issue of health care reform, the issue our late Senator Kennedy called the “cause of his life,” that this author can endorse CCH’s Analysis as a comprehensive, objective, summary of the Patient Protection and Affordable Care Act Including Reconciliation Act Impact.