

# NAELA JOURNAL

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Observing the NOTICE Act

By Professor Leigh Melton, JD, Amanda Bird, JD, and Lauren Ritter, JD

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## I. Introduction

In September 2014, after fainting in her bathroom, 76-year-old Caroline Giada suffered a severe injury, was rushed to an emergency room, and was placed under “observation status” while medical staff conducted various tests to diagnose her injury.<sup>1</sup> Six days later, health care providers finally discovered that Giada had a fractured lower spine.<sup>2</sup> Giada required surgery, but the necessary specialist could not operate on her for about a week. The hospital could not provide additional care in the interim, forcing Giada to choose between returning home alone or temporarily staying at a costly private nursing facility. Because she was in pain and needed assistance, Giada choose the latter under the assumption that Medicare would reimburse her for her stay.<sup>3</sup> After her surgery, Giada received a significant bill from the nursing facility.<sup>4</sup> Only then did the hospital explain to Giada that *she was under observation for the entirety of her 6-day stay*.<sup>5</sup>

The experience of Giada and thousands like her inspired a new Medicare law that requires hospitals to notify patients that they may incur huge out-of-pocket expenses if they stay more than 24 hours without being formally admitted. On August 6, 2016, Congress passed the Notice of Observation Treatment and Implication for Care Eligibility Act (the NOTICE

Act or the Act), which requires hospitals to provide oral and written notification to patients who are under observation for more than 24 hours of their observation status within 36 hours of being placed under observation.<sup>6</sup> The purpose of the Act is to “provide [Medicare] beneficiaries with accurate real-time information with respect to their classification, the services and benefits available to them, and the respective cost-sharing requirements they are subject to.”<sup>7</sup> However, the NOTICE Act, as enacted, fails to adequately address many problems stemming from the observation status classification.

## II. The NOTICE Act

### A. Observation Status Generally

In October 2013, the problematic consequences of Medicare’s observation status made their way into the public consciousness. *The New York Times* and *The Wall Street Journal* published articles focusing on the admission status of hospitalized Medicare recipients.<sup>8</sup> The articles describe how crucial it is not to receive the observation status label, which forces pa-

1 Elijah Wolfson, *The Dangerous Medicare Loophole of Observation Status*, Aljazeera Am. (Mar. 24, 2015, 5:00 a.m.), <http://america.aljazeera.com/articles/2015/3/24/the-dangerous-medicare-loophole-of-observation-status.html> (accessed Dec. 14, 2018). The name of the patient featured in the Wolfson article was changed for privacy purposes.

2 *Id.*

3 *Id.*

4 *Id.*

5 *Id.*

6 Ctr. for Medicare Advoc., *CMS Delays Implementation of NOTICE Act Until Fall 2016* (Aug. 4, 2016), <http://www.medicareadvocacy.org/cms-delays-implementation-of-notice-act-until-fall-2016> (accessed Dec. 14, 2018).

7 H.R. Rpt. 114-39 at 3 (Mar. 13, 2015), <https://congress.gov/114/crpt/hrpt39/CRPT-114hrpt39-pt1.pdf> (accessed Dec. 14, 2018).

8 Paula Span, *Two Kinds of Hospital Patients: Admitted, and Not*, N.Y. Times (Oct. 29, 2013), [http://newoldage.blogs.nytimes.com/2013/10/29/two-kinds-of-hospital-patients-admitted-and-not/?\\_r=0](http://newoldage.blogs.nytimes.com/2013/10/29/two-kinds-of-hospital-patients-admitted-and-not/?_r=0) (accessed Dec. 14, 2018); Anne Tergesen, *Beware Medicare’s ‘Observation’ Status*, Wall St. J. (Oct. 19, 2013, 8:26 p.m.), <http://www.wsj.com/articles/SB10001424052702303376904579135732284488114> (accessed Dec. 14, 2018).

tients to spend thousands of dollars out of pocket.<sup>9</sup> The touchstone for these articles was a 2012 Brown University study that identified a nationwide increase in hospital patients being kept under observation status as opposed to being admitted as inpatients.<sup>10</sup>

Under Medicare rules, when a Medicare recipient occupies a hospital bed under observation status, the patient is considered an outpatient.<sup>11</sup> As an outpatient, Medicare Part A does not cover the hospital stay; Medicare Part B only pays for the medical costs that accrue during the patient's hospital stay.<sup>12</sup> Observation status also affects an elderly patient's eligibility to receive Medicare support for rehabilitative care after hospital treatment. Inpatient status versus observation status has a huge impact on what medical expenses the patient will incur, as well as eligibility for skilled nursing facility care.

### B. Case Law

Alongside the Centers for Medicare & Medicaid Services (CMS) policy manuals, the courts have weighed in on how observation status should be understood with respect to guarantees of notice and procedural due process. *Bagnall v. Sebelius* was the first case to specifically address the question of whether failure to notify patients of their observation status violates the Due Process Clause of the Fifth Amendment.<sup>13</sup> *Bagnall* was a class

action suit brought by plaintiffs who were placed under observation status during their hospital visits but did not receive notice of their status and subsequently incurred extremely large bills.<sup>14</sup> The plaintiffs argued that the "[observation status] classification operate[d] to deny them Part A coverage to which they [were] entitled, and also violate[d] various procedural requirements."<sup>15</sup> The U.S. District Court for the District of Connecticut disagreed.<sup>16</sup>

The Connecticut District Court in *Bagnall* interpreted the plaintiffs' attempt to use observation status as a subterfuge to get around the ruling in *Estate of Landers v. Leavitt*, which was concerned with the Department of Health and Human Services' (HHS) interpretation of "inpatient" and "formal hospital admission."<sup>17</sup> In *Landers*, the U.S. Court of Appeals for the Second Circuit held that the CMS interpretation of "inpatient" in its own policy manuals was entitled to *Skidmore* deference<sup>18</sup> and therefore pre-formal admission to a hospital does not count toward the hospital time required to qualify for Medicare coverage in a skilled nursing facility.<sup>19</sup> The decision in *Bagnall*, similar to the *Landers* decision, hinged on the level of deference the CMS

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5346659 at \*1, \*5 (D. Conn. Sept. 23, 2013).

14 *Id.*

15 *Id.* at \*5.

16 *Id.* at \*9.

17 *Id.*; see *Est. of Landers v. Leavitt*, 545 F.3d 98, 109–111 (2d Cir. 2008).

18 *Bagnall*, 2013 WL 5346659 at \*1 (discussing *Landers*, 545 F.3d at 109–111); see also *Skidmore v. Swift & Co.*, 323 U.S. 134, 140 (1944) (finding that agency interpretations should be given deference based on the thoroughness of the agency's consideration and its power to persuade).

19 *Bagnall*, 2013 WL 5346659 at \*1; see *Landers*, F.3d at 109–111.

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9 Span, *supra* n. 8; Tergesen, *supra* n. 8.

10 Zhanlian Feng, *Sharp Rise in Medicare Enrollees Being Held in Hospitals for Observation Raises Concerns About Causes and Consequences*, 31 Health Affairs 1251, 1254 (2012).

11 Lawrence A. Frolik & Alison Barnes, *Elder Law: Cases and Materials* 191–192 (6th ed., LexisNexis 2015).

12 *Id.*

13 *Bagnall v. Sebelius*, No. 3:11cv1703, 2013 WL

policy manuals and interpretations were to receive and whether the plaintiffs had spent the requisite amount of time as patients formerly admitted to a hospital to receive Medicare subsidies for skilled nursing facility care.<sup>20</sup>

The Second Circuit affirmed in part the Connecticut District Court's decision in *Bagnall* — styled *Barrows v. Burwell* on appeal — but vacated the District Court's ruling that, as a matter of law, the plaintiffs did not demonstrate that they had a property interest in being admitted as inpatients and thus were not entitled to due process protections.<sup>21</sup> The Second Circuit's decision can ultimately be distilled to the following issue:

Therefore, the dispositive issue — whether plaintiffs possess a property interest sufficient to state a Due Process claim — turns on facts that are, at this stage, contested. If plaintiffs are able to prove their allegation that CMS “meaningfully channels” the discretion of doctors by providing fixed or objective criteria for when patients should be admitted, then they could arguably show that qualifying Medicare beneficiaries have a protected property interest in being treated as “inpatients.” However, if the Secretary is correct and, in fact, admission decisions are vested in the medical judgment of treating physicians, then Medicare beneficiaries would lack any such property interest. At this stage, it is simply unknown how, in

practice, the relevant admissions decisions are made.<sup>22</sup>

The Second Circuit held that the question of whether the plaintiffs had a property interest in their Medicare Part A benefits constituted a factual matter that could not be resolved on a motion to dismiss and remanded the issue to the trial court for limited discovery.<sup>23</sup>

The parties were ordered to complete discovery on the issue of whether the plaintiffs had a “protected property interest” in being admitted to the hospital as inpatients, which ultimately hinged on whether the decision to admit these patients was a “complex medical judgment” left to the treating physician or a decision directed by fixed criteria from the government.<sup>24</sup> After briefs were presented on the issue and a hearing was conducted on cross motions for summary judgment, the District Court issued a decision on February 8, 2017, which denied the motions and found that summary judgment was inappropriate because there were “widely divergent views of how the ultimate decisions [were] made — in particular, whether ‘fixed and objective’ criteria in the form of commercial screening tools effectively [overrode] the treating physicians’ medical judgment.”<sup>25</sup> Importantly, the District Court found that the plaintiffs, including representatives of deceased plaintiffs, had standing to bring this case because all plaintiffs were injured by the continuing lack of an administrative appeals process.<sup>26</sup> The District Court also found that although a treating physician's status order

20 *Bagnall*, 2013 WL 5346659 at \*1; see *Landers*, 545 F.3d at 109–111.

21 *Barrows v. Burwell*, 777 F.3d 106, 108–109, 115 (2d Cir. 2015). Specifically, the Second Circuit affirmed the District Court's holding regarding the plaintiffs' Medicare Act claims. *Id.* (“First, plaintiffs lack standing to challenge the adequacy of the notices they received. Second, nothing in the statute entitles plaintiffs to the process changes they seek—i.e., expedited notice of their placement into observation status, and an expedited hearing to challenge this placement.”).

22 *Id.*

23 *Id.*

24 *Id.*

25 *Alexander v. Cochran*, No. 3:11-cv-1703 (MPS) at \*20 (D. Conn. Feb. 8, 2017).

26 *Id.* at \*8.

plays a “role” in Medicare’s administrative review of a hospital claim, it is not dispositive or even presumed to be correct.<sup>27</sup>

After oral arguments on June 13 and June 28, 2017, and the submission of extensive briefs on the issue, on July 31, 2017, the District Court issued an order certifying a class composed of all Medicare beneficiaries who, since January 1, 2009, have received “observation services” as an outpatient during a hospitalization.<sup>28</sup> This certification of the class was a critical step for creating the opportunity for hospital patients placed under observation status to be heard. Presently, the Center for Medicare Advocacy, along with co-counsel Justice in Aging and Wilson Sonsini Goodrich & Rosati, are pursuing the nationwide class action lawsuit, seeking members of the class, and encouraging those people to tell their stories.<sup>29</sup>

### III. Legislative History

In 2016, Congress presented President Barack Obama with a bill for his signature requiring hospitals and critical access hospitals<sup>30</sup> to provide oral and written notification to patients who receive observation services for more than 24 hours of their observation status. These notifications must explain the reasons and

implications of observation status as opposed to inpatient status.<sup>31</sup> Also, receipt of the notifications must be acknowledged by the signature of the patient or the patient’s representative.<sup>32</sup> The bill, H.R. 876, titled Notice of Observation Treatment and Implication for Care Eligibility Act, or NOTICE Act, was unanimously passed by both chambers (by the House of Representatives on March 16, 2015, and by the Senate on July 27, 2015). H.R. 876 was introduced on February 11, 2015, by Rep. Lloyd Doggett (D-Tex.) and referred to the Committee on Ways and Means.<sup>33</sup>

H.R. 876 amended Title XVIII of the Social Security Act by requiring hospitals to provide written and oral notification to patients who are under observation for more than 24 hours.<sup>34</sup> Within 36 hours of placing such patients under observation, the hospital is required to provide notification that (a) explains the patient’s status as an outpatient under observation and not as an inpatient; (b) explains the reason for that classification; (c) explains the implications of the classification on eligibility for Medicare coverage of items and services, as well as cost-sharing requirements; (d) includes the name and title of the hospital staff member who gave an oral notification and its date and time; and (e) is signed by the patient to acknowledge its receipt.<sup>35</sup>

Before the passage of the bill, a hospital could either admit a patient as an inpatient or keep that patient under observation. To most people, the difference in status is often impossible to determine; however, the economic implications can

27 *Id.* at \*13.

28 *Alexander v. Price*, 275 F. Supp. 3d 313 (D. Conn. 2017).

29 Ctr. for Medicare Advoc., *Outpatient Observation Status*, <http://www.medicareadvocacy.org/medicare-info/observation-status> (accessed Dec. 14, 2018).

30 “Critical access hospital” is a designation given to eligible rural hospitals by CMS; see Ctrs. for Medicare & Medicaid Servs., *Critical Access Hospitals* (last modified Apr. 9, 2013, 4:53 p.m.), <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/CAHs.html> (accessed Dec. 14, 2018).

31 Notice of Observation Treatment and Implication for Care Eligibility (NOTICE) Act, H.R. 876, 114th Cong. (August 6, 2015).

32 *Id.*

33 *Id.*

34 *Id.*

35 *Id.*

be extreme. While a patient is in a hospital bed under observation, substantial hospital bills can accrue. After the patient's discharge, Medicare will not pay for nursing facility care unless the patient stayed in the hospital as an inpatient for 3 consecutive days, including 3 midnights (but the day the patient is transferred to the facility does not count; in essence, the patient needs to be categorized as an inpatient for four days).<sup>36</sup> Medicare will not pay if the beneficiary stayed in the hospital under observation.<sup>37</sup> Unfortunately, Medicare patients can be under observation and consequently outpatients for extended hospital stays of 3 days or more. As a result, thousands of vulnerable older adults

and people with disabilities, much to their surprise, are denied Medicare benefits for rehabilitation in skilled nursing facilities.

#### IV. The NOTICE Act Benefits and Shortcomings

The NOTICE Act requires hospitals to provide written and oral notice to patients who are under observation status. The notice must be provided to "each individual who receives observation services as an outpatient" at a hospital if the individual has been under observation status for more than 24 hours.<sup>38</sup> The notice must explain the reason that the patient is under observation status and describe the implications of that status for cost-sharing in the hospital and for subsequent "eligibility for coverage" in a skilled nursing facility.<sup>39</sup>

Providing notice is essential to ensuring that older patients have continuing autonomy over their medical decision-making.<sup>40</sup> However, the Act leaves many issues stemming from observation status and the 3-day rule unresolved. The Act provides no retroactive relief. It does not discourage hospitals from using observation stays as a cost-saving measure. It does not change the rule that observation stays do not trigger skilled nursing facility benefits. It does not give patients the right to administratively appeal their observation status once they receive notice. And the Act lacks bite because it does not specify the consequences of a hospital's failure to comply.

##### A. Resolving Lingering Constitutional Concerns

In addition to providing the obvious benefit that information yields when

36 Understanding the Medicare Two-Midnight Rule (hereinafter "2-midnight rule") and the Skilled Nursing Facility Three-Day Rule (hereinafter "3-day rule") can be confusing. In 2013, the 2-midnight rule came into play. Medicare arbitrarily based an individual's Medicare coverage on both their stay (a valid medical reason was necessary to be admitted), and also on the length of their stay – 2 midnights. However, because people may need skilled care after being hospitalized with an illness, they need to make sure they qualify for skilled nursing facility. Qualifying for inpatient admission, however, does not mean you necessarily qualify you for a stay in a skilled nursing facility. It all comes down to the 3-day rule, which states that you need to be admitted as an inpatient for 3 consecutive days, including 3 midnights and excluding the day you are transferred. Tayna Feke, *Understanding the Medicare Two-Midnight Rule and SNF Three-Day Rule*, Very Well Health (September 2, 2018), <https://www.verywellhealth.com/medicare-pays-for-hospital-care-based-on-midnights-4154260> (accessed July 31, 2019).

37 Ctrs. for Medicare & Medicaid Servs., *Are You a Hospital Inpatient or Outpatient? If You Have Medicare – Ask!* (revised Feb. 2011), <https://surveyservices.org/sites/default/files/medicare-medicaid-observation-status-coverage.pdf> (accessed Dec. 16, 2018).

38 42 U.S.C. § 1395cc(a)(1)(Y) (2018).

39 *Id.*

40 See generally Frolik & Barnes, *supra* n. 11, at 20.

making medical and financial choices, the NOTICE Act partially resolves due process issues on which courts are still undecided. Prior to implementation of the NOTICE Act, the Medicare Act was subject to several due process challenges for its failure to require any form of notice to patients that even remotely insinuated the costs of remaining an outpatient.<sup>41</sup> The Second Circuit in *Barrows* recently held that Medicare beneficiaries placed under observation are not entitled to expedited notice or administrative review.<sup>42</sup> As the plaintiffs in *Barrows* continue to litigate in the District Court since the case was remanded, the NOTICE Act provides protections for future patients by guaranteeing that patients placed under observation status have a statutory right to notice of their classification as well as the denial of their hospital admission.

The Act was implemented 12 months after its enactment,<sup>43</sup> and since March 8, 2017, all hospitals have been required to present the Medicare Outpatient Observation Notice (MOON) advisory to Medicare beneficiaries who receive at least 24 hours of hospital services under observation status. Although it does not provide a constitutional guarantee of notification of patients of their observation status, the NOTICE Act does provide guidance as to the amount of discretion involved in the admission decision process because the Act requires a written explanation of the reasons for a patient's observation status.<sup>44</sup>

## B. Problems the NOTICE Act Does Not Cure

### 1. The NOTICE Act Does Not Apply Retroactively

The NOTICE Act does not apply retroactively. The Act does not provide any relief or cause of action for patients who are left with onerous medical debt that accumulated while they unknowingly remained under observation. Thus, the plaintiffs in *Barrows* are at the mercy of the District Court to recover thousands of dollars in medical bills.<sup>45</sup> Similarly, there is no relief for Medicare beneficiaries such as 74-year-old Rosalie Winkworth, whose family cashed in her life insurance policy to pay for the skilled nursing facility care Rosalie needed following a 4-day hospital stay under observation status,<sup>46</sup> and 85-year-old Elizabeth Cannon, who owed more than \$40,000 for nursing home care after a 6-day hospital observation stay.<sup>47</sup>

### 2. The NOTICE Act Does Not Discourage Hospitals' Use of Cost-Shifting Measures

The NOTICE Act also does not discourage the use of the cost-shifting measures that hospitals employ to dodge multimillion-dollar audit charges. In 2005, Congress tested and eventually codified

<sup>45</sup> *Barrows*, 777 F.3d at 107.

<sup>46</sup> Ina Jaffe, *For Hospital Patients, Observation Status Can Prove Costly*, NPR (Sept. 4, 2013), <http://www.npr.org/sections/health-shots/2013/09/04/218633011/for-hospital-patients-observation-status-can-prove-costly> (accessed Dec. 14, 2018).

<sup>47</sup> Robert Pear, *New Medicare Law to Notify Patients of Loophole in Nursing Home Coverage*, N.Y. Times (Aug. 6, 2016), <http://www.nytimes.com/2016/08/07/us/politics/new-medicare-law-to-notify-patients-of-loophole-in-nursing-home-coverage.html> (accessed Dec. 14, 2018).

<sup>41</sup> See generally *Barrows*, 777 F.3d at 112; Bagnall, 2013 WL 5346659 at \*1, \*5.

<sup>42</sup> *Barrows*, 777 F.3d at 112.

<sup>43</sup> 42 U.S.C. § 1395cc(a)(1)(Y); Ctr. for Medicare Advoc., *supra* n. 6.

<sup>44</sup> 42 U.S.C. § 1395cc(a)(1)(y)(ii).



the Medicare Recovery Audit Contractor (RAC) Program, which sends independent contractors to hospitals to identify and correct improper payments under Medicare Parts A and B.<sup>48</sup> These auditors are paid a contingent fee based on the amount of overpayments recovered, and they are “eager to pursue the recovery of funds paid under [Medicare] Part A for post-hospitalization skilled care.”<sup>49</sup> Risk-averse hospitals have an incentive to place patients under observation to avoid the costly audit penalties resulting from incorrect hospital admissions.<sup>50</sup> Medicare covers fewer services and medications for observation patients versus inpatients, and observation patients are responsible for Medicare Part B’s 20-percent copayment.<sup>51</sup> To put the increased cost of observation stays in perspective, a Medicare observation patient suffering from syncope, a condition that causes temporary loss of consciousness,<sup>52</sup> pays more than \$1,000 more for a 3-day stay than an inpatient stay for the same amount of time.<sup>53</sup>

Although the NOTICE Act eliminates the initial shock Medicare observation patients feel when they receive their bill,<sup>54</sup> it does not alleviate the excess costs they incur. In addition to the denial of skilled nursing facility benefits, Medicare does not cover all routine drugs that observation patients need for conditions such as diabetes, high blood pressure, and high cholesterol.<sup>55</sup> This is especially troubling in light of spiking drug prices in hospitals around the country. According to Ruth Dockins, a senior advocate at the Southeast Missouri Area Agency on Aging, several Medicare beneficiaries placed under observation in Missouri were billed \$18 for a single baby aspirin.<sup>56</sup>

48 Lori J. Parker, *Observing Observational Status — Auditors and Inequities*, 16 Marquette Elder’s Advisor 83, 89–90 (2014).

49 *Id.* (“[O]bservational status was a favorite subject for audits during the demonstration period representing 55% of all recoveries.”).

50 See Dana Shilling, *Cinderella’s Slipper: Medicare Observation Status*, 274 Elder L. Advisory 1 (2014) (noting that one medical center paid \$5.3 million to settle charges stemming from incorrect admissions of patients who should have been placed under observation).

51 Christopher W. Baugh & Jeremiah D. Schuur, *Observation Care — High-Value Care or a Cost-Shifting Loophole?* 369 New Eng. J. Med. 303 (2013).

52 Am. Heart Assn., *Syncope (Fainting)* (last reviewed June 30, 2017), [http://www.heart.org/HEARTORG/Conditions/Arrhythmia/Symptoms/Diagnosis/MonitoringofArrhythmia/Syncope-Fainting\\_UCM\\_430006\\_Article.jsp#.VWRHdwn9Ko](http://www.heart.org/HEARTORG/Conditions/Arrhythmia/Symptoms/Diagnosis/MonitoringofArrhythmia/Syncope-Fainting_UCM_430006_Article.jsp#.VWRHdwn9Ko) (accessed Dec. 16, 2018).

53 Baugh & Schuur, *supra* n. 51, at 304. This

statistic is based on “traditional fee-for-service Medicare without a second payer.” *Id.*

54 *Id.* (noting that “patients have been surprised when they receive an observation bill for what was perceived as an inpatient stay, particularly when out-of-pocket costs exceed the Medicare inpatient deductible.”).

55 Daniel R. Levinson, *Vulnerabilities Remain under Medicare’s 2-Midnight Hospital Policy* at 6 (Dec. 2016), <https://oig.hhs.gov/oei/reports/oei-02-15-00020.pdf>. Before 2016, observation patients “[paid] a la carte for every X-ray, blood test or scan” compared with the single copayment that inpatients pay.” See Andrews, *infra* n. 69. In 2016, Medicare switched to a billing system that bundled some costs for observation status patients. Christopher Baugh and Michael Granovsky, *New CMS Rules Introduce Bundled Payments for Observation Care* (Mar. 16, 2016), <https://www.acepnow.com/article/new-cms-rules-introduce-bundled-payments-for-observation-care>. “Of note, the new rule does not address long-standing observation-related issues, including lack of coverage for self-administered medications and the vexing requirement for three inpatient nights in the hospital to qualify for a skilled nursing facility benefit.” *Id.*

56 Susan Jaffe, *\$18 for a Baby Aspirin? Hospitals Hike Costs for Everyday Drugs for Some Patients*, Kaiser Health News (Apr. 30, 2012), <http://khn.org/news/observational-care> (accessed



Following notice that they are under observation status, patients are presented with two equally undesirable options — stay in the hospital under observation and continue to incur the extra costs or leave the hospital and forego necessary treatment and recovery services. The latter undesirable option heightens the likelihood of reinjury. When their budgets are tight, however, patients with broken hips and other serious conditions may place financial stability over physical well-being.

This Heinz dilemma<sup>57</sup> is illustrated by the plight of Caroline Giada, the 76-year-old woman who fainted in her bathroom and fractured her spine.<sup>58</sup> Giada spent 6 days in the hospital under observation status in 2014, prior to the passage of the NOTICE Act.<sup>59</sup> When the hospital could no longer provide care to Giada, she chose to go to a skilled nursing facility for necessary assistance rather than return home where she would be in pain and alone.<sup>60</sup> Unaware that she was under observation during her entire 6-day hospital stay, Giada believed that Medicare would cover the costs of the nursing facility, only to be hit with a bill for more than \$2,000.<sup>61</sup> Regretting her decision, Giada said, “When you’re in a lot of pain, you really don’t think too clearly.”<sup>62</sup> With those sentiments in mind, it is unclear whether Giada would have willingly chosen skilled nursing facility care if she had been notified that she would bear the full cost of that care.

### 3. Observation Stays Do Not Trigger Skilled Nursing Facility Benefits

Giada’s quandary would have been avoided if Medicare had allowed her 6-day observation stay to trigger skilled nursing facility benefits. Providing notice does not change the troubling fact that none of the time spent under observation can be applied to the 3-day rule that is necessary to qualify for Medicare’s skilled nursing facility benefits.<sup>63</sup> Using Giada as an example, following a 3-day stay under observation status, she would pay \$248 per day for 7 days of needed skilled nursing facility care, totaling \$1,736.<sup>64</sup> In contrast, following a 3-day stay as an inpatient, she would pay *nothing* for the week spent in the skilled nursing facility because the 3-day inpatient stay triggered Medicare Part A benefits.<sup>65</sup> The only difference between zero-cost skilled nursing facility services and a nearly \$2,000 charge is the patient’s admission status.<sup>66</sup>

“Protocolized observation” is aimed at providing high-value care at a cost that is lower or equal to the cost of an inpatient stay.<sup>67</sup> Hospitals achieve this by establishing separate observation units where patients suffering from chest pain, asthma, or less serious conditions spend 24 hours or less under observation before a determination is made regarding the need to

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Dec. 14, 2018).

57 The Heinz dilemma is a scenario developed by psychologist Lawrence Kohlberg that focuses on ethics and moral development and reasoning.

58 See Wolfson, *supra* n. 1.

59 *Id.*

60 *Id.*

61 *Id.*

62 *Id.*

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63 *Id.*

64 *Id.*

65 *Id.*

66 See generally Parker, *supra* n. 48, at 90–91 (describing the “amorphous” nature of observation status and lack of guidelines used to distinguish between observation and inpatient services).

67 Baugh & Schuur, *supra* n. 51, at 304; see also *Emergency Nurses Association Position Statement: Observation Units/Clinical Decision Units* 1 (2011), <http://www.aaceus.com/courses/NL0111/Article9.pdf> (accessed Dec. 14, 2018).

admit them for an inpatient stay.<sup>68</sup> One study examining emergency department patients suffering from transient ischemic attack (an illness that causes stroke-like symptoms) found that patients referred to observation were discharged almost 38 hours sooner than inpatients.<sup>69</sup> The study also revealed that utilizing observation units cost the hospitals roughly one half the cost of inpatient care.<sup>70</sup> The low-cost benefits of observation are lost when, instead of using short stays and separate units, hospitals prolong patients' stays under observation status.<sup>71</sup> Just as the NOTICE Act does not assuage hospitals' desire to use observation stays to cut costs and avoid penalties, it does not change the 3-day rule.<sup>72</sup>

#### 4. Medicare Beneficiaries Lack Appeal Rights Under the NOTICE Act

As *Barrows* makes clear, Medicare ben-

eficiaries are not entitled to an expedited administrative review while under observation status.<sup>73</sup> Congress codified this denial of appeal rights in the MOON, which is the standard written and oral notice of a patient's observation status required under the NOTICE Act.<sup>74</sup> The MOON expressly denies appeal rights under the NOTICE Act.<sup>75</sup> The version of the MOON implemented by the Centers for Medicare and Medicaid Services explains, "[I]ssuance of the MOON by a hospital ... does not constitute an initial determination and therefore does not trigger appeal rights."<sup>76</sup>

The plaintiffs in *Jimmo v. Sebelius* settlement, individual Medicare beneficiaries, brought suit against the HHS secretary, alleging that the secretary imposed a "covert rule of thumb that operates as an additional and illegal condition of coverage."<sup>77</sup> Specifically, the plaintiffs took issue with the "Improvement Standard" used at the lower levels of Medicare's administrative review process.<sup>78</sup> Under this standard, according to the plaintiffs, the beneficiaries were allegedly denied coverage because their conditions were chronic, because their conditions had stabilized or plateaued, or because the beneficiaries were unlikely to improve or failed to improve.<sup>79</sup> The case was ultimately settled, and the Medicare policy manuals now make clear that improvement is *not*

68 Baugh & Schuur, *supra* n. 51, at 304.

69 Michelle Andrews, *Observation Units May Ease Burdens of ER Care, But Benefits to Patients Come at a Price*, Wash. Post (Feb. 11, 2013), [https://www.washingtonpost.com/national/health-science/observation-units-may-ease-burdens-of-er-care-but-benefits-to-patients-come-at-a-price/2013/02/08/84ddf37e-706d-11e2-a050-b83a7b35c4b5\\_story.html](https://www.washingtonpost.com/national/health-science/observation-units-may-ease-burdens-of-er-care-but-benefits-to-patients-come-at-a-price/2013/02/08/84ddf37e-706d-11e2-a050-b83a7b35c4b5_story.html) (accessed Dec. 14, 2018).

70 *Id.* In addition, the study found that hospitals spent \$2,092 per patient in observation care compared with \$4,992 per patient in inpatient care.

71 Christopher W. Baugh et al., *Making Greater Use of Dedicated Hospital Observation Units for Many Short-Stay Patients Could Save \$3.1 Billion a Year*, 31 Health Affairs 2314, 2319 (2012).

72 Moreover, the Act only serves to notify Medicare beneficiaries of their observation status. It does not provide notice to beneficiaries immediately admitted to the hospital as inpatients that their Medicare Part A benefits are not triggered until they have spent at least 3 days in the hospital. See Abbey, *infra* n. 94.

73 *Barrows*, 777 F.3d at 112.

74 Ctrs. for Medicare & Medicaid Servs., *Beneficiary Notices Initiative (BNI)* (last modified July 26, 2018, 8:55 a.m.), <https://www.cms.gov/Medicare/Medicare-General-Information/BNI/index.html> (accessed Dec. 16, 2018).

75 *Id.*; 81 Fed. Reg. 24945, 25134 (Apr. 27, 2016).

76 81 Fed. Reg. at 25134.

77 *Jimmo v. Sebelius*, No. 5:11-cv-17, 2011 WL 5104355 at \*1-\*2 (D. Vt. Oct. 25, 2011).

78 *Id.*

79 *Id.*

required to obtain Medicare coverage.<sup>80</sup> Pursuant to the settlement agreement, the parties agreed to a “maintenance coverage standard,” which provides that “[s]killed nursing services would be covered where such skilled nursing services are necessary to maintain the patient’s current condition or prevent or slow further deterioration so long as the beneficiary requires skilled care for the services to be safely and effectively provided.”<sup>81</sup> The settlement also created a re-review opportunity, in addition to the normal Medicare administrative appeals process, for Medicare beneficiaries who received a denial of skilled nursing facility care, home health care, or outpatient therapy services on or after January 18, 2011 that became that became final and non-appealable before or on January 23, 2014, due to a prior application of the Improvement Standard.<sup>82</sup> Denied claims that were still alive, or able to go further

through the appeals process, after January 23, 2014, were ineligible for the re-review process and needed to go through the normal Medicare administrative appeals process.<sup>83</sup>

To apply for an Medicare appeal under this re-review process, patients completed a six-question form that was published online by CMS.<sup>84</sup> On the form, patients checked boxes confirming that they are Medicare beneficiaries, they received skilled nursing or therapy services as an outpatient or from a skilled nursing facility, and they were denied services because their conditions did not improve.<sup>85</sup> Even though the re-review form and process helped to ensure that the Improvement Standard was not improperly applied to deny coverage, the process was likely time-consuming and did not guarantee protection to persons incorrectly placed under observation status for reasons other than failure to improve. The *Jimmo* settlement did not solve the observation status problem and arguably muddled the waters further.<sup>86</sup>

On August 17, 2016, the U.S. District Court for the District of Vermont issued an order requiring CMS to remedy the in-

80 Ctr. for Medicare Advoc., *Jimmo Corrective Action Plan Completed: CMS Adds Resources Regarding Medicare Coverage to Help People Who Need Skilled Maintenance Nursing or Therapy*, <http://www.medicareadvocacy.org/medicare-info/improvement-standard> (accessed Dec. 16, 2018).

81 *Jimmo v. Burwell*, No. 5:11-cv-17 (D. Vt. Aug. 17, 2016).

82 Ctr. for Medicare Advoc., *supra* n. 80; see also California Health Advocates, *Are You Eligible for a Re-Review of Past Denied Medicare Claims?* (May 12, 2014), <https://cahealthadvocates.org/are-you-eligible-for-a-re-review-of-past-denied-medicare-claims/> (accessed July 3, 2019). There are two different timelines for filling out the form and applying for a re-review: If a maintenance care denial became final and non-appealable on or after January 18, 2011 through January 24, 2013, the request for review was required to be postmarked no later than July 23, 2014. If a maintenance care denial became final and non-appealable on or after January 25, 2013 through January 23, 2014, the request for review was required to be postmarked no later than January 23, 2015.

83 California Health Advocates, *supra* n. 82.

84 See Ctrs. for Medicare & Medicaid Servs., *Request for Re-Review of Medicare Claims Related to the Settlement Agreement in Jimmo v. Sebelius* (Jan. 2014), [https://www.q2a.com/Portals/0/JIMMO\\_REREVIEWFORM-508.pdf](https://www.q2a.com/Portals/0/JIMMO_REREVIEWFORM-508.pdf) (accessed July 3, 2019).

85 Ctrs. for Medicare & Medicaid Servs., *supra* n. 74.

86 Pursuant to the *Jimmo* settlement, CMS published revisions to the Medicare Policy Manuals on December 6, 2013. These manual updates were drafted in efforts to clarify coverage for skilled nursing facility, home health, outpatient, and inpatient rehabilitation to ensure that Medicare will cover skilled care in order to maintain a beneficiary’s condition.

adequate Educational Campaign that was a cornerstone of the original settlement agreement.<sup>87</sup> The Court stated, “Plaintiffs bargained for the accurate provision of information regarding the maintenance coverage standard and their rights under the Settlement Agreement would be meaningless without it.”<sup>88</sup> Ultimately, on February 1, 2017, the Court ordered CMS to propose a Corrective Action Plan to address the deficient Educational Campaign, which was noncompliant with the original settlement agreement.<sup>89</sup> One of the most important parts of the plan includes a new webpage by CMS that is dedicated to the *Jimmo* settlement and includes frequently asked questions and a statement that affirmatively disavows the Improvement Standard.<sup>90</sup> The government was also required to certify its compliance with the Corrective Action Plan by September 4, 2017.<sup>91</sup> On the CMS webpage for the *Jimmo* settlement, the following statement appears:

The *Jimmo* Settlement Agreement may reflect a change in practice for those providers, adjudicators, and contractors who may have erroneously believed that the Medicare program covers nursing and therapy services under these benefits only when a beneficiary is expected to improve. The *Jimmo* Settlement Agreement is consistent with the Medicare program’s regulations governing maintenance nursing and therapy in skilled nursing facilities, home health services, and outpatient therapy (physical, occupational, and speech) and nursing and therapy in inpatient rehabilitation hospi-

tals for beneficiaries who need the level of care that such hospitals provide.<sup>92</sup>

## 5. Implementation and Enforcement of the NOTICE Act Are Not Guaranteed

Since March 8, 2017, all hospitals have been required to provide the MOON to patients.<sup>93</sup> However, there is still no guarantee that the notice requirements will be strictly implemented and enforced. Potential implementation issues stem from a lack of guidance from CMS regarding when observation status begins and ends, as well as whether observation services are continuous.<sup>94</sup> Enforcement problems may arise as a result of the NOTICE Act’s failure to designate penalties for noncompliant hospitals and the absence of a private right of action for Medicare beneficiaries who suffer adverse financial consequences resulting from not receiving notice of observation status.<sup>95</sup>

87 *Jimmo v. Burwell*, No. 5:11-cv-17 (D. Vt. Aug. 17, 2016).

88 *Id.*

89 *Jimmo v. Burwell*, No. 5:11-cv-17 (D. Vt. Feb. 1, 2017).

90 *Id.*

91 *Id.*

92 Ctrs. for Medicare & Medicaid Servs., *Important Message About the Jimmo Settlement*, <https://www.cms.gov/Center/Special-Topic/Jimmo-Center.html> (accessed Dec. 16, 2018).

93 Ctrs. for Medicare & Medicaid Servs., *Hospitals Must Give Patients Notice of Their Observation Status, Beginning March 8, 2017*, <https://www.medicareadvocacy.org/hospitals-must-give-patients-notice-of-their-observation-status-beginning-march-8-2017/> (accessed Feb. 3, 2019).

94 Duane Abbey, *Observation in the NOTICE Act: What Is Being Accomplished?* RACmonitor (Apr. 27, 2016), <http://www.racmonitor.com/rac-enews/2031-observation-in-the-notice-act-what-is-being-accomplished.html> (accessed Dec. 16, 2018).

95 The lack of a private right of action in the Act means that Medicare recipients not notified of their observation status have little to no recourse against hospitals. *See id.* (“On the compliance front, the issue of enforcement is not really addressed. CMS has indicated that this notice requirement is a condition of participation, as opposed to a condition of payment.”). If, however, Congress authorizes patients to

The Act requires hospitals to provide written and oral notice to patients under observation for more than 24 hours of their observation status within 36 hours of being placed under observation but does not provide clear parameters about the observation status timeline.<sup>96</sup> The treating physician controls when observation status begins and ends. In a hospital with a separate observation unit, a patient's observation status may begin while the patient is still in emergency care, which may result in confusion to the nursing staff and other clinical personnel. Additionally, it is unclear whether observation services are continuous. This lack of clarity is illustrated by the following case study from Duane Abbey, Ph.D., a health care management consultant:

An elderly patient presents at 3 p.m. with complaints of chest pain and shortness of breath. After an emergency department workup, at 4:30 p.m. the patient is placed in observation through the hospital's chest pain protocol. The patient is scheduled to have a cardiac catheterization the next morning. The patient is hydrated during the night to help reduce possible toxicity from the LOCMs (low osmolar contrast media) that will be used during the procedure. At 9 a.m. the patient undergoes cardiac catheterization, during which an-

gioplasty is performed on a coronary artery and a stent is placed in a different coronary artery. The patient goes to recovery and then returns to the observation bed at 2 p.m. At 6 p.m., the patient is discharged home.<sup>97</sup>

If the patient's observation services had been continuous, the patient was entitled to notice because the services spanned more than 24 hours (between 4:30 p.m. on day one and 6:00 p.m. the next day).<sup>98</sup> However, Dr. Abbey explains that the time spent during the catheterization procedure would *not* be considered observation for billing purposes; thus, notice was not technically required under the Act.<sup>99</sup> Imagine a scenario in which the patient had been moved to inpatient care rather than being discharged home. Now the lack of notice has dire consequences. If the patient spent 2 additional days as an inpatient, she may erroneously believe that her 3-day stay triggered skilled nursing facility benefits.

In addition to these implementation issues, enforcement may also prove to be problematic based on administration of similar statutes enacted in various states. Before Congress' nationwide implementation of the NOTICE Act, several states, including Virginia, Connecticut, Pennsylvania, New York, and Maryland, passed statutes requiring patients under observation to be notified of their status pursuant to state law.<sup>100</sup> These statutes, though well-

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pursue private damages actions against non-compliant hospitals, Caroline Giada and similarly situated elders will have an avenue to recover the costs of pricey post-hospitalization skilled nursing services. The threat of private lawsuits and cost of litigating individual claims will also incentivize hospitals to comply with the Act and requirements of the MOON. To control costs, Congress could cap damages by limiting a claimant's recovery to the amount that Medicare Part A *would have covered* had the hospital deemed the claimant an inpatient for his or her entire hospital stay.

96 42 U.S.C. at § 1395cc(a)(1)(Y).

97 Abbey, *supra* n. 94.

98 *Id.*

99 *Id.*

100 See Va. Code Ann. § 32.1-137.04 (West 2016) (enacted 2015); Conn. Gen. Stat. Ann. § 19a-508b (West 2016) (enacted 2014); 40 Pa. Stat. & Pa. Consol. Stat. Ann. § 3053 (West 2016) (enacted 2014); N.Y. Pub. Health Law § 2805-w (McKinney 2016) (enacted 2013); Md. HEALTH-GENERAL Code Ann. § 19-

intentioned, ultimately lack teeth. Pennsylvania's statute, for example, does not outline penalties for noncompliance.<sup>101</sup> The Pennsylvania statute also expressly alleviates hospitals' responsibility for coverage implications and notice requirements if a patient's inpatient stay is later re-categorized.<sup>102</sup> The MOON likewise does not designate penalties for noncompliance.

Since 2015, Virginia has required hospitals to provide oral and written notice to patients of their observation status within 24 hours of being placed under observation.<sup>103</sup> In *Cherrie v. Virginia Health Services, Inc.*, the Supreme Court of Virginia found no private right of action existed for individuals seeking to enforce the Virginia Board of Health's nursing home and hospital regulations.<sup>104</sup> The estates of two decedents who were residents in nursing homes prior to their deaths were the plaintiffs in *Cherrie*.<sup>105</sup> The executors of the estates asked the nursing homes to provide copies of all written policies and procedures that were in effect during the decedents' stays.<sup>106</sup> State law requires all medical facilities, including nursing homes, to make these documents available for review to residents and their representatives upon request.<sup>107</sup> When the nursing homes declined to produce the documents, the executors sought declaratory judgments to force the nursing homes to comply with the statute.<sup>108</sup> The Supreme

Court of Virginia ultimately affirmed the lower court's dismissal of the declaratory judgment complaints because the plaintiffs lacked a private right of action under both Title 32.1, Chapter 5, of the Virginia Code and the Declaratory Judgment Act, Virginia Code § 8.01-184 et seq.<sup>109</sup>

By finding no implied private right of action in Section 32.1, Chapter 5, of the Virginia code, *Cherrie* takes away any bite that Virginia's notice requirement otherwise has when a hospital fails to notify patients of their observation status. The practical effect of the holding is that Medicare beneficiaries who do not receive proper notice are unable to assert their own rights by pursuing or even threatening litigation against hospitals. Patients can do nothing more than file administrative complaints against hospitals that do not comply with notice requirements, after which they must rely on the administrative process to issue sanctions or the state health commissioner to file suit. It is unclear whether Congress contemplated providing a private right of action for Medicare beneficiaries to enforce the NOTICE Act and allow for recovery of damages for medical bills accrued by patients unknowingly placed under observation. Regardless, the proposed MOON does not appear to possess any language that a court would interpret as expressly or impliedly recognizing such a right.

## V. Beyond the NOTICE Act: What More Can Be Done to Avoid the Problems Surrounding the Increased Use of Observation Status?

Although notifying patients of their observation status has not been deemed constitutionally required by the courts,

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349.1 (West 2016) (enacted 2013).

101 See generally 40 Pa. Stat. & Pa. Consol. Stat. Ann. at § 3051 et seq.

102 *Id.* at § 3054.

103 Va. Code Ann. at § 32.1-137.04.

104 *Cherrie v. Va. Health Servs., Inc.* 787 S.E.2d 855, 858 (Va. 2016).

105 *Id.* at 857.

106 *Id.*

107 *Id.* (citing 12 Va. Admin. Code 5-371-140 (West 2016)).

108 *Id.*

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109 *Id.* at 868.

providing notice is virtually cost free. In terms of protecting older patients from the adverse consequences of hospitals' increased use of observation stays, the NOTICE Act is a minimalist solution. More can be done. To resolve the issues caused by hospitals' cost shifting and risk aversion, some doctors have proposed capping out-of-pocket expenses for patients under observation status at the inpatient's deductible amount.<sup>110</sup> Currently, no single charge to a patient under observation can exceed the cost of an inpatient deductible, but there is no limit on the total cost of an observation stay.<sup>111</sup> In addition to capping the observation bill, Medicare could cover the costs of medications during an observation stay that are covered during an inpatient stay.<sup>112</sup> Finally, Medicare could count days spent under observation toward their stay necessary to trigger skilled nursing facility benefits.<sup>113</sup>

The combination of the three solutions listed previously — capping the cost of an observation stay, covering the same medications during an observation stay that are covered during an inpatient stay, and tolling time spent under observation — puts the Medicare patient under observation on virtually equal footing with the inpatient. In that case, perhaps the solution should be to eliminate observation status altogether, which is what some proponents of the NOTICE Act have suggested.<sup>114</sup> Rep. Joseph Courtney (D-Conn.) has acknowledged that the notification requirement gives patients a fair chance to challenge the coding of their status before incurring thousands of dollars in observa-

tion charges; however, a better solution would be to restore the traditional 2-midnight rule to all Medicare patients, regardless of their classification as inpatient or under observation.<sup>115</sup> According to Rep. Courtney, "We should build on this legislation and again restore Medicare's promise, which ... from day one, has said that medically prescribed care will be covered by the system at time of discharge from a hospital for longer than [three] days. Thus anyone who meets the threshold of three days in the hospital receives the same benefit from Medicare."<sup>116</sup>

#### A. Proposed Solutions

##### 1. A 24-Hour Cap on Observation Stays

Rep. Courtney's vision is admirable. Others have pushed further asking for total elimination of observation status which unnecessarily strips Medicare, hospitals, and patients of the benefits stemming from the original use of observation. Situations still arise in which a patient is not infirm to the degree requiring immediate hospital admission but is not well enough to be discharged to home; thus, observation is necessary.<sup>117</sup> Capping observation stays at 24 hours strikes an appropriate balance among lowering patients' hospital bills, improving Medicare beneficiaries' ability to tap into skilled nursing facility benefits, and cutting costs for hospitals and Medicare. One study, which focused

110 Baugh & Schuur, *supra* n. 51, at 305.

111 *Id.* at 304.

112 *Id.*

113 *Id.*

114 161 Cong. Rec. H1645 (daily ed. Mar. 16, 2015) (state. of Rep. Joseph Courtney).

115 *Id.*

116 *Id.*

117 Shilling, *supra* n. 50 (citing Bob Wachter, *Medicare's Observation Status — and Why Attempts to Make Things Better May Make Them Worse*, Health Care Blog (July 30, 2013), <http://thehealthcareblog.com/blog/2013/07/30/medicare-observation-status-and-why-attempts-to-make-things-better-may-make-them-worse> (accessed Dec. 16, 2018)).



on observation stays with a mean length of 15 hours and maximum length of 24 hours, concluded that these short observation stays could save hospitals across the country \$3.1 billion annually by avoiding 2.4 million inpatient admissions.<sup>118</sup>

Proponents of restoring the traditional 2-midnight rule may resist a 24-hour cap for two reasons. First, the timing of this proposal is inopportune. Advocates for the elderly achieved a relative victory with the implementation of the NOTICE Act and may be unwilling to put the issue up for debate again, risking repeal of their progress. Second, hospitals and Medicare representatives may be equally unwilling to further reduce the length of observation stays at the risk of losing more of the financial benefits stemming from increased use of these stays.

Implementation of a 24-hour cap on observation stays requires eventual repeal of the 2-midnight rule as well as changes to the NOTICE Act. The NOTICE Act now requires notification not later than 36 hours after a patient receives observation services or “if sooner, upon release.”<sup>119</sup> If observation stays were capped at 24 hours, notification not later than 12 hours after receiving observation services is likely a reasonable time frame to provide notice. The New York, Connecticut, and Virginia statutes all require notice not later than or within 24 hours; therefore, this proposed timeline is feasible.<sup>120</sup> At what point notification could reasonably be given within 24 hours depends on hospitals’ patient volume and staff and other factors requir-

ing careful consideration by Congress.

## 2. Right to Appeal/Right to Seek Damages for Hospital Noncompliance

Medicare beneficiaries need the ability to begin the appeals process once they receive notice of their observation status. This requires change to the MOON, which, as discussed previously, does not provide appeal rights. Allowing the right to appeal under the NOTICE Act would likely result in an increase in administrative appeals from patients. As a result, hospitals might respond to this new administrative burden by aiming to *correctly* admit patients when necessary and shorten the length of observation stays. Additionally, patients should be able to seek compensatory damages for hospital bills unknowingly accumulated while under observation as a result of hospitals’ failure to provide notice in compliance with the Act. These two mechanisms, the right to appeal and the right to seek damages for hospitals’ noncompliance, are the teeth that the Act currently lacks.

## VI. Conclusion

The changes proposed in this article could take years to implement by statute. In the meantime, elder advocates must continue to lobby Congress to provide appeal rights and encourage hospitals to cap observation stays at 24 hours. The NOTICE Act neither unlocks the full extent of Medicare benefits nor ferociously protects older patients’ rights; however, its passage signifies that Congress is mindful of and responsive to concerns surrounding protection of the elderly. Until changes are made, elderly patients such as Caroline Giada will continue to be unknowingly placed under prolonged observation and unfairly surprised by sky-high hospital bills.

118 Baugh et al., *supra* n. 71, at 2320.

119 42 U.S.C. § 1395cc(a)(1)(Y).

120 See Va. Code Ann. at § 32.1-137.04 (requiring notice not later than 24 hours); Conn. Gen. Stat. Ann. at § 19a-508b (requiring notice not later than 24 hours); N.Y. Pub. Health Law at § 2805-w (requiring notice within 24 hours).



**A More Perfect Union: Eugenics in America**

*By Miriam H. Markfield, Esq.*

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**About the Author**

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Now that we know the laws of heredity, it is possible to a large extent to prevent unhealthy and severely handicapped beings from coming into the world. I have studied with great interest the laws of several American states concerning prevention of reproduction by people whose progeny would, in all probability, be of no value or be injurious to the racial stock. ... [T]he possibility of excess and error is still no proof of the incorrectness of these laws. It only exhorts us to the greatest possible conscientiousness.

— Adolph Hitler<sup>1</sup>

## I. Introduction

Most people have probably heard the term “eugenics” at some point. However, fewer people know that by the mid-20th century, two-thirds of American states had passed laws authorizing the sterilization of “unfit” citizens. Very few, I think, know that had American eugenics advocates had their way, they would have gone even further. While the definition of who was unfit varied across jurisdictions and became intertwined with the racism, sexism, and other prejudices already deeply rooted in American society, the eugenic argument always began by targeting people with disabilities. Elder and special needs law attorneys, who represent the interests of clients vulnerable to eugenic rhetoric and policy, are in a unique position to identify and combat eugenic threats to people with disabilities. Understanding the history of the American eugenics movement and the evolution of its rhetoric may help elder and special needs law attorneys better serve their clients and advocate for

these marginalized groups when they are targeted now and in the future. With that context in mind, here is the story.

Not every story has a clear beginning, but this one does. It begins in a monastery in Moravia, in what is now the Czech Republic. There, in the mid-19th century, a monk and failed high school teacher contented himself with studying pea plants. His name was Gregor Mendel, and through his meticulous research, he observed that there were predictable results when cross-breeding his vegetables. Depending on whether the plants he bred were tall or short, the pods smooth or wrinkled, he could identify dominant and recessive traits that might predict the form of the resulting organism.

Mendel’s work focused on plants — manipulating them to better serve the desires of humans. There was nothing new about the idea that humans could benefit from encouraging the survival of plants and animals with desired traits and from weeding out those with undesirable traits.<sup>2</sup> As far as anyone knows, this has been going on since humans began cultivating crops and breeding animals — though success, or lack thereof, was often attributed to divine intervention.<sup>3</sup> But Mendel’s work and that of others in the mid-19th century posited something new: the idea that humans not only could manipulate plant and animal characteristics with predictable results but also could replicate this feat. It was a revolutionary idea, yet few grasped the implications of

<sup>1</sup> Edwin Black, *War Against the Weak: Eugenics and America’s Campaign to Create a Master Race* 275–276 (Four Walls Eight Windows 2003).

<sup>2</sup> In an early written example, a treatise by Xenophon — a Greek philosopher and historian, among other things, who lived during the 4th and 5th centuries B.C. — discusses the breeding of dogs for hunting. See Xenophon, *The Works of Xenophon* (H.G. Dakyns trans., U. of Adelaide Lib. 2014) (first published 1897).

<sup>3</sup> Black, *supra* n. 1, at 13.

Mendel's research upon its publication in 1865. Mendel was disappointed in the reception his research received. He died in 1884. The monastery destroyed his notes.

And there it all might have ended, but Mendel's work on pea plants was rediscovered after his death and reread in the light of the works of Charles Darwin and others. Mendel's neglected work became the basis for a new science, a science that would seek to perfect humanity itself and to eliminate poverty, disease, and immorality once and for all. This new science promised to cure every ill the species had ever faced, and Americans, ever eager for novelty, technology, and science, embraced the promise. That promise would spread farther than Mendel could have dreamed. What began in a remote Moravian garden would spread to the hollers of Appalachia, the prisons of California, and the ovens of Auschwitz.

## II. Inventing the Human Race

While Mendel was studying his plants and just before the United States convulsed in civil war, Charles Darwin outlined his theory of evolution in *The Origin of Species*. Scientists the world over celebrated the work, but the implications of Darwin's theories also resonated in Darwin's own family. His younger cousin Francis Galton was especially enthralled by the theory of evolution. A keen observer of the people around him, Galton had long suspected that certain traits could be passed through generations of family members. The problem was that although humans had a long history of breeding animals and cultivating crops, it had always been assumed that humans existed on a separate plane, created in the image of God and therefore distinct from other living things. Darwin's theory freed Galton from that constraint and led him to extrapolate that if it were

possible "to obtain by careful selection a permanent breed of dogs or horses gifted with particular powers of running ... so it would be quite practicable to produce a highly gifted race of men by judicious marriages during several consecutive generations."<sup>4</sup>

If it sounds odd today to hear plant cultivation and animal breeding compared with human reproduction, it made perfect sense to Galton and his contemporaries. As Nancy Isenberg notes in her bestselling book, "Almost as a mantra, eugenicists compared good human stock to thoroughbreds, equating the wellborn with superior ability and inherited fitness."<sup>5</sup>

Francis Galton was a Renaissance man with an affinity for mathematics. The emerging field of statistics appealed to his desire to categorize things and draw connections between seemingly unrelated ideas. Galton studied the family trees of illustrious Britons, realized the need to differentiate the effects of nature versus nurture on individuals, came up with the concept of statistical correlation, and developed "a theory of the physical mechanisms of heredity."<sup>6</sup> The latter would be the basis for understanding genes and chromosomes and by extension their impact on human development.<sup>7</sup> Once taken with the idea of inheritable traits in humans, Galton devoted his life's work to understanding how to improve the human race. In 1883, he named his area of study "eugenics," a term that combines

4 Harry Bruinius, *Better for All the World: The Secret History of Forced Sterilization and America's Quest for Racial Purity* 91 (Alfred A. Knopf 2006).

5 Nancy Isenberg, *White Trash: The 400-Year Untold History of Class in America* 175 (Viking 2016).

6 Bruinius, *supra* n. 4, at 106.

7 *Id.*

the Greek words for “well” and “born.”<sup>8</sup> Galton concluded that men and women with the most desirable “mental, moral, and physical” traits should marry and produce offspring that would gradually improve the “race.”<sup>9</sup> By encouraging “eugenic marriage,” Galton posited that society could improve the entire human species. This approach became known as “positive eugenics.”<sup>10</sup>

The timing of Galton’s work could hardly have been better because experts in crime, economics, politics, medicine, and the emerging fields of psychology and sociology were beginning to grapple with how to fix problems that plagued Victorian society. Indeed, in the eyes of well-to-do men such as Galton, there seemed to be a great many social problems accompanying the Industrial Revolution. Poverty, disease, prostitution, and crime all seemed to be increasing at a terrifying rate. In the United States, there was the added complication of racial strife in a country recovering from the devastating Civil War. Eugenics, it was believed, offered a solution.<sup>11</sup>

It was around this time that Mendel’s work was rediscovered, due in part to a strange coincidence. In 1900, 16 years after Mendel’s death, a biologist named William Bateson was grading papers at Cambridge when he saw Mendel’s then-obscure work referenced by three separate students. Darwin’s theories had informed

Bateson’s study of the natural world, and as it happened, Bateson had already been conducting his own research on biological variation in plant cultivation and animal breeding. He presented his work and reintroduced Mendel’s theories to the Royal Horticultural Society and shortly thereafter expanded his studies to a new field he dubbed “genetics.”<sup>12</sup> This rediscovery of Mendel’s research, combined with Galton’s work and that of his cousin Darwin, added a veneer of scientific legitimacy to the eugenic cause.

While Galton and his followers were developing eugenics as a discipline in Britain, the United States was embroiled in its brutal Civil War, followed by the difficult task of reconstructing the defeated South. The world into which the once-more-united United States emerged seemed full of eugenic “promise.” Moreover, new threats to “Anglo-Saxon blood purity” multiplied. In the South, there was confusion about the meaning of race, class, and blood now that previously enslaved black people had become citizens. In the Northeast, pressure came from the waves of immigration from what were considered undesirable regions — Southern and Eastern Europe and Ireland, in particular. And besides the presence of new members of American society, there was a profound absence of the hundreds of thousands of white American men whose “prized” Anglo-Saxon blood had congealed in the dirt of Civil War battlefields.

Five years after Galton’s *Hereditary Genius* posited that positive human traits could be transferred from one generation to the next, an American named Richard Dugdale set out to prove that negative traits could be similarly transferred within families. Like Galton, Dugdale spent

8 Black, *supra* n. 1, at 15.

9 Bruinius, *supra* n. 4, at 94.

10 Black, *supra* n. 1, at 18. Of course, implicit in Galton’s notion of positive eugenics was the idea that reproduction would occur in the context of marriage. The fact that reality, especially for poorer people, was sometimes different would become a driving force behind the negative eugenics movement.

11 Bruinius, *supra* n. 4, at 139–140.

12 Black, *supra* n. 1, at 26.

years sifting through countless records to piece together family trees. The difference was the subject matter. Whereas Galton documented the lineages of prominent families, Dugdale studied the “criminals, vagrants and paupers,” people to whose records he, as the head of the New York Prison Association, had easy access.<sup>13</sup> He documented the lives of dozens of families, eventually concluding that more than 700 of these individuals shared a common ancestor he designated “Margaret, mother of criminals.” He called Margaret’s descendants the “Jukes.” In 1877, he published *The Jukes: A Study in Crime, Pauperism, Disease and Heredity*.<sup>14</sup>

It is difficult to overstate the impact of Dugdale’s work in American reformist circles. Though he stressed the importance of improving environmental factors and promoting education in order to reduce crime and poverty, Dugdale’s book quickly became a touchstone for anyone trying to prove that negative human tendencies were the result of nature, not nurture. To Galton and many other researchers and reformers, the study of the Jukes proved that criminality was an inherited trait. In subsequent years, multiple “studies” of other euphemistically named families appeared and pointed to similar conclusions.<sup>15</sup>

The improvement of humanity became the cause of the age. The idea that society valued some types of people more than others was not new. Alexis de Tocqueville observed, “The idea of [human] perfectability is ... as old as the world.”<sup>16</sup> “Aristo-

cratic nations,” he said, “are naturally too apt to narrow the scope of human perfectibility; democratic nations to expand it beyond compass.”<sup>17</sup> Essentially, although Tocqueville thought different countries might take different approaches to the idea, he believed that they were all predisposed to think that humans could create better versions of themselves over time. It stood to reason that “better breeding must assume a better breed, and the ‘survival of the fittest’ — believed to be the brutal and fundamental law of nature — must assume the presence of the ‘unfit.’”<sup>18</sup>

What was new was the idea that science, rather than piety, could enable human perfection. The cause could not be more urgent. Every indicator suggested that the population of the “right” kind of people was decreasing while the population of the “wrong” kind of people was reproducing at an alarming rate. In a letter written when he was British Home Secretary (February 1910 to October 1911), Winston Churchill expressed the concern of the day: “The unnatural and increasingly rapid growth of the feeble-minded and insane classes, coupled as it is with a steady restriction among all the thrifty, energetic and superior stocks, constitutes a national and race danger which it is impossible to exaggerate.”<sup>19</sup> Across the pond, in 1913 Theodore Roosevelt wrote that “the prime duty, the inescapable duty, of the good citizen of the right type is to leave his or her blood behind him in the world; and that we have no business to permit the perpetuation of citizens of the wrong type.”<sup>20</sup>

In 1889, Galton articulated the concept

13 *Id.* at 24.

14 *Id.*

15 Paul A. Lombardo, *Three Generations, No Imbeciles: Eugenics, the Supreme Court, and Buck v. Bell* 10 (Johns Hopkins U. Press 2008).

16 Alexis de Tocqueville, *Democracy in America* ch. VIII (Henry Reeve trans., Bantam Books 2000) (first published 1835).

17 *Id.*

18 Bruinius, *supra* n. 4, at 12.

19 *Id.* at 6.

20 Black, *supra* n. 1, at 99.

of the “germ-plasm,” the component that could pass certain traits from one generation to the next. This was essentially what we now know as a gene. Unfortunately for Galton, though his work attracted significant interest around the world, research funds in Britain were not forthcoming.

There was no shortage of cash in the United States though, as long as one knew where to look. A handful of men — politely termed “industrialists” and less politely “robber barons” — had prospered enormously in the years before antitrust regulation and a federal income tax. One of these was Andrew Carnegie, who sold his steel empire to J.P. Morgan in 1901 for \$400 million — equivalent to nearly \$12 billion today.<sup>21</sup>

From then on Carnegie dedicated his life and money to charitable causes, chief among them the mission of the Carnegie Institution for Science to pursue “the improvement of mankind” through science. Almost as soon as the institution was created in 1902, Charles Davenport, a Harvard-educated biologist and admirer of Galton, applied for funds to construct a Long Island research facility for the study of biological variation and “race change.”<sup>22</sup> In addition to Carnegie, Davenport also cultivated a relationship with Mary Harriman, the wealthy widow of a railroad tycoon.<sup>23</sup>

Around the same time, Davenport was securing his philanthropic funding, he cemented a relationship with the American Breeders Association (ABA), a new entity whose members believed “that their

emerging Mendelian knowledge about corn and cattle was equally applicable to the inner quality of human beings.”<sup>24</sup> The ABA, along with Davenport’s newly established Eugenic Records Office (ERO), in Cold Spring Harbor on Long Island, worked tirelessly to promote the eugenic cause. Davenport appointed passionate eugenicist Harry Laughlin to run the ERO, which gathered data on “defective” residents of state institutions as well as ordinary Americans who voluntarily completed and returned questionnaires asking about family histories of disability.<sup>25</sup> Relying on this information and on generous funding from like-minded philanthropists, the ERO and ABA embarked on a campaign to educate Americans about eugenics and to lobby those in power to enact eugenic policies.

In late the 19th and early 20th century America, one of the more glaring federal policy issues was immigration. The United States had always been a nation of immigrants, but for generations, many of those immigrants came from the British Isles, Western Europe, and Scandinavia. Moreover, they came at a fairly steady pace. For a number of reasons, this changed in the late 19th century. From 1890 to 1910, 12 million immigrants streamed into the United States, most from non-Nordic countries in Southern and Eastern Europe.<sup>26</sup>

To certain people, it seemed that unchecked immigration from what they considered less desirable countries might alter the Anglo-Saxon character of the United States. At the time, American society did seem in danger of tearing at the seams. Black Americans were ostensibly free in the

21 CPI Inflation Calculator, *\$400,000,000 in 1901 → \$11,816,295,185.88 in 2018*, Off. Data Found./Alioth LLC, <https://www.officialdata.org/1901-dollars-in-2018?amount=400000000> (accessed Dec. 30, 2018).

22 Black, *supra* n. 1, at 35–36.

23 Lombardo, *supra* n. 15, at 31.

24 Black, *supra* n. 1, at 39.

25 *Id.* at 44; Lombardo, *supra* n. 15, at 34–35.

26 Bruinius, *supra* n. 4, at 256.

South, and many moved north for greater opportunity. Conflict arose between employers and nascent labor unions. New political theories — communism, socialism, and anarchy — threatened the stability of the U.S. government. Technology promised to increase the speed of change, transform industry, and remake the economy. By 1914, the entire world became embroiled in the first-ever global conflict. Things were changing everywhere, terrifying many Americans.

Members of Congress were as concerned as anyone else about the effect non-Nordic immigration might have on the fabric of American society. Still, they believed they could only go so far in stemming the tide of such immigration without understanding more about the science of racial differences. Congress turned to Harry Laughlin, Charles Davenport's protégé, to educate them.<sup>27</sup>

In the spring of 1920, Laughlin appeared before Congress to explain the relationship between eugenic science and immigration policy. He began by narrating the story of the Jukes and similar accounts that suggested certain negative traits run in families.<sup>28</sup> He went on to explain terms of art such as "moron" and "idiot," which denoted different levels of intellectual functioning. According to Laughlin, the recent waves of immigration were troubling for two reasons. First, non-Nordic immigrants — Southern and Eastern Europeans and Jews — were disproportionately represented in American prisons and asylums. This, he explained, was because these immigrant groups produced "a higher rate of defective children."<sup>29</sup> Second, and equally troubling

to Laughlin, was his belief that immigrant women seemed naturally more fertile than Anglo-Saxon women. The biggest danger of all, he believed, was not that immigrants might outbreed "real Americans." It was that allowing Jews, Italians, Russians, and other "undesirables" into the country — not to mention the black population whose ancestors had not come willingly to the United States — would inevitably compromise the purity of Anglo-Saxon blood. The inevitability of race mixing, according to Laughlin, had everything to do with the documented promiscuity, fecundity, and strange allure of "women of a lower race." Their alleged tendency toward stupidity and vice notwithstanding, Laughlin believed that these women were irresistible to Anglo-Saxon men and must be guarded against. He believed that permitting them to reproduce would be "race suicide."<sup>30</sup>

Implicit in fears of race suicide and the quest for racial purity was the notion that a person's blood belonged to that person's racial community. As Laughlin explained to members of Congress, "The character of a nation is determined primarily by its racial qualities; that is, by the hereditary physical, mental, and moral or temperamental traits of its people."<sup>31</sup> To those who believed as Laughlin did, the fate of a nation was therefore directly related to and dependent on control of its bloodline. In *The Passing of the Great Race*, Madison Grant put this bluntly:

Mistaken regard for what are believed to be divine laws and a sentimental belief in the sanctity of human life, tend to prevent both the elimination of defective infants and the sterilization of such adults as are themselves of no value to

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<sup>27</sup> *Id.* at 15.

<sup>28</sup> *Id.* at 257.

<sup>29</sup> *Id.* at 258.

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<sup>30</sup> *Id.* at 259.

<sup>31</sup> *Id.* at 255.

the community. The laws of nature require the obliteration of the unfit, and human life is valuable only when it is of use to the community or race.<sup>32</sup>

Grant's work became phenomenally popular and influential all over the world. Grant even received a fan letter from a young German who called Grant's book "his Bible."<sup>33</sup> At the time, the young German was developing his own racial and eugenic theories. He eventually published them in a volume he titled *Mein Kampf*.

Four years after Grant's words appeared in print, his publisher — Scribner — debuted *The Rising Tide of Color Against White World-Supremacy*, by Lothrop Stoddard. Stoddard echoed the fear that the United States' pure white heritage could easily fall because of association with — and necessary contamination by — other races.<sup>34</sup>

Five years after Scribner published Stoddard's work, the publisher printed a novel that received mixed reviews. That novel was *The Great Gatsby*. Generations of Americans have read the work, yet it is easy to overlook a detail that F. Scott Fitzgerald included in the first chapter of the now-famous book. In it, the boorish Tom Buchanan asks:

Have you read "The Rise of the Colored Empires" by this man Goddard? ...

The idea is that if we don't look out the white race will be — will be utterly submerged. It's all scientific stuff. It's been proved.<sup>35</sup>

It is widely acknowledged that Fitzgerald was making a thinly veiled reference to Stoddard's book in this passage. What the publisher of all these works might have thought of this is lost to history. The reference, though, serves to illustrate how eugenic ideas about race had thoroughly permeated American society in the early 20th century.

American proponents of eugenics advanced their ideas in a systematic way — a eugenic continuum. It may be difficult to comprehend how Mendel's pea plants and Galton's family trees could have anything to do with forced sterilization, Jim Crow policies, and Nazi death camps, yet there is a direct line connecting all of them.

What is so dangerous about eugenic theory, particularly as it developed in the United States, is that it was and is so simple to convince people to support it. An examination of eugenic rhetoric and policy in different decades across different cultures reveals that the same ideas crop up over and over again, in more or less the same order. The steps along this eugenic continuum are differentiation, alienation, segregation, sterilization, and elimination. American eugenicists advocated every step along the way.

### III. The Eugenic Continuum

#### A. Differentiation

The first step on the eugenic continuum — differentiation — is the simplest. It just requires convincing a person or group

32 *Id.* at 265 (quoting Madison Grant, *The Passing of the Great Race* ch. I (Charles Scribner's Sons 1916)). As Bruinius notes, the book is currently accessible in its entirety on various websites that generally advocate Grant's position. The author elects not to direct the reader to any such sites.

33 Black, *supra* n. 1, at 259.

34 Hua Hsu, *The End of White America?* The Atlantic (Jan./Feb. 2009), <https://www.theatlantic.com/magazine/archive/2009/01/the-end-of-white-america/307208> (accessed Dec. 30, 2018).

35 F. Scott Fitzgerald, *The Great Gatsby* 17 (Simon & Schuster 1st Scribner Paperback Fiction ed. 1995) (first published 1925).



that he or she or the group differs from another person or group in some meaningful way. American eugenics proponents grasped that education was critical to helping the American public distinguish the fit from the unfit. For its part, the ERO offered courses to train social workers and concerned Americans on how to develop “family pedigrees” in furtherance of the ERO’s mission to collect data on American families and to justify concerns about the heredity of defective traits.<sup>36</sup> Eugenists created “fitter families” contests at state fairs to encourage fit families to submit eugenic pedigrees and medical information in exchange for a chance to win a trophy.<sup>37</sup> The American Eugenics Society sponsored the “better baby” contests that had become popular in the early 20th century because of support from women’s rights campaigners.<sup>38</sup>

A 1929 poster from a fair in Kansas illustrates a typical argument for designating certain people as different. It read: “Unfit human traits such as feeble-mindedness, epilepsy, criminality, insanity, alcoholism, pauperism and many others, run in families and are inherited in exactly the same way as color in guinea pigs.”<sup>39</sup> Typically, a set of stuffed guinea pigs in a range of color variations accompanied such displays.<sup>40</sup>

### *B. Alienation*

Once a person or group accepted that there were different types of people — whether based on differences in social class, ability, religious affiliation, race, or

something else — the eugenicists moved to the second step, alienation. In their rhetoric, eugenicists argued that not only were certain groups different but also their differences were in some way incompatible with the dominant social order. Eugenists believed that it was not simply that the group was different; it was that their differences were a problem. Sometimes, the problem was presented as a financial one; for example, “At the Sesquicentennial Exposition in Philadelphia, the American Eugenics Society exhibit included a board that ... revealed with flashing lights that every fifteen seconds a hundred dollars of [Americans’] money went for the care of persons with bad heredity.”<sup>41</sup>

For eugenicists, though, the real problem was that the people they considered unfit would spread their “afflictions” through reproduction, thereby perpetuating unnecessary suffering for generations to come. “The human race, one proponent [of eugenics] declared in 1909, was poised ‘to dry up the springs that feed the torrent of defective and degenerate protoplasm.’”<sup>42</sup> Eugenics proponents believed that for the sake of the human race, the unfit must be alienated from the fit population and exposed for the danger they posed. Proponents of eugenics quickly settled on a handful of what they considered especially dangerous types of people. Generally speaking, these categories included people with several types of obvious disabilities, people with certain diseases, and people whose behavior was deemed antisocial. In 1911, a group of

36 Lombardo, *supra* n. 15, at 34–35.

37 Daniel Kevles, *Annals of Eugenics: A Secular Faith II*, *The New Yorker* 52, 54 (Oct. 15, 1984).

38 Bruinius, *supra* n. 4, at 235.

39 Isenberg, *supra* n. 5, at 196.

40 Kevles, *supra* n. 37, at 57.

41 *Id.*

42 Andrea DenHoed, *The Forgotten Lessons of the American Eugenics Movement*, *The New Yorker* (Apr. 27, 2016) <https://www.newyorker.com/books/page-turner/the-forgotten-lessons-of-the-american-eugenics-movement> (accessed Dec. 30, 2018).

dedicated American eugenicists delineated 10 categories: “First, the feeble-minded; second, the pauper class; third, the inebriate class or alcoholics; fourth, criminals of all descriptions including petty criminals and those jailed for nonpayment of fines; fifth, epileptics; sixth, the insane; seventh, the constitutionally weak class; eighth, those predisposed to specific diseases; ninth, the deformed; tenth, those with defective sense organs, that is, the deaf, blind and mute.”<sup>43</sup>

### C. Segregation

After the step of alienation, the eugenic continuum left the realm of theory and entered the realm of policy. If certain groups of people were considered dangerous to society, it stood to reason that society should find ways of protecting itself from them. The third step was segregation. This came in many forms and was especially attractive because mechanisms of segregation already existed in most communities. Institutions such as prisons, almshouses, asylums, and hospitals for patients with specific conditions — such as epilepsy — were an established part of society.<sup>44</sup> For generations, these institutions had been the only means to deal with behaviors and conditions that science otherwise had been unable to address. Indeed, American proponents of eugenics frequently coordinated with these institutions to gather data on their charges in order to compile evidence that “defectives” could endanger the gene pool. In the early 20th century, the ABA approved a proposal to promote the segregation or long-term incarceration of the people it considered unfit during their fertile years.<sup>45</sup>

The Virginia State Colony for Epileptics and Feeble-minded was one such institution. It “was founded for the care of ... [unfit] women until their ability to have children had passed.”<sup>46</sup> Under the leadership of Dr. Alfred Priddy in the early 20th century, the Virginia State Colony adopted sterilization as a common practice for women who seemed feeble-minded or immoral. Priddy sometimes castrated boys at the colony, but he was particularly concerned with the danger posed to society by fertile women who might pass their unfit characteristics on to their children.<sup>47</sup>

There was another avenue of segregation as well, which involved preventing what was considered the wrong types of people from entering the country in the first place. Proponents of eugenics advocated limiting immigration to the United States based on race and ethnicity. Charles Davenport, ERO founder, gave voice to the concerns of many when he suggested that “we build a wall high enough around this country so as to keep out these cheaper races,” lest the country be surrendered to “the blacks, browns and yellows ... .”<sup>48</sup> On the West Coast, racism against Chinese and Japanese immigrants prompted Congress to pass the Chinese Exclusion Acts in 1882 and 1902.<sup>49</sup> In general, though, American immigration policy traditionally had been driven more by economic concerns than racial ones. Congress took the first step toward a targeted eugenic immigration policy with the Immigration Restriction Act of 1917. That act broadened existing bans on Asian immigrants and restricted immigration based on a person’s mental

43 Black, *supra* n. 1, at 58.

44 *Id.* at 54.

45 *Id.* at 60.

46 Lombardo, *supra* n. 15, at 62–63.

47 *Id.* at 60–61.

48 Black, *supra* n. 1, at 37.

49 Bruinius, *supra* n. 4, at 256.

health, political ideology, poverty and literacy.<sup>50</sup>

The final means of segregation advocated by American eugenicists was also primarily racially motivated — marriage restriction. In the early to mid-19th century, the United States expanded westward, and eugenicists believed that it was imperative that the people settling new territories be of pure Anglo-Saxon stock. In Texas, however, the Mexican government encouraged marriage between members of different races. After Texas gained its independence, it passed “its first antimiscegenation law in 1837,” largely in response to concerns that intermarriage with too many Mexicans would taint the Anglo-Saxon bloodline.<sup>51</sup> California followed Texas in implementing laws to protect the Anglo-Saxon bloodline, particularly from Chinese immigrants. Southern states, of course, were most concerned about what they considered the dangerous possibility of intermarriage between blacks and whites. As eugenic arguments gained traction in the early 20th century, eugenicists helped advance “‘one drop’ racial integrity laws” and antimiscegenation laws.<sup>52</sup> Though they enjoyed success in this area, proponents of marriage restriction acknowledged that “laws against intermarriage cannot solve the negro problem in any of its aspects — industrial, economic, political, social, biological or eugenical. They can, however, delay the evil day and give time for the evolution of an effective solution ... a real and final solution.”<sup>53</sup>

#### *D. Sterilization*

Although proponents of eugenics believed that segregation would keep healthy Americans safe from what they considered the poisoned genetic material of the unfit, it was not a perfect solution. One of the most significant problems was cost. Proponents of eugenics realized that mass incarceration of the unfit would require huge amounts of money from government and philanthropists, and they bristled at the idea of spending such amounts on groups of people whom they believed should not have existed in the first place. Margaret Sanger, birth control activist and sometime ally of the American eugenics movement, admonished Americans that “our eyes should be opened to the terrific cost to the community of this dead weight of human waste.”<sup>54</sup>

There was an alternative that was cheaper than incarceration and had the added benefit of guaranteeing that those who were considered unfit could not pass on their “defective” genes. Enter step four: sterilization. American proponents of eugenics were enthralled by the idea of compulsory sterilization of the unfit. It seemed to go to the very heart of their goal to protect the purity of the human bloodline.

While Davenport set up his Long Island laboratory and pondered the theoretical basis for eugenic policy, other men were quietly applying eugenic ideas to human specimens. It was doctors, not researchers or politicians, who first acted to guard against the “defective” germ-plasm. The specter of the Jukes haunted the imagina-

<sup>50</sup> *Id.*

<sup>51</sup> Isenberg, *supra* n. 5, at 141.

<sup>52</sup> Black, *supra* n. 1, at 174–175.

<sup>53</sup> *Id.* at 175.

<sup>54</sup> *Id.* at 130. It should be noted that Sanger frequently clashed with leading American eugenicists, particularly because she advocated access to birth control for wealthy “fit” women, whom eugenicists believed should be required to produce as many children as was practicable. *Id.* at 139.

tions of members of the medical community as much as anyone else. Many doctors accepted the premise that certain negative traits could run in families and that crime, disease, and immorality would continue as long as those “afflicted” with these traits continued to reproduce. Doctors working with charities, asylums, and prisons had frequent contact with persons who were considered sick, insane, or criminal, and these doctors were uniquely positioned to address the problem.

By the 1890s, certain physicians began to experiment with asexualization as a cure for masturbation, “unseemly sexuality” (particularly in women), and epilepsy.<sup>55</sup> The original prescribed remedy was castration for men and oophorectomy (removal of the ovaries) for women. A few doctors — in Pennsylvania, Massachusetts, and Kansas — admitted to using these surgeries for “therapeutic” purposes. One physician, who headed the evocatively named Kansas Asylum for Idiots and Feeble-minded Youths, castrated more than 50 children in his charge.<sup>56</sup> Many other doctors voiced support for the practice but refused to state whether they had performed the procedures themselves. It was generally understood, though, that asexualization operations were quietly taking place in institutions across the country.<sup>57</sup> There was, however, a problem with castrating wards of the state — the public abhorred it. When word got out about the children in the Kansas institution, for example, most people were shocked, but a number of physicians applauded efforts

to prevent undesirable people from reproducing.<sup>58</sup> Still, among the general public, castration was viewed as too brutal even for criminals.

A turning point came in 1899 when Dr. A.J. Ochsner published a journal article explaining how males could be sterilized by vasectomy, a much less aggressive procedure than “emasculat[ion].”<sup>59</sup> Reducing the brutality of the procedure made it easier for eugenicists to promote sterilization. Within less than 10 years, bills began popping up in state legislatures and state governments, encouraged by doctors, to sanction sterilization of “unfit” persons.<sup>60</sup>

Michigan was the first state to introduce a bill legalizing the sterilization of criminals. In an interesting antecedent to the habitual offender or “three-strikes” laws that would sweep the country a century later, the 1897 Michigan bill recommended sterilization for male and female “three-time felons.”<sup>61</sup> The Michigan bill narrowly failed in the state senate, as did a similar bill put forth in Kansas.<sup>62</sup>

A few years later, Pennsylvania attempted to legalize sterilization of anyone whose “offspring ... will be necessarily a curse to society.”<sup>63</sup> The bill, which focused on “mental defectives” and was supported by the state’s medical community, passed both houses of the Pennsylvania legislature.<sup>64</sup> The Pennsylvania governor, however, was alarmed both at the sweeping discretion the bill afforded surgeons and by the “cruelty” of involuntarily sterilizing “a helpless class in the community which

55 Lombardo, *supra* n. 15, at 20–21. It should be noted that at the time, “epilepsy” was often used as an umbrella term to describe many mental illness symptoms, antisocial behavior, and seizure disorders.

56 Bruinius, *supra* n. 4, at 148.

57 Lombardo, *supra* n. 15, at 21–22.

58 Bruinius, *supra* n. 4, at 148.

59 *Id.* at 149.

60 *Id.* at 150–151.

61 Lombardo, *supra* n. 15, at 21.

62 *Id.*

63 Bruinius, *supra* n. 4, at 150.

64 Lombardo, *supra* n. 15, at 22.

the state has undertaken to protect.”<sup>65</sup> The governor vetoed the bill.

Indiana became the first state to pass a eugenic sterilization law. While the idea of “therapeutic” sterilization enjoyed broad support in the state’s medical community, Dr. Harry C. Sharp of the Indiana Reformatory was particularly instrumental in demonstrating the usefulness of sterilization. Sharp, who declined to administer anesthesia to his patients,<sup>66</sup> claimed to have performed vasectomies on hundreds of male inmates “for the purpose of producing mental and physical improvement, as well as for the prevention of procreation.”<sup>67</sup> In light of Sharp’s successes, the Indiana legislature took up a bill that was similar to the Pennsylvania measure. Unlike the governor of Pennsylvania, however, Indiana’s governor had no qualms about signing a law predicated on the notion that “[h]ereditry plays a most important part in the transmission of crime, idiocy and imbecility.”<sup>68</sup>

Other states soon adopted similar measures, though the target population varied somewhat. New Jersey passed a bill along the lines of the Pennsylvania and Indiana models. The New Jersey measure gave broad discretion to an appointed panel of physicians to determine whether and how certain criminals, the mentally ill, and “other defectives” should be asexualized. Woodrow Wilson, then governor of

New Jersey, supported the measure.<sup>69</sup> The New Jersey law, however, did not survive the state’s Supreme Court, for reasons explored below.

In 1909, California adopted the broadest eugenic sterilization law in the country. It effectively allowed the heads of most state institutions (e.g., prisons, hospitals, homes for children) to decide which of their charges to surgically asexualize.<sup>70</sup> Connecticut took up a similar law.<sup>71</sup> Eventually, 32 states legalized involuntary sterilization for certain population groups.

Despite the enthusiasm for state eugenics laws, there remained an impediment to a eugenic America. There was no judicial precedent to justify sterilization of the so-called unfit. In fact, eugenic sterilization laws faced significant opposition in some cases. As in Pennsylvania, a few governors vetoed sterilization bills. The general public never really warmed to the idea of government determining who should and should not reproduce. Moreover, while many physicians advocated eugenic sterilization, there was still no consensus in the medical community that sterilization of the so-called unfit was effective or appropriate. In South Dakota, a group of doctors simply refused to perform the operations after that state passed its sterilization law.<sup>72</sup>

A few challenges to the constitutionality of the state laws arose, though in general, the people targeted by the laws lacked the resources to bring cases to court. This was certainly true in Virginia, which may be why the *Mallory* case came as such a surprise. Like many other states, Virginia had considered various eugenic measures,

65 Bruinius, *supra* n. 4, at 151.

66 Lombardo, *supra* n. 15, at 22.

67 Ltr. From Dr. Harry C. Sharp to Gov. Thomas H. Marshall, *Opposition to the Possible Unconstitutional Ruling of the Sterilization Law* (May 13, 1909), <http://ulib.iupuidigital.org/cdm/ref/collection/Eugenics/id/1610> (accessed Dec. 30, 2018).

68 Lombardo, *supra* n. 15, at 25; Bruinius, *supra* n. 4, at 151.

69 Lombardo, *supra* n. 15, at 26.

70 *Id.*

71 *Id.*

72 *Id.* at 91.

typically with vocal support from the state's medical community, but several early attempts to pass a eugenic sterilization measure failed.<sup>73</sup> Eugenics advocates kept pushing and in 1916, Virginia approved a law granting doctors broad discretion to perform sterilization surgeries on people held in prisons or asylums as long as the goal was to benefit the individuals physically, mentally, or morally.<sup>74</sup>

The 1916 law did not explicitly refer to sterilization, but it could be interpreted as permitting sterilizations of individuals in state institutions. Dr. Albert Priddy, eugenics enthusiast, certainly took that view, and in his capacity leading the Virginia State Colony for Epileptics and Feeble-minded had a captive population of women he considered unfit. Even though some of the women might have had legitimate mental health or substance abuse problems, Priddy focused his eugenic interest on something altogether different: female sexuality. It seems that one of the main functions of the colony was to isolate prostitutes, unwed mothers, women who were suspected of wanting to engage in sexual activity, and other "immoral" types.<sup>75</sup> The idea was that if they could be kept out of the community, they could not spread their "degeneracy" by reproducing. However, it was clear to eugenics proponents that many of the women, if they could be prevented from breeding, could function outside the colony. To eugenics proponents, sterilization seemed like the perfect solution.

Authorizing sterilizations of women and girls was fairly straightforward. It was easy to label them as "feeble-minded,"

sometimes as a result of an IQ test,<sup>76</sup> or as "immoral," a term that could encompass all manner of behaviors. One 16-year old girl was sterilized for showing an interest in boys and passing them notes.<sup>77</sup> Though less common, Priddy did approve boys for sterilization, often due to their "feeble-mindedness" and sometimes to cure them of masturbation. Priddy had one boy circumcised in order to treat his alleged epilepsy.<sup>78</sup> Because of his position of authority and because most of the people he dealt with were poor and uneducated, Priddy was able to convince family members to consent to have their loved ones sterilized. So it is not surprising that Priddy expected no resistance when he began his involvement with the Mallory family.

The Mallorys were poor, and they were numerous. Willie Mallory, the mother, birthed 12 children, nine of whom survived. George Mallory, the father, often worked out of town, leaving Willie at home with the children for long stretches of time. Because the family sometimes was forced to rely on charity to get by, Sarah Roller, who worked for the Richmond Juvenile and Domestic Relations Court, knew the Mallorys. Roller frequently notified Priddy about "problem girls who might become future Colony inmates."<sup>79</sup> Priddy and Roller corresponded about the Mallory family and targeted them for sterilization after the passage of the 1916 Virginia law.

One night while George Mallory was out of town, police took his family away on trumped-up charges. The young chil-

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73 *Id.* at 59.

74 *Id.* at 60.

75 *Id.* at 61.

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76 Intelligence tests were also developed and promoted by eugenicists in order to prove the transmissibility of intelligence or feeble-mindedness. Black, *supra* n. 1, at 76.

77 *Id.* at 61.

78 *Id.* at 63.

79 *Id.* at 64.

dren were placed in the custody of a foster agency. Sarah Roller had Willie Mallory and her two teenage daughters declared “feeble-minded” and committed them to the Virginia State Colony, bypassing the proper legal channels.<sup>80</sup> While the women were in the custody of the colony, George frantically tried to get his wife and daughters released. Priddy refused repeated requests to release them, even though he had no commitment papers to justify their detention. He eventually let Willie and her older daughter leave the colony, but only after he had them sterilized. Priddy kept the other daughter at the colony for months longer, clearly intending to subject her to the same procedure.<sup>81</sup>

What Priddy did not anticipate was George Mallory’s persistence. Though he was poor and barely literate, George wrote many letters demanding his daughter’s freedom and warning Priddy “not to opreated [sic] on my child.”<sup>82</sup> Unfazed by Priddy’s threats to have him arrested for objecting to his family’s mistreatment, Mallory sued.<sup>83</sup> Eventually, all of the Mallory children were returned home. Priddy narrowly avoided having to pay damages for sterilizing Willie Mallory because the jury accepted the argument that the surgery was medically necessary. The trial judge, however, admonished Priddy not to try the same thing again. The *Mallory* case had a chilling effect on sterilization programs, at least for the time being.<sup>84</sup>

Virginia eugenicists did not give up, however. The *Mallory* case simply showed them that they would have to proceed carefully if they wanted eugenic steriliza-

tion to be the law of the land. For years, Priddy and his fellow eugenicists promoted their cause. One such proponent was Aubrey Strode, an attorney for the Virginia State Colony and a man with significant political contacts. After reviewing various legal challenges to the constitutionality of other state sterilization laws, Strode drafted his own bill to avoid the common pitfalls. Strode’s bill became law in 1924. The next month, Priddy submitted a list of women he wanted to sterilize.

Despite the careful preparation of the 1924 law, its supporters knew it would face a challenge. The best strategy was to get ahead of it. The Virginia State Colony hired Strode himself to defend against the anticipated lawsuit.<sup>85</sup> The woman selected for the test case was named Carrie Buck. As a young girl, Carrie had been taken in by a Charlottesville family named Dobbs. She was more or less their foster child, though she did work around the house to earn her keep. When she was 16 and unmarried, Carrie became pregnant.<sup>86</sup> This was scandalous for the Dobbs family not only because of Carrie’s condition but because she said the family’s nephew was the father. Moreover, she claimed that the nephew had raped her.<sup>87</sup> The Dobbses sent Carrie away to give birth, after which they committed her to the colony, claiming that she was feeble-minded and prone to epileptic seizures.<sup>88</sup> Priddy himself examined Carrie after her arrival at the colony and found that she was literate and exhibited “no evidence of psychosis.”<sup>89</sup>

Nevertheless, two things made Carrie Buck supposedly dangerous. First, her

80 *Id.* at 66.

81 *Id.* at 67–68.

82 *Id.* at 70.

83 *Id.* at 68.

84 *Id.* at 76.

85 *Id.* at 101.

86 *Id.* at 103.

87 *Id.* at 140.

88 *Id.* at 104.

89 *Id.* at 105.

claim of rape notwithstanding, her out-of-wedlock pregnancy suggested sexual immorality, which Priddy detested. Second, Carrie's mother Emma had been committed to the colony years earlier, accused of prostitution, drug use, out-of-wedlock pregnancies, and general untidiness, among other things. It is difficult to know how accurate any of those claims were. For one thing, there was evidence that she had been married and that her children were legitimate.<sup>90</sup> Nevertheless, Carrie's treatment and that of other young women reveal that authorities were willing to distort facts in order to commit women they did not like. At any rate, Emma Buck received the diagnosis of "moron."<sup>91</sup>

This is what made Carrie Buck's case such a perfect test of the new sterilization law. Priddy carefully followed all the proper procedures to have Virginia State Colony officials agree to sterilize Carrie. Priddy wanted no repeat of the Mallory case. Carrie's interests were represented by a guardian appointed by the colony's board. Once the board agreed to the operation, the guardian simply had to hire an attorney to challenge the determination. Having Carrie represented by an attorney was part of Strode's plan to show that Carrie had received due process.

Carrie's guardian hired Irving Whitehead, a respected Virginia attorney who also happened to be a "confidant of Priddy, boyhood friend to Aubrey Strode, former Colony director, and sterilization advocate."<sup>92</sup> Considering his personal views and connections, Whitehead was perhaps not the best person to advocate for Carrie Buck. On the other hand, Whitehead was an experienced attorney and was

doubtless aware of his duty of loyalty to his client. Yet by almost any standard, his representation of Carrie left much to be desired. For example, he allowed an expert to assert that Carrie had syphilis, though Whitehead knew she did not. In questioning the same expert, Whitehead essentially conceded that Carrie was feeble-minded and sexually immoral, as her mother had been.<sup>93</sup> Worst of all, the eugenic argument went, the same defective germ-plasm ran through the veins of Carrie's baby girl. That Carrie had produced a "deficient" child was supported by a social worker's assertion that the 8-month-old looked "not quite normal."<sup>94</sup> Carrie's attorney did not question the assessment of the child.

The conduct of Carrie's attorney was egregious, and the expert testimony speculative at best. The majority of witnesses to Carrie's "feeble-mindedness" had by their own admission never even met her.<sup>95</sup> Nevertheless, Carrie's sterilization under the 1924 Virginia law was affirmed time and again, all the way up to the U.S. Supreme Court. In 1927, Justice Oliver Wendell Holmes Jr. wrote the majority opinion in *Buck v. Bell*. Because Justice Holmes took such pride in the opinion,<sup>96</sup> it seems fitting to reproduce his words here:

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world if instead of waiting to execute degenerate offspring for crime or to let them

90 *Id.* at 106.

91 *Id.*

92 *Id.* at 107.

93 *Id.* at 127.

94 Bruinius, *supra* n. 4, at 67.

95 Lombardo, *supra* n. 15, at 117.

96 Bruinius, *supra* n. 4, at 72.



starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough.<sup>97</sup>

Carrie Buck worked hard for the rest of her life, though she never escaped poverty. She died in a nursing home in 1983. Her daughter, Vivian, did not live to adulthood. She succumbed to measles at the age of 8 — after making the honor roll at school.<sup>98</sup>

Within 4 years of the decision in *Buck v. Bell*, 28 states passed sterilization bills such as Virginia's.<sup>99</sup> Perhaps the best evidence of the case's effect on eugenic sterilization in the United States is the marked increase in sterilization surgeries after *Buck v. Bell*. While a number of states had sterilization laws on the books before 1927, there was enough uncertainty that many states had not put them into practice. By 1940, more than 35,000 American adults had been sterilized through state programs. Nearly 30,000 of these operations took place after *Buck v. Bell*.<sup>100</sup>

### *E. Elimination*

In some cases, American proponents of eugenics believed that even sterilization was not enough; therefore, these proponents reserved a final step on the eugenic continuum: elimination. Similar to other aspects of the continuum, even this extreme option had precedent that society had long approved. There was one group of people that human societies had always authorized killing — criminals. To Ameri-

can eugenicists, criminality was just as hereditary as blindness or any other condition and criminality was just as dangerous to the racial stock. The problem was finding a way to humanely kill large numbers of people. Once again, 19th-century Victorian technological advancements offered a solution. It was called a “lethal chamber.” Originally developed “as a means of humanely killing stray dogs and cats” with cyanide gas, the lethal chamber immediately appealed to eugenicists.<sup>101</sup> Discussion of using lethal chambers to kill the so-called unfit prompted some backlash in Britain, but many British and American eugenics proponents still touted the merit of the idea.<sup>102</sup>

As with sterilization, when it came to killing people who were considered unfit, individual doctors with eugenic sympathies sometimes took matters into their own hands. It was widely understood among the Chicago medical community that “[q]uiet euthanasia of [defective] newborns was not uncommon.”<sup>103</sup> In 1915, Dr. Harry Haiselden caused a sensation when he deliberately withheld lifesaving treatment for a newborn he claimed was “deformed” (a witness who pleaded for him to save the baby's life disagreed that there was anything wrong with the child).<sup>104</sup> In a hearing before Chicago's health commission, the panel of physicians also disagreed that there was any reason to believe “that the child would have become mentally or morally defective.”<sup>105</sup> Nevertheless, they determined that as a physician, Haiselden was entitled to make the final decision about whether to save

97 *Buck v. Bell*, 274 U.S. 200, 207 (1927).

98 Bruinius, *supra* n. 4, at 76–77.

99 *Id.* at 72.

100 Black, *supra* n. 1, at 122–123.

101 *Id.* at 247.

102 *Id.* at 248–249.

103 *Id.* at 253.

104 *Id.* at 252.

105 *Id.* at 253.

the child's life.<sup>106</sup> Significantly, their reasoning suggests that they might have even approved euthanasia if there had been more evidence that the child was unfit. After his vindication, the doctor admitted in several interviews that in addition to refusing lifesaving treatment, he had also allowed babies he deemed unfit to bleed to death and even killed some of them himself with injections of opiates. Some Americans were stunned, but eugenicists such as Davenport praised the use of "one of Nature's greatest racial blessings — death."<sup>107</sup>

Adolph Hitler, long an admirer of American eugenic theory, became chancellor of Germany in 1933. Within the year, Hitler and his Nazi party had taken over the German government. This total control allowed Hitler to institute his Law for the Prevention of Progeny With Hereditary Diseases,<sup>108</sup> which he modeled on American eugenic theory and legislation. American proponents of eugenics were thrilled with Hitler's progress, and some of them carried on friendly correspondence with Nazi leaders, including Hitler himself. At the same time, the Americans were frustrated that their efforts could not keep up with the Nazi program. In 1934, Dr. Joseph DeJarnette lamented to a Virginia newspaper, "The Germans are beating us at our own game."<sup>109</sup> DeJarnette's words carried some weight at the time, as he was the longstanding superintendent of Virginia's Western State Hospital. Indeed, he had held the same position 10 years earlier, when he appeared as an expert witness in Carrie Buck's first trial.<sup>110</sup>

The original German eugenic sterilization program targeted the so-called feeble-minded and epileptics, of course, in addition to people diagnosed with schizophrenia, manic depression, alcoholism, Huntington's disease, physical abnormalities, deafness, and blindness. The last three categories applied specifically to people with congenital physical disabilities, deafness, or blindness.<sup>111</sup> Injured people were not targets of the program. After all, many German veterans of World War I had limbs amputated or experienced another disability as a result of their service. The thinking was that their defects were not hereditary and therefore not dangerous. During his military service in World War I, the Führer himself was treated for blindness, which he claimed was caused by mustard gas. Doctors attributed it to some sort of mental collapse.<sup>112</sup> Either way, Hitler did not seem to perceive that he had anything in common with the population of "defectives" he planned to eliminate.

We all know what happened. The Nazis proceeded through the eugenic continuum that American eugenicists had only dreamed about. First, what were considered defective populations were segregated from healthy Germans. As in the United States, many people with disabilities and mental illnesses were already housed in hospitals and asylums. For certain other "undesirables" and political opponents of the Nazis, the first concentration camp, Dachau, opened in 1933. Later the same year, the Nazis passed a eugenic sterilization law. Compulsory sterilizations began in 1934.<sup>113</sup> Also in 1934, IBM began work-

106 *Id.*

107 *Id.* at 254.

108 *Id.* at 299.

109 *Id.* at 277.

110 Lombardo, *supra* n. 15, at 127.

111 Black, *supra* n. 1, at 299.

112 Peter Caddick-Adams, *The Secret Madness of Adolph Hitler*, Salon (Jan. 3, 2015), [https://www.salon.com/2015/01/03/the\\_secret\\_madness\\_of\\_adolf\\_hitler](https://www.salon.com/2015/01/03/the_secret_madness_of_adolf_hitler) (accessed Dec. 30, 2018).

113 Black, *supra* n. 1, at 299.

ing with the Nazi government to develop a punch card system that could record health and racial characteristics of all Germans. The system was similar to the categorization system the ERO had developed to track negative eugenic traits in Americans. The technology was just more advanced by the 1930s. IBM's machine could sort 25,000 cards per hour with the ultimate goal of "eradicating the unhealthy, inferior segments of German society."<sup>114</sup> With the tracking system in place, in 1935, the Nazis implemented the Nuremberg Laws, which stripped Jews of their German citizenship and prevented them from marrying non-Jews.<sup>115</sup> The Nuremberg Laws and the coordinated violence of Kristallnacht in 1938 were designed not only to terrify the Jewish population but also to make living in Nazi territory so unpleasant that Jews would emigrate.<sup>116</sup> In 1939, the first ghettos were created to segregate Jews from Germans of pure blood and eventually to funnel Jewish populations into the concentration camp network.<sup>117</sup>

Segregation and sterilization alone, the Nazis believed, were not enough. By the late 1930s, Nazi policy shifted toward eliminating so-called unfit populations altogether. In 1940, the Nazi state directed physicians in state institutions to select candidates for euthanasia. As many as 100,000 people who were considered burdens on the state — the elderly, disabled, and mentally ill — were gassed to death in the backs of sealed trucks.<sup>118</sup> The Nazis "improved" their technique over the years,

culminating in the systematic killing of millions of Jews and other minorities in "showers" pumped full of Zyklon B. That part of the story is more familiar to most of us, but it all began with groups of disabled people selected by their own doctors to be suffocated with carbon monoxide.

#### IV. Manifest Destiny

It is easy to invoke Nazi atrocities as the inevitable result of extreme ideology. Rhetorically lazy or not, "the widespread phenomenon of glibly comparing someone else to Hitler or Nazis to win an online argument" became so common in the internet age that it was given a name: Godwin's Law.<sup>119</sup> The law states, "As an online discussion continues, the probability of a reference or comparison to Hitler or Nazis approaches 1."<sup>120</sup>

It would be easy to believe that the Holocaust was an aberration born of Hitler's own madness and the evil lure of fascism. It would be comforting to think that if American eugenicists had known the horror that would be perpetrated in the name of eugenics, they would have reconsidered their theories. In truth, the evidence suggests that what happened in Nazi-occupied Europe was the logical outcome of American eugenic theory. First, each step in the Nazi "final solution" had been proposed first in American eugenic circles. Second, eugenicists and others in the United States knew a good deal about

<sup>114</sup> *Id.*, at 309.

<sup>115</sup> *Id.* at 311.

<sup>116</sup> *Id.* at 316.

<sup>117</sup> U.S. Holocaust Meml. Museum, *Ghettos*, Holocaust Encyclopedia, <https://www.ushmm.org/wlc/en/article.php?ModuleId=10005059> (accessed Dec. 30, 2018).

<sup>118</sup> Black, *supra* n. 1, at 317.

<sup>119</sup> Abby Ohlheiser, *The Creator of Godwin's Law Explains Why Some Nazi Comparisons Don't Break His Famous Internet Rule*, Wash. Post (Aug. 14, 2017), [https://www.washingtonpost.com/news/the-intersect/wp/2017/08/14/the-creator-of-godwins-law-explains-why-some-nazi-comparisons-dont-break-his-famous-internet-rule/?utm\\_term=.1986e94fb443](https://www.washingtonpost.com/news/the-intersect/wp/2017/08/14/the-creator-of-godwins-law-explains-why-some-nazi-comparisons-dont-break-his-famous-internet-rule/?utm_term=.1986e94fb443) (accessed Dec. 30, 2018).

<sup>120</sup> *Id.*

what Hitler was doing before and during World War II. Third, American eugenics programs continued even after the disclosure of the Nazi crimes. For example, in North Carolina, the sterilization program “expanded after World War II, even as most other states pulled back in light of the horrors of Hitler’s Germany.”<sup>121</sup>

Even today, a misconception persists that Americans and the world were largely ignorant of Nazi atrocities until the end of the war. The truth is that these atrocities “were chronicled daily on the pages of America’s newspapers, by wire services, radio broadcasts, weekly newsreels, and national magazines.”<sup>122</sup> Nevertheless, the trials at Nuremberg laid bare the full extent of Nazi crimes for the first time. Prosecutors devoted considerable time and particular attention to the eugenic policies and practices of the Nazi regime, but they needed a new term to describe a type and scale of crime unlike anything the world had ever seen. They chose the word “genocide” to describe the crimes that arose from the Nazi eugenic policy.<sup>123</sup> Prior to the Nuremberg proceedings, the United Nations approved the Convention on the Prevention and Punishment of the Crime of Genocide, which provides as follows:

[G]enocide means any of the following acts committed with intent to destroy, in whole or in part, a national, ethnical, racial or religious group, as such:

- (a) Killing members of the group;
- (b) Causing serious bodily or mental harm to members of the group;
- (c) Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part;
- (d) Imposing measures intended to prevent births within the group;
- (e) Forcibly transferring children of the group to another group.<sup>124</sup>

Prosecutors had ample evidence to prove the Nazi defendants — many of whom were physicians — guilty of genocide.<sup>125</sup> There was, however, something discomfiting about the defenses employed by the Nazis. Their attorneys insisted on pointing out that the policies underlying the Holocaust had a great deal in common with American eugenics.<sup>126</sup>

## V. An American Dream

The countless human lives damaged or simply wiped off the face of the earth because of eugenic belief did not result from “excess and error,” as Hitler put it. This erasure of human lives was contemplated from the very beginning of the eugenics movement. It was the price of perfection — blood for blood. In his seminal *The Souls of Black Folk*, W.E.B. DuBois wrote, “It is a hard thing to live haunted by the ghost of an untrue dream.”<sup>127</sup>

121 Kevin Begos, *Lifting the Curtain on a Shameful Era*, Winston-Salem J. (Dec. 9, 2002). This piece was part of an award-winning series about the history of North Carolina’s eugenics program. The series, titled *Against Their Will*, ran in 2002.

122 Black, *supra* n. 1, at 299.

123 The term was actually coined before the end of World War II by Raphaël Lemkin, a Jewish attorney of Polish descent who escaped the Nazis and became a professor at Duke University. Black, *supra* n. 1, at 402. Lemkin’s research on the Nazi eugenics campaign influenced the Allies and the Nuremberg prosecutors as they built a case against the Nazis. *Id.* at 404.

124 *Id.* at 404–405 (quoting U.N. Off. of the High Commr. for Human Rights, *Convention on the Prevention and Punishment of the Crime of Genocide* (1948), <https://www.ohchr.org/en/professionalinterest/pages/crimeofgenocide.aspx> (accessed Dec. 30, 2018)).

125 Bruinius, *supra* n. 4, at 316.

126 *Id.* at 315.

127 W.E.B. Du Bois, *The Souls of Black Folk* pt.

What the eugenicists failed to realize was the seductive but wrong assumption underlying their dream. DuBois articulated the assumption in the same seminal work: that to be different is to be “a problem.” Eugenicians decided that certain people — those with disabilities, nonwhites, the poor, the mentally ill, and so many others — were problems. You see this in the language they employed. The existence of certain people was a problem. Eugenics proponents offered a “final solution.”

The story is not over, and eugenic ideas have not disappeared. Today, eugenic ideas appear in the news regularly. There is an ongoing debate among people with disabilities and their allies about the ethics of prenatal screening for disabilities and selective abortion if disabilities are detected.<sup>128</sup> Setting aside the politics of abortion, this discussion is particularly fraught in the United States, where a child’s medical needs might bankrupt his or her family.

Eugenic ideas appear in the courts and prisons, where the state exercises considerable control over the accused and convicted. California, home to the country’s largest eugenics program in the early to mid-20th century, allegedly sterilized 150 women in its prisons from 2006 to

2010.<sup>129</sup> In February 2018, an Oklahoma judge gave a woman a reduced sentence on fraud and drug charges after she agreed to the judge’s suggestion that she be sterilized.<sup>130</sup>

Marginalized populations, especially people with disabilities, remain vulnerable to eugenic threats and abuse. Every eugenics movement, from Britain to the United States to Nazi Germany, began by targeting people with disabilities and differences. It was easy to designate them as problems, whether because of the costs of their care, society’s unwillingness to accommodate their needs, or fundamentally, the fact that their lives were not seen as valuable. As we learn more about addressing disabilities, these arguments will not go away. They will simply evolve. Language may change or soften, but the underlying assumption will remain: Some people are problems in want of a solution. Therefore, it is imperative that elder advocates, elder and special needs law attorneys in particular, understand eugenic rhetoric and the very real danger it poses.

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V (1903) (2008 ebook published by Project Gutenberg at <https://www.gutenberg.org/files/408/408-h/408-h.htm>) (accessed Dec. 30, 2018).

128 Marsha Saxton, *Disability Rights and Selective Abortion*, in *Abortion Wars: A Half Century of Struggle*, 1950–2000 374 (Rickie Solinger ed., U. of California Press 1998).

129 Lisa Ko, *Unwanted Sterilization and Eugenics Programs in the United States*, PBS - Independent Lens (Jan. 29, 2016), <http://www.pbs.org/independentlens/blog/unwanted-sterilization-and-eugenics-programs-in-the-united-states/> (accessed Feb. 18, 2019).

130 Tom Jackman, *Judge Suggests Drug-Addicted Woman Get Sterilized Before Sentencing, and She Does*, Wash. Post (Feb. 8, 2018), [https://www.washingtonpost.com/news/true-crime/wp/2018/02/08/judge-suggests-drug-addicted-woman-get-sterilized-before-sentencing-and-she-does/?utm\\_term=.317dfcf2b8ef](https://www.washingtonpost.com/news/true-crime/wp/2018/02/08/judge-suggests-drug-addicted-woman-get-sterilized-before-sentencing-and-she-does/?utm_term=.317dfcf2b8ef) (accessed Dec. 30, 2018).



**Health Care Decision-Making  
During a Crisis When Nothing Is in Writing**

*By David Godfrey*

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**About the Author**

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## I. Introduction

Every day in a hospital near you, a patient is critically ill, near death, or unable to make or communicate his or her health care decisions, with no one named by the patient to make these decisions under such circumstances.

In 2017, only slightly more than one-third of adults in the United States had advance health care directives.<sup>1</sup> The highly personal decisions made in moments of crisis involve complex medical, social, and ethical factors<sup>2</sup> and determine the quality of life or death of the patient. In those moments, one hopes the choices being made for the patient most closely reflect the choices the patient would make if he or she were able to do so.

Understanding health care decision-making in the absence of an advance health care directive will help elder and special needs law attorneys in two ways. First, people caring for an incapacitated family member without an advance directive will come to these attorneys for advice. Understanding accepted medical practice and standards of care will help attorneys advocate for families and advise them on what to expect. Second, attorneys can use this knowledge to urge all of their clients to create effective advance directives.

This article is based on a 24-month original research project conducted by the American Bar Association (ABA)

Commission on Law and Aging, in collaboration with the Society of Critical Care Medicine (SCCM)<sup>3</sup> and Society of Hospital Medicine (SHM),<sup>4</sup> and funded by the Retirement Research Foundation.<sup>5</sup> Researchers studied health care decision-making in critical care settings when patients lacked capacity and had no advance directive. The research team compared default surrogate consent laws with clinical practice. The team also studied how health care providers respond to conflict among family members and how health care providers make decisions for patients who have no readily identifiable family or friends to make health care decisions for them.

The research project started with a review of existing statutory provisions and

1 Carolyn Crist, *Over One Third of U.S. Adults Have Advanced Medical Directives*, Reuters Health News (July 11, 2017), <https://www.reuters.com/article/us-health-usa-advance-directives-idUSKBN19W2NQ> (accessed Nov. 15, 2018).

2 Am. College of Phys., *Critical Care Medicine*, <https://www.acponline.org/about-acp/about-internal-medicine/subspecialties/additional-training-options/critical-care> (accessed Nov. 15, 2018).

3 The Society of Critical Care Medicine (SCCM) is composed of a diverse group of intensive care professionals, including physicians, nurses, pharmacists, respiratory therapists, and other providers specializing in critical care and dedicated to achieving “the highest quality care for all critically ill and injured patients.” See Socy. of Critical Care Med., *About SCCM*, <http://www.sccm.org/About-SCCM> (accessed Nov. 15, 2018).

4 The Society of Hospital Medicine (SHM) is “dedicated to serving the needs of the entire hospital medical team, including physicians, nurse practitioners, physician assistants, residents, medical students, practice administrators, and more to universally improve patient care.” Socy. of Hosp. Med., *Join SHM*, <https://store.hospitalmedicine.org/PersonifyEbusiness/Default.aspx?TabID=335> (accessed Nov. 15, 2018).

5 The Retirement Research Foundation (RRF) is a private nonprofit foundation based in Chicago, incorporated and endowed by John D. MacArthur prior to his death in 1978. The foundation’s mission is to “improve the quality of life for older people in America.” Ret. Research Found., *About RRF: Mission, Vision, Values*, <http://www.rrf.org/about-rrf/mission> (accessed Nov. 15, 2018).



a literature review, followed by a survey of health care providers, 527 of whom responded. After the survey, a roundtable of national experts on health care decision-making was conducted. The researchers found deep differences between accepted medical practice and statutory law. These findings, reflecting the reality of what happens on the front line of health care when a patient is critically ill, are expected to impact the advice that elder and special needs law attorneys offer clients.

## II. The Research Project

### A. The Question

The research team asked, who makes health care decisions if the patient cannot and how should treatment proceed if a patient who lacks capacity has no advance directive?<sup>6</sup> Every state has laws related to delegating health care decision-making,<sup>7</sup> and all but five states have statutory provisions on who can make health care decisions for a patient who lacks capacity.<sup>8</sup> The goal of this research project was to discover what, if any, impact these laws have on health care decision-making in critical care clinical practice.

### B. Project Scope and Limitations

The researchers narrowed the focus of the project to patients who lost capacity and had nothing in writing naming a surrogate. The inquiry focused on three distinct legal issues: (1) default health care surrogates, (2) conflict among potential health care decision-makers, and (3) patients in inpatient critical care settings without readily identifiable family or friends to make health care decisions for them. Studying the effectiveness of advance health care directives was beyond the scope of this project. The researchers instead focused on care in hospital and critical care settings — where people are most likely to receive health care during a crisis. The results of a similar study in noncritical care settings may differ from this study's results.

The survey sample was limited to members of the two medical societies: SCCM and SHM. The respondents were health care providers with a primary focus on critical care, often end-of-life care, of patients with very complex and life-threatening illnesses. The views of this sample may not reflect those of the broader health care provider community. The researchers received 527 responses, about a 1.7 percent response rate; respondents were self-selecting.<sup>9</sup> The nature of the sample and response rate prevent the researchers from making broad projections, and the results are best characterized as the views of the respondents to this survey. The focus was

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6 ABA Funding Proposal to the Retirement Research Foundation July 22, 2015 (copy on file with author).

7 ABA Commn. on L. & Aging, *State Health Care Power of Attorney Statutes, Selected Characteristics* (Jan. 2018), [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/state-health-care-power-of-attorney-statutes.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/state-health-care-power-of-attorney-statutes.authcheckdam.pdf) (accessed Nov. 15, 2018).

8 ABA Commn. on L. & Aging, *Default Surrogate Consent Statutes* (Jan. 1, 2018), [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2014\\_default\\_surrogate\\_consent\\_statutes.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf) (accessed Nov. 15, 2018).

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9 Self-selection may result in a statistical bias because those responding may have stronger than average interest in the question or issues. Methods of correcting for self-selection bias were not used in this research. For more information, see Lisa Luth, *An Empirical Approach to Correct Self-Selection Bias of Online Panel Research* (2008), [https://luthresearch.com/wp-content/uploads/2015/12/Luth\\_CASRO\\_Paper\\_b08.pdf](https://luthresearch.com/wp-content/uploads/2015/12/Luth_CASRO_Paper_b08.pdf) (accessed Nov. 15, 2018).

on global questions about health care decision-making, not on differences among individual health care providers; hence, the researchers chose not to focus on the impact of respondent demographics.

C. Terminology

1. Health Care Provider

A health care provider is any person who is involved in providing a patient’s medical care or treatment and who usually is involved in seeking patient consent. More than three-fourths of the respondents were physicians (see Table 1). Nurse practitioners and physician assistants made up slightly more than 10 percent of respondents, who understood that ultimate responsibility for obtaining consent may fall to the physician.<sup>10</sup>

2. Consent

Consent is the authorization of the patient, or someone acting on behalf of the patient, given to the health care provider for the provision, withholding, or withdrawal of medical care.<sup>11</sup> For some treatments, such as surgery, consent is formally obtained in writing. For more routine treatment, consent is provided verbally and recorded in the patient’s medical records. Consent may also be implied when the treatment is described and started and no one objects.<sup>12</sup> In emergency circum-

Table 1. Respondents’ Fields of Practice

Field of Practice	% of Respondents
Physician	76.69
Resident Physician	0.75
Fellow Physician	1.75
Pharmacist	0.00
Nurse Practitioner	8.77
Physician Assistant	2.26
Registered Nurse	5.76
Other	4.01
Total	100

stances when the patient is unable to communicate and no one is on hand to speak for the patient, consent is inferred for emergency, lifesaving, and life-prolonging care. The researchers specifically excluded emergency inferred consent in the survey design.

3. Do Not Resuscitate and Do Not Attempt Resuscitation Orders

Do not resuscitate (DNR) and do not attempt resuscitation (DNAR) orders are medical orders directing health care providers not to take steps to restart a patient’s breathing or cardiac function if it stops.<sup>13</sup> In some states, DNR and DNAR orders are being replaced by more detailed physician orders for life-sustaining treatment (POLSTs), also known as medical orders for life-sustaining treatment (MOLSTs). POLSTs and MOLSTs contain more specific directions on medical care that a person wants or does not want at the end

10 *Valles v. Albert Einstein Med. Ctr.*, 805 A.2d 1232, 1239 (Pa. 2002).

11 Daniel E. Hall et al., *Informed Consent for Clinical Treatment*, 184(5) Canadian Med. Assn. J. 533 (2012), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3307558> (accessed Nov. 15, 2018).

12 Robert Wheeler, *Consent in Surgery*, 88(3) Annals Royal College Surgeons Eng. 261 (2006), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1963696> (accessed Nov. 15, 2018).

13 See generally MedlinePlus, U.S. Natl. Lib. of Med., *Do-Not-Resuscitate Order*, <https://medlineplus.gov/ency/patientinstructions/000473.htm> (accessed Nov. 15, 2018).

of life and are intended to be portable — moving with the patient from health care setting to health care setting.<sup>14</sup>

#### 4. Health Care Surrogate

A health care surrogate or proxy is a person who makes health care decisions for another person.<sup>15</sup> A surrogate may be appointed by the patient, may become a default surrogate by law, or may be assumed to have authority based on common law or generally accepted medical practice.

#### 5. Health Care Wishes/Health Care Values/Health Care Goals

The terms wishes, values, and goals were used somewhat interchangeably in the research process. To be more specific “wishes” refer to expressed instructions for health care treatment. Values are strongly held personal beliefs that shape choices or instructions. Health care goals are the desired outcomes of health care treatment.

### III. The Law and Health Care Surrogates

The question of who has control over making decisions about medical treatment has been an evolving area of the law since the 1960s.<sup>16</sup> Although not explicit in the U.S. Constitution, the U.S. Supreme Court in *Griswold v. Connecticut* inferred a person’s right to control health care decisions as part of a penumbra of constitutional rights.<sup>17</sup> Under the principle of informed consent and accepted medical practice, health care providers have long

asked family members for consent for the treatment of children and adults who lack capacity. However, concern about liability for lack of consent and shifting family structures left some providers wary of family consent.<sup>18</sup> As a result, many states codified the common law, expanding it with definitions of who could provide consent.<sup>19</sup>

When this project started, 42 states had laws defining who is authorized to make health care decisions for a patient lacking capacity and with nothing in writing. The survey referred to these persons as “default health care surrogates.” Of these states, 38 had a hierarchy statute. Under a hierarchy statute, the highest-ranking person on the list in the statute who is available and willing to provide consent is authorized to make health care decisions. The laws generally authorize the nearest living relative, or next of kin, as the surrogate.<sup>20</sup> The laws vary from state to state on the order of priority of family members and from how far out into the family tree these surrogates can be chosen. The Colorado<sup>21</sup> and Hawaii<sup>22</sup> laws offer a list of suggested persons and ask the persons on that list to decide who should serve as surrogate. Tennessee<sup>23</sup> and West Virginia<sup>24</sup> laws provide a list of potential surrogates and direct health care

14 See generally Natl. POLST Paradigm, <http://polst.org> (accessed Nov. 15, 2018).

15 Ctrs. for Disease Control & Prevention, *Glossary*, <https://www.cdc.gov/training/ACP/page/32360.html> (accessed Nov. 15, 2018).

16 *Griswold v. Conn.*, 381 U.S. 479 (1965).

17 *Id.* at 484.

18 Ann McNary, *Consent to Treatment of Minors*, 11(3-4) *Innovations in Clinical Neuroscience* 43 (2014); Peter M. Murray, *The History of Informed Consent*, 10 *Iowa Orthopedic J.* 104 (1990), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2328798>.

19 See ABA Commn. on L. & Aging, *supra* n. 7.

20 *Id.*

21 Colo. Rev. Stat. Ann. § 15-18.5-101–103 (West 2018).

22 Haw. Rev. Stat. Ann. § 327E-2, E-5 (West 2018).

23 Tenn. Code Ann. § 68-11-1806(c)(1)–(4) (West 2018).

24 W. Va. Code Ann. § 16-30-8 (West 2018).

providers to select a surrogate based on criteria described in the law.

The researchers wanted to know whether these laws influence health care decisions. Therefore, the researchers explored if these laws result in health care providers seeking consent from the surrogate designated in the laws, how providers navigate multiple surrogates, and whether providers are aware of the laws on health care decision-making.

*A. Surrogate Selection/Awareness of Default Surrogate Consent Laws*

Survey participants were asked to respond to a series of hypothetical questions involving a medical crisis in which a patient is incapable of making his or her own health care decisions. Following is the first question researchers asked:

- **A patient, age 87, has a terminal condition, and a decision needs to be made about a DNR/DNAR order. The spouse and adult child are at the hospital. With whom would you discuss treatment options and from whom would you seek consent?**

If close family members are available — specifically, the patient’s spouse and adult child — a small majority of respondents (55.4 percent) said they would discuss treatment options with and seek consent from both the spouse and adult child, whereas 44.6 percent said they would select the spouse alone (see Table 2). No one selected the adult child exclusively. The prevailing law for consent in most states designates the spouse to provide consent.

During the roundtable discussion, the researchers asked about the desire to discuss treatment options with the spouse and adult child. The responses fell into two categories: (1) a concern about obtaining consent from a person who knows the patient’s wishes best and (2) a desire to

**Table 2. Selection of Surrogate: Spouse or Adult Child?**

Response	% of Respondents
Spouse	44.59
Adult child	0.00
Both	55.41

promote agreement and family harmony. Despite the prevailing legal authority of the spouse, the results suggest the practice of seeking group consensus, at least with immediate family.

The next question follows:

- **In a similar situation, the spouse and adult child disagree. You tried to reach consensus but were unsuccessful. From whom would you seek consent?**

If the spouse and adult child disagree on a course of treatment and consensus is not possible, 91 percent of respondents said they would frequently seek the spouse’s consent, although more than one-third (35 percent) said they would frequently choose “whoever appears to know the patient best” (see Table 3). The most frequent answer shows a clear preference for asking next of kin for consent. The second most frequent answer reflects a concern about making the best decisions based on the patients’ values.

Next question:

- **Also, in a similar situation, conflict exists between the patient’s only adult child and a close friend familiar with the patient’s values. You tried to reach consensus but were unsuccessful. What would you do?**

If an irreconcilable conflict exists between an adult child and a close friend of the patient familiar with the patient’s values, a large majority of respondents (80 percent) said they would frequently accept

**Table 3. Selection of Surrogate When Spouse and Adult Child Disagree**

<b>Response</b>	<b>Frequently % (No. of Respondents)</b>	<b>Sometimes % (No. of Respondents)</b>	<b>Rarely % (No. of Respondents)</b>	<b>Never % (No. of Respondents)</b>	<b>Total No. of Respondents</b>
Spouse	90.76 (383)	6.40 (27)	0.95 (4)	1.90 (8)	422
Adult child	6.60 (26)	42.89 (169)	27.41 (108)	23.10 (91)	394
Whoever appears to know the patient best	35.11 (138)	24.17 (95)	13.74 (54)	26.97 (106)	393
Whoever you feel supports the best medical option	7.95 (31)	20.77 (81)	21.03 (82)	50.26 (196)	390
Seek guidance from an ethics committee or consultant	26.44 (110)	37.26 (155)	26.44 (110)	9.86 (41)	416
Seek guidance from risk management or legal department	18.45 (74)	32.17 (129)	34.41 (138)	14.96 (60)	401

consent from the adult child; only 0.5 percent said they would accept consent from the close friend (see Table 4). However, more than one-third (36 percent) said they would frequently “seek guidance from an ethics committee or consultant.” This predominant reliance on close family versus nonfamily is consistent with the hierarchical preference dictated in the majority of state statutes.<sup>25</sup> In narrative comments and at the roundtable, health care providers expressed a desire to determine who knows the patient’s values best before accepting consent.

To assess survey participants’ awareness of default surrogate consent laws, researchers asked the following question:

- **Are you aware of any laws in your state that designate a surrogate decision-maker when there is no advance directive naming a person to make health care decisions and no guardian?**

More than two-thirds (68 percent) of respondents reported awareness of default surrogate consent laws (see Table 5). When isolating data from states with such laws, awareness grew slightly to 71 percent of respondents. Surprisingly, when isolating data from states without these laws, 55 percent of respondents thought that their states did have them. Health care providers are more likely to ask next of kin for consent than they are to be aware of laws directing them to do so.

**How does this information impact the advice lawyers give to clients?**

Not only did the survey reveal that health care providers are most likely to seek consent from next of kin, it also revealed that respondents in states with default surrogate consent laws are more likely to seek consent from next of kin than they are to be aware of any laws directing them to do so. Nonfamily members can expect to be listened to, but when it comes time to ask for consent, health care providers are most likely to ask the nearest next of kin.

25 ABA Commn. on L. & Aging, *supra* n. 7.

Table 4. Selection of Surrogate When Patient’s Only Adult Child and Patient’s Close Friend Disagree

Response	Frequently % (No. of Respondents)	Sometimes % (No. of Respondents)	Rarely % (No. of Respondents)	Never % (No. of Respondents)	Total No. of Respondents
Accept consent from the adult child	79.81 (328)	14.84 (61)	3.65 (15)	1.70 (7)	411
Accept consent from the close friend	0.52 (2)	15.75 (60)	34.12 (130)	49.61 (189)	381
Accept consent from whichever side you feel supports the best medical option	3.44 (13)	15.61 (59)	24.34 (92)	56.61 (214)	378
Accept consent from whoever you feel knows the patient best	11.84 (45)	25.26 (96)	21.32 (81)	41.58 (158)	380
Seek guidance from an ethics committee or consultant	35.57 (143)	31.59 (127)	19.15 (77)	13.68 (55)	402
Seek guidance from risk management or legal department	23.97 (93)	30.67 (119)	25.00 (97)	20.36 (79)	388

If a client is not next of kin, the client will need to make a strong case that he or she best understands the patient. Even in states without default surrogate consent laws, health care providers are most likely to seek consent from the patient’s next of kin. In fact, more than half of the respondents in states without default surrogate consent laws believe that such laws requiring them to consent next of kin exist.

When more than one family member is present, health care providers are likely to talk to everyone, not just the person authorized by law to make health care decisions. Health care providers try to ensure that everyone understands the treatment plan and seek input on what the patient would want. Clients need to be open to input from everyone; doing this builds trust and understanding with health care providers.

If conflict exists among family members or family and nonfamily members, the discussion should include everyone. Health care providers try to determine who best understands the patient’s values. When there is conflict, health care providers may trust the person who shows the greatest level of understanding. When in doubt, providers call on an ethics committee or consultant for guidance. Lawyers and clients should never assume that health care providers know who is next of kin or that health care providers are aware of the laws of the state.

Health care providers are likely to listen to everyone who shows a genuine interest in the patient. Lawyers and clients should not expect health care providers to limit the discussion to the person responsible for granting consent. Limiting discussion in this manner diminishes trust by

**Table 5. Awareness of Default Surrogate Consent Laws**

Response	% of Respondents	No. of Respondents
Yes	68.30	278
No	31.70	129
Total	100.00	407

health care providers. In conflicts among family members and close friends, health care providers are likely to listen to close friends and try to determine who best understands the patient. This may lead to an extended consultation aimed at determining the patient's wishes, values or health care goals — even if the law is clear in the jurisdiction that the legal next of kin is authorized to give or withhold consent.

#### *B. Conflict Among Multiple Surrogates*

A risk of conflict or disagreement also exists among multiple surrogates. When a conflict or disagreement arises among multiple surrogates of different degrees of consanguinity, prevailing law and medical practice resolve in favor of asking the closest next of kin, or highest-ranking person, for consent. Default surrogate consent laws may result in appointment of joint or multiple surrogates of the same class, such as siblings of the patient.

Four basic models of dispute resolution exist in state default surrogate consent laws. As shown in Table 6, 20 states share the most common model, which is majority rule. Majority rule allows the majority of the surrogates of the same class to make health care decisions. Two states refer conflicts to ethics committees, and two states avoid conflicts by asking the health care provider to select a single surrogate based on criteria in the law.

The researchers explored the usefulness

of the majority rule by asking this question:

- **The situation is similar to the one presented previously (87-year-old with a terminal condition who is incapable of making his or her own health care decisions), but there is no spouse and the conflict is among the three adult children, with two favoring DNR/DNAR and one against. You tried to reach consensus but were unsuccessful. What would you do?**

In this situation, in which there is no spouse and an irreconcilable conflict exists among three adult children over a DNR/DNAR decision, only 14 percent of respondents reported that they would frequently accept consent from a majority of the adult children, whereas a majority of respondents (60 percent) favored seeking guidance from an ethics committee or consultant (see Table 7). Twenty states provide that in the case of such disagreements among surrogates of equal level, the physician should accept the decision of the majority.<sup>26</sup> Looking only at the data from the states with a majority rule mechanism, there were 267 responses. Of these, less than 7 percent said that they would frequently accept consent from the majority of the adult children. By contrast, 49 percent said they would *never* accept consent from the majority of the adult children, indicating that a majority rule approach to dispute resolution among surrogates is not a generally accepted clinical practice among the respondents.

It is clear that majority rule is largely rejected by health care providers as a so-

26 The language in most of the statutes is that the health care provider “shall accept consent from the majority,” implying that this is a requirement; however, there is seldom, if ever, a legal action to enforce these laws. See ABA Commn. on L. & Aging, *supra* n. 7.

Table 6. Dispute Resolution Models in State Default Surrogate Consent Laws

Majority Rule (20 States)	Alaska, Arizona, Florida, Illinois, Iowa, Kentucky, Louisiana, Maine, Mississippi, Montana, Nevada, New Hampshire, New Mexico, North Carolina, Ohio, Oregon, Pennsylvania, Utah, Virginia, Wyoming
Ethics Committee	<p>Delaware, Maryland</p> <p>Del. Code Ann. tit. 16, § 2507(b)(9) (West 2018) the attending physician or an individual [in the surrogate list] may refer the case to an appropriate committee of the health-care institution for a recommendation in compliance with this chapter, and the attending physician may act in accordance with the recommendation of the committee or transfer the patient in accordance with [transfer rules].</p> <p>Md. Code. Ann., Health-Gen. § 5-605(b)(1) (West 2018) the attending physician or an individual [in the surrogate hierarchy] shall refer the case to the institution's patient care advisory committee, and may act in accordance with the recommendation of the committee or transfer the patient in accordance with [transfer rules]. A physician who acts in accordance with the recommendation of the committee is not subject to liability for any claim based on lack of consent or authorization for the action.</p>
Health Care Provider Selects Surrogate	<p>Tennessee, West Virginia</p> <p>Tenn. Code Ann. § 68-11-1806(c)(1)-(2) (West 2018) the patient's surrogate shall be identified by the supervising health care provider and documented in the current clinical record of the institution or institutions at which the patient is then receiving health care. The patient's surrogate shall be an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values, who is reasonably available, and who is willing to serve.</p> <p>W. Va. Code Ann. § 16-30-8(b) (West 2018)</p> <ol style="list-style-type: none"><li>Where there are multiple possible surrogate decision-makers at the same priority level, the attending physician or the advanced nurse practitioner shall, after reasonable inquiry, select as the surrogate the person who reasonably appears to be best qualified. The following criteria shall be considered in the determination of the person or entity best qualified to serve as the surrogate:<ol style="list-style-type: none"><li>Whether the proposed surrogate reasonably appears to be better able to make decisions either in accordance with the known wishes of the person or in accordance with the person's best interests;</li><li>The proposed surrogate's regular contact with the person prior to and during the incapacitating illness;</li><li>The proposed surrogate's demonstrated care and concern;</li><li>The proposed surrogate's availability to visit the incapacitated person during his or her illness; and</li><li>The proposed surrogate's availability to engage in face-to-face contact with health care providers for the purpose of fully participating in the decision-making process;</li></ol></li><li>The attending physician or the advanced nurse practitioner may select a proposed surrogate who is ranked lower in priority if, in his or her judgment, that individual is best qualified, as described in this section, to serve as the incapacitated person's surrogate. The attending physician or the advanced nurse practitioner shall document in the incapacitated person's medical records his or her reasons for selecting a surrogate in exception to the priority order provided in subsection (a) of this section.</li></ol>



**Table 7. Selection of Surrogate When Adult Children Disagree**

<b>Response</b>	<b>Frequently % (No. of Respondents)</b>	<b>Sometimes % (No. of Respondents)</b>	<b>Rarely % (No. of Respondents)</b>	<b>Never % (No. of Respondents)</b>	<b>Total No. of Respondents</b>
Accept consent from the two children favoring DNR because they constitute a majority	13.91 (53)	22.57 (86)	27.03 (103)	36.48 (139)	381
Accept consent from whichever side you feel supports the best medical option	3.96 (15)	20.32 (77)	26.39 (100)	49.34 (187)	379
Accept consent from whoever you feel best knows the patient	26.87 (104)	27.13 (105)	17.83 (69)	28.17 (109)	387
Seek guidance from an ethics committee or consultant	59.67 (250)	24.58 (103)	12.17 (51)	3.58 (15)	419
Seek guidance from risk management or legal department	43.83 (174)	27.71 (110)	19.90 (79)	8.56 (34)	397

lution to family conflict. The narrative comments on this question and input at the roundtable offer insight into this. Providers are concerned about agreement among family members for two reasons: (1) fear of liability or litigation and (2) a desire to promote family harmony. One commentator explained that taking sides breaks the family in ways that may never heal. Others said that they want the family to survive the death of the patient. Even when the law offers a safe harbor to providers accepting consent from the majority, about 90 percent of providers who responded to the survey decline to do so. Feedback in the narrative comments and at the roundtable express the desire to seek consensus and, if not consensus, at least an understanding of the prognosis by all involved and the reasons the choice is being made.

### **Implications of this information for lawyers counseling clients**

If a patient who lacks capacity lives in a state with majority rule and the lawyer's client would be one or more of the default health care surrogates, the lawyer can offer two options. One is to seek conflict resolution, seeking common ground and understanding with other family members. The other is the adversarial option of seeking to enforce the law. If a lawyer is working with the majority of the class of surrogates, he or she can seek to enforce the majority rule. If the lawyer is representing the minority of the class, he or she can work to convince a court that majority rule will result in an unwanted outcome or an outcome not in the best interests of the patient. Many lawyers tend to default to the adversarial model of proving that the client is right, or that the other party is

wrong. Looking at this issue through the clinicians’ model of seeking family harmony, attorneys can offer conflict resolution as a tool for preserving or healing the family. The success of conflict resolution varies based on how far apart the parties are, how deeply entrenched they are, and the level of trust among them. Under the ABA Model Rules of Professional Conduct, the client decides on the objectives of the representation.<sup>27</sup> Options to offer would include family harmony or a purely legal solution.

Similar to health care providers, lawyers can make clients aware of the long-term impact of legal solutions on relationships and family. Although some families are so divided that there is no option short of litigation, other families are divided by a lack of trust and communication and, in the role of counselor-at-law, attorneys can help those families resolve conflict and heal.

Going beyond the scope of this research project, when engaged in advance care planning with a client who still has capacity, it is important to ask about potential or active conflicts among family members. Conflicts that surface after the client is no longer able to be a part of the discussion can be difficult to resolve. If the differences among family members are not great, a facilitated family meeting or family counseling could resolve the issues. If the differences are great or the sides are deeply entrenched, strong advance care planning with instructions to resort to court action if necessary may be the only way to ensure that the client’s wishes are honored.

**Table 8. Encounters With Patients Without Readily Identifiable Family or Friends**

No. of Patients	% of Providers	No. of Respondents
0	16.55	68
1 or 2	44.28	182
3–5	23.60	97
6–9	7.79	32
10–19	5.11	21
20 or more	2.68	11
Total	100	411

*C. Patients Without Readily Identifiable Family or Friends*

The “unbefriended,”<sup>28</sup> patients without readily identifiable family or friends, challenge both the law and health care providers. This research was started using the term “unbefriended,” but in testing the survey instrument with health care providers, the researchers rapidly learned two things. Most providers did not know what “unbefriended” meant, and most of those who did found the term offensive. For purposes of the survey, the researchers used “patients without readily identifiable family or friends.” This topic was the subject of a lengthy discussion during the roundtable portion of this project. Even though a couple of people argued that the term “unbefriended” had passed into common usage, most agreed that the term makes it sound as if the unbefriend-

27 Model R. Prof. Conduct 1.2 (ABA 2018).

28 Naomi Karp & Erica Wood, *Incapacitated and Alone: Healthcare Decision Making for Unbefriended Older People*, 31 Human Rights 20, 21 (2004).

**Table 9. Nonjudicial Decision-Making for Patients Without Readily Identifiable Family or Friends**

Attending physician in some combination with an ethics committee and/or second physician	Alabama, Arizona, Arkansas, Georgia (DNR only), Louisiana, New York, Tennessee, Texas
Social worker selected by the facility and ethics committee if forgoing life-prolonging care	Florida
Attending physician with multidisciplinary team review	California (for nursing home residents only)
Attending physician	North Carolina, Oregon
Anyone specified by regulation	West Virginia
Member of the clergy	Texas (which has two statutory provisions)

ed are unloved — when in reality many have simply outlived family and friends. Roundtable participants settled on the term “unrepresented.”

Persons without readily identifiable family or friends represent a small percentage of the overall population. In 1998–2010, an estimated 6.6 percent of U.S. adults (8.3 million) age 55 and older had no spouse or children; 1 percent (835,000) had no spouse, children, siblings, or parents.<sup>29</sup> According to the Alzheimer’s Association, “An estimated 70 percent of older adults with Alzheimer’s or other dementias live in the community, compared with 98 percent of older adults without Alzheimer’s or other dementias. Of those with dementia who live in the community, 74 percent live with

someone and the remaining 26 percent live alone.”<sup>30</sup>

When the research team asked health care providers how many times in the past 3 months they encountered patients without readily identifiable family or friends, more than half reported seeing one to five such patients (see Table 8).

As presented in Table 9, 13 states have statutes dealing with health care decision-making when a patient has no readily identifiable family or friends. Among those 13 states, six different statutory models exist for decision-making. The most common statutory model is for health care decisions to be made by the attending physician in consultation with an ethics committee or second physician.

The researchers asked the following question to elicit health care providers’ responses to situations involving patients without readily identifiable family or friends:

29 Rachel Margolis & Ashton M. Verdery, *Older Adults Without Close Kin in the United States*, 72(4) *Journals of Gerontology: Series B* 688 (2017), <https://doi.org/10.1093/geronb/gbx068> (accessed Nov. 15, 2018); U.S. Census Bureau, American Fact Finder, *Age and Sex: 2011–2015 American Community Survey 5-Year Estimates*, [https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_15\\_5YR\\_S0101&prodType=table](https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_15_5YR_S0101&prodType=table) (accessed Nov. 15, 2018).

30 Alzheimer’s Assn., *2018 Alzheimer’s Disease Facts and Figures*, <https://alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf> (accessed Dec. 15, 2018) (citations omitted).

Table 10. Treating a Patient Without Readily Identifiable Family or Friends

Response	Frequently % (No. of Respondents)	Sometimes % (No. of Respondents)	Rarely % (No. of Respondents)	Never % (No. of Respondents)	Total No. of Respondents
Seek the opinion of a second physician	55.25 (221)	24.75 (99)	14.00 (56)	6.00 (24)	400
Seek guidance from an ethics committee or consultant	58.19 (238)	24.45 (100)	14.18 (58)	3.18 (13)	409
Seek guidance from hospital risk management or legal department	45.23 (180)	29.40 (117)	18.09 (72)	7.29 (29)	398
Seek court- ordered guardianship	39.29 (156)	26.70 (106)	24.69 (98)	9.32 (37)	397
Make a decision yourself, abiding by professional ethics and standards	10.53 (42)	21.80 (87)	29.07 (116)	38.60 (154)	399

• **Same case, there are no relatives or friends willing to discuss treatment options or give consent. What would you do? (See Table 10.)**

This data shows no clear answer. More than half the respondents would frequently seek a second physician’s opinion (55 percent) or seek guidance from an ethics committee or consultant (58 percent). Close behind, 45 percent would frequently seek guidance from the hospital risk management or legal department. The option of going to court for a guardianship was frequently chosen by a substantial minority (39 percent), whereas the option of making a decision by oneself was frequently chosen by only 10.5 percent of respondents. When isolating data from North Carolina and Oregon, the two states that allow the treating physician alone to make health care decisions for patients who have no one to speak for them, only 7 percent said that they would frequently do so.

During the roundtable, health care providers cited the time needed as an obstacle to locating family and friends for patients unable to communicate and with no one to speak for them. The cost and time needed for guardianship was often cited as an obstacle to finding someone to provide consent for these patients.

If health care providers are unable to locate family or close friends, a stranger makes health care decisions for these critically ill patients. Faced with such a situation, most of those responding to the survey said that they would use the laws or turn to other physicians, ethics professionals, or risk management to make decisions.<sup>31</sup>

In narrative comments on the survey and during the roundtable, health care providers spoke of the resources consumed in providing care for patients who

31 See Table 10.

have no one to speak for them.<sup>32</sup> While effort is expended trying to find family or friends, medical care is provided without knowing what the person would or would not want. Decision-making for these patients involves multiple consultations. Some medical providers go beyond the expected effort and send staff into the community searching for someone to speak for the patient. In some areas, seeking guardianship takes months and costs thousands of dollars as the patient is being cared for. Several providers reported difficulty transferring patients from hospitals to skilled nursing homes, sometimes waiting months for a guardianship order to approve the transfer.

#### **How does this information impact lawyers?**

When an attorney preparing an advance directive or health care power of attorney asks a client whom he or she wants to name as a health care surrogate and the client does not have a clear answer, the client is at risk. Even if the client is able to name someone, lawyers should inquire further by asking about the client's contact with the named agent. How frequently do the patient and the agent talk? How often do they see each other? How well does the proposed surrogate know the client's values? If the answers to these questions are "not frequently," "not often," and "not well," respectively, the client is at risk of naming an agent who at best will have little basis on which to make decisions and at worst will be unavailable or decline to help when needed.

What does an attorney do to help a client who has no one to name? A starting point is helping the client document his or her health care values. Clients with

the ability to pay can hire professionals to assist with health care decisions. Clients who are unable or unwilling to pay for professional help can be encouraged to share their values with health care providers, neighbors, and others who might be called on for help making health care decisions when needed.

#### **IV. Conclusion**

This research shows that (a) health care providers who care for individuals during medical crises generally turn to the same people the laws suggest as default health care surrogates, (b) disputes between surrogates or between family members are not well addressed by statutory attempts, and (c) persons without readily identifiable family or friends to serve as surrogates present a great challenge in law and medicine.

Health care providers are more likely to ask next of kin for consent than they are to be aware of laws directing them to do so. Even in states without such laws, accepted medical practice dictates asking family members for consent. If a client's wishes are outside the normal assumption of asking next of kin for consent, the client needs to put these wishes in writing and may need the attorney's help explaining the document and the law to health care providers.

Health care providers dislike family disputes and are much more likely to try to mediate, explain, or seek common ground, consensus, or understanding among family members than they are to be aware of, or to take refuge in, laws offering a clear answer to family disputes about health care decision-making.

Unrepresented clients, or clients without readily identifiable family or friends, are the greatest challenge in the law, with little agreement among the handful of

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32 Transcripts of the narrative comments and roundtable are on file with the researchers.

states that have attempted to address this challenge. These patients present a great ethical dilemma for health care providers, with little agreement on how to best make decisions for them. Lawyers can play a role in helping identify clients at risk and suggesting steps — such as leaving instructions for potential health care decisions.

**Case Note**  
**Kindred Nursing Centers v. Clark:**  
**United States Supreme Court Decisions**  
**on Mandatory Arbitration Provisions**

*By Laurence I. Gendelman, Esq.*

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**About the Author**

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## I. Introduction

On February 22, 2017, the U.S. Supreme Court heard arguments regarding *Kindred Nursing Centers v. Clark*<sup>1</sup> on writ of certiorari from the Kentucky Supreme Court.<sup>2</sup> The Kentucky Supreme Court found that an arbitration agreement executed by a principal's agent under a power of attorney was invalid because the power of attorney document did not specifically include a *clear statement* that the agent could enter into an arbitration agreement.<sup>3</sup> The U.S. Supreme Court reversed the Kentucky Supreme Court's decision, holding that the "clear-statement rule violates the Federal Arbitration Act by singling out arbitration agreements for disfavored treatment."<sup>4</sup> The opinion is consistent with the U.S. Supreme Court's trend of promoting the enforceability of arbitration agreements.

## II. Background

Beverly Wellner held a power of attorney for her husband, Joe Wellner.<sup>5</sup> Janis Clark held a power of attorney for her daughter, Olive Clark.<sup>6</sup> Joe's power of attorney provided Beverly with the ability to "institute legal proceedings" and make "contracts of every nature in relation to both real and personal property."<sup>7</sup> Olive's power of attorney provided Janis with the "full power ... to transact, handle, and dispose of all matters affecting [Olive] and/or [Olive's] estate in any possible way," including the ability to enter into agreements.<sup>8</sup>

In 2008, Beverly placed her husband and Janis placed her daughter in the Winchester Centre, an assisted living facility operated by Kindred Care Nursing Centers.<sup>9</sup> As part of the placement process, agents Beverly and Janis entered into arbitration agreements with the facility, which were included in the admission contracts on behalf of their family members.<sup>10</sup> Specifically, the agreements provided that any claim related to Joe's or Olive's stay at the facility would be resolved through arbitration.<sup>11</sup>

## III. Decision of the Kentucky Supreme Court

In 2009, both residents died and their estates brought lawsuits against Kindred Care Nursing Centers in Kentucky state court, alleging that Kindred Care Nursing Centers provided the residents with substandard care.<sup>12</sup> Kindred attempted to dismiss the cases, arguing that the agreements that the plaintiffs signed precluded them from resolving their disputes in court.<sup>13</sup> The Kentucky trial court denied their motion, and the Kentucky Court of Appeals affirmed the trial court's decision.<sup>14</sup> The Kentucky Supreme Court affirmed the decision of the Kentucky Court of Appeals but did so on somewhat different grounds.<sup>15</sup>

The Kentucky Supreme Court's analysis began by evaluating the language in each power of attorney document. In Joe's document, the Court found that Beverly could not enter into an arbitration agree-

1 137 S. Ct. 1421 (2017).

2 *Kindred Nursing Ctrs. L.P. v. Clark*, 478 S.W. 206 (Ky. 2017).

3 137 S. Ct. at 1429.

4 *Id.* at 2.

5 *Id.*

6 *Id.*

7 *Id.* (citing app. 10-11).

8 *Id.*

9 137 S. Ct. at 1425.

10 *Id.*

11 *Id.* (citing app. at 14, 21).

12 137 S. Ct. at 1425.

13 *Id.*

14 *Id.* (citing app. to pet. for cert. 125a-126a, 137a-138a).

15 137 S. Ct. 1421.



ment on her husband's behalf. However, the Court found that Olive's document did authorize Janis to enter into an arbitration agreement. Nonetheless, the Court held that both arbitration agreements were invalid because an agent under power of attorney cannot enter into an arbitration agreement without a clear statement expressly providing for such authority.<sup>16</sup> In essence, the Kentucky Supreme Court held that the power to enter into an arbitration agreement is what is commonly known as a "hot power," meaning that a grant of such a power must be expressly provided for in a power of attorney document. The Court's holding hinged on the belief that the Kentucky Constitution declares the right to a jury trial as "sacred" and "inviolable."<sup>17</sup>

In reaching its conclusion, the Kentucky Supreme Court recognized that federal law provides that arbitration agreements cannot be treated differently from other types of agreements. However, the Court justified its opinion on the grounds that its holding would apply to any agreement that implicates such fundamental and constitutional rights, not only arbitration agreements.<sup>18</sup>

#### IV. Decision of the U.S. Supreme Court

The U.S. Supreme Court focused its analysis on its interpretation of the Federal Arbitration Act (FAA) in *AT&T Mobility LLC v. Concepcion*.<sup>19</sup> The FAA states that arbitration agreements are "valid, irrevocable, and enforceable, save upon such grounds as exist at law or in equity for the revocation of any contract."<sup>20</sup> State

laws that disfavor arbitration agreements are displaced by the FAA.<sup>21</sup>

The U.S. Supreme Court found that the "Kentucky Supreme Court's clear-statement rule [i.e., that the power to enter into an arbitration agreement must be explicitly provided for in a power of attorney document] fails to put arbitration agreements on an equal plane with other contracts."<sup>22</sup> Based on the sacred and inviolate nature of the right to a jury trial, the Court quickly disposed of the argument that such an explicit provision is necessary, and the Court found that creating such a rule "did exactly what [*AT&T Mobility LLC v. Concepcion* barred]."<sup>23</sup> Ultimately, the Court found that the clear statement rule demonstrates hostility toward arbitration agreements.

Beverly and Janis advanced that the FAA does not apply to issues of contract formation but rather to contract enforcement.<sup>24</sup> The U.S. Supreme Court disposed of this argument by looking at the text of the FAA and relevant case law, writing that "[a] rule selectively finding arbitration contracts invalid because improperly formed fares no better under the Act than a rule selectively refusing to enforce those agreements once properly made."<sup>25</sup> The Court essentially found that such a finding would undermine the intent of the FAA and provide states with carte blanche to disfavor arbitration agreements.<sup>26</sup>

The U.S. Supreme Court reversed the Kentucky Supreme Court's judgment with respect to Olive's estate. With respect to Joe's estate, the Court articulated that if

16 *Id.* (citing 478 S.W.3d 306, 313 (Ky. 2015)).

17 137 S. Ct. at 1427 (citing 478 S.W.3d at 328–329).

18 137 S. Ct. at 1428.

19 563 U.S. 333 (2011).

20 9 U.S.C. § 2 (2018).

21 563 U.S. at 343 (citing *Preston v. Ferrer*, 522 U.S. 346, 353 (2008)).

22 137 S. Ct. 1423–24.

23 *Id.*

24 *Id.* at 7.

25 *Id.* at 8.

26 *Id.*

the finding that the power of attorney was not broad enough to give Beverly the authority to enter into the arbitration agreement and was made independent of the clear statement rule, the Court's opinion would not have any effect. However, the U.S. Supreme Court found that if the clear statement rule did influence the finding that the document was not broad enough to cover arbitration agreements, the Kentucky courts must re-evaluate the document consistent with the Court's opinion.

#### A. Implications of the Decision

During the past 10 years, the U.S. Supreme Court's decisions reveal a strong distaste for state law that interferes with the enforceability of arbitration agreements.<sup>27</sup> In *Marmet Health Care Center, Inc. v. Brown*, the Court invalidated a state law prohibiting agreements to arbitrate personal injury claims against nursing homes, holding that such a rule is incompatible with the FAA.<sup>28</sup> In *Concepcion*, the Court deemed that the FAA pre-empts a California law providing that class action waivers in arbitration agreements are unenforceable in certain circumstances.<sup>29</sup>

The U.S. Supreme Court's opinion affirms *Concepcion* and *Marmet Health Care Center* and promotes the enforceability of arbitration clauses, at least to the same extent as any other contractual provision. However, the Court appears particularly unsympathetic to the argument that the right to enter into an arbitration clause in a power of attorney document may be determined to be a hot power as a matter of state law.

Pursuant to the Uniform Power of Attorney Act,<sup>30</sup> which has been adopted by several states, the power to create a trust, make a gift, change rights of survivorship, delegate authority, and disclaim property, among other powers, must be expressly and specifically provided for.<sup>31</sup> Such powers must be expressly provided for because "of the risk those acts pose to the principal's property and estate plan."<sup>32</sup> An arbitration requirement in a nursing home contract, or any contract for that matter, may certainly pose a risk to the value of a principal's property or the property of his or her estate. The right to waive a jury trial and enter into an arbitration agreement would seem, logically, to be exactly the type of power that requires express authorization by a principal.

On the other hand, arbitration clauses frequently appear in consumer contracts, which are commonly executed by agents pursuant to a power of attorney. Making the power to waive a jury trial a hot power would essentially disable an agent under power of attorney from entering into routine consumer contracts without the express consent of the principal.

Under the U.S. Supreme Court's logic, a state's decision to require that certain powers be expressly provided for in a power of attorney, even for the purpose of preserving a fundamental constitutional right, such as the right to a trial by jury, may be subject to scrutiny by the federal courts.

#### B. Practical Considerations

The U.S. Supreme Court's position that the FAA pre-empts state law cannot be clearer. Arbitration agreements are en-

27 *E.g.* 563 U.S.; *Stolt-Nielsen S.A. v. Animalfeeds Int'l Corp.*, 559 U.S. 662 (2010); *American Express Co. v. Italian Colors Restaurant*, 133 S. Ct. 2304 (2013).

28 565 U.S. 530 (2012).

29 563 U.S. at 352.

30 Unif. Power of Atty. Act (2006).

31 *Id.* at art. 2, § 201.

32 *Id.* at art. 2, *General Comment*.

forceable to the same extent as any other agreement. If a principal does not want his or her agent to be able to enter into an arbitration agreement, a practitioner can draft the power of attorney accordingly. However, in doing so, the practitioner should be aware that many routine consumer contracts include binding arbitration agreements, which often waive the right to participate in a class action and the right to a trial by jury.

Thus, if a power of attorney expressly disallows an agent from entering into an

arbitration agreement, the power of attorney may be ineffective for entering into many, if not most, types of contracts that the principal may expect his or her agent to enter. A principal's decision to prohibit an agent from entering into an arbitration agreement should be weighed extremely carefully with the assistance of counsel because such a prohibition would likely prevent the agent from entering into necessary contracts for the benefit of the principal, including contracts related to health care, investments, and financial affairs.



**Book Review**  
**The Gentle Art of Swedish Death Cleaning:  
How to Free Yourself and Your Family  
From a Lifetime of Clutter**

*By Margareta Magnusson  
Scribner, 2018, 128 pp.*

*Reviewed by Shelley D. Coelho, Esq.*

Margaret Magnusson provides a pragmatic approach to *döstädning*, or “death cleaning,” in her recent book, *The Gentle Art of Swedish Death Cleaning: How to Free Yourself and Your Family From a Lifetime of Clutter*. Magnusson, who professes to be “aged between eighty and one hundred,” prefers to deal with disposing of her belongings herself, instead of placing the burden on her family after her death. She relates her experiences of clearing out after the death of her mother and husband and philosophizes that most people will not want to “take care of what you didn’t take care of yourself.”

Magnusson’s approach includes doing the work in a meaningful way, such as leaving items with those who will most appreciate them, starting with the easy items (e.g., clothes) and saving the most difficult items (e.g., photos) for last. She writes of keeping a small box of items that are only meaningful to her and marking the box “throw away” to spare her family from having to take the time to sort items that are meaningless to them and others.

With a lighthearted approach, Mag-

nusson mentions taking care of the “secrets” (Grandfather’s ladies’ underwear and Grandma’s 15 dildos), but in doing so reminds us that there may be secrets that, if discovered, could hurt those we leave behind. Although the idea of this book is to bring our attention to eliminating clutter and making the clearing out process easier on our loved ones when we are gone, she also speaks of how good it makes her feel to clear out. After all, she relates, this isn’t just about things — it is also about memories. It is something we do for ourselves, and if started soon enough (she suggests at age 65), it allows us to contemplate the history of our belongings, recalling the memories and considering the worth of the items. She suggests sharing the story of the retained items with others so that they can also appreciate their worth and history.

Magnusson invites us to ask ourselves, “Will anyone I know be happier if I save this?” If the answer is “no,” she suggests sending the item to the shredder or donation bin. She further postulates that, if clearing out is left to others to accom-

**About the Reviewer**

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plish at the time of our passing, the items that we appreciated and would likely be appreciated by others will simply land in the dump. She speaks briefly of the planet perishing under “the weight of consumerism.”

Magnusson suggests that it is our duty to take care of our possessions and that, in doing so, we may minimize discord among family members, protect the planet, simplify our lives, foster a greater appreciation of the possessions we keep or share, and make the process of clearing out after we die easier on those left behind. The book is easy to read and is filled with useful ideas, especially for those who find it difficult to part with belongings.

This book is relevant to elder law attorneys because we often counsel clients on the very subject of how to dispose of someone’s belongings. In our practices, we see too often the stress related to the handling of tangible goods. We have all heard stories of a family member who tucked valuable items away in the most unlikely places, families that were broken apart when many family members wanted the same item, and the many dollars spent on the disposal of goods. The idea of *döstädning* is something for us to consider and possibly discuss with our clients.

## **Book Review**

### **In the Slender Margin: The Intimate Strangeness of Death and Dying**

*By Eve Joseph*  
*Arcade Publishing, 2014, 211 pp.*

*Reviewed by Elle Tauer*

When it comes to death and dying, perceptions are shaped by culture, and in *The Intimate Strangeness of Death and Dying* Eve Joseph takes us on a lyrical journey of historic and contemporary interpretations of the process. She weaves together her career in hospice with her experiences losing her older brother at a young age, as well as the death of her mother to create a patchwork quilt exploring various experiences of death, mixed with tidbits from literature, art, and mythology. Readers are treated to the origins of language used to describe all things death, and how, over time, specific death-related terms developed particular meanings. Her poetic touch is evidenced by the succinct brevity of her chapters and the seamless integration of literary quotes, linguistics, etymology, and the beautiful imagery that runs throughout her narrative.

An easy read, this book is a good starting point for expanding understanding of the various permutations of death. Joseph includes anecdotes of conversations with members of staff, palliative care team members, doctors, and her own memories, to attempt a more universal, holistic, and rational approach to death. There are

many references to various Native North American tribal rituals with their ancient and mystical qualities. The author uses lovely imagery intertwined with later experiences and memories of her brother's death, as she discusses a deeper understanding of her own life through the evolution of her grief and personal loss.

Fears commonly associated with death start to peel away with the calmness and resoluteness carrying the tone of the narrative. There is a strong sense of futility as Joseph analyzes the time-honored practice of fearing death and engaging in many various activities in an attempt to outwit it and live forever. The book suggests that there is no point in avoiding the discussion of what will happen when one eventually dies as this is a singular guarantee for all living things without exception. The ease with which she brings the reader to this conclusion, mostly through her personal narrative of her own journey of understanding, offers the potential for reconciliation for those who are resentful or struggling with loss. Therefore, the unspoken conclusion resonates: death will not be avoided or negated; death is a partner to be treated with respect and dignity.

#### **About the Reviewer**

Elle Tauer graduated from the University of Denver College of Law in 2002 and completed her LLM in Taxation in 2005. She currently lives in Aurora, Colorado, with her husband and two daughters.

No longer something to shy away from or to discuss in shadowed corners with whispered breaths, death brings ultimate peace and serenity. Death has its own purpose, which is not disclosed to the living, but the presence of those who have died are a constant comfort for those who believe in such things.

The most interesting facet of this book is the ongoing discussion of the place in-between life and death, or rather, of individuals who have been dead by all current measure of medical equipment, yet inexplicably remain among the living. Joseph alludes to the various lessons that can be learned through death and those who are in the current act of dying. Her quiet acceptance offers a wide berth of experience for those who may be in-between life and death. According to Joseph, in such a place, there may lie a choice of returning to life or leaving it behind.

For those who do pass on, the author explores various conceptual rituals such as burial and cremation, as well as the need to remember those who have passed with gravestones and celebrations. She expounds upon the different philosophies behind these rituals and how such choices are fundamentally intertwined with how one views life. In Joseph's opinion, the practical matter of disposal is tied quite closely with how groups of individuals believe the physical form should be handled after death, or what type of ritual would be appropriate to honor or assist the deceased.

An overarching theme of fluidity permeates this book, both through the cadence of the writing in brief sections, as well as the ease with which Joseph blends her past and present experiences. She describes death as a transition — a passage through to the unknown or a rebirth, rather than simply an end of what was

known. She explains that the necessity and objective factuality of death does not deter one from finding a way to keep the dead among the living in both real and metaphorical aspects. Throughout the book, she supports the idea of a very real sense of the dead surrounding or even coexisting with the living. The relationship between the qualities of being alive and those of not being alive seem almost symbiotic or even necessary for the author, and by extension the reader, to reach a fuller understanding of death and acceptance of grief.

She explains expressions of wholeness being divided into the two opposing forces of light and dark, or life and death. The constant reference to the author's much older brother and her memories of him, as well as accounts from her mother, sister, and other individuals who knew him in life, render an almost tribute-like feeling to the narrative. As the reader joins the author on the journey, one easily connects with memories of personal loss, and perhaps find insight that brings additional and unexpected comfort to the reader.

As we struggle to assist clients who recently lost loved ones, or who are considering their own eventual demise, this book can bring a measure of comfort. Elder law and estate planning attorneys may be wise to add this to their book recommendations for clients. It offers a practical way to experience different ideas about death through sharing the author's experiences. It provides a viewpoint on death which is not frightening and in some ways not even sad, but a natural and expected progression of life. As is often the case, when discussing planning for death, there can be an uneasiness of mentioning one's own demise and what may occur after such an event. Some of the author's tenor and references could be useful in these discussions.



In conclusion, this book was a delight to read and somehow made a heavy and not often discussed subject more accessible and lighthearted.



## Book Review

### What Stephen King Can Teach Lawyers About Writing — *On Writing: A Memoir of the Craft*

*By Stephen King*  
*Scribner, 2000, 288 pp.*

*Reviewed by Charles P. Golbert, Esq.*

*“The first draft of anything is sh\*t.”*

— Ernest Hemingway

What can the King of Horror teach attorneys about writing? A lot, it turns out.

Stephen King’s memoir, *On Writing: A Memoir of the Craft*, has become a widely cited text on the craft. King is the best-selling author of dozens of horror novels, including such classics as *Carrie*, *The Shining*, and *Misery*. Although *On Writing* is intended for authors of fiction, it offers wisdom for attorneys struggling to write compelling motions and briefs.

King maintains that there are two keys to becoming a good writer: You must read a lot and write a lot. He describes reading as the “creative center of a writer’s life” and explains that it doesn’t matter what you enjoy reading — you need to read like a writer by being an active reader. As you read, you must think about what makes the writing compelling and a joy to read.

Your writing will improve with practice, but King cautions that “practice will never make you perfect. Why should it? What fun would that be?”

King emphasizes the importance of using plain language. He describes using big words when small words will do as

“dressing up a household pet in evening clothes.” King suggests using the first word that comes to mind as long as it is appropriate.

King hates the “timid” passive voice. He also loathes adverbs, admonishing that “the road to hell is paved with adverbs.”

Similarly, King advises, “[N]ever tell us a thing if you can show us instead.” This reminded me of one of the first appellate briefs I wrote in a child abuse case. I wrote that the mother tortured her children. The head of our appellate department told me to simply delineate what the mother did to the children and let the appellate court conclude on its own that what she did was torture.

King maintains that, in addition to telling a story, all writing should have a theme that appeals to a moral force. He explains, “[E]very book — at least every one worth reading — is about *something*. Your job ... is to decide what something ... yours is.”

Similarly, legal pleadings, in addition to advancing a theory of the case, should have a theme. Lawyers, in their trial advocacy, are adept at using both theory and theme to the best advantage. But for some reason, attorneys sometimes forget about theme, which is an invaluable advocacy

#### About the Reviewer

Charles P. Golbert is the acting Cook County (Illinois) public guardian and former *NAELA Journal* editor in chief.

tool, when they write. Just as a good novel has a story and a theme, a legal pleading — like a trial — should be a persuasive synthesis of theory and theme.

Some of the best lines in the book are about editing. My favorite: “Kill your darlings, kill your darlings, even when it breaks your egocentric little scribbler’s heart, kill your darlings.”

King recommends trying to cut your first draft by at least 10 percent. He attempts to delete everything that does not drive the story. In our writing, we should strive to eliminate everything that does not advance our theory, theme, and entitlement to the relief we seek. This means deleting, without mercy, all superfluous words, sentences, paragraphs, and even entire sections.

Whether you are penning a horror novel or a brief, editing is critical. Editing entails correcting grammar and spelling, removing passive voice, searching for logical weaknesses, ensuring that nothing is incoherent, and evaluating organization at the micro (sentence and paragraph) and macro (entire document) levels.

King encourages having others edit your writing. He teaches that when you hand your work over to be edited, the editor is always right. Editors will also appreciate his maxim that “to write is human, to edit is divine.”

*On Writing* contains anecdotes about King’s life and career, overcoming alcohol and drug addiction, and inspiration for some of his most famous works. The memoir closes with a postscript describing how King’s love of his family, and his need to write, helped him recover from life-threatening injuries after a van struck him when he was taking a walk.

When I was a new associate at a large firm some 28 years ago, a partner squirmed when I used the term “legal writing.” He explained that legal writing is simply writing and that good legal writing is simply good writing. He maintained that some lawyers are poor writers because they believe that legal writing is somehow different from other writing.

I’ve tried to follow this advice in my writing. Because good legal writing is simply good writing, the King of Horror has much to offer us attorneys.

## Book Review

### Who Moved My Teeth? Preparing for Self, Loved Ones & Caregiving

*By Cathy Sikorski, Esq.  
Corner Office Books, 2016, 174 pp.*

*Reviewed by Kathleen Martin, CELA*

Cathy Sikorski, author of *Who Moved My Teeth? Preparing for Self, Loved Ones & Caregiving*, is an elder law attorney who writes from her experiences with clients in her chosen area of law as well as from her life experience as a self-professed “serial caregiver” for more than 25 years. This is a short book, jam-packed with important information that elder law attorneys wish everyone — individuals, caregivers, and caregivers-to-be — would pay attention to. The information is delivered in a humorous way, with a light hand, grounded in accuracy. The book is easy to read and structured so that one can go back to review sections that become relevant as one’s journey as a caregiver or as a senior progresses. The author’s specific examples of situations in which attorneys, individuals, and caregivers find themselves are side-splittingly funny but also leave the reader with those “I know what she is talking about” moments. Seeing the humorous side helps smooth frustrations — at least sometimes. Sikorski explains legal matters in comfortable language that neither talks down to nor talks over the reader, always injecting humor along the way.

Sikorski begins the book by explain-

ing how the title evolved as she simultaneously provided care for her 92-year-old grandmother and her 2-year-old daughter. Sikorski shares what she learned along her journey, and the journey of her clients, in a straightforward and down-to-earth manner. Throughout the book, she emphasizes that planning is key and, moreover, that knowledge is power. Many fail to plan, believing that planning is unnecessary. Sikorski presents information on planning succinctly and clearly, giving the reader up-to-date information they need to know.

Part 1, “Start Here and Now,” begins with the chapter “What Should I Have Already Done?” Sikorski discusses power of attorney documents, both financial and health care powers of attorney, and living wills. She also discusses the differences between the two types of powers of attorney and a living will and touches on long-term care insurance. Sikorski peppers her exposition with examples that make it easier for the layperson to understand. Chapter 2 takes the reader through the complicated worlds of Medicare, Medicaid, and Medigap and discusses what each means and how to find out more given a person’s

#### About the Reviewer

Kathleen Martin, CELA, is a member of the *NAELA Journal* Editorial Board.

particular situation. Chapter 3 discusses money, especially when Medicaid might become necessary. Sikorski emphasizes frequently, especially in this chapter, the need for the assistance of an elder law attorney to avoid making costly mistakes. Chapter 4 delves into the murky waters of Social Security benefits and lists resources for readers to enable them to learn more.

Part 2 is titled “You might be a caregiver ...” . Chapter 5, “Now Will You Talk to Me?” is a primer on how to cut through red tape with insurance companies, not just for the benefit of the people caregivers help but also for the benefit of caregivers themselves. Most of us, as attorneys or as caregivers, have entered that twilight zone in which the person on the other end of the line (or letter) apparently speaks a language that differs from ours. This situation can be so much more fraught for new caregivers. Sikorski likely will make the reader laugh and nod his or her head as the familiarity of the situation sinks in. Chapter 6 gives tips on how to ask for help. Most caregivers need assistance but often do not know how to ask for it, or they assume that others know when they need it. Chapter 7, “The Seven Dwarfs of Hidden Symptoms,” addresses

symptoms of medical problems, especially the dangerous and sneaky urinary tract infection and what happens when it is not recognized in time. In Chapter 8, Sikorski implores caregivers to stop paying medical bills without researching their validity. Chapter 9 is about patience — what it is and how to achieve it. She extolls 60 ways to find and hold onto patience. Chapter 10 explores methods to care for caregivers, and Chapter 11 talks about how to make employment actually work for them. Many caregivers are employed, and many employers employ caregivers, but the two groups need to discuss how to accommodate one another, making a difficult situation “work” for both (pun intended). Chapter 12, “Ain’t No Shame in Laughing,” sums everything up.

This book is a good read as well as a handy resource for elder law attorneys to recommend to clients, especially new caregivers thrust into the caregiving role. It also gives attorneys a commonsense way of explaining legal matters to clients. Several times I heard my own words echoed in Sikorski’s comments. This practical guide can help caregivers muddle through the complex issues of caregiving and encourages them to find humor in their situations.

**Directed Trusts: A Primer on the Bifurcation  
of Trust Powers, Duties, and Liabilities in  
Special Needs Planning**

*By William D. Lucius, Esq., and Shirley B. Whitenack, Esq., CAP, Fellow*

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**About the Authors**

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## I. Introduction

The provision of legal services in the fields of elder law and special needs planning has expanded over the past decade into a client-focused, holistic, and collaborative approach.<sup>1</sup> Consequently, this developing philosophy has permeated into the estate plans and trust instruments related to these fields, such as special needs trusts (SNTs)<sup>2</sup> and settlement preservation trusts (SPTs),<sup>3</sup> wherein the selection of an

appropriate fiduciary is no longer a choice between two or among several individuals or corporate trustees. Nontraditional “multiparticipant trust agreements,”<sup>4</sup> in which the “powerholders”<sup>5</sup> may be a potpourri of trustees, co-trustees, distribution directors, investment advisers, trust advisory committees, and trust protectors, are becoming more commonplace.<sup>6</sup> With the advent of directed trusts, these powerholders may now encroach upon the traditional trustee’s once overarching authority and compel the trustee to act (or not act) in furtherance of the trust’s objective.<sup>7</sup>

Consider the case of Nathaniel.<sup>8</sup> Like most 4-year-olds, Nathaniel was curious and adventurous in equal measure. Due to the alleged negligence of a day care employee, Nathaniel left his day care facility through an open gate and wandered unsupervised to an adjacent parking lot. When Nathaniel attempted to climb through a half-open car window, his head became stuck and he could no longer support his

1 Rebecca C. Morgan, *Elder Law in the United States: The Intersection of the Practice and Demographics*, 2 J. Intl. Aging L. & Policy 103, 106 (Summer 2007).

2 SNTs are commonly referred to as either first-party or third-party SNTs depending on the source of funds used to establish them. A first-party SNT, funded with the assets of a beneficiary with a disability, is created pursuant to Title 42 U.S.C. § 1396p(d)(4)(a) (2018); a third-party SNT, funded with the assets of a third party, is largely a creature of state law. For purposes of this article, “SNT” is used to refer to both types of SNTs because the distinction does not bear heavily on the topic of this article. Moreover, intentionally omitted from this article are pooled SNTs authorized by Title 42 U.S.C. § 1396p(d)(4)(c) and Qualified Income Trusts as found in Title 42 U.S.C. § 1396p(d)(4)(b). The authors assume the readers are knowledgeable of the definitions, types, and purposes of SNTs.

3 SPTs are a type of irrevocable, discretionary support trust commonly used in special needs planning. SPTs do not have a federal authorizing statute and do not protect the beneficiary’s ability to receive means-tested benefits (e.g., Supplemental Security Income, Medicaid); therefore, they do not need to comply with the Medicaid payback requirements of Title 42 U.S.C. § 1396p(d)(4)(a). In addition to affording a minimum level of creditor and spendthrift protection, SPTs may be useful planning tools for minor beneficiaries, beneficiaries with incapacity considerations, and those who may be vulnerable or susceptible to undue influence. See Thomas D. Begley Jr., *Settlement Protection Trusts*, 30 NAELA News 4 (Nov. 2018).

4 A multiparticipant trust, unlike the traditional single-fiduciary trust, employs a team of multiple trustees and/or advisers with specific roles and responsibilities. See John P.C. Duncan & Anita M. Sarafa, *Achieve the Promise — and Limit the Risk — of Multi-Participant Trusts*, 36 ACTEC L.J. 769, 772 (2011).

5 Powerholders are loosely defined in this article to include trust directors, trust advisers, trust protectors, trust advisory committees, and other parties with the power to direct another fiduciary on some aspect of the trust instrument.

6 Duncan & Sarafa, *supra* n. 4, at 773.

7 John D. Morley & Robert H. Sitkoff, *Making Directed Trusts Work: The Uniform Directed Trust Act*, 44 ACTEC L.J. 1 (Winter 2019).

8 Nathaniel’s story is loosely based on the real events of a beneficiary of an SNT administered by one of the authors. Although Nathaniel’s guardian gave permission to share his story, Nathaniel’s name and certain substantive facts have been changed to protect his privacy.



weight. The near-strangulation caused a significant, irreversible traumatic brain injury. Now 8 years old, Nathaniel is incapacitated, has no gait strength or swallowing reflexes, has frequent seizures, and requires 24-hour supervised care. Nathaniel's parents sued the day care provider and parking lot owner, securing an \$8 million cash settlement, which includes a 40-year guaranteed structured annuity payment of \$4,500 per month, adjusted 3 percent annually. The court that approved the settlement ordered the establishment of a first-party SNT for Nathaniel's benefit that included, in part, the following language:

Art. 1.1 — Trust Company, N.A., shall serve as the initial Corporate Trustee. Distribution Directors, Inc., shall serve as the initial Distribution Director under this Agreement. Each of the entities shall serve as fiduciaries but shall only be responsible for the decisions that fall within their respective authorities as defined hereunder. Both may rely conclusively on the other if that instruction relates to a matter under the other's purview, and neither shall have a duty nor obligation to review the underlying actions of the other.

Art. 1.2 — During the lifetime of Nathaniel, Distribution Director may direct Corporate Trustee to distribute, from income, principal, or both of this Trust, such amounts as the Distribution Director, in its sole, absolute, and unfettered discretion, may from time to time deem advisable or reasonable for Nathaniel's special needs.

Art. 9.1 — Nathaniel's mother is appointed as Trust Protector. The Trust Protector shall not be entitled to compensation for services rendered but shall be entitled to reimbursement of reasonable expenses in the exercise of her services. The Trust Protector is authorized, in her sole and absolute discretion, to remove from office, without Court approval, any Corporate Trustee or Distribution Director appointed herein, with or without cause and for any reason

whatsoever, and may replace such Corporate Trustee or Distribution Director with another Corporate Trustee or Distribution Director who is not related to or subordinate to the Beneficiary (within the meaning of Internal Revenue Code § 672(c)) to act in place of the Corporate Trustee or Distribution Director so removed.<sup>9</sup>

In Nathaniel's case, by ordering a trust with bifurcated duties among various parties, the court followed the advice of the guardian ad litem, who recommended a multiparticipant directed trust arrangement to best address the investment management and discretionary decision-making complexities that will likely last the length of the trust's administration.

#### *A. The Confluence of Multiparticipant and Directed Trusts*

A directed trust, similar to Nathaniel's SNT, includes individuals or entities with a power to direct the trustee on some aspect of the trust, such as investment management, administration, and distribution decisions, powers historically reserved to the trustee.<sup>10</sup> In Nathaniel's case, the distribution director is the directing party (the powerholder) on matters pertaining to discretionary distribution decisions; therefore, the traditional trustee is a "directed trustee"<sup>11</sup> insofar as the distribution director holds the power to direct and compel the trustee to act (or not act) in this regard.

<sup>9</sup> This sample language is a consolidation of various trust provisions from governing instruments spanning multiple jurisdictions. This language is being offered for example only and should not be construed as language suggested for use.

<sup>10</sup> Unif. Directed Trust Act § 2 cmt (5).

<sup>11</sup> Unif. Directed Trust Act § 2(3) defines "directed trustee" as a "trustee that is subject to a trust director's power of direction."

This article emphasizes this “power of direction”<sup>12</sup> as well as the attendant powers, duties, and liabilities of powerholders and directed trustees. Although a directed trust is a multiparticipant trust by design, because there must be both a directing party and directed party, it does not follow that all trusts with multiple parties are directed trusts or that all parties to a directed trust are powerholders.<sup>13</sup> Although Nathaniel’s mother, in her capacity as trust protector, has the authority to remove and appoint the trustee or distribution director, the governing instrument in this case does not afford her any powers to direct the trustee or distribution director in the administration of the trust. It is the inclusion, or absence, of a power of direction in the governing instrument that is dispositive.

Powerholders are often referred to inconsistently among practitioners; however, powerholders are most commonly known as trust protectors, trust or investment advisers, trust advisory committees, and trust directors.<sup>14</sup> Each role has its own advantages and limitations. Again, each may or may not be a powerholder,

depending on whether the individual or committee has been provided a power of direction in the governing instrument.

Trust protectors originated in the early 1990s in response to the increased use of then-popular foreign-based asset protection trusts.<sup>15</sup> Trust protectors have morphed into a check on trustees of SNTs and discretionary support trusts by providing increased oversight of the trustee-beneficiary relationship.<sup>16</sup> A trust protector, a person or entity the settlor nominates to ensure that the trustee adheres to the settlor’s wishes, is distinct from a trust adviser inasmuch as the trust protector is often granted broader powers, including the ability to remove and appoint trustees and amend or terminate the trust.<sup>17</sup> Certain states now embody the definition of “trust protector” in their probate codes and enumerate the rights and responsibilities of the role.<sup>18</sup>

The value of a trust protector is found in his, her, or its ability to monitor the trustee’s conduct and interaction with the beneficiary, amend burdensome or unintended dispositive provisions, change situs, and modify or terminate the trust. However, this value is restrained by whether the trust protector serves in an active or passive role, the relationship the

12 Unif. Directed Trust Act § 2(5) defines “power of direction” as “a power over a trust granted to a person by the terms of the trust to the extent the power is exercisable while the person is not serving as trustee. The term includes a power over the investment, management, or distribution of trust property or other matters of administration. ...”

13 Morley & Sitkoff, *supra* n. 7, at 10.

14 Unif. Directed Trust Act, *Prefatory Note*. Also note that the term “trust director” is defined in § 2(9) of the Uniform Directed Trust Act as a “person that is granted a power of direction by the terms of a trust to the extent the power is exercisable while the person is not serving as a trustee. The person is a trust director whether or not the terms of the trust refer to the person as a trust director and whether or not the person is a beneficiary or settlor of the trust.”

15 J. Andy Marshall, *Trust & Estates Law — Trust Protectors — Increasing Trust Flexibility and Security While Decreasing Uncertainty of Liabilities for Doing So: How Amending Ark. Code Ann. § 28-73-808 to Better Conform With the Modern Trend of Clarifying Trust Protection Could Effectively End the Fiduciary Guessing Game in Arkansas*, 35(4) UALR L. Rev. 1137, 1140 (2013).

16 *Id.* at 1141.

17 Richard C. Ausness, *The Role of Trust Protectors in American Trust Law*, 45 Real Prop. Tr. & Est. L.J. 319, 321 (Summer 2010).

18 Idaho Code § 15-7-501 (West) (Current through ch. 329 of 2019 reg. sess.)

trust protector has with the trustees and beneficiaries, additional fees imposed due to this added layer of protection, and most important, whether the trust protector is considered to be serving in a fiduciary capacity, which varies by state and presumably impacts who may be willing to serve.<sup>19</sup>

Trust advisers, trust advisory committees, and trust directors are prevalent in special needs planning inasmuch as they may assist a trustee, in particular a professional trustee, who may not know the beneficiary well, may not fully understand the beneficiary's special needs, or may be removed geographically from the beneficiary.<sup>20</sup> These roles may be filled by one or several advisers (e.g., relative of the beneficiary, attorney, financial adviser, accountant, case manager, advocate, health care professional) who provide a range of insight and services for the trustee.<sup>21</sup> The Uniform Trust Code posits that a trust adviser assists with certain trustee functions (e.g., determining the appropriateness of a particular distribution request, opining on the structure of an investment portfolio), whereas a trust protector connotes a grant of larger powers.<sup>22</sup>

Trust advisers, trust advisory committees, and trust directors may support the trustee; provide guidance in helping the trustee understand the nature and extent of the beneficiary's medical, social, and therapeutic needs; review investment management decisions to ensure that they

are consistent with the settlor's investment philosophy; direct distributions; identify government and private benefits programs; resolve disputes among co-trustees; and remove and appoint trustees. Yet these entities can frustrate the trust administration process if the trust is drafted in such a way that their purpose, the extent of their authority, or their relationship with the trustee is ambiguous. Without a clear dispute resolution and governance process, a lack of consensus among these entities and trustees can stall the trust administration process.<sup>23</sup> And trust advisers, advisory committees, and directors may be too disinterested, lack the time and commitment, or be too ill-informed to adequately perform their obligations under the governing instrument.

Just as the comments on § 703 of the Uniform Trust Code caution that "co-trusteeship should not be called for without careful reflection," by extension, when employing multiple parties to a trust who may be called upon to hold a power of direction over the trustee, drafting attorneys must proceed judiciously and balance the utility of the nontrustee participant's role and services with the settlor's objectives. Attorneys also must be mindful that the use of multiple participants in a trust has eclipsed the available case law and state statutes that define and govern these various roles.<sup>24</sup>

19 Alexander A. Bove Jr., *The Case Against the Trust Protector*, 37 ACTEC L.J. 77 (2011).

20 B. Bailey Liipfert III, *Trust Advisory Committees Can Guide Trustee Decisions*, Spec. Needs Alliance (2016), <https://www.specialneedsalliance.org/trust-advisory-committees-can-guide-trustee-decisions> (accessed Apr. 24, 2019).

21 *Id.*

22 Unif. Trust Code § 808 cmts. (2000).

23 Daniel P. Felix, *Opportunities and Pitfalls in the New Illinois Directed Trust Statute*, 101 Ill. B.J. 6 (June 2013).

24 Andrew T. Huber, *Trust Protectors: The Role Continues to Evolve*, ABA Real Prop., Trust & Est. L. (Mar. 14, 2018), [https://www.americanbar.org/groups/real\\_property\\_trust\\_estate/publications/probate-property-magazine/2017/january-february-2017/2017\\_aba\\_rpte\\_pp\\_v31\\_1\\_article\\_huber\\_trust\\_protectors](https://www.americanbar.org/groups/real_property_trust_estate/publications/probate-property-magazine/2017/january-february-2017/2017_aba_rpte_pp_v31_1_article_huber_trust_protectors) (accessed Apr. 24, 2019).

### *B. A Departure From Traditional Delegation Principles*

To better understand the concept of a directed trust arrangement, contrast this structure with what it is not — delegation, whereby the trustee's authority over a particular function is transferred or delegated to another party.<sup>25</sup> Historically, trustee delegation rules generally limited trustees from delegating any function that a trustee could be reasonably expected to perform himself or herself, including investment management.<sup>26</sup> Trustees were (and still are) required to rely on any special skills they have in the administration of a trust, especially in cases in which the settlor relied upon those skills when selecting the trustee.<sup>27</sup>

The Uniform Prudent Investor Act, Restatement (Third) of Trusts, and Uniform Trust Code have since changed course and now encourage trustees to evaluate whether they are competent enough to perform the obligations and duties imposed on them by the governing instrument and if they are not, whether and to whom they should delegate this authority.<sup>28</sup> The two-fold dilemma with delegation is not only that the trustee has an ongoing statutory duty to exercise “reasonable care, skill and caution” in selecting the agent, establishing the scope of the agent's authority, and reviewing the agent's actions<sup>29</sup> but also that the settlor may not want the selected trustee to have complete autonomy in outsourcing key components of the trust administra-

tion and investment management process.<sup>30</sup>

Rather than using the top-down approach that accompanies delegation, a directed trust separates assigned trust functions *ab initio* among the multiple participants pursuant to the settlor's intent and without necessary consideration of the trustee's preference or selection of those participants.<sup>31</sup>

### *C. Avoiding the Paralysis of Decision-Making by Committee*

Directed trusts are a response to the always-evolving area of sophisticated estate planning, which has been impacted by a renewed focus on achieving the settlor's objectives.<sup>32</sup> An increase in regulatory and litigious activity, complex dispositive provisions, the consequences of improper distributions, and portfolios that contain significantly concentrated positions in assets that are not traditional marketable securities — which have long plagued wary fiduciaries — become more palatable through a directed trust arrangement.<sup>33</sup> With proper planning, a powerholder under a directed SNT may do the following:

- Direct the trustee to hold a concentrated position;
- Invest in illiquid assets including busi-

25 Unif. Trust Code § 807(a) (2010).

26 *Restatement (Second) of Trusts* § 171 cmt. (h) (1959).

27 Unif. Trust Code § 806.

28 Unif. Prudent Investor Act § 9 (1994); *Restatement (Third) of Trusts* § 171 (2003); Unif. Trust Code § 807.

29 Unif. Trust Code § 807(a)(1)–(3).

30 David A. Diamond & Todd A. Flubacher, *The Trustee's Role in Directed Trusts*, 149 J. Wealth Mgt. Trust & Ests. 11, 24–25 (Dec. 2010).

31 Todd A. Flubacher, *Directed Trusts: Panacea or Plague?* NAEPC J. Est. Tax Plan. (Sept. 2015), <http://www.naepcjournals.org/journal/issue22i.pdf> (accessed Apr. 24, 2019).

32 For example, Florida Senate Bill 478 was introduced in 2017 to amend the Florida Trust Code to ensure, in part, that the settlor's intent is paramount in trust interpretation, thereby relegating the best-interest-of-the-beneficiary standard.

33 Diamond & Flubacher, *supra* n. 30.

ness entities, real estate and timber, and oil and gas interests;

- Structure and manage the portfolio;
- Provide asset valuations for hard-to-value assets;
- Remove and appoint trustees;
- Communicate with third parties on behalf of the trust; and/or
- Compel or prohibit distributions.<sup>34</sup>

Directed trusts are also a counterbalance to the old adage that a “camel is a horse designed by a committee” and may be employed to clear the logjams that are common in decision-making associated with multiparticipant trusts, in which roles and responsibilities are often blurred, overlapping, or ambiguous.<sup>35</sup>

The efficacy of directed trusts is not without limitations. State law remains scattered and judicial guidance is limited regarding the powers, duties, and liabilities imposed on the directed trustee and powerholder. In Massachusetts, the trust protector and the trustee of a trust in which the trust protector has the authority to advise the trustee on socially responsible investing<sup>36</sup> has fiduciary considerations that are entirely different from those of a directed trustee and investment adviser of a trust with an Alaska situs in which the investment adviser holds a power of direction on the same socially responsible investment philosophy.<sup>37</sup>

Would a directed SNT really benefit Nathaniel? Are the additional fees and other costs that result from removing traditional trustee functions (e.g., the exercise of discretion) and transferring them to a distribution director reasonable? What protections, if any, are afforded the directed trustee, powerholder, and beneficiary? This brief primer on the bifurcation of trust powers, duties, and liabilities in the context of special needs planning attempts to answer these questions by first summarizing the legislative evolution of directed trusts. Next, the various ap-

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form Trust Code approach to directed trustee liability and admonishes the trustee not to act in accordance with the attempted exercise of power by another if doing so would be “manifestly contrary to the terms of the trust or the trustee knows the attempted exercise would constitute a serious breach of a fiduciary duty that the person holding the power owes to the beneficiaries of the trust.” Mass. Gen. Laws ch. 203E, § 808(b) (West)(Current through Ch. 12 of 2019 First Annual Sess.). Alaska protects directed trustees and absolves them from liability for following the instructions of a powerholder by stating that a directed trustee “required to follow the directions of the advisor is not liable, individually or as a fiduciary, to a beneficiary for a consequence of the trustee’s compliance with the advisor’s directions, regardless of the information available to the trustee, and the trustee does not have an obligation to review, inquire, investigate, or make recommendations or evaluations with respect to the exercise of a power of the trustee if the exercise of the power complies with the directions given to the trustee. An advisor under this subsection is liable to the beneficiaries as a fiduciary with respect to the exercise of the advisor’s directions by a trustee as if the trustee were not in office, and the advisor has the exclusive obligation to account to the beneficiaries and to defend an action brought by the beneficiaries with respect to the exercise of the advisor’s directions by the trustee.” Alaska Stat. § 13.36.375(c) (West)(Current through 2018 Second Regular Sess. of 30th Legis.)

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<sup>34</sup> *Id.*

<sup>35</sup> Morley & Sitkoff, *supra* n. 7, at 44–50.

<sup>36</sup> Socially responsible investing is an investment management strategy that combines financial return with the investor’s desire to bring about positive social and/or environmental change through selected investments. See Adam Connaker & Saadia Madsbjerg, *The State of Socially Responsible Investing*, Harv. Bus. Rev. (Jan. 17, 2019), <https://hbr.org/2019/01/the-state-of-socially-responsible-investing> (accessed Apr. 26, 2019).

<sup>37</sup> Massachusetts, for example, follows the Uni-

proaches states employ in addressing the powers, duties, and liabilities imposed on a directed trustee and powerholder are proffered. The article concludes with drafting and other practitioner considerations that clearly delineate the rights and duties among the various parties while balancing the best interests of the beneficiary with the settlor's intent.

## II. Evolution of Directed Trust Law

### *A. Restatement (Second) of Trusts and Restatement (Third) of Trusts*

Published in 1959, the Restatement (Second) of Trusts first addresses directed trusts in § 185, which states the following:

If under the terms of the trust a person has power to control the action of the trustee in certain respects, the trustee is under a duty to act in accordance with the exercise of such power, unless the attempted exercise of the power violates the terms of the trust or is a violation of a fiduciary duty to which such person is subject in the exercise of the power.<sup>38</sup>

The premise of the first part of § 185 is that a trustee has a general duty to act in accordance with a powerholder's direction. This duty is not absolute, however, given the trustee's obligation to ensure that the powerholder's direction does not violate the terms of the trust or the powerholder's fiduciary duty.

The comments on § 185 suggest that the trustee's level of inquiry depends on whether the powerholder's exercise of the power of direction in a fiduciary capacity was in favor of the powerholder or whether the powerholder exercised this power for the beneficiary's benefit.<sup>39</sup> If the power-

holder's exercise of the power of direction was in favor of the powerholder only, the trustee's inquiry is limited to confirming whether the direction was consistent with the terms of the governing instrument.<sup>40</sup> But if the powerholder exercised his or her power of direction in favor of others, the trustee must determine whether any applicable fiduciary duty the powerholder owed was violated.<sup>41</sup> Should the trustee have doubt about, or knowledge of, a breach of duty by the powerholder, the trustee should not follow the disputed direction and instead petition the court for instructions.<sup>42</sup>

Although the Restatement (Third) of Trusts likewise opined on directed trusts nearly a half-century later, as evidenced by the following excerpt, the trustee's analysis when weighing the appropriateness of the powerholder's direction remains largely unchanged:

if the terms of a trust reserve to the settlor or confer upon another a power to direct or otherwise control certain conduct of the trustee, the trustee has a duty to act in accordance with the requirements of the trust provision reserving or conferring the power and to comply with any exercise of that power, unless the attempted exercise is contrary to the terms of the trust or power or the *trustee knows or has reason to believe* that the attempted exercise violates a fiduciary duty that the power holder owes to the beneficiaries.<sup>43</sup>

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Neeno, *Directed Trusts: Can Directed Trustees Limit Their Liability?* 21 Prob. & Prop. 45 (Nov/Dec 2007).

40 *Restatement (Second) of Trusts* § 185 cmts. (c), (d).

41 *Id.* at § 185 cmts. (c), (e).

42 *Id.* at § 185 cmt. (f).

43 *Restatement (Third) of Trusts* § 75 (emphasis added).

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38 *Restatement (Second) of Trusts* § 185.

39 *Id.* at § 185 cmts. (b)–(f). See also Richard W.

The most noticeable deviation from § 185 of the Restatement (Second) of Trusts pertains to the trustee's review of the powerholder's direction that was exercised in a fiduciary capacity. In such instances, under § 75 of the Restatement (Third) of Trusts, the trustee must refuse to comply with the direction if he or she knows, or has reason to suspect, that the powerholder is violating a fiduciary duty. This is a less exacting standard than § 185, which does not take into account the trustee's knowledge, or lack of knowledge, about whether the powerholder was in breach.

### *B. Uniform Trust Code*

The Uniform Trust Code, considered the first national codification of trust law, was promulgated by the National Conference of Commissioners on Uniform State Laws in 2000 and was last amended in 2010.<sup>44</sup> According to the Uniform Trust Code Prefatory Note, the commissioners realized that, given the greatly expanding use of trusts, trust law was thin and fragmentary in many states. The Uniform Trust Code was drafted to provide a comprehensive guide on trust law issues and was modeled on California's trust statute in close coordination with the Restatement (Third) of Trusts.

The Uniform Trust Code formerly contained § 808, titled "Power to Direct." It stated:

- (b) If the terms of a trust confer upon a person other than the settlor of a revocable trust power to direct certain actions of the trustee, the trustee shall act in accordance with an exercise of

the power unless the attempted exercise is manifestly contrary to the terms of the trust or the trustee knows the attempted exercise would constitute a serious breach of a fiduciary duty that the person holding the power owes to the beneficiaries of the trust.

- (c) The terms of a trust may confer upon a trustee or other person a power to direct the modification or termination of the trust.
- (d) A person, other than a beneficiary, who holds a power to direct is presumptively a fiduciary who, as such, is required to act in good faith with regard to the purposes of the trust and the interests of the beneficiaries. The holder of a power to direct is liable for any loss that results from breach of a fiduciary duty.<sup>45</sup>

The comment on Uniform Trust Code § 808 noted:

Subsections (b)-(d) ratify the use of trust protectors and advisers. Subsections (b) and (d) are based in part on Restatement (Second) of Trusts § 185 (1959). Subsection (c) is similar to Restatement (Third) of Trusts § 64(2) (Tentative Draft No. 3, approved 2001). "Advisers" have long been used for certain trustee functions, such as the power to direct investments or manage a closely-held business.<sup>46</sup>

Importantly, the comment is also the first codification that the holder of a power of direction is "presumptively acting in a fiduciary capacity with respect to the powers granted and can be held liable if the holder's conduct constitutes a breach of trust, whether through action or inaction."

Section 808 was removed when the Uniform Trust Code was amended in

<sup>44</sup> Natl. Conf. of Commrs. on Unif. St. Laws, *Uniform Trust Code*, <https://www.uniformlaws.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=e9c00113-601a-cd94-3aec-97c75a9f6d5a&forceDialog=0> (accessed Apr. 26, 2019).

<sup>45</sup> Unif. Trust Code § 808.

<sup>46</sup> *Id.* at § 808 cmts.

2010. A legislative note was added, stating, “A state that has enacted the Uniform Directed Trust Act (UDTA) should repeal Section 808 and revise certain other provisions of the [Uniform Trust Code] as indicated in the legislative notes to the UDTA.”<sup>47</sup> Former Section 808 was vague regarding the power to direct. Accordingly, some states, such as New Jersey, added specific provisions dealing with the power to direct to their versions of the Uniform Trust Code.<sup>48</sup>

47 Unif. Trust Code, *Legislative Note* on former § 808 (last revised or amended in 2010).

48 See e.g. N.J. Rev. Stat. § 3b:31-62 (2018), which states:

- a. When one or more persons are given authority by the terms of a governing instrument to direct, consent to or disapprove a fiduciary’s actual or proposed investment decisions, such persons shall be considered to be investment advisers and fiduciaries when exercising such authority unless the governing instrument otherwise provides.
- b. If a governing instrument provides that a fiduciary is to follow the direction of an investment adviser, and the fiduciary acts in accordance with such a direction, then except in cases of willful misconduct or gross negligence on the part of the fiduciary so directed, the fiduciary shall not be liable for any loss resulting directly or indirectly from any such act.
- c. If a governing instrument provides that a fiduciary is to make decisions with the consent of an investment adviser, then except in cases of willful misconduct or gross negligence on the part of the fiduciary, the fiduciary shall not be liable for any loss resulting directly or indirectly from any act taken or omitted as a result of such investment adviser’s failure to provide such consent after having been requested to do so by the fiduciary.
- d. For purposes of this section, “investment decision” means with respect to any investment, the retention, purchase, sale, exchange, tender or other transaction affecting the ownership thereof or rights therein and with respect to nonpublicly traded

### C. Uniform Directed Trust Act

In the ongoing statutory evolution of multiparticipant trusts and in an effort to corral the various state approaches to directed trusts, which are discussed in Section III of this article, the National Conference of Commissioners on Uniform State Laws commissioned the Uniform Directed Trust Act Drafting Committee

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investments, the valuation thereof, and an adviser with authority with respect to such decisions is an investment adviser.

- e. Whenever a governing instrument provides that a fiduciary is to follow the direction of an investment adviser with respect to investment decisions, then, except to the extent that the governing instrument provides otherwise, the fiduciary shall have no duty to:

- (1) Monitor the conduct of the investment adviser;
- (2) Provide advice to the investment adviser or consult with the investment adviser; or
- (3) Communicate with or warn or apprise any beneficiary or third party concerning instances in which the fiduciary would or might have exercised the fiduciary’s own discretion in a manner different from the manner directed by the investment adviser.

Absent clear and convincing evidence to the contrary, the actions of the fiduciary pertaining to matters within the scope of the investment adviser’s authority, such as confirming that the investment adviser’s directions have been carried out and recording and reporting actions taken at the investment adviser’s direction, shall be presumed to be administrative actions taken by the fiduciary solely to allow the fiduciary to perform those duties assigned to the fiduciary under the governing instrument. Such administrative actions shall not be deemed to constitute an undertaking by the fiduciary to monitor the investment adviser or otherwise participate in actions within the scope of the investment adviser’s authority.



to draft proposed legislation.<sup>49</sup> According to the Uniform Directed Trust Act Prefatory Note, the drafting committee was charged with designing a uniform act that combines a settlor's value for "freedom of disposition" with increasingly conservative trustees who seek limited liability in following the direction of a third party, while imposing mandatory minimum fiduciary duties on both the directed trustee and the powerholder in order to protect the beneficiary. The drafting committee's efforts culminated with the final adoption of the Uniform Directed Trust Act during the July 2017 annual conference of the commissioners.

The Uniform Directed Trust Act contains 20 sections, yet the integral part of the Act lies in §§ 6 through 8, which outline the duties, powers, limitations, and liabilities of the powerholder and directed trustee. The remainder of the Act considers ancillary technical differences between the Act and existing state law as well as often-overlooked drafting considerations.<sup>50</sup>

Much like the Restatement (Second) of Trusts, Restatement (Third) of Trusts, and Uniform Trust Code § 9, the Uniform Directed Trust Act requires a directed trustee to comply with a powerholder's exercise (or nonexercise) of a power of direction and is not liable for doing so.<sup>51</sup> Unlike both Restatements and the Uniform Trust Code, however, the Uniform Directed Trust Act does not require the trustee to

follow the powerholder's direction if the exercise (or nonexercise) of the power of direction requires the trustee to engage in willful misconduct.<sup>52</sup> No longer is the trustee required to look at the powerholder's duties or actions in determining whether to follow a direction. Instead, the trustee must only look at himself or herself to ensure that the direction given does not cause the trustee to knowingly or intentionally engage in misconduct. Therein lies the principal cornerstone of modern directed trusts.

Regarding the powerholder's powers, duties, and liabilities, although the trust instrument may confer a broad power of direction to the powerholder, absent contrary language in the trust document, § 8 of the Uniform Directed Trust Act imposes on the powerholder the same fiduciary duties and attendant liabilities in the exercise (or nonexercise) of a power of direction as a trustee "in a like position and under similar circumstances."<sup>53</sup> The Uniform Directed Trust Act Drafting Committee believed that because the powerholder acts much like a fiduciary of a traditional trust, the powerholder should have the same duties as a similarly situated trustee and the directed trustee's duties with respect to the powerholder's power should be reduced accordingly.<sup>54</sup> For example, in New Jersey, where a trust vests the power to make investment decisions in a person other than the trustee, the trustee cannot be liable, absent willful misconduct or gross negligence, for any loss that may result from the retention or sale of an investment.<sup>55</sup>

By inference, a powerholder with the power of direction over discretionary dis-

49 Natl. Conf. of Commrs. on Unif. St. Laws, *Unif. Directed Trust Act* (2017), <https://www.uniformlaws.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=cedab7b6-8fd9-29f1-835f-ed4f385e12aa&forceDialog=0> (accessed Apr. 26, 2019).

50 *Id.*

51 Unif. Directed Trust Act § 9(a).

52 *Id.* at § 9(b).

53 *Id.* at § 8(a)(1)(A).

54 *Id.* at *Prefatory Note*.

55 N.J. Rev. Stat. § 3b:31-62(b), (d).

tributions from an SNT would presumably have the same fiduciary responsibility in exercising his, her, or its discretion as a sole trustee of a similar trust; thus, the directed trustee's liability pertaining to discretionary decision-making would be reduced. This fact is punctuated by the Uniform Directed Trust Act's mandate that a powerholder be subjected to the same rules as a trustee in a similar position regarding Medicaid payback provisions necessary to comply with the requirements of Title 42 U.S.C. § 1396p(d)(4)(a).<sup>56</sup>

Both the powerholder and the trustee are required to share information necessary to fulfill their duties.<sup>57</sup> But under the Uniform Directed Trust Act, the trustee does not have a duty to (1) monitor the powerholder or (2) inform or advise the settlor or beneficiary concerning an instance in which the trustee may have acted differently from the powerholder.<sup>58</sup> It is in these two provisions that a directed trust, at least through the lens of a directed trustee, becomes more palatable than delegation, as discussed in Section I of this article.

States are beginning to view the Uniform Directed Trust Act as a model as the special needs, estate planning, and fiduciary communities are beginning to view multiparty trusts as comprehensive, beneficiary-centered, and holistic planning tools.<sup>59</sup>

In Michigan, a recent state to amend its trust code to conform to the spirit of the Uniform Directed Trust Act (with support from the State Bar of Michigan Probate & Estate Planning Section Governing Council), practitioners have already opined that the recent legislative changes will allow fiduciaries to seriously consider a settlor's desire to bifurcate administrative duties in a directed trust, previously viewed as posing unnecessary fiduciary risks and being labor intensive, which in turn should incentivize pricing competition among professional fiduciaries.<sup>60</sup>

Unfortunately, states, even those that have adopted or are considering adopting the Uniform Directed Trust Act, largely remain divided on directed trusts, the level of trustee oversight required, and attendant trustee liability to impose. Therefore, drafting attorneys must be cautious when employing a directed trust and be familiar with the law in the state the trust is situated.

### III. State Approaches and Other Considerations

#### A. State Approaches to Directed Trustee Liability

In today's regulatory and litigious environment, most fiduciaries are keenly aware that when held to account, a court will impose upon them an exacting standard that Justice Benjamin Cardozo eloquently described as "not honesty alone, but the punctilio of an honor the most sensitive."<sup>61</sup> It follows, therefore, that in the context of directed trusts involving

<sup>56</sup> Unif. Directed Trust Act § 7(1).

<sup>57</sup> *Id.* at § 10(a).

<sup>58</sup> *Id.* at § 11(a)(1)(A)-(B).

<sup>59</sup> Eleven states have recently introduced or enacted legislation to adopt some version of the Uniform Directed Trust Act: Utah H. 314 (2019), Conn. H. 7104 (2019), R.I. H. 5476/R.I. Sen. 344 (2019)(introduced), Colo. Sen. 105 (2019), Ark. H. 1765 (2019), Mich. H. 6130 (2019), Neb. Legis. Doc. 536 (2019), Maine Legis. Doc. 1468 (2019), Indiana Sen. 265 (2019), Ga. H. 121 (2018), and N.M. S.

101 (2018).

<sup>60</sup> James P. Spica, *Michigan's Proposed Adoption of the Uniform Directed Trust Act*, 97 Mich. B.J. 11 (Nov. 2018).

<sup>61</sup> *Meinhard v. Salmon*, 164 N.E. 545, 465 (N.Y. 1928).

multiple parties, a directed trustee would be hesitant to serve in such a capacity if the trustee would be responsible for the acts of the powerholder. Directed trusts tend to be preferable arrangements — at least from the directed trustee’s perspective — only when state law imposes a lower standard on a trustee acting at the powerholder’s direction.<sup>62</sup>

Apart from the six states that do not have a directed trust statute on point,<sup>63</sup> 13 states and the District of Columbia follow the Uniform Trust Code § 808 approach,<sup>64</sup> one state follows the Restatement (Second) of Trusts § 185 approach,<sup>65</sup> and 30 states have statutes that protect directed trustees.<sup>66</sup> Ten of the states that protect directed trustees have enacted some version of the Uniform Directed Trust Act.<sup>67</sup> Those states that follow either the Restatement (Second) of Trusts

§ 185 approach or the Uniform Trust Code § 808 approach effectively gut the bifurcated arrangement<sup>68</sup> insofar as both approaches require the trustee to affirmatively monitor the powerholder to ensure that the exercise of the power of direction (a) is not “inconsistent with the terms of the trust,”<sup>69</sup> (b) is not “manifestly contrary to the terms of the trust,”<sup>70</sup> or (c) does not constitute a serious breach of fiduciary duty that the powerholder owes to the beneficiaries.<sup>71</sup> Imposing on a directed trustee a continued obligation to monitor a third party’s actions, with the potential for liability in the event of a breach by the third party, does not distinguish this arrangement from that of traditional delegation, except that the directed trustee had no opportunity to select the powerholder at trust inception.

Even though directed trustees clearly have an advantage in states that have protective statutes, the protection afforded by these statutes varies broadly.<sup>72</sup> Several states completely limit a directed trustee’s liability for complying with a powerholder under the idea that “duty should follow power.”<sup>73</sup> Other protective statutes, consistent with the Uniform Directed Trust Act approach, apply a willful or intentional misconduct standard premised on the idea that the trustee — a pinnacle of the trust relationship — bears some modicum of duty to the beneficiary simply because the settlor chose not to make the powerholder the sole trustee.<sup>74</sup> It is important to note that the protective approach does not limit the recourse a beneficiary has in the

62 Diamond & Flubacher, *supra* n. 30, at 26.

63 Those states are California, Hawaii, Louisiana, Minnesota, New York, and Rhode Island. Rhode Island recently introduced legislation to adopt the Uniform Directed Trust Act.

64 Those states are Alabama, Florida, Kansas, Maryland, Massachusetts, Montana, New Jersey, Oregon, Pennsylvania, South Carolina, Vermont, Virginia, and West Virginia.

65 This state is Iowa. Only Iowa, however, deviates from the language in § 185 and includes a requirement that the trustee not act if the trustee knows that the powerholder is not competent. Iowa Code § 633A.4207(2) (West)(Current through legis. effective May 22, 2019, subj. to change by Iowa Code Editor for Code 2020).

66 Those states are Alaska, Arizona, Arkansas, Colorado, Connecticut, Delaware, Florida (only if powerholder is a co-trustee), Georgia, Idaho, Illinois, Indiana, Kentucky, Maine, Michigan, Mississippi, Missouri, Nebraska, Nevada, New Hampshire, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, South Dakota, Tennessee, Utah, Washington, Wisconsin, Wyoming, and Texas.

67 *Id.* at n. 59.

68 Diamond & Flubacher, *supra* n. 30, at 26–27.

69 Restatement (Second) of Trusts § 185.

70 Unif. Trust Code § 808(b).

71 Restatement (Second) of Trusts § 185; *id.*

72 Unif. Directed Trust Act § 9 cmt.

73 *Id.*

74 *Id.*

event of a breach.<sup>75</sup> The beneficiary may bring an action against the powerholder for breach of fiduciary duty and against the directed trustee for any willful misconduct — the liability does not necessarily shift among the parties.

Interestingly, the Uniform Directed Trust Act Drafting Committee decided to use the willful misconduct standard based on findings that states that have updated their directed trust statutes (e.g., Delaware) are abandoning the Uniform Trust Code § 808 approach in favor of legislation more protective of the trustee.<sup>76</sup> According to the drafting committee, such trustee protection need not be unlimited. The drafting committee rejected the suggestion that the Uniform Directed Trust Act eliminate the fiduciary duty of a directed trustee entirely, even a directed trustee's duty to avoid engaging in willful misconduct, finding that Delaware's "prominent directed trust statute" is workable for practitioners and that the more protective total exclusion standard is "unnecessary to satisfy the needs of directed trust practice."<sup>77</sup> Of course, prefatory language in a uniform act is not binding, and as states such as Michigan continue to adopt their modified versions of the Uniform Directed Trust Act, the issue of

directed trustee liability will continue to evolve.

Although the statutory landscape of directed trusts may appear to be adapting and evolving, the inconsistencies among state laws, especially regarding directed trustee liability, require increased due diligence by drafting attorneys and fiduciaries operating in this space.

### B. Planning Considerations

When engaging in special needs planning that involves a directed trust, the threshold the drafting attorney should consider is whether the trust jurisdiction authorizes such an arrangement.<sup>78</sup> If the jurisdiction has a directed trust statute, the practitioner should determine the approach the state takes in addressing directed trustee liability because this could impact the identification of fiduciaries willing to serve under the instrument. Should the state employ the more restrictive approach of Uniform Trust Code § 808 or Restatement (Second) of Trusts § 185 (or simply have no statute at all), the drafting attorney will need to review the choice-of-law principles of the trust's home state to determine whether a state with more favorable directed trust statutes may be selected as the law that governs the trust.<sup>79</sup>

When parties seek to modify or amend the governing instrument of an existing trust to include directed trust provisions, counsel must undertake the more arduous process of determining whether the trust may be amended, modified (either by judicial or nonjudicial means), or decanted into a trust that includes the preferred directed trust language.<sup>80</sup> Of course, counsel

<sup>75</sup> *Id.*

<sup>76</sup> *Id.* Delaware's directed trust statute was tested in *Duemler v. Wilmington Trust Co.*, 2004 WL 5383927 (Del. Ch. 2004) (unpublished trial order). The chancery court found that a corporate fiduciary did not engage in willful misconduct by failing to oversee or provide information to an investment adviser, who had the power to direct the trustee on investment management decisions, and upheld the trustee's statutory defense under Del. Code Ann. tit. 12, § 3313 (West)(Current through ch. 22 of 150th Gen. Assembly 2019-2020).

<sup>77</sup> Unif. Directed Trust Act, *Prefatory Note*, § 9 cmt.; see also Del. Code Ann. tit. 12, § 3313.

<sup>78</sup> Nenno, *supra* n. 39.

<sup>79</sup> *Id.*

<sup>80</sup> Diamond & Flubacher, *supra* n. 30, at 28.

must fully explore significant federal and state tax and government benefits eligibility issues (which are beyond the scope of this article) before attempting to modify, amend, or transfer the situs of an SNT. There is no guarantee that counsel will find a sympathetic judge willing to make substantive changes to a governing instrument. For example, *In re Will of Flint*, an unsympathetic judge expressly denied the petition of an income beneficiary of a testamentary trust seeking to change the trust from a traditional trustee-managed structure to a directed trust, which was governed by Delaware law rather than the original situs of New York, concluding the requested modification departed too far from the testator's intent.<sup>81</sup>

Once the choice-of-law analysis has been performed or consideration has been given to modification, the drafting attorney's attention should move to the specific language delineating the powerholder's and trustee's powers, duties, and liabilities. The Uniform Directed Trust Act, for example, does not contain statutory default powers and simply provides a powerholder those powers granted under the terms of the trust.<sup>82</sup> By affording a broad grant of power, the Uniform Directed Trust Act Drafting Committee attempted to validate a powerholder's power by deferring to the terms of the trust and, by extension, the settlor's intent.<sup>83</sup> The drafting committee contemplated that a trust may confer to a powerholder a broad breadth of powers, including powers to (a) direct investments; (b) modify, reform, terminate, or decant the trust; (c) change the trust's situs or governing law; (d) determine the capacity of a settlor, beneficiary, or trustee;

(e) set fiduciary compensation; (f) grant permission or direct a trustee in the exercise of a power reserved to the trustee; and (g) release the trustee or another director from liability.<sup>84</sup>

The drafting attorney needs to structure how the powerholder will exercise the power of direction under the governing instrument. The settlor, in conjunction with counsel, must decide in what capacity the powerholder will serve, such as trust protector, distribution director, investment adviser, or trust advisory committee, because that will impact the specific powers and duties to be bestowed. When drafting powerholder language, it is important to be as detailed and comprehensive as possible, while limiting the trustee's and powerholder's powers only to those that the settlor intends each to have.<sup>85</sup> The powerholder's and trustee's respective powers under the governing instrument must be clearly delineated to avoid confusion, ineffective trust administration, and most important, overlap, which could give rise to additional trustee liability.<sup>86</sup> For example, an aggrieved SNT beneficiary could argue that although the trustee acted at the powerholder's direction, the trustee possessed a similar but independent power under the instrument that, if exercised prudently, could have mitigated the loss caused by the powerholder's exercise of the power of direction.<sup>87</sup>

Even though a settlor has wide latitude in shaping a directed trust, the practitioner must still consider whether the governing document should deviate from any statutory minimum default provisions. Such considerations should include at a

81 118 A.3d 182 (Del. Ch. 2015).

82 Unif. Directed Trust Act § 6(a).

83 *Id.* at § 6(a) cmt.

84 *Id.*

85 Diamond & Flubacher, *supra* n. 30, at 28.

86 *Id.*

87 Flubacher, *supra* n. 31.

minimum: (a) whether the powerholder should be held to a fiduciary standard; (b) whether the trustee should have a continuing duty to monitor the powerholder's actions; and (c) if state law allows, whether the trustee's liability should be limited to either willful or intentional misconduct or gross negligence.<sup>88</sup>

Regarding the allocation of liability, careful attention should be given to the inclusion of exculpatory clauses in the governing instrument and whether such clauses are consistent with and enforceable under state law. A governing document that completely relieves a directed trustee or powerholder of liability, rather than simply reduces the trustee's or powerholder's standard of care, may be unenforceable.<sup>89</sup> In fact, the Uniform Directed Trust Act applies the same rules as the Uniform Trust Code and Restatement (Third) of Trusts to the extent that if a directed trust fully exonerates the powerholder from liability, the powerholder nevertheless has the same liability as a trustee under a similar exculpatory clause.<sup>90</sup> Should there be concern about the potential mutual liability

of a directed trustee and powerholder based on the acts of the other, practitioners may consider the use of indemnification provisions similar to the following sample provision, rather than complete exculpation:

Art. 10.5 Indemnification of Trustee — Trust Company, N.A., and each of its agents, employees, heirs, successors, and assigns are hereby indemnified by Distribution Director, Inc., against all claims, liabilities, fines, or penalties and against all costs and expenses, including attorneys' fees and disbursements, imposed upon, asserted against, or reasonably incurred in connection with or arising out of any claim, demand, action, suit, or proceeding in which he, she, or it may be involved by reason of being or having been the Trustee or affiliated with the Trustee as set forth above, whether or not he, she, or it continued to serve as such at the time of incurring such claims, liabilities, fines, or penalties and costs and expenses or at the time of being subjected to the same. However, Trust Company, N.A., and each of its agents, employees, heirs, successors, and assigns shall not be indemnified with respect to matters as to which he, she, or it is finally determined to have been guilty of willful misconduct in the performance of any duty by a court of competent jurisdiction. This right of indemnification shall not be exclusive of, or prejudicial to, other rights to which Trust Company, N.A., and each of its agents, employees, heirs, successors, and assigns may be entitled as a matter of law or otherwise.<sup>91</sup>

Fiduciary compensation must also be addressed when recommending or drafting

88 Nenno, *supra* n. 39. In Arizona, for example, and under the Uniform Trust Code, unless the governing instrument provides otherwise, a powerholder is only "presumptively" a fiduciary. Ariz. Rev. Stat. Ann. § 14-10808(d) (West) (Current through legis. eff. May 27, 2019 of First Regular Sess. of Fifty-Fourth Legis. 2019).

89 See e.g. Fla. Stat. Ann. § 736.1011(1)(a) (West) (Current with chapters from 2019 First Regular Sess. of 26th Legis. in effect through June 7, 2019); Unif. Trust Code § 1008; *Restatement (Third) of Trusts* § 96. These state that a term of a trust relieving the trustee of liability for breach of trust is unenforceable to the extent that it relieves the trustee of liability for acts committed in bad faith or because of reckless indifference.

90 Unif. Directed Trust Act § 8 cmt. and § 14 cmt.

91 This sample language is a consolidation of various trust provisions from governing instruments spanning multiple jurisdictions. This language is offered for example only and should not be construed as language suggested for use.

ing a directed trust. Multiple parties can impact the overall fees assessed to a particular trust, which can be off-putting to fee-sensitive settlors, beneficiaries, and judges, regardless of whether a directed trust arrangement is appropriate under the circumstances. Unless the trust specifies otherwise, a fiduciary is only entitled to compensation that is reasonable.<sup>92</sup> Even if the trust specifies the compensation to be provided, a court may allow more or less compensation if the duties are substantially different from those contemplated or if the compensation specified under the agreement is unreasonably high or low.<sup>93</sup> Although the Uniform Directed Trust Act applies the reasonable compensation standard of the Uniform Trust Code and Restatement (Third) of Trusts to powerholders,<sup>94</sup> the Uniform Directed Trust Act Drafting Committee understood that fees in a directed trust arrangement may be higher, yet reasonable nonetheless.<sup>95</sup> To best mitigate fee disputes, the powerholder's compensation should clearly align with the services provided and the directed trustee should reduce his, her, or its fee accordingly for those powers removed from the directed trustee's purview.

### *C. Best Interests of the Beneficiary Versus Settlor Autonomy*

University of Iowa Professor Thomas Gallanis posited:

In navigating between the extremes of settlor control and beneficiary control, the law of trusts has at times taken a position more favorable to the settlor, and at other times a position more favorable to the beneficiaries. ... American trust law, after de-

cades of favoring the settlor, is moving in a new direction, with a reassertion of the interests and rights of the beneficiaries.<sup>96</sup>

It is true that certain states are shifting back to a focus on the settlor's intent in matters of trust interpretation and construction.<sup>97</sup> Even the Uniform Directed Trust Act was drafted with the goal of achieving maximum settlor autonomy consistent with fiduciary minimums.<sup>98</sup> But for those practitioners who operate in the special needs space and are accustomed to trust language that admonishes a trustee to administer the trust for the beneficiary's sole benefit and in a way that enriches the beneficiary's life and makes it more enjoyable, Professor Gallanis' forecast becomes clear that an SNT's foundational structure hyperfocuses on the beneficiary and the trust administration process's impact on the beneficiary's quality of life. Thus, when advising a client on the advantages and disadvantages of a directed SNT that presumably will be drafted because the settlor wishes to control the downstream actors who will be involved in the trust administration, the burden is on the practitioner to design a trust that, while mindful of the settlor's intent and a fiduciary's desire to limit liability, will further the beneficiary's interests above all. All fiduciaries under a trust instrument are bound by the unwaivable duties of loyalty, impartiality, and prudent administration.<sup>99</sup> Therefore, the practitioner should be cautious about adding third parties or creating a structure, directed or otherwise, that will impede a fiduciary's ability to achieve these foundational duties.

<sup>92</sup> Unif. Trust Code § 708(a).

<sup>93</sup> *Id.* at § 708(b)(1), (2).

<sup>94</sup> Unif. Directed Trust Act § 16(3).

<sup>95</sup> *Id.* at § 16 cmts.

<sup>96</sup> Thomas P. Gallanis, *The New Direction of American Trust Law*, 97 Iowa L. Rev. 215, 216 (2011).

<sup>97</sup> *Supra* n. 32.

<sup>98</sup> Unif. Directed Trust Act, *Prefatory Note*.

<sup>99</sup> Unif. Trust Code §§ 801–803.

A directed SNT that provides the following is a relatively new planning tool:

- A trustee with investment management prowess and back-office capabilities (e.g., fiduciary tax preparation, accounting, statement and check issuance);
- A distribution director who, because of the trustee's lack of geographic proximity to the beneficiary, can provide a concierge-level of service for a beneficiary with catastrophic needs;
- A trust advisory committee attuned to the beneficiary's daily medical, social, and government benefits and therapeutic needs; and/or
- A trust protector related (or not related) to the beneficiary with the power to remove a powerholder to ensure an effective trust administration process.

As this niche practice area continues to advance in an integrated way while serving the best interests of the most vulnerable members of our population, a directed SNT should be considered.

#### IV. Conclusion

Nathaniel's mother remembers the settlement process as a time when profoundly confusing and complex long-term decisions had to be made in short order. With the assistance of counsel, she trudged through myriad state and federal laws and regulations concerning benefits eligibility and trust creation and administration issues. Her attorney drafted a comprehensive SNT that she believed focused on Nathaniel's best interests, preservation of his eligibility for much-needed government benefits, and protection and growth of the trust estate. Even as a layperson, when developing the SNT, Nathaniel's mother knew that her time was better served focusing on Nathaniel's daily needs rather than serving as a co-trustee

(thus setting aside the apparent conflict of interest that would exist if she opted to serve in such a capacity). Even so, she wanted to maintain some level of review and control of the trustee's actions. She understood that Nathaniel would likely never receive employment-related income and that the corpus of his trust, although significant, represented the sum total of all available funds throughout his life, which underscored the need to select a reputable trustee with proven investment management capabilities. Finally, she wanted a person or entity involved in the day-to-day coordination and management of Nathaniel's 24-hour skilled care, housing, social, recreational, therapeutic, and benefits eligibility needs.

Counsel advised that a single-fiduciary trust would not likely achieve the creative decision-making approach the mother was seeking and encouraged her to consider taking a team approach by implementing a multiparticipant directed SNT. Tennessee, a state protective of directed trustees,<sup>100</sup> was the situs of Nathaniel's trust. Consequently, a corporate fiduciary with national recognition for investment management and special needs planning was comfortable serving as sole trustee alongside a local distribution director appointed under the document, who was charged with directing the trustee on all matters pertaining to discretionary distributions. Nathaniel's mother was selected as trust protector to satisfy her goal of fiduciary oversight and was vested with the authority under the trust and state law to remove and appoint trustees, advisers, and

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100 Tenn. Code Ann. § 35-15-808(e) (West)(Current with laws from 2019 First Reg. Sess. of 111th Tenn. Gen. Assembly, eff. through May 17, 2019).



other powerholders.<sup>101</sup>

This article should not be construed as an endorsement to implement multiparticipant or directed SNTs under all circumstances. On many occasions, the traditional single-fiduciary approach or some other arrangement may be more appropriate or a directed trust is unavailable. While exploring whether to bifurcate powers, duties, and liabilities in the context of special needs planning, the practitioner should (a) clearly appreciate the settlor's objectives; (b) consider whether a

trustee's power to delegate, rather than a bifurcated arrangement, may achieve the settlor's stated goals; (c) know what directed trustee and powerholder liability approach the state with jurisdiction over the trust employs; (d) draft the instrument to clearly define the powers, duties, and liabilities of all trustees and powerholders consistent with state law and the settlor's intent; and (e) be comfortable that the trust and all related parties have the best interests of the beneficiary at the forefront — the most important consideration in the context of special needs planning.

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101 *Id.* at § 35-15-1201(a).



**Portable Medical Order Sets (POLST®):  
Ethical and Legal Landscape**

*By Professor Sharona Hoffman*

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## I. Introduction

Anyone who has observed the dying of a loved one or who has thought about medical care in the final months of life may be concerned about end-of-life care. How can individuals ensure that their care fits their needs and preferences if they cannot express these because of dementia, confusion, or other frailties? Some worry that they will receive care that is painful and aggressive in the last stages of disease even though they would prefer comfort care only. By contrast, others worry that physicians will withhold therapeutic care because they assume that such care is unwanted by patients who are near death.

Reassurance can come in the form of POLST. POLST has traditionally been an acronym for “physician orders for life-sustaining treatment,” but the National POLST Paradigm now defines it as “a portable medical order form.”<sup>1</sup> A POLST form is a tool that can help actualize patients’ wishes for end-of-life care because it consists of a set of medical orders that are integrated into the patient’s medical record. The POLST concept, however, raises significant ethical and policy concerns.

This article describes and assesses POLST. Focusing on patient autonomy, the article analyzes POLST benefits and risks. In addition, it surveys the laws and regulations that govern POLST.

## II. What Is a POLST Form?

A POLST form consists of medical orders indicating a patient’s wishes regarding life-saving medical interventions. POLST forms vary from state to state; however, they commonly allow patients to indicate whether they want to receive treatments such as the following that are listed by the Patients Rights Council:

- Cardiopulmonary resuscitation (CPR)
- Antibiotics
- Artificially administered nutrition and fluids
- Blood transfusions
- Dialysis
- Future hospitalization
- Comfort measures only (which orders that even non-invasive curative medical treatment should not be provided)<sup>2</sup>

POLST forms translate patient preferences into actionable medical orders because they are signed by a health care professional and become part of the patient’s medical record.<sup>3</sup> Significantly, they are portable and accompany patients across care settings, thus making them applica-

1 National POLST Paradigm, *POLST Frequently Asked Questions (FAQ)*, <http://www.polst.org/wp-content/uploads/2016/04/2016.04.03-POLST-FAQs.pdf> (last updated February 17, 2016); National POLST Paradigm, *Names of POLST Programs*, <https://polst.org/programs-in-your-state/> (accessed May 1, 2019); National POLST Paradigm, *What Is POLST?*, <https://polst.org/professionals-page/> (accessed May 1, 2019).

2 Patients Rights Council, *POLST: Important Questions & Answers* (2015), <http://www.patientsrightscouncil.org/site/polst-important-questions-answers>; see e.g. Ind. St. Dept. of Health, *Indiana Physician Orders for Scope of Treatment (POST)* (2018), <http://polst.org/wp-content/uploads/2018/07/2018.07.01-Indiana-POST-form-SAMPLE.pdf>; Natl. POLST Paradigm, *Resource Library*, [http://polst.org/resources/resource-library/?resource\\_type\\_url=Forms](http://polst.org/resources/resource-library/?resource_type_url=Forms) (providing links to other POLST forms) (all three sources accessed Feb. 13, 2019).

3 *Momentum to Better Respect Patients’ End-of-Life Wishes “Growing Every Day,”* 29 Med. Ethics Advisor 37, 37 (2013); Natl. POLST Paradigm, *POLST Legislative Guide 5* (approved Feb. 28, 2014), <http://polst.org/wp-content/uploads/2017/02/2014.02.20-POLST-Legislative-Guide-FINAL.pdf> (accessed Feb. 13, 2019).

ble everywhere, including at hospitals and nursing homes.<sup>4</sup>

POLST forms are designed for seriously ill or frail individuals. The National POLST Paradigm characterizes these individuals as those:

- Whose health care professional would not be surprised if they died within 1-2 years; or
- Who are at an increased risk of experiencing a medical emergency based on their current medical condition and who wish to make clear their treatment preferences, including about CPR, mechanical ventilation, ICU; or
- Who have had multiple unplanned hospital admissions in the last 12 months, typically coupled with increasing frailty, decreasing function, and/or progressive weight loss.<sup>5</sup>

It is critically important that patients or their authorized surrogates have one or more thorough conversations about end-of-life treatment wishes with trained personnel<sup>6</sup> before POLST forms are signed.<sup>7</sup> It must be clear that the patient or surrogate understands different treatment options and has distinct preferences.

The concept of POLST, now often called the POLST paradigm,<sup>8</sup> was developed in the early 1990s at the Oregon Health & Science University Center for Ethics in Health Care. In 2004, the National POLST Advisory Panel (later called the National POLST Paradigm Task Force and now simply the National POLST Paradigm) was established to formulate quality standards for POLST forms and to help states develop POLST programs.<sup>9</sup>

POLST forms consist of check boxes that clinicians mark to indicate whether patients desire certain types of medical interventions. Traditionally, POLST forms were one-page, double-sided, brightly colored documents that were placed at the front of patients' medical records.<sup>10</sup> Today, the forms are often integrated into patients' electronic health records, ideally using a prominent, unique POLST tab.<sup>11</sup> Some states have established POLST registries to which POLST forms can be submitted so that physicians and emergency care providers can easily access them from a centralized database.<sup>12</sup>

4 Charlie Sabatino, *POLST: Avoid the Seven Deadly Sins*, 39 *Bifocal* 60, 60 (2018), <http://polst.org/wp-content/uploads/2018/04/2018.04.25-POLST-Avoid-The-7-Deadly-Sins.pdf> (accessed Feb. 13, 2019)

5 Natl. POLST Paradigm, *National POLST Paradigm: Intended Population & Guidance for Health Care Professionals*, <https://polst.org/wp-content/uploads/2019/01/2019.01.14-POLST-Intended-Population.pdf> (last revised January 14, 2019).

6 See *infra* nn. 27–29 and accompanying text for a discussion of the various professionals who may conduct such a conversation.

7 Natl. POLST Paradigm, *Appropriate POLST Paradigm Form Use Policy*, <https://polst.org/wp-content/uploads/2018/04/2018.04.27-Appropriate-Use-of-POLST-Paradigm.pdf> (last updated Apr. 27, 2018).

8 Natl. POLST Paradigm, *About the National POLST Paradigm*, <http://polst.org/about-the-national-polst-paradigm> (accessed Feb. 13, 2019).

9 Patients Rights Council, *supra* n. 2.

10 *Id.*

11 Natl. POLST Paradigm, *Recommendations for Integrating Physicians Orders for Life Sustaining Treatment (POLST) Forms with Electronic Health Records* (approved Aug. 25, 2016), <http://polst.org/wp-content/uploads/2017/04/2016.08.25-Recommendations-for-Integrating-POLST-Paradigm-Forms-with-EHRs.pdf> (accessed Feb. 13, 2019).

12 Off. of the Natl. Coord. for Health Info. Tech., *Electronic End-of-Life and Physician Orders for Life-Sustaining Treatment (POLST) Documentation Access through Health Information Exchange (HIE)* 5, <https://www.healthit.gov/sites/default/files/topiclanding/2018-07/POLSTRegistryKnowledge.pdf> (accessed Feb. 13, 2019).

In various states, POLST are called by different names. These include POST (physician orders for scope of treatment), MOLST (medical orders for life-sustaining treatment), and MOST (medical orders for scope of treatment).<sup>13</sup>

### III. Benefits of POLST

#### A. Goals and Outcomes

All adults are encouraged to complete advance directives, consisting of a living will and a health care power of attorney.<sup>14</sup> However, only about one-third of individuals have done so.<sup>15</sup> Moreover, some individuals have advance directives that were written decades ago and do not necessarily reflect their current wishes. Consequently, POLST forms, which are filled out toward the end of life, are an important tool for effectuating patients' care preferences.<sup>16</sup> The forms can be used in the absence of advance directives or as an adjunct to them (though confusion may arise if they contradict wishes that are clearly expressed in existing advance directives).<sup>17</sup>

Without explicit instructions regarding end-of-life care or a trusted individual who

has been appointed as the decision-maker, patients may be subject to unwanted and even tormenting care. For example, patients with late-stage cancer who can no longer articulate their wishes may be treated aggressively with difficult therapies, fed artificially, intubated, and have their dying process protracted significantly even if they would prefer to receive comfort care only. In addition, some patients may be denied desired life-prolonging treatments because doctors wrongly assume that a patient with end-stage illness would decline such interventions.

POLST portability is particularly valuable. It enables all medical facilities in which a patient is treated to learn of the patient's wishes if he or she is unable to communicate them.

Studies confirm the benefits of POLST. For example, a three-state study of 90 nursing homes showed that people with a POLST form who indicated they wanted "comfort measures only" experienced a lower rate of unwanted hospitalizations.<sup>18</sup> Another study, which reviewed the medical records of 300 patients who participated in a POLST program and died in 2015, found that 290 of these patients received care that was consistent with the care listed on their POLST forms.<sup>19</sup> Of these patients, 19 percent revised their wishes as their circumstances changed.<sup>20</sup>

A 2015 review of POLST literature concluded that "POLST orders reflect-

13 National POLST Paradigm, *Names of POLST Programs*, <https://polst.org/programs-in-your-state/> (last accessed May 1, 2019); Patients Rights Council, *supra* n. 2.

14 Sharona Hoffman, *Aging with a Plan: How a Little Thought Today Can Vastly Improve Your Tomorrow* 41–48 (Praeger 2015).

15 Kuldeep N. Yadav et al., *Approximately One in Three U.S. Adults Completes Any Type of Advance Directive for End-of-Life Care*, 36 Health Affairs 1244, 1244 (2017).

16 John E. Jesus et al., *Physician Orders for Life-Sustaining Treatment and Emergency Medicine: Ethical Considerations, Legal Issues, and Emerging Trends*, 64 Annals Emerg. Med. 140, 140 (2014).

17 See *infra* n. 58 and accompanying text for a discussion of state laws that address such conflicts.

18 *Id.*

19 Jennifer Hopping-Winn, *The Progression of End-of-Life Wishes and Concordance with End-of-Life Care*, 21 J. Palliative Med. 541, 541 (2018) (finding that only three patients received care that was inconsistent with their wishes and seven did not have enough data in their charts to determine whether their care reflected their preferences).

20 *Id.* at 542–543.

Table 1. Comparison of POLST Forms and Advance Directives<sup>24</sup>

	POLST Form	Advance Directive
Type of document	Medical order	Legal document
Who completes?	Health care professional (who can sign varies by state: <a href="https://polst.org/wp-content/uploads/2019/03/2019.03.06-Signature-Requirements-by-State.pdf">https://polst.org/wp-content/uploads/2019/03/2019.03.06-Signature-Requirements-by-State.pdf</a> )	Individual
Who needs one?	Any patients considered to be at risk for a life-threatening clinical event because they have a serious life-limiting medical condition, which may include advanced frailty.	All competent adults
Is completion voluntary?	Yes	Yes
Appoints a surrogate?	No	Yes
Can patient's surrogate complete, change or void?	In most states	No
What is communicated?	Specific medical orders	General wishes about treatment wishes
Can emergency personnel follow?	Yes	No
Ease in locating	Should be easy. Patient has original. Copy is in medical record. Copy may be in a registry (if state has a registry).	May be difficult. Depends on where individual keeps it and if they have told someone where it is, given a copy to surrogate, or to health care professional to put in his/her medical record.
Periodic review	Health care professional is responsible for reviewing with patient or surrogate upon: <ul style="list-style-type: none"><li>• transfer to a new facility;</li><li>• when there is a substantial change inpatient's medical condition; or</li><li>• when patient's goals of care or treatment preferences change.</li></ul>	Up to the individual about how often it is reviewed and/or updated.

ing decisions to withhold interventions are usually honored and that treatments are largely consistent with orders.<sup>21</sup> However, because of limitations of the studies that have been conducted, only weak evidence exists regarding whether POLST

forms accurately reflect patient wishes.<sup>22</sup> Thus, in some cases, clinicians may have checked boxes on a patient's POLST form without verifying (a) that the patient understood the concept of POLST and the treatment options listed on the form and (b) that the patient made thoughtful choices about these options. Health care providers were generally enthusiastic about POLST forms and found them

21 Susan E. Hickman et al., *Use of the Physician Orders for Life-Sustaining Treatment Program in the Clinical Setting: A Systematic Review of the Literature*, 63 J. Am. Geriatrics Soc'y 341, 347 (2015).

22 *Id.* at 348.

helpful in making treatment decisions. However, they cited a variety of problems, such as difficulty understanding and explaining the form and challenges associated with transferring POLST across care settings.<sup>23</sup>

#### B. POLST Forms vs. Advance Directives

POLST forms can be easily confused with advance directives, but the two are quite different. Advance directives (consisting of a living will and health care power of attorney) are safeguards that all adults, regardless of age, should have. By contrast, a POLST form is useful only near the end of life and addresses an individual's current medical circumstances. In addition, advance directives can be signed at any location, whereas POLST forms are signed at medical facilities by health care professionals. Table 1 offers further comparison.<sup>24</sup>

### IV. POLST Concerns: Does the POLST Paradigm Adequately Promote and Protect Patient Autonomy?

Personal autonomy is the ability to act independently in a manner that is "free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice."<sup>25</sup> The POLST paradigm is intended to promote patient autonomy by ensuring that patients' health care preferences are followed. However, ethicists and patient advocates have questioned the degree to which patient autonomy is truly safeguarded in the POLST context. Do

POLST forms faithfully record patients' wishes? Do patients always understand the forms' contents and implications? Are POLST forms reviewed periodically and amended promptly in case patients' preferences evolve? Sections III(A)–(D), which follow, analyze several objections to the POLST paradigm related to patient autonomy.

#### A. Patient Comprehension and Voluntariness

Critics assert that the POLST paradigm does not include sufficient safeguards to ensure that POLST forms reflect patients' true wishes and are signed voluntarily. For example, there is little oversight concerning the quality of POLST conversations that patients should have with their health care providers. Commentators have noted that POLST forms are at times signed without a sufficiently comprehensive discussion of the patient's goals and priorities.<sup>26</sup>

The POLST paradigm does not require the patient's attending physician to discuss POLST with the individual or to sign the POLST form.<sup>27</sup> Instead, a nurse practitioner or physician assistant can often sign the form.<sup>28</sup> Unfortunately, these

23 *Id.* at 347.

24 Natl. POLST Paradigm, *supra* n. 5, tbl. at [https://polst.org/wp-content/uploads/2019/05/2019\\_04.30-POLST-vs-ADs-chart.pdf](https://polst.org/wp-content/uploads/2019/05/2019_04.30-POLST-vs-ADs-chart.pdf) (accessed Feb. 13, 2019).

25 Patricia A. King et al., *Law, Medicine and Ethics* 46 (Foundation Press 2006).

26 Sabatino, *supra* n. 4, at 61.

27 Natl. POLST Paradigm, *Signature Requirements for a Valid POLST Form by State* (last updated Dec. 14, 2018), <https://polst.org/wp-content/uploads/2019/01/2018.12.14-Signature-Requirements-by-State.pdf> (accessed Feb. 14, 2019).

28 Natl. POLST Paradigm, *National POLST Paradigm Task Force Supports Nurse Practitioners and Physician Assistants Signing POLST Paradigm Forms*, <https://polst.org/wp-content/uploads/2017/04/2016.12-NPPTF-Supports-Nurse-Practitioners-and-Physician-Assistants-Signing-POLST-Paradigm-Forms.pdf> (approved Dec. 15, 2016); Patients Rights Council, *supra* n. 2; see e.g. Ctr. for End-of-



clinicians may not be as familiar with the patient as the attending physician. Moreover, the person who actually discusses POLST with the patient and fills out the form does not have to be a trained health care professional at all. Rather, he or she can be a chaplain, social worker, or other person who serves as a “facilitator.”<sup>29</sup> Although these individuals may have ample time and patience to discuss POLST details, they may not have the scientific knowledge required to explain the medical implications of particular treatment decisions. Thus, at the very least, facilitators who are not health care providers should be required to undergo training regarding end-of-life decision-making.

Some states do not mandate that the patient sign the POLST form.<sup>30</sup> In other states, the patient’s signature is required, but the form does not state that by signing the form, the patient is affirming that he or she thoroughly discussed treatment choices with a health care professional or facilitator.<sup>31</sup> Notably, as a rule, POLST

forms do not require the signature of witnesses who observe patients signing the document and could attest to the patients doing so knowingly and voluntarily.<sup>32</sup>

The check-box format of POLST forms is also vulnerable to criticism. Some consider the format too simplistic for the very complex decision-making entailed in end-of-life care.<sup>33</sup> POLST forms aim to be unambiguous and concise; thus, they do not leave space for explanations related to various contingencies and unusual circumstances that may arise.<sup>34</sup> For example, some patients may prefer comfort measures only at the end of life but want antibiotics or IV fluids if they suffer from an easily treatable infection several months before they are expected to die.

### B. Timing of Implementation

Another concern is that POLST may be implemented prematurely.<sup>35</sup> In fact, the orders are effective immediately, as soon as the forms are signed.<sup>36</sup> The National POLST Paradigm provides in part that POLST forms are appropriate for “[p]atients with serious life-limiting medical condition or advanced frailty ... whose health care professional would

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Life Care, Robert C. Byrd Health Sci. Ctr. of W.Va. U., *West Virginia Physician Orders for Scope of Treatment (POST)* (2017), <http://polst.org/wp-content/uploads/2018/02/2017-West-Virginia-POST-Form-pink.pdf> (accessed Feb. 14, 2019).

29 Robert B. Wolf et al., *The Physician Orders for Life-Sustaining Treatment (POLST) Coming Soon to a Health Care Community Near You*, 49 Real Prop. Tr. & Est. L.J. 71, 112 (2014); Natl. POLST Paradigm, POLST & Advance Directives, <http://polst.org/advancecare-planning/polst-and-advance-directives> (accessed Feb. 13, 2019); Patients Rights Council, *supra* n. 2.

30 Natl. POLST Paradigm, *supra* n. 27.

31 Stanley A. Terman, *It Isn't Easy Being Pink: Potential Problems with POLST Paradigm Forms*, 36 Hamline L. Rev. 177, 182 (2013); *see e.g.* Iowa Physician Orders for Scope of Treatment (IPOST) (2012), <http://idph.iowa.gov/Portals/1/Files/IPOST/FORM%20GUIDAN>

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[CE%20-%20IPOST%20Revised%206%2025%2012%20SAMPLE.pdf](http://polst.org/wp-content/uploads/2019/01/2019-Oregon-POLST-Form-Sample.pdf) (accessed May 30, 2019).

32 Terman, *supra* n. 31, at 182.

33 E. Christian Brugger et al., *POLST and Catholic Health Care*, 37 Ethics & Medics 1, 3 (2012).

34 *See e.g.* Ctr. for Ethics in Health Care, Or. Health & Sci. U., *Oregon POLST* (2019), <http://polst.org/wp-content/uploads/2019/01/2019-Oregon-POLST-Form-Sample.pdf> (accessed May. 28, 2019).

35 Wolf et al., *supra* n. 29, at 102. Some states explicitly require that POLST forms be filled out only by patients with a terminal illness. *See infra* n. 55 and accompanying text.

36 Patients Rights Council, *supra* n. 2.

not be surprised if they died within 1-2 years.”<sup>37</sup> Some patients who fall into this category may live several years longer. If such patients require antibiotics to treat an infection but the antibiotics are withheld because of their POLST forms, these patients may be robbed of significant time during which they could still enjoy a high quality of life.

Moreover, there is no mandate that patients or their surrogates review POLST forms with a trained professional periodically or before a significant treatment decision is implemented (e.g., antibiotics are given or withheld). Some forms provide spaces for indicating that they underwent such review and were subsequently retained or voided. However, these reviews *are not required at any time*, let alone at specific intervals or treatment junctures.<sup>38</sup>

Because the orders go into effect immediately, no signature is required for verification from either the patient or the attending physician at the time an order is implemented (e.g., a life-saving treatment is given or withheld). This is true even when the patient or surrogate is able to provide a signature quickly and the circumstances are not emergent. For example, the North Carolina form states explic-

itly, “When the need occurs, first follow these orders, then contact physician.”<sup>39</sup> Consequently, little if any effort may be made to verify that the patient’s preferences have not changed.

Frail and ill patients may experience many changes in their health status.<sup>40</sup> These patients may improve temporarily and wish to have more aggressive treatment to prolong their lives. They may also modify their views about end-of-life care as they come closer to death. It is extremely important, therefore, to encourage patients to review and update their POLST forms as appropriate.<sup>41</sup>

### C. Incentives to Promote POLST

Health care facilities may promulgate financial or other incentives to encourage physicians to pursue POLST with their patients.<sup>42</sup> From an institutional perspective, POLST forms are very appealing because they eliminate uncertainty about the course of treatment for patients at the end of life and provide caregivers with clear instructions and perhaps liability protection.

On the other hand, incentives may threaten patient autonomy because they can motivate health care providers to pressure patients to sign a POLST form. If incentives are based on the number of POLST forms signed, clinicians could be tempted to have briefer conversations with patients in order to move quickly to the next individual. To safeguard the integrity of the POLST paradigm, health care

37 Natl. POLST Paradigm, *supra* n. 7.

38 See e.g. Ctr. for End-of-Life Care, *supra* n. 28. But see, National POLST Paradigm Task Force, *POLST Legislative Guide*, National POLST Paradigm, <https://polst.org/wp-content/uploads/2017/02/2014.02.20-POLST-Legislative-Guide-FINAL.pdf> (approved Feb. 28, 2014). The guidance recommends that POLST be reviewed periodically and especially under the following circumstances:

- The patient is transferred from one care setting or care level to another, or
- There is a substantial change in the patient’s health status, or
- The patient’s goals of care and/or treatment preferences change.

39 N.C. Dept. of Health & Human Servs., *Medical Orders for Scope of Treatment (MOST)* (2014), <http://polst.org/wp-content/uploads/2018/01/2014-NC-MOST.pdf> (accessed Feb. 14, 2019).

40 Sabatino, *supra* n. 4, at 62.

41 *Id.*

42 *Id.*

institutions should avoid establishing any form of incentive to promote POLST.<sup>43</sup>

#### D. Religious Concerns

Many religious adherents believe that human beings have a duty to preserve their own lives.<sup>44</sup> Some religious authorities are uncomfortable with POLST forms because they enable patients to establish medical orders to withhold life-saving treatments. Thus, the National Catholic Bioethics Center on Health Care and the Life Sciences issued a paper in which it argued that POLST forms “pose unacceptable risks to the well-being of patients and the ethical values of Catholic health care.”<sup>45</sup> Indeed, in some cases, patients whose doctors encourage them to sign POLST forms may sign a form despite being unsure of whether there is a conflict between the orders on the form and their religion.

One solution is to include an explicit statement on the POLST form about religious beliefs for patients who indicate that religion is important to them. During the POLST discussion, patients could be asked whether they have religious beliefs that may be relevant to end-of-life care. If patients are uncertain, they can be urged

to speak with their clergy, after which they can include a specific statement regarding religious doctrine in the “additional orders” or “other instructions or clarification” section of the POLST form.<sup>46</sup> Dr. Stanley Terman, a POLST expert, suggests some helpful language. The patient could assert, “If I reach an advanced stage of dementia (as detailed in my living will), then I DO want to receive tube feeding indefinitely, since I am Catholic.” In the alternative, the patient could state, “If I reach an advanced stage of dementia (as detailed in my living will), then I DO NOT want to receive tube feeding, even though I am Catholic.”<sup>47</sup>

#### V. State Law

The majority of states use POLST forms either statewide or in pilot programs.<sup>48</sup> Thirty states and the District of Columbia address POLST by statute;<sup>49</sup> of

43 *Id.*; Natl. POLST Paradigm, *National POLST Paradigm: Appropriate POLST Paradigm Form Use Policy* (updated Apr. 27, 2018), <http://polst.org/wp-content/uploads/2018/04/2018.04.27-AppropriateUse-of-POLST-Paradigm.pdf> (accessed Feb. 14, 2019).

44 *See e.g.* Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, Holy See (May 5, 1980), [http://www.vatican.va/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cfaith\\_doc\\_19800505\\_euthanasia\\_en.html](http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html) (accessed Feb. 14, 2019) (stating that “believers see in life ... a gift of God’s love, which they are called upon to preserve and make fruitful.”).

45 Brugger et al., *supra* n. 33, at 3.

46 *See e.g.* Ctr. for Ethics in Health Care, Or. Health & Sci. U., *Oregon POLST* (2019), <http://polst.org/wp-content/uploads/2019/01/2019-Oregon-POLST-Form-Sample.pdf> (2019) (accessed March 8, 2019); Utah Dept. of Health, *Provider Order for Life-Sustaining Treatment (POLST): Utah Life with Dignity Order* (2016), <http://polst.org/wp-content/uploads/2018/01/2016-UT-POLST.pdf> (accessed Feb. 14, 2019).

47 Terman, *supra* n. 31, at 187.

48 *See* Natl. POLST Paradigm, *National POLST Paradigm: POLST Adoption by State* (as of Apr. 2018), <http://polst.org/wp-content/uploads/2018/04/2018.04.24-State-POLST-Adoption-Map.pdf> (accessed Feb. 14, 2019).

49 The states are Arkansas, California, Colorado, Connecticut, Delaware, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maryland, Mississippi, Nevada, New Hampshire, New Jersey, New York, North Carolina, Oklahoma, Oregon, Rhode Island, Tennessee, Utah, Vermont, Virginia, Washington, West Virginia, and Wyoming. *See* Natl. POLST Paradigm, *POLST Program Legislative Comparison* (as of Apr. 1, 2018), <https://polst.org/wp-content/>

these, 20 states have added regulations or other guidance.<sup>50</sup> One state, Montana, addresses the use of POLST by regulation but has no POLST statute.<sup>51</sup> The 19 states that do not use POLST forms have neither statutes nor regulations or other official guidance on POLST, but many have established POLST programs by voluntary consensus or practice.<sup>52</sup>

Some state POLST programs vary in significant ways.<sup>53</sup> For example, 26 states and the District of Columbia allow POLST forms for minors, while four explicitly prohibit this.<sup>54</sup> Some states place other restrictions on the availability of POLST, such as only permitting patients with an advanced illness to complete a POLST form.<sup>55</sup> Many states recognize out-of-state POLST forms, but a large number are silent on the matter, and Oklahoma deems out-of-state forms valid for only 10 days after a patient's admission to an Oklahoma medical facility.<sup>56</sup>

Maryland has adopted a unique ap-

proach by making its POLST program mandatory under some circumstances. POLST forms must be completed for patients served by assisted living programs, home health agencies, hospices, kidney dialysis centers, or nursing homes, and for those being transferred from one hospital to another or to one of these institutions.<sup>57</sup>

Most states with POLST legislation or regulations recognize that POLST forms may contradict existing advance directives. The majority establish that the most recently executed instrument takes precedence over older documents.<sup>58</sup> Detailed information about POLST legislation and regulations appears on the National POLST Paradigm website.<sup>59</sup>

## VI. Conclusion

POLST forms can be greatly beneficial to patients and health care providers. They can assure patients that their treatment preferences will be honored at the end of their lives and offer clinicians clear guidance about their patients' course of treatment.

However, the POLST paradigm also raises significant concerns for ethicists and patient advocates. To address these concerns, medical facilities should ensure that patients or their surrogates have one or more thorough conversations with a

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[uploads/2019/04/2019.04.02-POLST-Legislative-Comparison-Chart.pdf](#) (accessed Apr. 24, 2019).

50 See *id.* The states are California, Connecticut, Delaware, Georgia, Idaho, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maryland, Nevada, New Jersey, Oregon, Rhode Island, Tennessee, Utah, Vermont, West Virginia, and Wyoming.

51 See *id.*

52 See *id.* The states are Alabama, Alaska, Arizona, Florida, Kansas, Maine, Massachusetts, Michigan, Minnesota, Missouri, Nebraska, New Mexico, North Dakota, Ohio, Pennsylvania, South Carolina, South Dakota, Texas, and Wisconsin.

53 Natl. POLST Paradigm, *National POLST Paradigm Program Designations* (as of Nov. 2018), <http://polst.org/programs-in-your-state> (accessed Feb. 14, 2019).

54 *Id.* The rest of the states have not addressed this issue.

55 See Natl. POLST Paradigm, *supra* n. 48.

56 *Id.*

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57 Md. MOLST Training Task Force, *Maryland MOLST FAQs* 1 (Aug. 2018), [http://www.marylandmolst.org/docs/Maryland\\_MOLST\\_FAQs.pdf](http://www.marylandmolst.org/docs/Maryland_MOLST_FAQs.pdf) (accessed Feb. 14, 2019).

58 Natl. POLST Paradigm, *supra* n. 48. Exceptions include Idaho (if the POLST was signed by a surrogate), Iowa (POLST does not supersede do not resuscitate (DNR) orders or power of attorney), Kentucky (living will prevails), North Carolina (POLST form may state that it suspends conflicting advance directives), Utah (POLST always controls), and West Virginia (advance directive always controls).

59 Natl. POLST Paradigm, *supra* n. 53.

qualified expert about the nature and content of POLST forms. Patients or their surrogates should also be asked to review POLST forms periodically or at important treatment junctures to ensure that they accurately indicate current care preferences.

In addition, because POLST forms leave little if any space for narrative explanations, all patients should have an advance directive (consisting of a living will and health care power of attorney) that furnishes greater detail about their end-of-life wishes. Advance directives should be included in electronic health records and

be referenced in POLST forms so that clinicians know they exist. Also, renewed efforts should be made to encourage American adults to complete advance directives.

All states should have laws that address POLST and detail POLST requirements. They should also undertake educational initiatives to ensure that health care providers and the public at large are knowledgeable about the POLST paradigm.

With appropriate safeguards, POLST forms can fulfill their promise of consistently promoting patient autonomy and welfare, thus serving as a valuable component of end-of-life care.



**POLST®:  
Co-Piloting, Not Hijacking, the Advance Directive**

*By Fay Blix, CELA, CAP, and Susan W. Tolle, MD*

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I. Introduction

Nearly 30 years have passed since the portable orders for life-sustaining treatment (POLST®) initiative began.<sup>1</sup> Oregon was the first state to establish a POLST program, in 1991. POLST programs have now been initiated, with some variation, in almost every state.<sup>2 3</sup> The growth in the use of POLST speaks to the overwhelming

yearning of individuals to have their preferences regarding end-of-life care known and respected. However, the phenomenal increase in those availing themselves of POLST also presents new challenges,<sup>4, 5</sup> particularly in the present climate of managed care. Attorneys frequently express concern that POLST form orders have replaced the advance directive. Although an advance directive is often not sufficient, POLST form orders were always meant to

1 Oregon POLST, *POLST History Timeline*, <https://oregonpolst.org/history-timeline> (accessed May 7, 2019).

2 Natl. POLST Paradigm, *National POLST Paradigm [State] Program Designations*, <http://www.polst.org/programs-in-your-state> (accessed May 7, 2019).

3 U.S. Govt. Accountability Off., *Advance Care Planning: Selected States’ Efforts to Educate and Address Access Challenges* (Feb. 2019), <https://www.gao.gov/assets/700/696985.pdf> (accessed May 7, 2019).

4 Charlie Sabatino, *POLST: Avoid the Seven Deadly Sins*, 39(4) *Bifocal* 60 (2018), [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/bifocal-39-4-final.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/bifocal-39-4-final.pdf) (accessed May 7, 2019).

5 Thaddeus Mason Pope & Melinda Hexum, *Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment*, 23(4) *J. Clinical Ethics* 353 (2012).



support, not supplant, the advance directive. Part of the reason for the misunderstanding concerning how POLST form orders complement the advance directive is that attorneys often lack familiarity with what actually happens in the clinical setting throughout the trajectory of a client's illness.

This article presents scenarios in which medical doctors work with patients and their families throughout the course of an illness to ensure quality care for patients and implementation of their end-of-life treatment preferences. The article also illustrates how both the medical and legal professions can ensure that patient's and client's wishes for care near the end of life are elicited sensitively, recorded accurately, and honored when needed. In addition, to highlight several important new developments in POLST programs, the article builds on the excellent in-depth POLST review by Wolf and colleagues in 2014.<sup>6</sup> Elder law attorneys, in collaboration with health care professionals, can play a vital role in preserving the public trust by ensuring the integrity of advance directive and POLST discussion and implementation.

To illustrate the practical approach to the challenging medical and legal issues in health care decision-making, in Section II we trace the journey of an aging couple working with their children, their attorney, and the health care system as the couple's health declines. As we present the unfolding narrative in a series of scenarios, we discuss the key common legal issues confronting the attorney. In Section III, we provide a summary of lessons learned that

may serve as a helpful reference for legal professionals working with elderly clients.

## II. Scenarios

### A. Scenario 1: An Elderly Couple Faces Progressive Cognitive Impairment

#### 1. Legal Issues Explored

This initial scenario presents a slow-moving tragic situation common among the elderly: progressive cognitive impairment. As a geriatric specialist begins to recognize her patient's symptoms, the patient's longstanding attorney is about to become engaged in the myriad legal challenges arising from his client's mental decline. This scenario focuses on (a) determination of the client's decision-making capacity, (b) identification of a surrogate to help the client make medical and legal decisions, and (c) the ethical and legal duties related to sharing the client's personal health information.

#### 2. Scenario

Ralph O'Holleran is an extremely successful 82-year-old businessman. He and his wife, Judy, have been married for 60 years. They met in college and married the year they graduated. Judy is also 82 and mentally sharp. (She usually wins bridge games.) Judy raised the couple's three children and kept the household running while Ralph worked long hours building his business. Judy is involved in a range of volunteer activities and has always deferred all decision-making to Ralph. He manages all the finances and is the patriarch of the extended family. All three children live out of state. The oldest child, Jonathan, is a software engineer and tends to be somewhat overbearing with his siblings. His sister, Rachel, is a professor of English at a liberal arts college. She

6 Robert B. Wolf et al., *The Physician Orders for Life-Sustaining Treatment (POLST) Coming Soon to a Health Care Community Near You*, 49 Real Prop. Tr. & Est. L.J. 71 (2014).

returns home when emergencies arise but does not visit frequently. The youngest child, Larry, has struggled with substance use disorder and has been in and out of treatment for years.

During the past year, Ralph has experienced several memory lapses. Learning new tasks and remembering people's names have become more difficult; twice he forgot he paid a bill and paid it a second time. His geriatrician conducts formal cognitive testing and diagnoses mild cognitive impairment (MCI). She encourages Ralph to complete an advance directive and appoint a health care decision-maker.

### 3. The Geriatrician's Response

The geriatrician is acutely aware that receiving an MCI diagnosis is overwhelming and devastating for many patients. Although many patients are aware of forgetting things and may fear the onset of dementia, without a formal diagnosis, they commonly experience some degree of denial. The goal of Ralph's geriatrician at this visit needs to be modest; she must be supportive in sharing the diagnosis with Ralph and in providing him with the initial steps he needs to move forward on his new path.

After explaining the results of Ralph's formal cognitive testing and how the results were scored, the geriatrician pauses. Most patients are unable to process further information immediately after being given such bad news. By pausing, the geriatrician gives Ralph time to digest what he heard and to ask further questions when he is ready. It is important for the geriatrician not to give Ralph more medical information than he is ready to hear at this time. It is also entirely possible that Ralph is not yet ready to discuss the possibility of MCI progressing to dementia. The amount of information patients want

about a poor prognosis varies greatly.<sup>7, 8</sup> As patients develop cognitive impairment, it becomes increasingly difficult for them to process information without a friend or family member present to help them remember what the doctor said and to follow through on next steps.

The geriatrician realizes that Ralph needs to begin planning while he is still able to participate and is capable of sharing his wishes and values. She knows that most people initially find it easier (less emotionally charged) to talk about who would serve as an appropriate surrogate than to talk about care preferences near the end of life. The geriatrician has cared for Ralph for a long time and realizes the heartache that Ralph and Judy have experienced because of their son Larry's problems with substance use disorder. The geriatrician is also aware that Judy is extremely passive and has always deferred to Ralph in decision-making and that none of the children live in the area.

Although Ralph may not yet be ready to engage in philosophical discussions about his goals of care, the geriatrician knows the importance of a cognitively impaired patient consulting an attorney. She feels strongly that Ralph should consult an attorney to appoint a surrogate decision-maker by completing an advance directive. She provides Ralph with the American Bar Association (ABA) list of resources on advance care planning,<sup>9</sup>

7 Kuldeep N. Yadav et al., *Approximately One in Three U.S. Adults Completes Any Type of Advance Directive for End-of-Life Care*, 36(7) Health Affairs 1244 (2017).

8 Nancy L. Schoenborn et al., *Older Adult Preferences for Discussing Long-Term Life Expectancy: Results From a National Survey*, 16(6) Annals Fam. Med. 530 (2018).

9 ABA, *Advance Care Planning Resource List*, <https://www.americanbar.org/content/dam/>

gives him a state-specific booklet<sup>10</sup> about advance directives, and emphasizes that his first priority should be to formally appoint a surrogate. Although the geriatrician indicates that she can help with this, Ralph feels more comfortable doing this with his attorney.

In addition to the attorney referral, the geriatrician encourages Ralph to begin involving others in his health care. She senses that this will be extremely difficult for Ralph, who has always been the person in charge. She strongly urges Ralph to grant access to his medical portal to the person he will appoint as his surrogate and explains how the Health Insurance Portability and Accountability Act (HIPAA) authorization is done in her practice. She also indicates that over time he should begin bringing to his clinic visits those he trusts most. She suggests that he bring Judy at first and later bring one of his adult children.

The geriatrician strongly encourages Ralph to see his attorney and formally appoint a surrogate. This is an important first step in promoting attorney and health care professional collaboration.

As noted in number 10 in Section III, Lessons Learned, good advance care planning is the product of teamwork.

### *B. Scenario 2: The Attorney Introduces an Advance Directive*

#### 1. Legal Issues Explored

Following the suggestion of his geriatrician, Ralph consults with his attorney regarding an advance directive. This

scenario focuses on lost opportunities in such a legal consultation: (a) the attorney's cavalier attitude toward the client's advance directive, (b) the attorney's failure to explore the client's concerns about the diagnosis and end-of-life wishes, and (c) the attorney's failure to provide adequate instruction on what to do with the advance directive once it is signed.

#### 2. Scenario

Ralph and Judy meet with their business attorney to update their estate plan. Ralph mentions his recent diagnosis in passing, and the attorney "throws in" advance directive forms as part of the couple's updated estate plan. No discussion occurs regarding Ralph's health care wishes other than Ralph indicating that because he does not want to burden Judy with difficult medical decisions, he wants to appoint his oldest son, Jonathan, as his surrogate and daughter Rachel as his alternate surrogate. He also mentions that he wants the "plug pulled" if he no longer recognizes his family members. Judy tells the attorney to name Ralph's surrogates to serve as her surrogates, and Ralph agrees.

Because Ralph is an especially private person and is ashamed of his diagnosis, he does not discuss his health care wishes with anyone other than making Judy promise that she will never put him in a nursing home. He does inform Jonathan and Rachel that he named them as his surrogates. Ralph mails copies of the estate planning documents for them to sign and return but does not provide them or his geriatrician with a copy of his signed advance directive.

#### 3. The Attorney's Insufficient Response

It is perfectly natural for Ralph to meet with his business attorney to get his affairs in order. The business attorney knows

[aba/administrative/law\\_aging/acp-resource-list-final.pdf](#) (accessed May 7, 2019).

10 Natl. Hospice & Palliative Care Org., *Advance Care Planning*, <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3277> (accessed May 7, 2019).

Ralph well and is the attorney with whom Ralph feels most comfortable. However, if the attorney is not familiar with aging issues and advance directives, he could be doing Ralph a disservice by not referring him to an experienced elder law attorney.

Unfortunately, many attorneys make the same mistake that Ralph's attorney did in considering the advance directive a "throw-in" document. This practice not only devalues the document but also deprives Ralph of a discussion with another trusted professional about his choice of surrogate and his preferences regarding his future health care. In an elder law practice, the advance directive should be considered one of the most important documents the client will ever sign.

The fact that Ralph mentioned his MCI diagnosis should have triggered the attorney to be especially diligent about eliciting discussion on an appropriate surrogate. Ralph still may be too sensitive about his diagnosis to discuss his concerns about dementia and end-of-life decision-making; however, it is incumbent on the attorney to push Ralph a little by urging him to explore some of the resources suggested by his geriatrician. This may require several meetings, but it is well worth the effort.

The ABA Commission on Law and Aging recently published an excellent resource, *Advance Directives: Counseling Guide for Lawyers*, which details best practices for attorneys in drafting and disseminating advance directives.<sup>11</sup> It provides a checklist of issues for attorneys to discuss with clients. Because this guide was developed with input from both medical and

legal professionals, it effectively addresses the concerns of both professions in assisting patients and clients with advance care planning.

The guide suggests that the attorney send a copy of the advance directive to the client's primary health care professional along with a cover letter eliciting his or her input. It also suggests that the attorney provide copies of the advance directive to all surrogates named in the document and a list of resources to assist them in their future duties.<sup>12, 13</sup>

It might also be useful for the attorney to seek the client's permission to send copies of the advance directive to all family members not appointed as surrogates to ensure that any concerns can be addressed while the client is still able to speak for himself or herself. This may minimize anger and surprise at a time of crisis, helping the family focus on the needs of the client, not on the ensuing battle concerning surrogacy. It may even be appropriate for the attorney to offer a family meeting if the client is worried about the consequences of sharing the advance directive.

In this scenario, Ralph's attorney makes the same mistake regarding Judy's advance directive. Little discussion takes place with Judy regarding her choice of surrogates or her health care preferences. Even though Ralph's need for an advance directive is

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11 ABA Commn. on L. & Aging, *Advance Directives: Counseling Guide for Lawyers* (2018), [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/lawyers-ad-counseling-guide.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/lawyers-ad-counseling-guide.pdf) (accessed May 7, 2019).

12 ABA Commn. on L. & Aging, *Making Medical Decisions for Someone Else: A How-To Guide* (2009), <https://www.americanbar.org/content/dam/aba/administrative/staff-diversity-council/making-hc-decisions-for-someone-else-final.pdf> (accessed May 7, 2019).

13 The Conversation Project & Inst. for Healthcare Improvement, *How to Choose a Health Care Proxy & How To Be a Health Care Proxy* (2017), <http://theconversationproject.org/wp-content/uploads/2017/03/ConversationProject-ProxyKit-English.pdf> (accessed May 7, 2019).

somewhat more urgent due to his diagnosis, the attorney should not have underestimated the importance of Judy's advance directive. When meeting with a couple, it is essential that both partners be given the opportunity to fully express their wishes and values and that "me too" utterances be explored for nuances and differences.

Above all, the attorney should emphasize that advance care planning is more than the preparation of a "one-and-done" document — it is a process over time.<sup>14</sup> It is imperative to explore the client's willingness for the attorney to become involved with the client's health care professionals and surrogates and to have the client sign the appropriate waiver and consent forms if the client is willing.

The attorney should definitely suggest that Ralph discuss his new advance directive with his geriatrician and ensure that the physician places a copy of the document in Ralph's medical record.

For more suggestions, see numbers 1, 2, 3, and 4 in Section III, Lessons Learned.

### *C. Scenario 3: Ralph's Health Slowly Declines*

#### 1. Legal Issues Explored

Ralph's illness has progressed significantly in 2 years. This scenario focuses on (a) the issues involved when the client loses his or her driver's license and (b) the importance of revisiting the client's legal needs at various stages of progressive illness.

#### 2. Scenario

Ralph's cognitive abilities are slowly declining. Although he and Judy never

speak of his memory lapses, she is increasingly covering for him, reminding him of peoples' names, all of his appointments, and when to take his medications and giving him driving directions on how to get home. About 2 years after his diagnosis, Ralph got lost while driving home, and Judy reported the incident discretely to the department of motor vehicles. Ralph failed the test the department subsequently gave him, and his driver's license was revoked. It is now slowly dawning on other family members and friends that Ralph is becoming increasingly cognitively impaired.

#### 3. Loss of Ralph's Driver's License

The loss of Ralph's driver's license is a big wake-up call that Ralph needs assistance and must ensure that his affairs are in order while he is still able to express his wishes and values. He visits his geriatrician soon after losing his driver's license, reluctantly allowing Judy to attend the appointment. The geriatrician learns that Ralph has completed an advance directive and requests a copy. She makes a note in her medical record that Ralph has selected his oldest son, Jonathan, to serve as his surrogate, with his daughter, Rachel, as the alternate. She again encourages Ralph to give Jonathan access to the medical portal and consider giving access to Judy to enable her to help with appointments and follow-up. The geriatrician offers another visit with Jonathan to discuss supporting Judy in the home, maximizing Ralph's ability to stay engaged with friends now that he can no longer drive, and helping Ralph and his family have a conversation about what matters most to him.

Much of Ralph's geriatrician visit after losing his driver's license focuses on his anger and depression related to that loss, his despair about his worsening memory

14 Amber E. Barnato, *Challenges in Understanding and Respecting Patients' Preferences*, 36(7) Health Affairs 1252 (2017).

loss, and his frustration with his growing dependence. The geriatrician encourages Ralph to have a follow-up conversation with the attorney to ensure that his affairs, including his financial affairs, are in order and offers additional resources to support Ralph's advance care planning.<sup>15, 16, 17</sup>

Had the attorney shared Ralph's advance directive with his geriatrician and surrogates shortly after Ralph signed it, the family may have been more prepared to support Ralph through the trauma of the loss of his driver's license.

See numbers 1, 2, 3, 4, and 10 in Section III, Lessons Learned.

#### *D. Scenario 4: Four Years After Diagnosis, the Couple's Health Worsens*

##### 1. Legal Issues Explored

Judy's illness trajectory, which differs from Ralph's, presents its own inherent challenges. This scenario shows (a) the importance of listening to the client even if an advance directive exists, (b) how the advance directive could be a helpful springboard for discussion, (c) the value of supported decision-making for elderly clients, and (d) how the discussion about goals of care guides the POLST discussion.

##### 2. Scenario

Ralph is beginning to wander; therefore, Judy no longer feels it is safe to leave him alone at home. When she attempts to arrange for additional help in the home to give herself some relief, Ralph fires everyone the home health care agency provides. Judy, at age 86, is becoming increasingly

stressed and exhausted and experiences more frequent chest pain. One day, while Jonathan is visiting, Judy has a severe episode of chest pain, and he drives her to the academic health center about 15 miles away. Judy is diagnosed with a severe myocardial infarction (heart attack), and Jonathan notifies Rachel, who arranges to fly in that afternoon. Fortunately, Judy remains cognitively intact, but she is now too frail to care for Ralph at home.

Judy's myocardial infarction was severe enough to reduce her heart's pumping ability, causing congestive heart failure. Judy's heart pumps out only 25 percent of the total amount of blood in its left ventricle with every beat compared with a normal heart that pumps out 55 percent. This loss of contraction ability causes Judy to become short of breath when walking. She tires easily and needs help with housework, grocery shopping, and other instrumental activities of daily living. She needs to limit the amount of salt in her diet and take medications for her heart failure. Judy's condition requires that she be closely followed by her medical team.

Judy is at increased risk of having a life-threatening abnormal heart rhythm at any time. As a result, she is offered an internal cardiac defibrillator (ICD), a surgically implanted device that will give her heart an electric shock if she experiences a severely abnormal heart rhythm, with the goal of preventing sudden cardiac death. Judy informs Jonathan and Rachel that she is unsure whether she wants an ICD and wants their help in making this decision.

Judy's reservations and the severity of her heart disease lead the medical team to begin asking questions about her goals of care. The team asks whether Judy has an advance directive. She tells the team she has one and has appointed Jonathan as

15 ABA Commn. on L. & Aging, *supra* n. 11.

16 The Conversation Project & Inst. for Healthcare Improvement, *supra* n. 13.

17 Prepare for Your Care website, <https://prepareforyourcare.org/welcome> (accessed May 7, 2019).

her surrogate and Rachel as the alternate. Judy tells Rachel where all of her legal paperwork is at home, and Rachel agrees to bring in a copy of Judy's advance directive for placement in her medical record.

Because Judy is a capable decision-maker, her medical team, without having a copy of her advance directive, begins discussing with Judy (and with her permission, Jonathan and Rachel) her goals of care. Judy, after talking with Jonathan and Rachel, indicates that she wants to return to the hospital if she has another cardiac event but does not want cardiopulmonary resuscitation (CPR) or to be placed on a breathing machine. Her medical team records these wishes as medical orders on a POLST form as "do not attempt resuscitation (DNR) and limited treatment." Both Judy and her doctor sign the form, a copy is placed in her medical record, and Judy is given a copy to take home. With Judy's permission, copies are provided to Jonathan and Rachel.

### 3. Judy's Declining Health

Judy's trajectory to death<sup>18</sup> is profoundly different from Ralph's; therefore, her medical team approaches the discussion of her goals of care differently from the approach Ralph's geriatrician used to discuss his goals. Although frail, Judy is cognitively intact and capable of serving as her own decision-maker. Thus, her advance directive is not determinative because she is still capable of guiding her own care. Nonetheless, if Judy's advance directive had been available to her medical team, the team would have become aware of her ultimate intention to involve Jonathan and Rachel in her care. Discussing what

Judy wrote in her advance directive would have been an excellent starting point to facilitate deeper conversation with her medical team about her care goals<sup>19</sup> in the context of her congestive heart failure.

Being able to refer to a patient's advance directive provides a helpful way for health care professionals to initiate a deeper conversation with families regarding a specific medical decision. For many patients, the advance directive makes it easier to express their goals beyond the four corners of the document and to speak more specifically about treatments related to their current state of health.

Judy's medical team should review the advance directive with her while she is still capable of doing so to confirm that the document still reflects her wishes and that the surrogates she listed are still the people she wants to speak on her behalf if she becomes unable to speak for herself.

Because Judy has capacity, an advance directive is not needed for making a decision about placement of an ICD. However, having an advance directive is important for Judy in the event she someday loses capacity. In most states, her default decision-maker is her spouse,<sup>20</sup> Ralph, who, unfortunately, is now incapable of making medical decisions on his own behalf, let alone hers. In addition, she definitely does not want Larry (her youngest son) making any medical decisions for her. Thus, in Judy's case, it is especially im-

18 Jennifer Moore Ballentine, *Supporting Patients During Serious Illness* (Cal. St. U. Inst. for Palliative Care 2018).

19 Rachele E. Bernacki & Susan D. Block, *Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices*, 174(12) JAMA Internal Med. 1994 (2014).

20 ABA Commn. on L. & Aging, *Default Surrogate Consent Statutes* (Jan. 1, 2018), [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2014\\_default\\_surrogate\\_consent\\_statutes.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf) (accessed May 7, 2019).



portant to ensure that a formal appointment of a surrogate is made in an advance directive and that a copy of the advance directive is placed in her medical record to ensure that she receives care according to her wishes.

It is common, however, for frail elders who are still capable of making their own health care decisions to seek support and consultation from their surrogates. The terms “assisted decision-making” and “supported decision-making” are often used to describe the process of frail but capable elders turning to trusted advocates for consultation and reinforcement.

Judy differs from Ralph in another important way. She not only has capacity to make her own medical decisions but also is more comfortable and willing to engage in a goals-of-care conversation. She is more interested in receiving information about her prognosis and treatment options than Ralph is in receiving information about his. Following a conversation about the risks and benefits of treatment with her medical team, Judy indicates her preference for “DNR and limited treatment” on her POLST form.

Judy’s medical team makes her aware that few people with similar advanced health problems survive an out-of-hospital cardiac arrest.<sup>21</sup> The team informs her that television and movies misrepresent the truth by portraying survival rates for out-of-hospital cardiac arrest that are much higher than those in real life.<sup>22</sup> Studies of out-of-hospital cardiac arrest for patients of all ages and health conditions have found an approximately 8 percent rate of

successful resuscitation. For patients with advanced illness and frailty, rates drop to 3 percent or less depending on the health condition.<sup>23</sup>

As a result of this discussion and reflection on her wishes and values, Judy feels strongly about avoiding resuscitation, intensive care, and mechanical ventilator support. Because emergency medical personnel are obligated to provide all indicated life-sustaining treatments unless they have medical orders to the contrary, her medical team is aware that her advance directive alone will not be enough to ensure that her wishes are honored in a crisis. Emergency medical personnel are not allowed to act on an advance directive because it is not a medical order.

The short video “POLST: When Advance Directives Are Not Enough”<sup>24</sup> helps demonstrate the importance of POLST form orders. POLST form orders are necessary to turn wishes expressed in advance directives into action as medical orders when patients want their wishes to be implemented in their medical care.<sup>25</sup> Attorneys and health care professionals alike might suggest to clients and patients that they and their surrogates watch this video together to enhance their understanding of the advance care planning process.

In Judy’s current situation, Jonathan and Rachel benefit from being integrated

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- 21 Robert M. Taylor et al., *Improving Do-Not-Resuscitate Discussions: A Framework for Physicians*, 8(1) J. Supportive Oncology 42 (2010).
- 22 Susan J. Diem et al., *Cardiopulmonary Resuscitation on Television: Miracles and Misinformation*, 334(24) New Eng. J. Med. 1578 (1996).

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- 23 Patricia Jabre et al., *Family Presence During Cardiopulmonary Resuscitation*, 368(11) New Eng. J. Med. 1008 (2013).
- 24 Oregon POLST, YouTube, *POLST: When Advance Directives Are Not Enough* (Apr. 8, 2013), <https://www.youtube.com/watch?v=mdPtHu0-KPU> (accessed May 7, 2019).
- 25 Oregon POLST, *POLST Guidebook for Health Care Professionals*, click link to guidebook, which is titled *Guidance for Oregon’s Health Care Professionals* (rev. Feb. 14, 2019), <https://oregonpolst.org/polst-guidebook> (accessed May 7, 2019).



into the decision-making process early and serving as consultants in supporting their mother's decisions. By doing so, they are able to learn much more about her wishes and values.

Jonathan and Rachel could have obtained further guidance on their roles as surrogates by watching the video "POLST: When Is the Right Time?"<sup>26</sup> when they initially agreed to become surrogates for their parents. All too often, those who are appointed as surrogates receive little guidance on how to perform their responsibilities. Surrogates need guidance from the person they represent, along with an in-depth understanding of his or her wishes and values, as well as guidance from the medical team. Both medical and legal professionals can provide assistance on how to conduct conversations about end-of-life care and provide tools for facilitating them.<sup>27, 28</sup>

To more fully understand their role, surrogates need guidance on how the wishes expressed in a patient's advance directive will ultimately need to be turned into medical orders with a POLST form. In this case, Judy remains a capable decision-maker and signs the POLST form with her doctor. She may indicate that it may be more appropriate for her care to focus on her comfort when she no longer has capacity to make her own medical decisions. In this context, Jonathan would work with her medical team to complete a new POLST form that reflects her wishes for comfort measures only when she is in a more compromised state of health. See

numbers 3, 5, 7, and 10 in Section III, Lessons Learned.

### *E. Scenario 5: Challenging Surrogate Decisions Arise During Ralph's Acute Illness*

#### 1. Legal Issues Explored

This scenario describes the consequences of inadequate end-of-life care discussions with clients and their families, vague advance directives, and the lack of early surrogate involvement. The scenario focuses on (a) the need for good communication between clients and their families regarding end-of-life wishes, (b) the need for the advance directive to be part of the client's medical record; and (c) the need for greater specificity about the client's values guiding end-of-life wishes in the advance directive.

#### 2. Scenario

Larry (the youngest son) comes to town later the same day that Judy is admitted to the hospital. He goes to his parent's home and finds Ralph, now 87, with a fever and extreme breathlessness. He calls 911, and Ralph is admitted, with aspiration pneumonia, to the nearest hospital (which is not the academic health center where Judy has been admitted). Because communication is terrible between Larry and his siblings, Larry does not immediately notify Jonathan and Rachel that Ralph has been taken to the hospital. Thus, Larry is the only family member in the emergency department, and Ralph is not able to provide any information. The hospital does not have a copy of Ralph's advance directive in his medical record. Larry instructs the emergency physicians to "do everything" to save Ralph. Ralph is placed on a mechanical ventilator in the intensive care unit (ICU).

When Jonathan and Rachel return to

26 Oregon POLST, *POLST: When Is the Right Time?* (Apr. 30, 2018), <https://www.youtube.com/watch?v=LoGM-ayzKc0> (accessed May 7, 2019).

27 ABA Commn. on L. & Aging, *supra* n. 11.

28 The Conversation Project & Inst. for Healthcare Improvement, *supra* n. 13.

the family home that evening, they find Larry's belongings and no sign of their father or Larry. They call Larry and go to the local hospital to find their father in restraints, sedated, and on a ventilator in the ICU. They tell the medical team that their father did not want Larry to make medical decisions for him and that they, not Larry, were appointed as surrogates in their father's advance directive. The medical team instructs Jonathan and Rachel to bring in a copy of Ralph's advance directive and schedules a family meeting for the next day. Fortunately, Judy told Rachel where their important papers are located. Rachel was able to find both Ralph's and Judy's advance directives, which confirmed that Jonathan is Ralph's chosen surrogate and that Rachel is the alternate. However, the directive gives no guidance about Ralph's treatment wishes other than stating that he does not want life-sustaining treatment if he no longer recognizes his family.

When Jonathan and Rachel return to the hospital with their families, Ralph has awakened confused; he appears to recognize Jonathan and Rachel but not his grandchildren. Jonathan and Rachel do not know what to do and cannot agree on treatments their father would want. Meanwhile, Ralph remains in the ICU for 4 days until he is breathing again on his own and is discharged to another medical unit to regain strength while plans are made to discharge him to a skilled nursing facility.

### 3. Consequences of Ralph's Advance Directive Not Becoming Part of His Medical Record

Had the attorney provided a copy of the advance directive to the geriatrician for placement in Ralph's medical record, much of this confusion would have been avoided. In addition, had the attorney

encouraged Ralph to have early surrogate involvement and discussion with the children, Jonathan and Rachel would have been more cognizant of his wishes and Larry would have been made aware that he was not appointed as surrogate.

Hospital personnel followed Larry's instructions because there was no advance directive in Ralph's medical record. They had no other choice because they were unaware of Ralph's treatment wishes for this emergency and the only family member available was urging the medical team to "do everything." Thus, the very person Ralph did not want making medical decisions for him gave directions for his care.

Even if the advance directive had been in Ralph's medical record, Ralph's advance directive would have provided little guidance as to his wishes. Although the advance directive would have clarified who is the appropriate surrogate, the vague instructions would have been of limited help to Jonathan. A previous discussion about Ralph's wishes and values would have provided greater guidance. Vague statements such as "when I no longer recognize my family" are of limited assistance without further clarification about who Ralph means by "family" and what "no longer recognize" really means.<sup>29</sup>

If Ralph had discussed his goals of care with his geriatrician while he was still able to, it is likely that he would have expressed the desire to avoid mechanical ventilation and ICU admission as his dementia advanced.<sup>30</sup> Had Ralph involved Jonathan

29 Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34(2) Hastings Ctr. Rpt. 336 (2004).

30 Bertrand Guidet et al., *Effect of Systematic Intensive Care Unit Triage on Long-Term Mortality Among Critically Ill Elderly Patients in France: A Randomized Clinical Trial*, 318(15)

and Rachel in his medical care earlier, as Judy did, the three could have had meaningful discussions with Ralph's medical team on how to deal with such medical scenarios should they arise.

See numbers 3, 4, and 10 in Section III, Lessons Learned.

#### *F. Scenario 6: Ralph Is Admitted to a Skilled Nursing Facility*

##### 1. Legal Issues Explored

The family has now reached the point of having to make the painful decision of placing Ralph in a skilled nursing facility. This scenario focuses on (a) the appropriate signatories for the POLST form orders, (b) the surrogate's role in the POLST discussion, (c) the interplay between the advance directive and POLST form orders, and (d) the appropriateness of offering a feeding tube to a client with advanced dementia.

##### 2. Scenario

Judy feels tremendously guilty about placing Ralph in a memory care unit of a skilled nursing facility, but Jonathan and Rachel realize that she can no longer care for him at home. During Ralph's admission, the social worker asked Jonathan and Rachel for a copy of Ralph's advance directive and discussed how much medical treatment they thought he would want. The social worker indicated that they would need to meet with the advanced practice nurse, who is part of the care team at Ralph's nursing facility.

When Jonathan and Rachel meet with the care team, they agree that Ralph would not want CPR but cannot agree on whether he would want to return to the hospital if he became ill or whether

he would want to have a feeding tube placed. Thus, orders for both these options were included on his POLST form, which the advanced practice nurse and Jonathan signed.

##### 3. Changes to POLST Form Orders as Ralph's Health Status Changes

The medical landscape has changed significantly since the POLST program initiative began. As a result, several important changes have occurred in the POLST environment, particularly since the comprehensive POLST review by Wolf and colleagues in 2014.<sup>31</sup> One of those changes is the growing number of states that permit advanced practice nurses to sign POLST form orders.

The scope of practice for advanced practice nurses has expanded substantially since the early 1990s, when the POLST initiative began, in Oregon.<sup>32</sup> At that time, only physicians could write medical orders regarding life-sustaining treatment; thus, the term "physician" was incorporated into the original POLST name when Oregon developed its POLST program. In 2001, advanced practice nurses were authorized to sign POLST forms in Oregon. A growing number of states, including California, West Virginia, and New York, have more recently authorized advanced practice nurses to sign their state's specific version of POLST forms. A study examining more than 25,000 POLST forms completed by advanced practice nurses in Oregon found that by 2015, 11 percent of all POLST forms in the state were being completed by advanced practice nurses.<sup>33</sup>

31 Wolf et al., *supra* n. 6, at 71.

32 Pope & Hexum, *supra* n. 5, at 353.

33 Sophia A. Hayes et al., *The Role of Advanced Practice Registered Nurses in the Completion of Physician Orders for Life-Sustaining Treatment*, 20(4) J. Palliative Med. 415 (2017).

A small West Virginia study compared the rate of errors (e.g., failure to date the document) between physicians and advanced practice nurses signing POLST forms. Forms completed by advanced practice nurses had fewer errors than those completed by their physician colleagues.<sup>34</sup> Thus, having an advanced practice nurse meet with the family to complete the patient's POLST form is common practice in an increasing number of states.<sup>35</sup> As a result, in 2019, Oregon changed the first term of the POLST abbreviation: Physician orders for life-sustaining treatment became *portable* orders for life-sustaining treatment to include advanced practice nurses and physician assistants.<sup>36</sup>

A second substantive change since the 2014 Wolf and colleagues review is the growing awareness in the medical community that feeding tubes are not effective for patients with advanced dementia. When POLST forms were created in the 1990s, the initial form included four sections: (1) Resuscitation, (2) Scope of Treatment (patient wishes regarding hospitalization, ICU admission, and mechanical ventila-

tor support); (3) Antibiotics; and (4) Artificial Nutrition by Tube. In 2011, Oregon removed the section related to antibiotics, finding that the medications were offered about one-third of the time in the final 60 days of life regardless of the orders on the POLST form.<sup>37</sup> An increasing number of states have removed the antibiotic section or never put it on their forms in the first place. In addition, there is no agreement in the medical community on a definition of "antibiotics for comfort," one of the treatment options offered in the antibiotics section of the early versions of the POLST form. Thus, in keeping with the commitment to data-driven quality improvement, it made sense to remove the antibiotics section from the form.<sup>38</sup>

The section of the POLST form orders about artificial nutrition by tube has come into question more recently. Recent data about the use of long-term artificial nutrition by tube have not shown to be beneficial for those with advanced dementia.<sup>39 40</sup> Specifically, such treatment does not lengthen life for those with advanced dementia and increases suffering. The rate of pressure ulcers is twice as high (likely due to the use of restraints) in patients receiving artificial nutrition by tube.<sup>41</sup> Increasingly, national medical organizations have recommended against the placement

34 Lori A. Constantine et al., *Nurse Practitioners' Completion of Physician Orders for Scope of Treatment (POST) Forms in West Virginia: A Secondary Analysis of 12 Months of Data From the State Registry*, 30(1) J. Am. Assn. Nurse Practs. 10 (2018).

35 Natl. POLST Paradigm, *New Resource With POLST Form Signature Requirements for Each State* (Mar. 6, 2018), <https://polst.org/2018/03/06/new-resource-with-polst-form-signature-requirements-for-each-state> (accessed May 7, 2019).

36 Oregon POLST, *2019 Oregon POLST Form Summary of Changes Made* (authorized Jan. 2, 2019), <https://static1.squarespace.com/static/52dc687be4b032209172e33e/t/5bbbc8678165f02248927e2/1539033193475/2018.1.0.08+2019+POLST+Form+Summary+of+Changes.pdf> (accessed May 7, 2019).

37 Susan E. Hickman et al., *The Consistency Between Treatments Provided to Nursing Facility Residents and Orders on the Physician Orders for Life-Sustaining Treatment (POLST) Form*, 59(11) J. Am. Geriatrics Socy. 2091 (2011).

38 Oregon POLST, *supra* n. 1.

39 Joan M. Teno et al., *Feeding Tubes and the Prevention or Healing of Pressure Ulcers*, 172(9) Archives Internal Med. 697 (2012).

40 Shao-Hwan Lan et al., *Tube Feeding Among Elders in Long-Term Care Facilities: A Systematic Review and Meta-Analysis*, 21(1) J. Nutrition Health Aging 31 (2017).

41 Teno et al., *supra* n. 39, at 697.

of feeding tubes in those with advanced dementia.<sup>42, 43</sup>

Artificial nutrition by tube does lengthen life in other medical contexts such as amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease), permanent vegetative state, and stroke resulting in difficulty swallowing. In all these contexts, an informed consent process is completed (often with surrogates) prior to the surgical placement of a feeding tube. However, such placement is never a medical emergency, providing an opportunity to weigh the risks and benefits of the treatment. Medical science is becoming clearer about the lack of benefit of feeding tubes in patients with advanced dementia.<sup>44 45</sup> As a result, Oregon removed feeding tube orders from the POLST form in January 2019. Other states are also considering removal of these orders from their states' version of the POLST form.

Thus, it was not appropriate for Ralph's medical team to offer Jonathan the option of artificial nutrition by tube for Ralph, considering Ralph's advanced dementia, because it is anticipated that the treatment would increase Ralph's suffering without providing any medical benefit. Because such treatment is used in other situations, the advanced practice nurse could have in-

dicated to Jonathan why feeding by tube for his father would not meet his father's goals of care. Jonathan then would not have to wonder later why tube feeding was never considered as a possible treatment. It was appropriate for Jonathan to choose no CPR, given Ralph's present state of health and the low likelihood of treatment success.

For more in-depth discussion, see numbers 5, 6, and 8 in Section III, Lessons Learned.

### G. Scenario 7: Ralph's Life Comes to an End

#### 1. Legal Issues Explored

Despite some unnecessary interventions and some communication glitches along the way, Ralph reaches the end of his life without a final trip to the hospital, at peace with his family. This scenario focuses on (a) the correlation between POLST form orders and place of death, (b) how POLST form orders complement the client's advance directive, and (c) how POLST form orders change to reflect the client's goals of care while still honoring his or her advance directive.

#### 2. Scenario

During the next 6 months, Ralph's cognition declines further. He rarely speaks and no longer recognizes Judy or his children. He is admitted twice to the hospital with pneumonia. He becomes agitated during his second hospital stay, has to be restrained to prevent him pulling out his IV, and develops a pressure ulcer. He is having increasing difficulty swallowing and is losing weight despite careful hand-feeding and supplements.

When not in the hospital, Ralph sleeps most of the time, is passive, and appears to be relatively content. Troubled by his obvious decline, Jonathan and Rachel

42 Am. Geriatrics Socy. Ethics Comm. & Clinical Prac. & Models of Care Comm., *American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement*, 62(8) J. Am. Geriatrics Socy. 1590 (2014).

43 Alzheimer's Assn., *Feeding Issues in Advanced Dementia* (2015), <https://www.alz.org/media/Documents/feeding-issues-statement.pdf> (accessed May 7, 2019).

44 Susan W. Tolle et al., *It Is Time to Remove Feeding Tubes From POLST Forms*, 67(3) J. Am. Geriatrics Socy. 626 (2019).

45 Oregon POLST, *Professional Resource Library*, <https://oregonpolst.org/professional-resource-library> (accessed May 7, 2019).

have heated discussions about Ralph's goals of care. Rachel is concerned about how trips to the hospital have become distressing for her father and thinks he should not be admitted to the hospital if he gets pneumonia again. Jonathan doubts what to do and sincerely wishes he had done more than just sign the advance directive as surrogate. He and Rachel both wish they had talked with their father about his care goals when he was still capable.

Judy quietly shares with Jonathan and Rachel the conversation she had with Ralph about "pulling the plug" if he no longer recognizes his family. A care conference is held at the nursing home, and Jonathan and Rachel decide the focus of their father's care should be completely on his comfort. Jonathan and the advanced practice nurse complete and sign a new POLST form, with orders for "DNR and comfort measures only," and Ralph is enrolled in hospice. Three weeks later, he dies peacefully at the skilled nursing facility with Judy holding his hand.

### 3. Location of Death

A majority of Americans prefer not to die in the hospital.<sup>46</sup> States vary substantially in the likelihood of people dying in hospitals, in nursing homes, or in homelike settings and of people receiving intensive care in the final 30 days of life.<sup>47</sup> Many factors, in addition to advance care planning, are at work in these regional differences, but it appears that differences in patient preferences are not.

Although a randomized controlled trial of POLST use has not been conducted,<sup>48</sup> multiple studies have shown a strong association between location of death and specific orders on a POLST form — stronger than that seen with an advance directive.<sup>49</sup> The first study demonstrating a strong association between POLST form orders and reduced deaths in the hospital, conducted in 1995, showed that 5 percent of patients with orders stating "DNR and comfort measures only" died in the hospital.<sup>50</sup> Subsequent studies in Oregon and West Virginia showed that the rate of in-hospital death of patients with POLST form orders for comfort measures only was substantially lower, 6.8 percent in Oregon and 10.8 percent in West Virginia.<sup>51, 52, 53</sup> These studies support the use of POLST to turn pa-

46 Amber E. Barnato et al., *Are Regional Variations in End-of-Life Care Intensity Explained by Patient Preferences? A Study of the U.S. Medicare Population*, 45(5) *Med. Care* 386 (2007).

47 Susan W. Tolle & Joan M. Teno, *Lessons From Oregon in Embracing Complexity in End-of-Life Care*, 376(11) *New Eng. J. Med.* 1078 (2017).

48 Kendra A. Moore et al., *The Problems With Physician Orders for Life-Sustaining Treatment*, 315(3) *JAMA* 259 (2016).

49 Sandra L. Pedraza et al., *POST Forms More Than Advance Directives Associated With Out-of-Hospital Death: Insights From a State Registry*, 51(2) *J. Pain Symptom Mgt.* 240 (2016).

50 Susan W. Tolle et al., *A Prospective Study of the Efficacy of the Physician Order Form for Life-Sustaining Treatment*, 46(9) *J. Am. Geriatrics Socy.* 1097 (1998).

51 Alvin H. Moss et al., Ltr. to the Ed., *Physician Orders for Life-Sustaining Treatment Medical Intervention Orders and In-Hospital Death Rates: Comparable Patterns in Two State Registries*, 64(8) *J. Am. Geriatrics Socy.* 1739 (2016).

52 Erik K. Fromme et al., *Association Between Physician Orders for Life-Sustaining Treatment for Scope of Treatment and In-Hospital Death in Oregon*, 62(7) *J. Am. Geriatrics Socy.* 1246 (2014).

53 Dana M. Zive et al., *Change Over Time in the Oregon Physician Orders for Life-Sustaining Treatment Registry: A Study of Two Decedent Cohorts*, *J. Palliative Med.* (2018), <https://doi.org/10.1089/jpm.2018.0446> (accessed May 7, 2019).

tient wishes in advance directives into action as medical orders when patients desire treatment limits.

Jonathan and Rachel did not hold a conversation with Ralph regarding his wishes related to life-sustaining treatment in the event he developed advanced dementia. His advance directive stated and his limited communication with Judy indicated that he did not want life-sustaining treatment if he no longer recognized his family. It is difficult to know exactly when that line was crossed because Ralph had difficulty recognizing family members for some time, yet Jonathan and Rachel continued to authorize hospitalizations, including intensive care. Hospitalizations in those with advanced dementia are often associated with increased agitation and the use of restraints. Such transitions between care settings near the end of life are common and are considered burdensome by family members.<sup>54</sup>

Some attorneys have raised questions about POLST form orders supplanting advance directives.<sup>55, 56</sup> The completion of POLST form orders does not mean that the orders supplant the patient's advance directive. POLST form order changes are

common near the end of life as a patient's health status changes.<sup>57, 58</sup>

When the patient has an advance directive, changes to his or her POLST form orders are guided by the advance directive, thus ensuring that the patient's wishes are honored more effectively as his or her health declines. As was true in Ralph's case, a POLST form order is changed not because the patient's wishes as expressed in his or her advance directive changed, but because the patient's health status changed. Thus, the POLST form orders must change in order to apply the patient's wishes to his or her change in health status.

Many frail patients wish to be hospitalized to receive basic medical treatment, not intensive care. As they get sicker (as in Ralph's case, no longer recognizing family members), a change in POLST form orders may be needed to comply with the patient's original goals of care. Patients often desire to have comfort-focused care as they near the end of their lives.<sup>59</sup> Although it appears that Ralph may have wished to limit trips to the hospital much sooner than Jonathan and Rachel authorized, in the end, his dying peacefully with his wife holding his hand and without life-sustaining treatment appears to align with his original goals.

Some people mistakenly believe that setting limits on specific medical treatment is the same as withdrawing care.<sup>60</sup>

54 Joan M. Teno et al., *Site of Death, Place of Care, and Health Care Transitions Among U.S. Medicare Beneficiaries, 2000–2015*, 320(3) JAMA 264 (2018).

55 Kerry R. Peck & Kyle T. Fahey, *POLST Updates: What Attorneys Need to Know* (Sept. 27, 2018), [https://www.americanbar.org/groups/health\\_law/publications/aba\\_health\\_esource/2014-2015/october/polst](https://www.americanbar.org/groups/health_law/publications/aba_health_esource/2014-2015/october/polst) (accessed May 7, 2019).

56 Cal. Advocs. for Nursing Home Reform, *CANHR Policy Brief: Physician Orders for Life-Sustaining Treatment ("POLST") Problems and Recommendations* (2010), [http://canhr.org/reports/2010/POLST\\_WhitePaper.pdf](http://canhr.org/reports/2010/POLST_WhitePaper.pdf) (accessed May 7, 2019).

57 Dana M. Zive et al., *Timing of POLST Form Completion by Cause of Death*, 50(5) J. Pain Symptom Mgt. 650 (2015).

58 Jennifer Hopping-Winn et al., *The Progression of End-of-Life Wishes and Concordance With End-of-Life Care*, 21(4) J. Palliative Med. 541 (2018).

59 Fromme et al., *supra* n. 52, at 1246.

60 Anna DeForest, *Better Words for Better Deaths*, 380(3) New Eng. J. Med. 211 (2019).



However, one can withhold or withdraw medical treatment and have a complex and extensive plan of care for comfort. A comfort-focused care plan is much more than the absence of specific treatments. It is an extensive care plan that, with the combined efforts of loved ones and the medical team, maximizes the patient's comfort and minimizes his or her physical, emotional, and spiritual suffering. Even though it was not possible for Judy to take Ralph home as he was dying, it was possible for Judy to be present and be supported as she spent her final moments with her dying husband.

See numbers 5, 9, and 10 in Section III, Lessons Learned, which follows.

### III. Lessons Learned

Although Ralph died peacefully with Judy by his side, there are lessons to be learned from Ralph and Judy's journey. Their journey could have gone much more smoothly with much less angst and suffering for both Ralph and his family if Ralph's attorney and geriatrician had partnered more effectively with each other and the entire family. Lessons learned from Ralph and Judy's journey follow.

#### A. Lesson 1

One of the most important actions an attorney can take is to send a copy of the advance directive to the client's health care professional to ensure that it becomes part of the client's medical record. To rely on the client to do this, particularly a client with MCI, is unwise. Had the advance directive been available to Ralph's geriatrician at her next consultation with Ralph, she would have had the opportunity to review the document with Ralph and been able to clarify his wishes and enter his choice of surrogates into his medical record. In addition, the act of the attorney reaching out

to Ralph's geriatrician could have served as an impetus for dialogue between these two professionals as well as for a more in-depth discussion with Ralph himself.

#### B. Lesson 2

The second most important action an attorney can take is to send a copy of the advance directive to all surrogates appointed in the document. Many states do not require surrogates to sign the advance directive.<sup>61</sup> As a result, many surrogates are not aware that they have been named in the advance directive until it is too late for them to discuss the principal's wishes because he or she lost capacity to engage in such a discussion. Even though Ralph told Jonathan and Rachel that he chose them as his surrogates and they each signed the advance directive, they neither understood the full import of the document nor recognized the need for further discussion. Relying on the client, particularly a client with MCI, to share copies of the advance directive with appointed surrogates is ill-advised.

#### C. Lesson 3

Sending a copy of the advance directive to the named surrogates without a copy of suggested resources to help them understand their responsibilities is insufficient. Many excellent resources are available that adapt to individuals' different learning styles, health literacy levels, and language and cultural backgrounds.<sup>62</sup>

Although it may not be cost-effective for all clients, some clients welcome the opportunity to have the attorney meet

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61 Charles P. Sabatino, *Overcoming the Balkanization of State Advance Directives*, 46(4) J.L. Med. & Ethics 978 (2018).

62 Natl. POLST Paradigm, *Resource Library*, <https://polst.org/resources/resource-library> (accessed May 7, 2019).



with them and their surrogates to discuss the advance directive and explain what duties are expected of the surrogates. Some attorneys offer an annual “Surrogacy 101” class, inviting clients to bring their surrogates for a general education about the surrogate role. Occasionally, attorneys invite a health care professional to join the teaching team to provide a more directed discussion about medical issues and various health care system challenges.

Had Jonathan and Rachel had the benefit of educational resources that encouraged them to hold conversations with Ralph about his goals of care while he was still able to converse with them, much of the family anguish could have been avoided and Ralph may have been spared some unwanted and uncomfortable invasive interventions.

#### *D. Lesson 4*

The attorney should send a copy of the advance directive, with the client’s permission, to all immediate family members not named as surrogates in the advance directive. Had Larry been made aware that he was not named as Ralph’s surrogate after Ralph signed the advance directive, he may not have been happy about Ralph’s choices, but he would have had the opportunity to discuss the situation with Ralph while Ralph still had capacity. This would have enabled Larry to better understand Ralph’s rationale. Also, Larry would have been made aware of his father’s wishes and may have been able to relay this information to the emergency medical team.

The emergency room is not the ideal location for a child to learn that he or she was not chosen as surrogate. It is difficult enough for the chosen surrogate to make immediate serious medical decisions on a loved one’s behalf without having to deal with an upset and angry family member.

It is also not fair for health care professionals to be forced to mediate such conflict when their focus should be on the patient’s needs.

Had Ralph called a family meeting right after he signed the advance directive, Larry would have had an opportunity to ask questions and Ralph could have appealed to all his children to support Jonathan as his chosen surrogate should a crisis occur. Of course, Larry could still have gone rogue, but there would have been less opportunity for him to interfere with his father’s care if everyone involved had been made aware of Ralph’s wishes and his advance directive had been placed in his medical record. If Larry had gone rogue, Ralph’s care could have been referred to the hospital ethics committee for appropriate resolution.

#### *E. Lesson 5*

Even though an advance directive is not enough, a POLST form should not be viewed as a replacement for an advance directive. In Ralph’s case, the advance directive, once accessed, provided the valuable service of naming Ralph’s surrogates — the people Ralph chose to make his health care decisions for him in the event of his incapacity. However, his advance directive provided little guidance to the health care professionals and Jonathan and Rachel about his wishes because it was difficult to determine when to act on the vague wishes that he did express.

Ideally, an advance directive should share more detail about a client’s values, wishes, goals of care, and philosophy of life than about specific treatment preferences. It should also provide the surrogate with enough flexibility to nimbly respond to unexpected complexities and circumstances that might occur in the course of an illness. Such an advance directive pro-

vides an excellent springboard for goals-of-care discussions with surrogates and health care professionals and encourages dialogue between the medical and legal professionals. Nevertheless, an advance directive does not provide actionable medical orders. The POLST form is needed to turn the wishes expressed in an advance directive into medical orders. Thus, the advance directive and POLST form orders work together to ensure that the patient's wishes are honored.

If a patient has capacity to discuss goals of care during a health care crisis, as Judy did, it is possible for a POLST form orders to be completed without an advance directive. However, POLST form orders should not be generated in a vacuum without either the patient's input or advance directive. With an advance directive, the health care professional has the security of knowing that he or she is dealing with the surrogate chosen by the patient. In addition, the health care professional is able to guide the POLST discussion on how to apply the patient's wishes, values, goals of care, and philosophy of life when selecting the best treatment options given the patient's current health care status. Although not ideal, a POLST form may be completed for an incapacitated patient with no advance directive or named surrogate. In this case, the surrogate would be established by state laws and/or regulations.<sup>63</sup>

#### F. Lesson 6

A patient should never feel pressured into completing a POLST form.<sup>64</sup> Ralph's geriatrician was correct in dealing gently

with Ralph concerning his MCI diagnosis. Rather than launching into a discussion about POLST, she urged him to get an advance directive. Forcing Ralph into a POLST discussion after he received his diagnosis would have been inappropriate. At the time, Ralph was probably too healthy to have a POLST form. A POLST form is designed for individuals with an advanced illness or frailty in which death is likely in the foreseeable future. Signing a POLST form too early may cause a patient harm even if he or she agrees to full treatment of his or her illness.<sup>65</sup>

A POLST form with the orders "attempt CPR" and "full treatment" does not change the care the patient will receive. Emergency medical services automatically provide these treatments in a crisis to all patients, both those with and those without POLST form orders to the contrary. Unfortunately, a POLST form with these orders "attempt CPR" and "full treatment" may give the appearance that a thoughtful goals-of-care conversation took place with the patient. And a POLST form with out-of-date orders may increase the decision-making burden on the family.

POLST form completion should never be mandated or counted as a quality measure in a health care system. Regardless of any financial or other incentives offered, it is a mistake for health systems to use the number of POLST forms completed as a quality measure.<sup>66</sup> In addition, POLST form completion should not be an automatic part of the "Welcome to Medicare" preventive visit because this

63 Natl. POLST Paradigm, *POLST Legislative Guide* (Feb. 28, 2014), <http://polst.org/wp-content/uploads/2017/02/2014.02.20-POLST-Legislative-Guide-FINAL.pdf> (accessed May 7, 2019).

64 Sabatino, *supra* n. 4, at 60.

65 Susan W. Tolle & Joan M. Teno, *Counting POLST Form Completing Can Hinder Quality*, Health Affairs Blog, (July 19, 2018), <https://www.healthaffairs.org/doi/10.1377/hlbg20180709.244065/full> (accessed May 7, 2019).

66 *Id.*

encourages premature POLST form use in older adults who are “too healthy to have one,” and bases the POLST form orders on hypothetical circumstances in the future rather than on an individual’s current health status. The POLST form is most effective for making critical care decisions that are likely to be encountered in the here and now. In addition, premature use of the POLST form may affect the patient’s ability to obtain life insurance,<sup>67</sup> with underwriters falsely believing the patient has a limited life expectancy. For all these reasons, an advance directive is generally the more appropriate document for relatively healthy older adults.<sup>68 69</sup>

#### G. Lesson 7

The choice of “DNR” and “limited treatment” orders on a POLST form is not necessarily contradictory.<sup>70</sup> After learning the dismal survival rates of out-of-hospital cardiac arrest, Judy prefers DNR if she is discovered not breathing and without a pulse. Even though she declines intensive care and mechanical ventilator support, considering these interventions as burdensome and potentially nonbeneficial, Judy still wishes to be hospitalized if she experiences another cardiac event. She is not yet ready to choose comfort measures only.

Such treatment limitations are especially important from a medical perspective because decisions often have to be made quickly. Data from the Oregon POLST Registry shows clearly that other treatment wishes cannot be predicted by merely knowing the patient’s desire to avoid

CPR.<sup>71</sup> The data also show that POLST form orders are not only about a person’s desire to limit treatment, but they are also about honoring a person’s wishes to receive selected types of treatment. Many patients choose a middle ground,<sup>72</sup> and it is important to realize that critical illness is not necessarily the equivalent of the end of life.

#### H. Lesson 8

Education is needed about the ineffectiveness of tube feeding for the 86 percent of patients with advanced dementia who develop eating problems.<sup>73</sup> Research shows that tube feeding is of little benefit to those in the advanced stages of dementia; in fact, research has even shown potential for harm, with an increased rate of agitation and pressure ulcers.<sup>74</sup> Nevertheless, the option is frequently offered to families whose loved ones have advanced dementia, just as it was offered to Jonathan on Ralph’s behalf.

Reasons for offering feeding tube treatment include false beliefs in its effectiveness to achieve a goal of care (e.g., prolonged life, wound healing, comfort) and the complicated underlying symbolic religious/cultural beliefs related to food. For example, in one study, 74.6 percent of physicians believed erroneously that a feeding tube would offer improved healing of a pressure ulcer, yet pressure ulcers occur twice as often in those with feeding tubes, likely due to the use of restraints.<sup>75</sup>

Were families better informed about the natural progression of dementia as an illness, they would be able to understand

67 *Id.*

68 *Id.*

69 Sabatino, *supra* n. 4, at 60.

70 Terri A. Schmidt et al., *Physician Orders for Life-Sustaining Treatment (POLST): Lessons Learned From Analysis of the Oregon POLST Registry*, 85(4) *Resuscitation* 480 (2014).

71 Fromme et al., *supra* n. 52, at 1246.

72 Schmidt et al., *supra* n. 70, at 480.

73 Susan L. Mitchell et al., *The Clinical Course of Advanced Dementia*, 361(16) *New Eng. J. Med.* 1529 (2009).

74 Teno et al., *supra* n. 39, at 697.

75 *Id.*

and be prepared for the time when the patient experiences swallowing difficulties. It is not simply a decision to feed or not to feed. It is a realization that the disease has reached its terminal stage and that there are better ways to ensure the patient's comfort.

Elder law attorneys should understand the natural trajectory of dementia, partner with health care professionals, and encourage the use of decision aids in educating families about the course of the illness. Attorneys should also be aware of the research on the lack of feeding tube utility for those with advanced dementia in order to help surrogates understand why this intervention may not meet the patient's goals of care. They also should know that patients with advanced dementia live just as long with careful hand-feeding. Hand-feeding enables tender social interaction between caregiver and patient, provides person-centered care, respects food preferences, encourages family routine, and promotes a pleasant environment. The close contact inherent in hand-feeding has the potential to help people build relationships with patients with dementia near the end of life and increase the quality of their lives.<sup>76, 77</sup>

#### H. Lesson 9

POLST form orders work. Despite Ralph's convoluted journey as his dementia increased, Ralph's advance directive was ultimately honored because he did not receive any unwanted interventions at

the end of his life when he no longer recognized his family. Ralph's POLST form translated his wishes into orders for DNR and comfort measures only, allowing him to die peacefully in his skilled nursing facility.

POLST form orders do guide care, as shown by Ralph's story and by clinical research.<sup>78</sup> For example, studies in Oregon and West Virginia showed that those who chose "DNR and comfort measures only" had significantly decreased odds of attempted resuscitation and increased odds of having an out-of-hospital death.<sup>79 80</sup> Because of the strong association between POLST form orders and location of death, POLST form orders reduce unwanted transitions of patients (e.g., transfer from home to the hospital). Where a person dies strongly influences how he or she dies.<sup>81</sup>

#### I. Lesson 10

Good advance care planning is a process, a product of teamwork that takes place over a lifetime. Ralph and Judy's scenario reveals that documents alone are not enough. Honoring their wishes involved much more than pieces of paper. Ongoing discussions about a plan of care are vital.

Completing an advance directive should not be considered a one-step process. Also, POLST form orders are not static. Both documents require updates as a person's health status, values, or living situation change. Much depends on good

76 A.M. Wren & S.R. Bloom, *Gut Hormones and Appetite Control*, 132(6) *Gastroenterology* 2116 (2007).

77 Eric J. Palecek et al., *Comfort Feeding Only: A Proposal to Bring Clarity to Decision-Making Regarding Difficulty With Eating for Persons With Advanced Dementia*, 58(3) *J. Am. Geriatrics Socy.* 580 (2010).

78 Jean Abbott, *The POLST Paradox: Opportunities and Challenges in Honoring Patient End-of-Life Wishes in the Emergency Department*, 73(3) *Annals Emerg. Med.* 294 (2019), <https://doi.org/10.1016/j.annemergmed.2018.10.021>.

79 Moss et al., *supra* n. 51, at 1739.

80 Zive et al., *supra* n. 53.

81 Fromme et al., *supra* n. 52, at 1246.

communication and trust. Had Ralph's attorney elicited more discussion from him concerning his preferences for future care and performed the simple task of directly providing a copy of Ralph's advance directive to his geriatrician and surrogates, Ralph may have been spared unwanted transitions and suffering. At each stage in life and each change in health condition, a person's overall philosophy may remain the same, but his or her evolving medical condition may change what orders are needed to honor his or her goals of care.

As death approaches, changes in treatment preferences often occur. Updating the POLST form to reflect changing circumstances ensures that the patient's wishes embodied in his or her advance directive are honored. This is more likely if good communication and teamwork

occurs among the client, attorney, surrogates, and health care professionals.

#### IV. Conclusion

POLST form orders, when used appropriately, function much like a trust protector does for a trust. It ensures that the client's intent, the client's wishes as expressed in an advance directive, are consistently honored despite changing circumstances. Rather than usurping the advance directive, the POLST form order functions as the co-pilot, translating the patient's wishes into actionable medical orders near the end of life to preserve the patient's autonomy. Attorneys collaborating with health care professionals toward a common goal of honoring client's and patients' wishes is a worthy aspiration.

*Coming together is a beginning, keeping together is progress, working together is success.*

— Henry Ford



**The Social Security Administration’s Policy Overhaul:  
A Practitioner’s Guide to the 2018\*  
Special Needs Trust POMS Revisions**

*By Anna Sappington, Esq.*

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\* This article does not discuss the 2019 POMS changes. For a discussion of the 2019 changes, see *New POMS on Attorney’s Fees: Does Every Attorney Who Drafts a Special Needs Trust Require the Social Security Administration’s Permission to Be Paid or Risk Going to Jail?*, by Kevin Urbatsch, Esq., Aug. 15, 2019, [www.NAELA.org/News-Journal](http://www.NAELA.org/News-Journal).

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I. Introduction

Persons with disabilities rely on special needs trusts (SNTs) to pay for goods and services that enhance their quality of life. The rules that govern SNTs primarily come from the Social Security Administration (SSA). In 2018, SSA fundamentally altered its rules on how to establish and administer SNTs. This article reviews these changes and how special needs practitioners should respond.

As of January 2019, more than 7 million Americans were receiving Supplemental Security Income (SSI),<sup>1</sup> a needs-based cash benefit available to certain persons with disabilities, which is intended to pay for recipients’ food and shelter. In 2019, the federal benefit rate for a single SSI recipient is \$771 per month.<sup>2</sup> Eligibility for SSI is essential for persons with disabilities: Often it is their only source of funds to pay for food and shelter and is a gateway program for obtaining other public benefits such as Medicaid. However, SSI is a means-tested public benefit. To qualify for SSI, recipients must meet strict financial eligibility criteria. To be eligible for SSI in 2019, a single person cannot have more

than \$2,000 in countable assets and a couple cannot have more than \$3,000 in countable assets.<sup>3</sup> Income criteria also apply.<sup>4</sup>

For decades, the SNT has been the primary planning tool to protect persons with disabilities. Funds held in an SNT are not counted as a resource of the SNT beneficiary but may be used (at the trustee’s discretion) for the beneficiary’s benefit. A properly established and administered SNT maintains the beneficiary’s eligibility for means-tested public benefits while augmenting the meager standard of living afforded to the beneficiary by said benefits.

SSA is the federal agency that administers SSI. The federal policies governing SNTs are documented in the agency’s Social Security Program Operations Manual System (POMS). SSA describes the POMS as “a primary source of information used by Social Security employees to process claims for Social Security benefits.”<sup>5</sup> A public version of the POMS is available online.<sup>6</sup> Much of the implementation of SSI, and rules involving SSA’s evaluation of SNTs and SNT distributions in particular, is conducted as agency policy as set forth in the POMS and below the level of federal legislation

1 Soc. Sec. Administration, *Monthly Statistical Snapshot, January 2019* (Feb. 2019), [https://www.ssa.gov/policy/docs/quickfacts/stat\\_snapshot/2019-01.html](https://www.ssa.gov/policy/docs/quickfacts/stat_snapshot/2019-01.html) (accessed June 10, 2019). SSA’s SSI count includes persons receiving federal SSI, federally administered state supplementation, or both. *Id.*

2 Social Security Program Operations Manual System (POMS) SI 02001.020B.9.

3 *Id.* at SI 01110.003A.2.

4 *See Id.* at SI 00810.350, Income Break-Even Points General Information.

5 Soc. Sec. Administration, *POMS Home*, <https://secure.ssa.gov/apps10/poms.nsf/Home?readform> (accessed June 10, 2019).

6 *Id.*



or administrative rulemaking. Thus, the POMS has become the de facto law on how SNTs are evaluated by the federal government, many state agencies, and often, local probate courts.

In the context of SNTs, the POMS provides SSA field office personnel with operating instructions on evaluating trusts for eligibility purposes. As the U.S. Court of Appeals for the Eighth Circuit noted, “The POMS provisions demonstrate valid reasoning; that is, the detailed process required for establishing qualifying special-needs trusts contained in the POMS is consistent with ‘Congress’s command that all but a narrow class of an individual’s assets count as a resource when determining the financial need of a potential SSI beneficiary.’”<sup>7</sup> In the POMS revisions adopted in April 2018, SSA substantially revamped its policies on many aspects of SNT establishment and administration. This article describes these changes and how special needs practitioners should adjust their practices to conform to the new policies on establishing and administering SNTs.

Familiarity with the POMS is vital for

providing effective advocacy for SSI recipients, especially in cases involving SNTs. A qualifying safe-harbor SNT is not considered a countable resource for purposes of SSI eligibility,<sup>8</sup> and distributions from an SNT may be structured to avoid being counted as income to the SSI recipient. However, in SSA’s world, SNTs are not commonplace and field office workers may not be aware of or may misapply law or policies. An on-point POMS citation can often be helpful in persuading field office workers that an SNT meets the POMS requirements.

In April 2018, SSA released major revisions to four POMS sections relevant to SNT establishment and administration:

1. POMS SI 01120.200, Information on Trusts, Including Trusts Established Prior to January 01, 2000, Trusts Established with the Assets of Third Parties, and Trusts Not Subject to Section 1613(e) of the Social Security Act;
2. POMS SI 01120.201, Trusts Established with the Assets of an Individual on or after 01/01/00;
3. POMS SI 01120.202, Development and Documentation of Trusts Established on or After 01/01/00; and
4. POMS SI 01120.203, Exceptions to Counting Trusts Established on or after January 1, 2000.

Additionally, in March 2018, SSA revised POMS SI 01130.470, Achieving a Better Life Experience (ABLE) Accounts, to include a provision relevant to SNT establishment and administration.

While some of the changes incorporate SSA’s previously published administrative messages (AMs) or emergency messages (EMs) or memorialize typical agency

7 *Draper v. Colvin*, 779 F.3d 556, 561 (8th Cir. 2015) stating further: “We conclude that the district court properly held that the provisions in the POMS interpreting § 1396p(d)(4)(A) warrant *Skidmore* deference. According respect under *Skidmore* here is consistent with the Supreme Court’s conclusions that ‘[t]he Social Security Act is among the most intricate ever drafted by Congress,’ *Schweiker*, 453 U.S. at 43, 101 S. Ct. 2633, and that Congress routinely relies on agencies to fill gaps in the statutes they administer. See 42 U.S.C. § 405(a) (giving the Commissioner ‘full power and authority to make rules and regulations and to establish procedures’ to administer the Social Security Act); *Chevron*, 467 U.S. at 843, 104 S. Ct. 2778 (noting that Congress explicitly and implicitly delegates authority to agencies to fill statutory gaps)[.]” *Id.*

8 42 U.S.C. § 1396p(d)(4)(A), (C) (2019) (Casemaker current through Pub. L. No. 115-338).

practice, some of the revisions represent substantive changes or new policies. This article reviews the POMS revisions in terms of the following in order of importance:

1. Substantive changes and new policies;
2. Incorporation of Supplemental Security Income Trust Monitoring System protocols and pooled trust precedents;
3. Incorporation of previously published administrative and emergency messages; and
4. Articulations of prevailing agency policy.

## II. Substantive Changes and New Policies

### *A. Revamping of SSA's Sole Benefit Rule to a More Relaxed Primary Benefit Standard*

One of the biggest (if not *the* biggest) change to the POMS is SSA's relaxation of its sole benefit rule for first-party SNTs to a much more reasonable primary benefit standard. SSA has long stated that a first-party SNT (i.e., a trust established with funds belonging to the trust beneficiary) must be established "solely for the benefit of" the beneficiary.<sup>9</sup> SSA policy as set forth in the POMS defines "sole benefit" in uncompromising terms:

Consider a trust established for the sole benefit of an individual if the trust benefits no one but that individual, whether at the time the trust is established or at any time for the remainder of the individual's life.<sup>10</sup>

The POMS sets forth two exceptions for disbursements that do not violate the sole benefit rule. First, SNT trustees are permitted to pay expenses related to trust administration (e.g., reasonable fees

to trustees or for fees for professional investment or legal advice).<sup>11</sup> Second, SNT trustees may make limited disbursements for certain third-party payments.<sup>12</sup>

It is difficult to determine how SSA conceived of its strict sole benefit rule based on the law as written.<sup>13</sup> The federal law that created the safe-harbor exception exempting SNTs from being counted as a resource for SSI and Medicaid eligibility requires merely that an individual SNT be "established for the benefit of" the beneficiary with a qualifying disability.<sup>14</sup> The statutory exception for pooled SNTs requires that an individual account in the pool be "established solely for the benefit of" the beneficiary.<sup>15</sup> Based on these two phrases, SSA determined that all first-party SNTs (whether individual or pooled) must be established for the sole benefit of the beneficiary with a disability.<sup>16</sup> This is true even though Title 42 U.S.C. § 1396p(d)(4)(A) (individual SNTs) makes no mention of a sole benefit standard and § 1396p(d)(4)(C) (pooled SNTs) appears to refer to the individual beneficiary's account being used solely for him or her, not for any other pooled SNT beneficiary.<sup>17</sup> Unfortunately, SSA went in a different direction in setting its policy.

11 *Id.* at SI 01120.201F.4.

12 *Id.* at SI 01120.201F.3.

13 For an argument criticizing SSA's interpretation of sole benefit as ignoring state law concepts of fiduciary duty, see Ron M. Landsman, *When Worlds Collide: State Trust Law and Federal Welfare Programs*, 10 NAELA J. 25 (2014).

14 42 U.S.C. § 1396p(d)(4)(A) (Casemaker current through Pub. L. No. 115-338).

15 *Id.* at § 1396p(d)(4)(C)(iii) (Casemaker current through Pub. L. No. 115-338).

16 POMS SI 01120.203B.6 (sole benefit rule applicable to individual SNTs), 01120.203D.5 (applicable to pooled SNTs).

17 *See Id.* at SI 01120.203B.6, 01120.203C.4.

9 *Id.*

10 POMS SI 01120.201F.1.

The sole benefit rule has been plagued by confusing articulations of policy, inconsistent enforcement, and sudden changes in interpretation that dramatically affect the type of SNT distributions SSA allows. SSA has made several attempts to define what distributions are and are not for the beneficiary's sole benefit. The most notorious was in 2012, when SSA changed the POMS to substantially limit the types of disbursements allowed under the rule (e.g., refusing to allow reimbursements to third parties who purchased goods and services for the beneficiary). The 2012 changes to the POMS were later rescinded.

Prior to the revised POMS, a point of contention with many SSA field offices concerned the sole benefit rule in cases in which purchases were made to benefit the beneficiary but also provided some collateral benefit to the beneficiary's family and friends. For example, if an SNT trustee purchased a vehicle to be used by the beneficiary, family and friends likely accompanied the beneficiary while he or she used the vehicle, even if the beneficiary did not require their assistance. Or the SNT trustee purchased household items, such as furniture or electronics, that other household members or friends used. Such disbursements became a point of inquiry during SSI re-eligibility determinations. Some SSA field offices took the position that any collateral benefit (no matter how minor) violated SSA's sole benefit rule and was treated as an uncompensated transfer that resulted in SSI overpayments, thus affecting the beneficiary's SSI eligibility.<sup>18</sup>

In the revised POMS, SSA substantially relaxed its policy, modifying the sole

benefit rule by directing agency personnel to evaluate distributions under a more reasonable primary benefit standard. The revised POMS states:

The key to evaluating [the sole benefit rule] is that, when the trust makes a payment to a third party for goods or services, *the goods or services must be for the primary benefit of the trust beneficiary. You should not read this so strictly as to prevent any collateral benefit to anyone else.* For example, if the trust buys a house for the beneficiary to live in, that does not mean that no one else can live there, or if the trust purchases a television, that no one else can watch it. On the other hand, it would violate the sole benefit rule if the trust purchased a car for the beneficiary's grandson to take her to her doctor's appointments twice a month, but he was also driving it to work every day.<sup>19</sup>

The new primary benefit interpretation of sole benefit expressly allows other people to benefit from an SNT disbursement as long as the beneficiary receives the primary benefit. Under the revised POMS, as long as an SNT disbursement can be justified as primarily benefitting the beneficiary, it meets the sole benefit criterion, even if it also conveys collateral benefits to others (e.g., to a nonbeneficiary living with the beneficiary in a trust-purchased house). There is still a limitation on what can be distributed under the new rule. For example, a disbursement may violate the sole benefit rule if the purchased good or service is used disproportionately by nonbeneficiaries, as shown by the example of the car purchased by the trust for the grandmother but used most often by her grandson for his work commute.

The revised POMS does not change SSA rules concerning beneficiary income. Distributions of cash paid from a trust

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18 See *id.* at SI 01120.201F.2 (failure to deed or title an item purchased by the trust in the trust's name "may constitute evidence of a transfer of resources").

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19 *Id.* at SI 01120.201F.3.a (emphasis added).

directly to a beneficiary are considered unearned income and reduce the beneficiary's SSI benefits dollar for dollar, after a \$20 income disregard.<sup>20</sup> For example, if the SNT trustee distributes \$500 in cash to the beneficiary, the beneficiary will lose \$480 in SSI.

The other type of income that is affected by SNT disbursements is called "in-kind support and maintenance" (ISM).<sup>21</sup> An SNT distribution that results in the beneficiary receiving food or shelter is considered outside ISM. Even though outside ISM reduces an SSI recipient's SSI benefits, it does not reduce them dollar for dollar as unearned income does. Instead, the maximum reduction is subject to the presumed maximum value rule (PMV), which is a one-third reduction of the federal benefit rate plus the \$20 income disregard.<sup>22</sup> For example, if the SNT trustee pays \$1,000 a month for the beneficiary's rent, the beneficiary's SSI benefits in 2019 will be reduced by \$277 a month (SSI federal benefit rate of \$771 divided by 3 equals \$257 plus \$20 income disregard equals a \$277 reduction in the SSI amount).

However, SNT disbursements made directly to third-party vendors that result in the SNT beneficiary receiving goods or services other than food or shelter typically do not count as income to the beneficiary and do not affect SSI eligibility.<sup>23</sup> For example, if an SNT trustee pays \$100 per month directly to a cell phone company to pay the beneficiary's cell phone

bill, it has no impact on the beneficiary's SSI eligibility. SNT trustees therefore usually structure disbursements by purchasing goods or services for the beneficiary's benefit directly from third parties.

It could be argued that these purchases violate SSA's sole benefit rule because they convey a collateral benefit to the vendor by receiving payment for goods or services rendered. However, the POMS includes a specific exception to the sole benefit rule for payments made from an SNT to a third party that results in the receipt of goods or services by the beneficiary.<sup>24</sup> This exception, the unearned income reduction, and the ISM reduction continue unchanged from prior POMS iterations and remain in the revised POMS.

The revised POMS allows claimants and advocates to argue against overzealous application of the sole benefit rule and acknowledges the practical realities of the lives of SNT beneficiaries. Interpreting the rule to require that trust purchases convey no collateral benefits was unreasonable and required SNT beneficiaries to go to unnatural lengths to exclude third parties from tangential benefits that did not affect the beneficiary's use or enjoyment of the purchased item. Under the revised POMS, SSA field offices have discretion to dispute transactions that, fairly considered, benefit third parties more than the trust beneficiary while ignoring benefits that are collateral. This is a big win for people with disabilities and a big win for common sense.

### *B. Express Allowance of Payment of Companion Services and Caregiving Expenses*

SSA has long had issues with SNTs that include provisions for paying for

20 20 C.F.R. §§ 416.1121, 416.1123; POMS SI 01120.2011.1.a (first-party SNTs), 01120.200E.1.a (third-party SNTs).

21 20 C.F.R. at § 416.1102.

22 *Id.* at § 416.1140(a)(1); POMS SI 01120.200.E.1.b.

23 POMS SI 01120.2011.1.c (first-party SNTs), 01120.200E.1.c (third-party SNTs).

24 *Id.* at SI 01120.201F.3.

companion care services and caregiving. Arguably, these payments were permitted under the one-sentence exception in the prior POMS allowing payments to a third party that result in the SNT beneficiary receiving goods or services<sup>25</sup> (see Section II(A) of this article). However, because the prior POMS did not expressly permit SNT payments for companion services and caregiving, SSA representatives often approached these distributions with skepticism, objecting to them outright or imposing additional requirements that varied among field offices.

SSA also made an abortive attempt in 2012 to include additional requirements in the POMS for payment to caregivers (which later was rescinded). In response to this uncertainty, SNT trustees often were conservative when evaluating and approving requests for caregiving — an unfortunate result considering that caregiving is one of the best uses of SNT funds to enhance the quality of life for a person with a disability.

The revised POMS directly addresses this issue by including in the third-party payment exception the right of SNT trustees to make distributions for companion services and caregiving. The revised POMS notes that “[p]ayment for companion services can be a valid expense[,]” providing the example of an Alzheimer’s patient who cannot be left alone and requires a sitter.<sup>26</sup> Incidental expenses incurred by the companion in the course of providing services also can be paid by the trust.<sup>27</sup> The revised POMS also includes

express directions to field offices limiting the review of payments for companion services and caregiving. Under the revised POMS, when evaluating the propriety of trust disbursements to pay for companion services and caregiving, field offices are directed:

- Not to request evidence of medical training or certification of family members paid by the trust to provide care;<sup>28</sup>
- Not to request income tax information “or similar evidence” from a service provider to establish a business relationship;<sup>29</sup> and
- Not to routinely question the reasonableness of the compensation the trust pays to service providers. If there is a reason to question the reasonableness of compensation, field offices are directed to consider the time and effort involved in providing the service and the “prevailing rate of compensation” for similar services in the beneficiary’s geographic area.<sup>30</sup>

SSA has struggled for years to decide whether distributions from an SNT to the beneficiary’s family in payment for companion services and caregiving violated the sole benefit rule. The revised POMS emphatically resolves this struggle, stating, “Family members may normally [provide care] without compensation, but that

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expenses, defined as transportation, lodging, and food, are not covered as incidental expenses. *Id.* Payment of these expenses is discussed in Section II(C) of this article.

28 POMS SI 01120.201F3.a.

29 *Id.* However, as noted by the revised POMS, field offices may continue to request this information to determine a beneficiary’s SSI eligibility or benefit amount in circumstances in which the service provider’s income could affect the SSA’s determination. *Id.* (directing field offices in these cases to “request normal evidence of wages per SI 01820.130”).

30 *Id.*

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25 Prior POMS SI 01120.201F2.b.

26 POMS SI 01120.201F3.a.

27 *Id.* (“For example, if the trust pays a companion to take the beneficiary to a museum, the trust can pay for the admission of the companion to the museum, as this cost is part of providing the service.”) *Id.* The caregiver’s travel

does not prohibit the trust from paying for these services.”<sup>31</sup> The POMS also specifies that the policy allowing payments for companion services and caregiving should be applied uniformly regardless of who provides these services and care (family member, nonfamily member, or professional services company).<sup>32</sup>

Family members are the most likely candidates to be companions and caregivers. They are aware of the needs of the person with a disability, often provide better care, and may cost less than a third party hired through an agency. In most cases, family caregivers providing legitimate services in good faith have struggled to comply with training requirements and heightened scrutiny. Previous SSA policies in this regard were intrusive and unnecessary and likely resulted in many SNT trustees paying more money for third parties that did not provide the level of care that a family member would have provided.

SSA’s new policy is pragmatic, reasonable, and better serves the interests of SNT beneficiaries. Companion services and caregiving significantly enrich the quality of life for persons with disabilities. They not only assist beneficiaries with activities of daily living, provide companionship, and increase comfort but also offer beneficiaries additional opportunities for community involvement. The revised POMS policy authorizing companion services and caregiving expenses provides SNT trustees with confidence that is acceptable to pay companions and caregivers, even if they are family members.

### *C. Relaxation of Standards on Payment of Third-Party Travel Expenses to Enable Individuals to Accompany a Trust Beneficiary*

SSA’s policy in the prior POMS regarding SNT payment of travel expenses to enable third parties to accompany the beneficiary was extremely restrictive. Although an SNT trustee could pay the beneficiary’s travel expenses, the trustee was limited to paying a nonbeneficiary’s travel expenses to accompany the beneficiary only when the beneficiary was traveling to obtain medical treatment.<sup>33</sup> This was true even if the beneficiary required the assistance of others to travel safely.

The effect of SSA’s policy was harsh. In some cases, the SNT beneficiary was unable to travel or was forced to travel in an unsafe manner. The policy also was unfair: Forcing nonbeneficiaries to pay out of pocket meant that SNT beneficiaries who required support were less able to travel than those fortunate enough to be able to travel alone.

The revised POMS reverses this unsafe and unfair policy. SNT trustees are allowed to pay the travel expenses of third parties to accompany the beneficiary and to provide the beneficiary with services or assistance necessitated by his or her medical condition, disability, or age.<sup>34</sup> Providing services or assistance necessitated by the beneficiary’s age “means that the beneficiary is a minor and cannot travel unaccompanied.”<sup>35</sup>

The revised POMS defines travel expenses the same way the Internal Revenue Service defines them — expenses for transportation, lodging, and food.<sup>36</sup> The

31 *Id.*

32 *Id.* (“A third party service provider can be a family member, a non-family member, or a professional services company. The policy is the same for all.”) *Id.*

33 Prior POMS SI 01120.201F.2.b.

34 POMS SI 01120.201F.3.b.

35 *Id.*

36 *Id.*

revised POMS discourages undue scrutiny and second-guessing of SNT payment of such expenses for nonbeneficiaries:

Absent evidence to the contrary, accept a statement from the trustee that the service or assistance provided is necessary to permit the trust beneficiary to travel. Do not request a physician statement concerning medical necessity. You should not request evidence of medical training or certification for the person accompanying the trust beneficiary.<sup>37</sup>

Field offices are to review an SNT trustee's determination that assistance is necessary only when they have evidence indicating that it is not. Field offices also cannot require persons accompanying the beneficiary to have official medical training or certification.

The SNT trustee is limited in how many companions can be paid to accompany a beneficiary. In evaluating the number of people necessary to provide support, SSA field offices are to use a reasonableness test.<sup>38</sup> The POMS provides an example of an SNT trustee paying for "other individuals, such as parents or caretakers" to provide supervision and assistance to a minor child with a disability on vacation, noting, "Travel without this support would not be possible."<sup>39</sup>

However, in order for an SNT trustee to pay a third-party's expenses, the companion must actually provide services or assistance to the beneficiary necessary for the beneficiary to travel.<sup>40</sup> For example, an SNT trustee cannot pay for a third party to travel without providing care, simply to enable the care provider to travel and

provide care.<sup>41</sup> This request often arises in the context of parents requesting that an SNT trustee pay for the beneficiary's siblings to accompany them on a trip on the basis that the parents cannot leave the nonbeneficiary children home alone and cannot afford to pay for their travel. SSA expressly notes "the fact that ... parents or caretakers cannot afford to pay for the other children's trip, or cannot leave them at home, is not a consideration relevant to the sole-benefit requirement."<sup>42</sup> The revised POMS policy on paying for companion travel is another example of SSA creating a more reasonable standard for SNT trustees and beneficiaries to follow.

#### *D. Authorization of Payment of Third-Party Travel Expenses in Other Situations*

The prior POMS strictly limited the SNT trustee's ability to pay the travel expenses of nonbeneficiaries who did not accompany the beneficiary. Third-party travel expenses were limited to travel to visit the beneficiary "for the purpose of ensuring the [beneficiary's] safety and/or medical well-being[.]"<sup>43</sup> To qualify for this exception to the sole benefit rule, the beneficiary had to live in a "long-term care facility ... or other supported living arrangement in which a non-family member or entity [was] being paid to provide or oversee the [beneficiary's] living arrangement."<sup>44</sup> This limitation was strict — SNT trustees could not pay the travel expenses of third parties to visit a beneficiary living independently to ensure his or her safety or medical well-being.

The revised POMS incorporates the prior POMS exception, but expands it by

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37 *Id.*

38 *Id.*

39 *Id.*

40 *Id.*

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41 *Id.*

42 *Id.*

43 Prior POMS SI 01120.201F.2.b.

44 *Id.*

allowing certain travel expenses to be paid from an SNT to enable third parties to visit an SNT beneficiary living independently:

**c. Payment of third party travel expenses to visit a trust beneficiary**

The following travel expenses *to ensure the safety or medical well-being of the trust beneficiary* are allowable and do not violate the sole-benefit rule:

- Travel for a service provider to oversee the trust beneficiary's living arrangements when the beneficiary resides in an institution, nursing home, other long-term care facility (for example, group homes and assisted living facilities), or other supported living arrangements.
- Travel for a trustee, trust advisor named in the trust, or successor to exercise his or her fiduciary duties or to ensure the well-being of the beneficiary when the beneficiary does not reside in an institution.

**NOTE:** A third party can be a family member, non-family person, or another entity. If you have questions about whether a disbursement is permissible, please request assistance from your regional office.<sup>45</sup>

Expanding the prior POMS exception is a positive development; however, the POMS is not clear enough to enable field offices to uniformly apply the policy. For example, the requirement that the traveler visit the beneficiary is contained in the section heading only and is not mentioned in the exceptions that appear in the bulleted items. Similarly, it is unclear whether the various stated travel purposes — ensuring the safety or medical well-being of the trust beneficiary, overseeing the living arrangements of a beneficiary in a long-term care facility or other supported living arrangement, and exercising fiduciary duties

or ensuring the well-being of a beneficiary who does not live in an institution — are inclusive or exclusive of others. For example, would an SNT trustee permitting a distribution to allow an individual to travel to exercise fiduciary duties for the beneficiary also have to justify the distribution on the basis that it ensures the beneficiary's safety or medical well-being?

Finally, although the term “third party” is used in the section heading and defined in the note, the exceptions that appear in the bulleted items identify permitted travelers specifically as “service provider[s]” and “trustee[s], trust advisor[s] named in the trust, or successor[s].” Could a distribution to pay expenses for a family member to visit a noninstitutionalized trust beneficiary be disputed on the basis that the family member is not a trustee or trust adviser? As field offices attempt to apply the revised POMS to various fact patterns, these ambiguities will require them to interpret the POMS. Nationwide, the same fact pattern might result in different outcomes, depending on the specific field office's interpretation.

Taking the section heading's wording (“travel expenses to visit a trust beneficiary”) as an implicit requirement applicable to the exceptions that appear in the bulleted items, some justifiable distributions are still not permitted under the revised exception. For example, an SNT trustee might be asked to permit a service provider to travel to investigate living options for a beneficiary moving from Connecticut to Florida (travel to ensure the well-being of the beneficiary) or to pay for the trustee to visit a trust-owned home formerly occupied by the beneficiary (travel to exercise fiduciary duties). The expanded exception still does not cover these situations because the travel is not “to visit [the] trust

45 POMS SI 01120.201E3.c (emphasis in original).



beneficiary.”<sup>46</sup> Even though some issues still need to be worked out, the revised POMS is another example of SSA authorizing additional expenses from an SNT to enhance the beneficiary’s quality of life.

*E. Addition of New Special Needs Trust Distribution Method — Administrator-Managed Prepaid Cards*

1. Overview of Administrator-Managed Prepaid Cards

An ongoing challenge for SNT trustees is making SNT disbursements that do not violate SSA rules but allow some latitude for the beneficiary to directly purchase goods and services. The revised POMS adds a new way for SNT trustees to enable beneficiaries to be in control of their own lives: administrator-managed prepaid cards.<sup>47</sup> The best-known example of these cards is the True Link card, issued by True Link Financial.<sup>48</sup>

Administrator-managed prepaid cards work as follows. The account has an owner/administrator and an authorized user. The administrator can transfer money to the card and configure the card to block or allow certain categories of expenditures or

vendors. For example, an administrator (SNT trustee) could fund the card with \$1,000 a month and configure the card to prohibit cash withdrawals, payment for food or shelter items, purchases at bars, merchandise purchases from the Home Shopping Network, and so on. The authorized user (SNT beneficiary) is issued a nontransferable card in his or her name. The beneficiary can then use the card to purchase authorized items, without further assistance from the SNT trustee.

2. Lack of SSA Policy on Administrator-Managed Prepaid Cards

Prior to the POMS revisions, SSA did not have a separate official agency policy regarding administrator-managed prepaid cards. Some SSA field offices evaluated them under POMS SI 00830.522 rules regarding gift cards and gift certificates. Under POMS SI 00830.522, a gift card or gift certificate is not considered income or a resource to an SSI claimant if two criteria are met: (1) the card or certificate cannot be sold (i.e., it is nontransferable) and (2) the card or certificate cannot be used to purchase food or shelter items.<sup>49</sup> The penalty for violating the criteria is that the gift card or gift certificate is treated as unearned income, not ISM.<sup>50</sup>

This was a big trap for the unwary SNT trustee who thought that paying for food or shelter from a gift card or gift certificate was considered ISM (resulting in a limited ISM deduction), when in fact it was really considered unearned income (resulting in a dollar-for-dollar reduction in the beneficiary’s SSI benefits). For example, if an SNT trustee purchased a \$500 Visa card and a \$500 Best Buy card for the beneficiary and the beneficiary had a right to

<sup>46</sup> In a presentation about the POMS revisions, Kenneth A. Brown (formerly SSI Team Leader) suggested that these distributions would be permissible under POMS SI 01120.201F.4, Exceptions to the sole benefit rule for administrative expenses. Kenneth A. Brown, The New POMS (Pennsylvania Association of Elder Law Attorneys 11th Annual Winter Conference Feb. 23, 2019). This exception permits expenses “for reasonable compensation for (a) trustee(s) to manage the trust and reasonable costs associated with investment, legal, or other services rendered on behalf of the individual with regard to the trust.”

<sup>47</sup> POMS SI 01120.201I.1.e.

<sup>48</sup> True Link Financial, <https://www.truelinkfinancial.com> (accessed June 10, 2019).

<sup>49</sup> POMS SI 00830.522A.2.

<sup>50</sup> *Id.*

transfer both cards to someone else, the beneficiary would have \$980 in unearned income for the month and lose his or her SSI benefits.

Administrator-managed prepaid cards were established by companies to facilitate compliance with the gift card and gift certificate rules in the prior POMS. Because these cards are nontransferable, they have always met the first criterion in the prior POMS. SNT trustees would block payments for all food or shelter items, thus making the cards meet the second criterion. Several SSA field offices would verify that a card met the second criterion by reviewing card statements or an administrator's printout of the card's configuration to confirm that no purchases from vendors selling food or shelter items could be made.

In practice, however, this approach rendered the cards less useful for rural SNT beneficiaries. In order for an administrator-managed prepaid card not to be considered income or a resource to the beneficiary, the SNT trustee could not allow any purchases from vendors selling food or shelter items. In many rural areas, however, the majority of vendors are larger chain stores (e.g., Walmart, Target) that sell food items along with general wares.

### 3. Addition of SSA Policy on Administrator-Managed Prepaid Cards

The revised POMS adds administrator-managed prepaid cards as a new way to make SNT distributions and mentions the True Link card by name.<sup>51</sup> The revised POMS articulates policies that differ from (and are more easily met than) those applicable to gift cards and gift certificates. Under the revised POMS, if an administrator-managed prepaid card is nontrans-

ferable and the SNT trustee is the card's administrator (and thus has the authority to block access to cash withdrawals, purchases from specific vendors, and purchases in particular categories), the card is not considered income or a resource to the beneficiary.<sup>52</sup> "Whether the trust beneficiary receives income from trust disbursements *depends on the type of purchase reflected in the card statement.*"<sup>53</sup> SSA field offices are advised as follows.

Treat purchases in the following manner:

- If the administrator-managed prepaid card is used to obtain cash, such as at an ATM, the withdrawal counts as unearned income.
- If the administrator-managed prepaid card pays for food or shelter items, such as charges at a restaurant, the individual will generally be charged with ISM up to the PMV. [Under SSI program policies, receipt of ISM reduces SSI benefits because SSI is intended to meet claimants' food and shelter needs. POMS SI 00835 provides SSA policies related to ISM and calculation of ISM deductions].
- If the administrator-managed prepaid card pays for non-food, non-shelter items, such as for clothing at a department store, the individual usually does not receive income unless the item received would not be a totally or partially excluded non-liquid resource the following month.<sup>54</sup>

The revised POMS makes the administrator-managed prepaid card much more valuable. The test for compliance with SSA rules is not how the card is configured; it is that no cash withdrawals or food or shelter purchases appear on the card statement. If the SNT beneficiary's

<sup>52</sup> *Id.*

<sup>53</sup> *Id.* (emphasis added).

<sup>54</sup> *Id.*

<sup>51</sup> *Id.* at SI 01120.2011.1.e.

card statement shows no cash withdrawals, purchases of food or shelter items, or purchases of items countable as a resource under SSI program policies, the beneficiary is not considered to be receiving income or ISM and his or her SSI benefits will not be affected. Thus, since the revised POMS became effective, it is no longer necessary as a matter of policy to block purchases from vendors that sell food or shelter items.<sup>55</sup>

As long as an SNT beneficiary can be relied on to avoid making food or shelter (ISM) purchases using an administrator-managed prepaid card, the beneficiary's SSI benefits should not be affected even if he or she uses a card without spending restrictions. But if an SNT beneficiary does purchase food or shelter during the month with an administrator-managed prepaid card, the maximum reduction in the beneficiary's SSI is only \$277.

In order for the beneficiary to receive this favorable treatment, his or her card must be established with the SNT trustee as the owner of the account, which gives the trustee control over the card's configuration and use. The beneficiary should be a cardholder, but not an owner. If the beneficiary is the owner of the account, thus controlling card permissions, the funds on the card will be considered unearned income the month they are deposited on the card and countable resources beginning the month after deposit.<sup>56</sup>

55 A card also could be configured to allow cash withdrawals; however, this is not best practice. SNT beneficiaries often live under constant financial stress. The ability to make cash withdrawals might prove very tempting even at the expense of vital benefits later. Additionally, the ability to access cash might make the beneficiary a target for theft or exploitation.

56 POMS SI 01120.2011.1.e.

#### *F. Authorization of Transfers From a Special Needs Trust to an ABLE Account*

In 2014, Congress passed the Stephen Beck, Jr. Achieving a Better Life Experience (ABLE) Act,<sup>57</sup> under which states can create savings account programs to benefit certain persons with disabilities. Accounts under an ABLE program are subject to both an annual and total contribution limit; the total contribution limit is capped at the value allowed under the state's education savings plan (529 plan).<sup>58</sup> ABLE account balances of \$100,000 or less do not affect the accountholder's SSI eligibility and maintain the accountholder's Medicaid eligibility regardless of the account's balance, up to the state's 529 plan limit.<sup>59</sup> Funds withdrawn from an ABLE account and used within the same calendar month have no effect on SSI benefits eligibility.<sup>60</sup> ABLE accounts provide a valuable tool for eligible persons to hold — and exercise control over — resources while remaining eligible for vital means-tested public benefits.<sup>61</sup>

SSA previously published a POMS concerning the treatment of ABLE accounts;<sup>62</sup> however, it did not address whether accounts could be funded or increased by contributions from an SNT. Wary of interruptions to SNT beneficiaries' SSI benefits, some trustees were reluctant to make these SNT-to-ABLE account transfers. The revised POMS, however,

57 Pub. L. No. 113-295, 128 Stat. 4010 (2014).

58 20 U.S.C. § 529A(b)(2)(B) (annual contributions), 529A(b)(6) (total contributions).

59 *Id.* at § 103(a), 128 Stat. 4063.

60 See POMS SI 01130.740C.4 (distributions from ABLE accounts are not counted as income to the ABLE accountholder).

61 For a discussion of the policy goals driving adoption of the ABLE Act, see Nancy Susan Germany, *Disability, Poverty, and the Policy Behind the ABLE Act*, 14 NAELA J. 81 (2018).

62 POMS SI 01130.740, Achieving a Better Life Experience (ABLE) Accounts.

authorizes transfers from trusts to ABLE accounts. Under the revised POMS, a transfer to an ABLE account from a trust that is not counted as a resource to the trust beneficiary “generally will be considered” a third-party contribution; that is, a contribution by a person other than the ABLE accountholder.<sup>63</sup>

Funds transferred from an SNT to an ABLE account are not counted as income to the accountholder/SNT beneficiary.<sup>64</sup> An ABLE account provides an effective planning tool for an SNT trustee who does not want to trigger an ISM reduction by paying the beneficiary’s food and shelter costs directly from an SNT. If, instead, the SNT trustee distributes the monthly food and shelter costs to the ABLE account and the beneficiary pays for rent, food, and utilities from the ABLE account, an ISM reduction is not triggered. In 2019, this strategy is saving SNT beneficiaries \$3,324 a year in SSI benefits that otherwise would be lost due to ISM reductions.

*G. Requirement That Beneficiary of First-Party Special Needs Trust Be Disabled When Application for Means-Tested Benefits Is Made*

Both Title 42 U.S.C. §§ 1396p(d)(4) (A) and (C) define SNTs as trusts containing the assets of an individual “who is disabled (as defined [under SSA’s medical eligibility criteria]).”<sup>65</sup> Before April 2018, however, disability criteria always was evaluated when SSA reviewed the trust (i.e., when an SSI claimant’s SNT was funded or when an SNT beneficiary applied for SSI benefits). As amended in April 2018,<sup>66</sup> POMS SI 01120.203 in-

cluded a requirement that a person must be disabled at the time his or her first-party SNT was established. This requirement was new. In order to qualify an SSI claimant’s trust as an SNT, it had never been necessary before to prove that the SNT beneficiary was eligible for SSI as of the date his or her SNT was established.

Under the April 2018 POMS, in order for the trust to qualify as an individual SNT, “the individual whose assets were used to establish the [individual SNT] must be disabled for SSI purposes ... *at the time the trust was established.*”<sup>67</sup> This disability requirement also applied to pooled SNT accounts.<sup>68</sup> Under the April 2018 POMS, if the trust beneficiary was found not to meet the disability criteria, field offices were instructed to do the following:

evaluate the trust under instructions in [POMS] SI 01120.201, Trusts Established with the Assets of an Individual on or after 01/01/00]. Since the trust provisions take precedence over the transfer provisions (see [POMS] SI 01120.201D.5), depending on the terms of the trust, the trust may count as a resource or the transfer penalty may apply (see [POMS] SI 01150.121).<sup>69</sup>

POMS SI 01120.201 provides SSA’s general policies regarding self-funded trusts. Under these policies, self-funded trusts generally are countable for purposes of SSI financial eligibility. Irrevocable self-funded trusts are countable resources to the extent that payments, including dis-

63 *Id.* at SI 01130.740C.1.b.

64 *Id.* at SI 01120.201I.1.c, 01120.201I.1.h.

65 Emphasis added.

66 POMS SI 01120 TN 53 (Apr. 30, 2018).

67 *Id.* at SI 01120.203B.4 (emphasis added), 01120.203D.4 (B.4 requirements apply).

68 *Id.* at SI 01120.203D.2 (“[T]he individual whose assets were used to establish the trust account must be disabled for SSI purposes ... at the time the trust was established.”).

69 *Id.* at SI 01120.203B.4 (applicable to individual SNTs), 01120.203D.2 (applicable to pooled SNTs).

cretionary payments, may be made to or for the benefit of the grantor or the grantor's spouse.<sup>70</sup> SNTs are an exception to (or safe harbor from) the general trust rules.

The policy set forth in the April 2018 POMS was unfavorable to SNT beneficiaries. For various reasons, a person with a qualifying disability might not have an SSA disability determination dating back to when his or her SNT was established. First, medically eligible SSA applicants may not apply immediately for SSI benefits or may have difficulty navigating the application process successfully, resulting in delayed disability determinations or inaccurate disability onset dates. Second, an SSI application might not be made while a person is a minor, either because parental deeming rules<sup>71</sup> would cause the minor to be financially ineligible for SSI (thus, there would be no advantage in applying) or because SSA's medical eligibility requirements for minors are more restrictive than those applicable to adults.<sup>72</sup> The April 2018 requirements also were likely difficult for SSA field offices to apply. Field offices were asked to determine an SNT beneficiary's medical eligibility retroactively to when the trust was established. In some cases, this date could have been years before the beneficiary's SSI application was submitted.

Fortunately, on June 26, 2019, SSA issued POMS SI 01120 TN 58, which revised POMS SI 01120.203, expressly adopting the approach field offices previously used. Individuals must be disabled "as of the date on which the trust's resource status could affect the individual's SSI eli-

gibility" (rather than "as of the date on which the trust was established").<sup>73</sup> This revision better serves the interests of SSA field offices as well as SNT beneficiaries. Tasking field offices with verifying that an SNT beneficiary met SSA medical eligibility criteria *before* the beneficiary even applied for SSI was not the best use of SSA resources. There are compelling disincentives not to use an SNT unless necessary (e.g., the cost of establishing and administering an SNT, trustees' total discretion over SNT distributions). Thus, in practice, SNTs only are indicated for those persons medically eligible for means-tested benefits. Policing by SSA is not necessary.

POMS SI 01120.203B now includes two examples showing the application of the new policy:

**Example Scenario 1:** Mark, a special needs trust beneficiary whose trust was established in 2015, applies for SSI Aged benefits in 2019. Even though disability is not a requirement for SSI Aged benefits, we must develop disability as of Mark's SSI application date in 2019 for purposes of the Medicaid trust exception.

**Example Scenario 2:** Sally has a special needs trust that was established in 2010 when she was 10 years old. At the time, she was not eligible for SSI Child benefits because of her deeming parents' income and resources. However, she applies for SSI Adult benefits in 2018. We must develop disability as of Sally's SSI application date in 2018. 2010 is not relevant because the trust did not present as a resource issue until the SSI application date in 2018.<sup>74</sup>

In these examples, the medical eligibility determination is made once, as of the

<sup>70</sup> *Id.* at SI 01120.201D.2.a.

<sup>71</sup> 20 C.F.R. at § 416.1202(b)(1); POMS SI 01330.200.

<sup>72</sup> 20 C.F.R. at §§ 416.905 (adult), 416.906 (minor).

<sup>73</sup> POMS SI 01120.203B.4 (first-party SNTs), 01120.203D.2 (pooled SNTs).

<sup>74</sup> *Id.* (examples in § 01120.203D.2 apply to pooled SNTs).

date of the SSI application. It is not necessary for the SSA field office to verify that the applicant was medically eligible for SSI when the SNT was funded in order to find the trust qualifies as an SNT.

#### *H. Creation of a Better Procedure to Amend Disqualifying Special Needs Trusts*

SNTs can last for decades, through many changes in SSA administration, personnel, and policy. Once SSA receives and reviews a trust, should it ever re-evaluate the trust's terms for compliance with current policy? Are SSA's decisions regarding specific trusts (trust determinations) subject to reopening and revision? Who has standing to request reopening? Can defective trusts ever be cured? Several POMS revisions touch on these issues.

Regarding SSA's ability to review a previously evaluated trust, under revised POMS SI 01120.200L, field offices are directed not to re-evaluate trusts that have a resource determination unless there is:

- an amendment to the trust,
- a change of or clarification in policy that affects the resource determination,
- a request for reopening, or
- a situation [in which the field office becomes] aware of a prior erroneous determination.<sup>75</sup>

75 *Id.* at 01120.200L. Some of these instructions were provided previously in SSA administrative message (AM)-15032, issued in May 2015. AM-15032 directed field offices not to open determinations "unless there is new and material evidence, such as an amendment to the trust or a clarification or change in policy that may affect the trust resource determination." AM-15032.D. However, field offices were told, "Do not voluntarily reopen cases [involving certain court-established trusts] where we erroneously determined that the trust was countable . . . . The SSI claimant, recipient or representative payee must file an appeal or request reopening if he or she disagrees

The revised POMS policy serves SNT beneficiaries well. Absent a trust amendment or significant change in policy, annual SSI eligibility reviews or audits of trust disbursements should not prompt re-evaluation. Once SSA makes a determination that a trust is not countable and its beneficiary is eligible for SSI, post-eligibility determinations are subject to SSA's rules of administrative finality. Requests for reopening must be made in writing within the applicable time limit.<sup>76</sup> Reopening a matter can be requested for up to 1 year from the date of the determination or decision for any reason; up to 2 years from the date of the determination or decision for good cause; and indefinitely upon a finding of fraud or similar fault.<sup>77</sup>

Prior to the POMS revisions, the POMS generally applicable to reopening a matter governed who could request a reopening. Reopening a matter could be requested by the SSI applicant/recipient; his or her representative payee, guardian, or spouse; or a person eligible for an SSI underpayment.<sup>78</sup> The POMS revisions add SSA as a party able to request the reopening of a trust determination.<sup>79</sup>

Under the prior POMS, if a post-eligibility review determined a previously exempted trust to be a countable resource, SSA issued a notice that the trust was countable and a notice of overpayment of benefits for the lesser of either (a) the period of time the trust was noncompliant

with our determination." AM-15032C.3.

76 POMS SI 04070.015A.

77 *See id.* at SI 04070.010F.4. "Good cause" is defined at POMS SI 04070.010F.5. "Fraud" and "similar fault" determinations are discussed at POMS SI 04070.020.

78 *Id.* at SI 04070.10F.2.

79 *Id.* at SI 01120.202A.1.f. However, SSA's request also must be in writing and within the applicable time limit. *See id.*

or (b) 2 years (the time limit for SSA to reopen a determination for good cause and the maximum time limit for SSA to reopen a determination absent fraud). Moreover, the trust beneficiary would be ineligible for SSI prospectively for as long as the trust contained the faulted provision.

Defective trusts could then be amended, after which the SNT beneficiary again became eligible for SSI benefits. Unfortunately, this led to retroactive periods of ineligibility that could not be cured, as in the following example.

Darren is the beneficiary of a court-established SNT created in December 2015 with funds he received as a result of a legal settlement. Unfortunately, the trust contained a defective postmortem Medicaid reimbursement provision. When SSA reviewed the trust in January 2016, the field office erroneously found that the trust met the requirements applicable to SNTs and exempted it from resource counting. Darren therefore continued to receive SSI benefits until February 2018, when he met with his SSA field office for a redetermination appointment.

At redetermination, SSA reopened its original finding under the 2-year “good cause” administrative finality provisions. SSA determined that the trust had been a countable resource since February 2016 and suspended Darren’s SSI benefits beginning March 2018. In April 2018, the Medicaid reimbursement provision was amended and brought to compliance. SSA subsequently found the trust to be noncountable from May 2018 forward; however, Darren was subject to an overpayment for the benefits he received from February 2016 to April 2018 (the month the trust was amended).

The prior POMS contained only limited exceptions, providing a 90-day safe harbor to amend a noncompliant trust.

These exceptions applied only for violations of POMS policies related to trust provisions involving premortem trust terminations,<sup>80</sup> third-party travel expense provisions,<sup>81</sup> pooled trust management provisions,<sup>82</sup> and null and void clauses.<sup>83</sup> In these situations, the trust would continue to be exempt from resource counting if corrected within 90 days after SSA notified the beneficiary that the trust had a faulted provision.

The revised POMS extends the 90-day safe harbor to all situations in which SSA previously determined a trust to be exempt from resource counting but later determined it countable due to a change in policy, a policy clarification, or SSA’s reopening of a prior erroneous determination.<sup>84</sup> The 90-day period begins on the day SSA informs the SNT beneficiary or his or her representative payee that the trust contains provisions SSA believes make it countable as a resource.<sup>85</sup> Only one 90-day period is available; however, the field office may grant an “extension request ... for good cause if the recipient requests it and provides evidence that the disqualifying issue cannot be resolved within the 90-day period ... .”<sup>86</sup> As in pre-

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80 *Id.* at SI 01120.199A.2 (“A trust that was previously determined to be excepted from resource counting [as an SNT] shall continue to be excepted from resource counting, provided the trust is amended to conform with the requirements of this section within 90 days.”).

81 Prior POMS SI 01120.201E.2.d.

82 POMS SI 01120.225A.2.

83 *Id.* at SI 01120.227A.2.

84 *Id.* at SI 01120.200K.2 (self-funded trusts established before January 1, 2000, and supplemental needs trusts funded by third parties), 01120.201K.2 (self-funded trusts established on or after January 1, 2000).

85 *Id.*

86 *Id.* at SI 01120.201K.2.d (applicable to self-funded trusts established on or after January 1,

vious safe harbors, the trust is not counted as a resource during the 90-day period and will not be counted as a resource at all if corrected within the 90-day period, plus any extension.<sup>87</sup>

To take advantage of SSA's 90-day right-to-amend provision, all practitioners should send SSA a copy of the SNT document by certified mail to ensure that SSA receives a copy and obtain proof that it did.<sup>88</sup> It is not uncommon for SSA to fail to keep a record that it received an SNT. Failure to provide SSA with a copy of the SNT document means that the SNT beneficiary will be subject to an overpayment if SSA later finds an error in the document or implements a new policy. For third-party SNTs, the revised POMS states that unfunded third-party SNTs should not be sent to SSA until they are actually funded.<sup>89</sup>

### III. Incorporation of Supplemental Security Income Trust Monitoring System Protocols and Pooled Trust Precedents

Over time, increased use of SNTs and the prevalence of pooled SNTs highlighted a problem: SSA field offices were not issuing uniform decisions regarding SNTs. Field offices often were not aware of or misapplied SNT criteria. A pooled trust might

have been accepted in one region as valid but considered defective and found countable in another. In response to this variability, SSA developed a systematic process to review trust documents, now delineated in revised POMS SI 01120.200L.

As described in the revised POMS, SSA now has three levels of trust review:

1. Field office claim specialists collect necessary documentation and make a preliminary determination as to whether a trust is countable.<sup>90</sup> This information is forwarded to the appropriate regional trust review team for review.<sup>91</sup>
2. Once the field office's decision is reviewed and approved, a trust determination is processed by the field office claims specialist.<sup>92</sup>
3. The beneficiary receives a letter regarding his or her SSI eligibility. If the trust is counted as a resource and thus affects the beneficiary's eligibility, the results of the trust determination are disclosed in the eligibility notice.

Regional trust leads (RTLs) are senior members of the regional trust review teams. RTLs are tasked with evaluating new pooled trusts, conducting re-evaluations requested by field offices, and evaluating appeals.<sup>93</sup> In conjunction with the regional chief counsel, RTLs develop precedents for pooled trusts originating in their respective regions, which, once made, are the basis for acceptance of the pooled trust nationwide.<sup>94</sup> RTLs may re-

2000), 01120.200K.2.c (applicable to supplemental needs trusts funded by third parties and to self-funded trusts established before January 1, 2000).

87 *Id.* at SI 01120.201K.2.e (applicable to self-funded trusts established on or after January 1, 2000), 01120.200K.2.d (applicable to supplemental needs trusts funded by third parties and to self-funded trusts established before January 1, 2000).

88 Some SSA field offices demanded the original SNT document, but the revised POMS expressly states that an original is unnecessary. *Id.* at SI 01120.202A.1.b.

89 *Id.* at SI 01120.200J.1.b.

90 *Id.* at SI 01120.200L.1, 01120.202B.1.

91 *Id.* at SI 01120.200L.1.a, 01120.202B.1.a.

92 *See id.* at SI 01120.200L.1.b, 01120.202B.1.b.

93 *Id.* at SI 01120.200L.3, 01120.202B.3.

94 *Id.* at SI 01120.202B.3, 01120.202C. Under POMS SI 01120.202B.2, regional trust review team members refer pooled trusts with a precedent established in another region to the regional trust lead, who then "[refers] the trust to the appropriate region."



quest guidance from SSA's central office or regional chief counsel.<sup>95</sup>

#### IV. Incorporation of Previously Published Administrative and Emergency Messages

The revised POMS incorporates several previously published AMs and EMs that announced substantive policy changes, as follows.

- **Manual notices issued when trusts are found countable must contain certain information.** For many years, SSA required field offices to manually draft an individual notice to inform a claimant that SSA found his or her trust countable, rendering the claimant ineligible for SSI.<sup>96</sup> The revised POMS incorporates EM-16012, a 2016 message that presents the information required to appear in these notices. The message was issued after SSA found that the notices field offices were issuing “sometimes provide[d] incomplete information about ineligibility due to excess resources that include a countable trust.”<sup>97</sup> Under the revised POMS, the notice must “specify using free-form text each reason the trust is countable (that is, why it does not meet the relevant exception(s) or requirements).”<sup>98</sup> The notice also must cite the section of the trust (or joinder agreement) that is faulted, the POMS citation that contains the policy requirements alleged not to have been met, and a sentence indicating where the POMS appears on-

line.<sup>99</sup> In the author's experience, many SSA field offices are still noncompliant with this requirement and SSA faces no real penalty for failing to comply.

- Individuals are permitted to establish their own individual self-settled SNTs. From 1993 (when the SNT exception was created) until enactment of the 21st Century Cures Act on December 13, 2016,<sup>100</sup> the statutory language of Title 42 U.S.C. § 1396p(d)(4)(A) permitted individual self-settled SNTs to be established by a parent, grandparent, legal guardian, or a court. Persons with disabilities were not listed and thus were unable to establish their own individual SNTs. The statute was changed to allow persons with disabilities to establish their own individual SNTs. Revised POMS SI 01120.203, Exceptions to Counting Trusts Established on or after January 1, 2000, incorporates this change, which SSA originally discussed in EM-16053, a message it issued after enactment of the Act. POMS SI 01120.203C and 01120.203I.2 add “the individual [with special needs]” as a party able to establish an SNT. POMS SI 01120.203C criteria for individual SNTs are supplemented by SI 01120.203B.
- **A Court-Established SNT Must Meet Certain Requirements.** A court is one of the entities that is allowed to establish (or fund) a first-party SNT under Title 42 U.S.C. §§ 1396p(d)(4)(A) and (C). AM-15032, issued May 2015, provided guidance as to what qualified as a court-established trust; this guidance has been incorporated into revised POMS SI 01120.203B.8. Under the revised POMS, in order for an SNT

<sup>95</sup> *Id.* at SI 01120.200L.3, 01120.200B.3.

<sup>96</sup> *Id.* at SI 01120.204A (“A manual notice is required whenever an individual ... is ineligible due to excess resources and those resources include a trust.”).

<sup>97</sup> Soc. Sec. Administration, *Emergency Message (EM)-16012 § B* (effective Mar. 2, 2016).

<sup>98</sup> POMS SI 01120.202A.1.g.

<sup>99</sup> *Id.*

<sup>100</sup> Pub. L. No. 114-255 (2016).

to be considered court established, the SNT must be either (a) established by the court or (b) prospectively ordered by the court to be established.<sup>101</sup> Retroactive approval of an already-executed trust document is not sufficient.<sup>102</sup> A trust is established by the court even if the order is issued in response to a petition; it is not necessary for the court to act *sua sponte*.<sup>103</sup> Practitioners should make sure that a first-party SNT for court establishment is not already signed or executed when submitted.

## V. Articulations of Prevailing Agency Policy

The revised POMS also includes a variety of express statements of policy that special needs practitioners will consider helpful.

- **ABLE accounts are not trusts.** ABLE accounts are not trusts subject to SSA's trust resource-counting and exceptions criteria.<sup>104</sup> For purposes of SSI eligibility, amounts up to \$100,000 held in an ABLE account are considered an excluded resource belonging to the account holder.<sup>105</sup>
- **Registered or titled purchases made by an SNT must be held in the name of the beneficiary or the trust.** Items purchased by the SNT must be held in the name of the beneficiary or the trust, unless not permitted under state

law.<sup>106</sup> However, if permitted by the beneficiary's state Medicaid program, a car may be titled in a third party's name as long as the SNT holds a lien on the car, thus preventing its sale by the third party.<sup>107</sup> The lien prevents the purchase from being considered a gift to the third party,<sup>108</sup> which violates the sole benefit rule.

- **Military Survivor Benefit Plan (SBP) payments received by an SNT are not counted as income to the trust beneficiary.** An assignment of SBP payments to an SNT is considered irrevocable; therefore, SBP payments received by the trust are not counted as income to the trust beneficiary.<sup>109</sup>
- **Court-ordered payments of income to an SNT are not considered income to the trust beneficiary.** Court orders directing legally assignable payments to an SNT are considered irrevocable; therefore, payments received by the trust are not considered income to the trust beneficiary.<sup>110</sup> Structured settlement annuity payments, child support, and alimony are legally assignable payments as long as the assignment is completed before the SSI recipient's 65th birthday.
- **SSI payments received by an SNT beneficiary are not counted as income if they are later deposited into**

101 POMS SI 01120.203B.8.

102 See *id.* at SI 01120.203B.8.d (The court's order purportedly establishing a previously executed trust "simply approved the existence of the already established special needs trust.").

103 *Id.* at SI 01120.203B.8 ("The court order establishes the trust, not the individual's petition. Petitioning a court to establish a trust is not establishment by an individual.").

104 *Id.* at SI 01120.200C.1.c.

105 See *id.* at SI 01130.740D.1.

106 *Id.* at SI 01120.201F.3.a.

107 *Id.*

108 *Id.*

109 *Id.* at SI 01120.200G.1.d, 01120.201J.1.e.

110 *Id.* at SI 01120.200G.1.d ("A legally assignable payment that is assigned to a trust or trustee is income for SSI purposes, to the individual entitled or eligible to receive the payment, *unless* the assignment is irrevocable. We consider assignment of payment by court orders to be irrevocable." (emphasis in original)). Some payments are not legally assignable. See *id.* at SI 01120.200G.1.c.

**an SNT.** SSI payments received by an SNT beneficiary and later deposited into an SNT are not counted as unearned income to the beneficiary when deposited to the trust.<sup>111</sup> SSI and Social Security Disability Insurance (SSDI) benefits cannot be directly deposited into an SNT.<sup>112</sup>

- **Disbursements to SNT beneficiary's debit card are unearned income.** Disbursements from the SNT to the beneficiary's personal debit card are treated as unearned income to the beneficiary in the month the disbursement is made.<sup>113</sup>
- **An agent under a power of attorney may fund an SNT using the principal's assets.** If state law allows (and the principal confers authority to do so), an agent under a power of attorney may use his or her authority as agent to transfer the principal's assets to an SNT established for the principal.<sup>114</sup>

## VI. Conclusion

Many of the substantive changes to SSA policy articulated in the 2018 SNT POMS revisions are advantageous for beneficiaries. A number of the policy changes are designed to provide a checklist for SSA field office review and to deter field offices from applying extraneous criteria in making determinations. The modification of the sole benefit rule clarifies that third parties may receive some collateral benefit from an SNT disbursement as long as the disbursement primarily benefits the beneficiary. The revised POMS also expressly permits distributions by an SNT trustee to pay the beneficiary's companion services and caregiving expenses and advises

field offices regarding what considerations are (and are not) relevant in evaluating these distributions.

The POMS revisions also include policy changes liberalizing SNT distribution criteria. SSA now allows an SNT trustee to pay expenses for third parties to accompany the trust beneficiary during travel when the third parties provide assistance necessary to the beneficiary. This is a huge step forward for SNT beneficiaries and their advocates: The prior POMS policy only allowed SNT payment of third-party travel expenses for the beneficiary's medical travel, making recreational travel impossible for many beneficiaries requiring assistance. Furthermore, the revised POMS endorsement of administrator-managed prepaid cards and SNT-to-ABLE transfers simplifies SNT administration and increases trust beneficiaries' independence and flexibility.

The revised POMS favorably modifies SSA policies regarding SNT resource determinations and options for correcting SNTs it finds to be defective. The revised POMS limits SSA's right to reopen trust determinations and limits re-evaluations of previously accepted trusts. This change provides SNT beneficiaries with added security that future POMS changes will not affect their SSI eligibility. Similarly, the expansion of the 90-day right to amend all trusts previously accepted as SNTs gives practitioners confidence that any future changes to the POMS can be managed without interruptions in the beneficiary's eligibility.

The 2018 SNT POMS revisions make many positive changes; however, the revised provision permitting SNTs to pay travel expenses for third parties who do not accompany the beneficiary is ambiguous, which may result in SNT trustees being more conservative and field offices

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111 *Id.* at SI 01120.200G.1.d.

112 *Id.* at SI 01120.201J.1.f.

113 *Id.* at SI 01120.201I.1.a.

114 *Id.* at SI 01120.203B.9.

adopting different interpretations of what is (and is not) acceptable.

Despite this minor issue, the overall effect of the 2018 SNT POMS revisions is a huge boon to persons with disabilities and the professionals who advise them. SSA has indicated that it is not done making changes to the POMS in the context of SNTs. Stay tuned for additional changes.

**Case Note**  
***Sveen v. Melin*, 138 S. Ct. 1815 (2018)**

*By Elizabeth J. Hartery, Esq.*

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## I. Introduction

In recent years, the prevalence of revocation-on-divorce statutes, in which dissolution or annulment of a marriage automatically revokes provisions related to a former spouse in an instrument executed prior to the event, has been increasing. Most states have enacted laws that provide for automatic revocation of dispositions for a former spouse in a will executed prior to divorce.<sup>1</sup> With the rise of will substitutes, similar issues have arisen with instruments governing nonprobate transfers, including revocable trusts, life insurance policies, and retirement accounts. In response to this trend and similar statutes enacted by multiple states,<sup>2</sup> the 1990 revisions to the Uniform Probate Code (UPC) expanded the application of its revocation-on-divorce provision from wills to revocable living trusts, life insurance policies, retirement accounts, transfer-on-death accounts, and similar accounts.<sup>3</sup> The drafters of the UPC revisions explained that this expansion was an attempt to “unify the law of probate and nonprobate transfers.”<sup>4</sup> By 2018, 26 states had adopted the UPC revocation-on-divorce provision or a similar statute.<sup>5</sup>

Most courts agree that there is no violation of the Contracts Clause of the U.S. Constitution when these laws are applied prospectively — that is, when the laws are

applied to life insurance and similar contracts entered into after enactment of the laws.<sup>6</sup> But *Sveen v. Melin* answers a different question: Does the retroactive application of revocation-on-divorce statutes to contracts entered into prior to enactment of the statutes violate the Contracts Clause?

## II. Facts of the Case and Procedural Posture

The underlying facts of *Sveen* are simple. In 1997, Ashley Sveen bought a life insurance policy insuring his life, and later that year he married Kaye Melin.<sup>7</sup> In 1998, Sveen named Melin as primary beneficiary on the policy and named his two adult children from a previous marriage as contingent beneficiaries.<sup>8</sup> In 2002, Minnesota amended its revocation-on-divorce statute, which previously had only applied to wills executed prior to dissolution or annulment of marriage, to include “any revocable: (1) disposition, beneficiary designation, or appointment of property made by an individual to the individual’s former spouse . . . .”<sup>9</sup> Sveen and Melin divorced in 2007, but Sveen never changed the beneficiary designations on his life insurance policy.<sup>10</sup> When Sveen died in 2011, the life insurance company filed an interpleader requesting a judgment on who should be the recipient of the life insurance proceeds: Melin or Sveen’s children.<sup>11</sup>

Sveen’s children moved for summary

1 *Sveen v. Melin*, 138 S. Ct. 1815, 1819 (2018).

2 See e.g. Mich. Comp. Laws Ann. § 552.101 (West); Ohio Rev. Code Ann. § 1339.63 (Lexis); Okla. Stat. Ann. tit. 15, § 178 (West); Tex. Fam. Code Ann. §§ 3.632–633 (Vernon).

3 Unif. Prob. Code § 2-804 (2013). The provision also automatically revokes similar designations involving an ex-spouse’s relatives (e.g., in-laws) and severs joint tenancy between spouses, changing property ownership to tenants in common.

4 *Sveen*, *supra* n. 1, at 1819.

5 *Id.* at 1819 n. 1.

6 See e.g. *Paronese v. Midland Nat. Ins. Co.*, 550 Pa. 423, 434, 706 A.2d 814, 819 (1998); *id.* at 1826.

7 *Sveen*, *supra* n. 1, at 1821.

8 *Id.*

9 Minn. Stat. § 524.2-804, subdiv. 1 (2002).

10 *Sveen*, *supra* n. 1, at 1821.

11 *Metro. Life Ins. Co. v. Melin*, 2016 WL 9000457 at \*2 (D. Minn. Jan. 7, 2016).

judgment, contending that the revocation-on-divorce statute automatically revoked the policy's designation of Melin as primary beneficiary, leaving Sveen's children to take the proceeds. Melin, on the other hand, asserted that she should receive the proceeds based on the argument that the retroactive application of the Minnesota statute violated the Contracts Clause of the Constitution, which "prohibits any state Law impairing the Obligation of Contracts."<sup>12</sup>

The U.S. District Court for the District of Minnesota granted summary judgment for the Sveen children and awarded them the insurance proceeds.<sup>13</sup> The court reasoned that the beneficiary of a life insurance policy has no vested interest in the policy until the insured dies.<sup>14</sup> Without a vested interest, Melin had no "protectable contractual relationship, and thus [there was] no impairment of contract."<sup>15</sup>

The U.S. Court of Appeals for the Eighth Circuit reversed and remanded.<sup>16</sup> The Eighth Circuit was bound by its decision in *Whirlpool Corp. v. Ritter*, in which the court found that a similar revocation-on-divorce statute in Oklahoma violated the Contracts Clause when applied retroactively.<sup>17</sup> The facts in *Whirlpool* were nearly identical to those in *Sveen*, and the Eighth Circuit found that in the *Whirlpool* case "[the policyholder] was entitled to expect that his wishes regarding the insurance proceeds, as ascertained pursuant to this then-existing law, would be

effectuated."<sup>18</sup> The court found that the policyholder's ability to opt out of the law by redesignating his now ex-wife as the beneficiary of the policy did not resolve the constitutional issue because the statute's effect still "directly alter[ed]" expectations of the policyholder.<sup>19</sup>

### III. Circuit Split

The U.S. Supreme Court granted certiorari in *Sveen* to resolve a circuit split on the question presented. For more than 25 years, courts had disagreed about whether retroactive application of the UPC revocation-on-divorce provision and similar statutes to contracts made prior to enactment of the statutes violated the Contracts Clause.

When analyzing potential Contracts Clause violations, courts must consider several factors. First, the question is whether the law "operated as a substantial impairment of a contractual relationship."<sup>20</sup> Factors include "the extent to which the law undermines the contractual bargain, interferes with a party's reasonable expectations, and prevents the party from safeguarding or reinstating his rights."<sup>21</sup> If a court finds substantial impairment of a contractual relationship, the court must then decide whether the law was "drawn in an appropriate and reasonable way to advance a significant and legitimate public purpose."<sup>22</sup>

Several decisions finding the retroactive application of revocation-on-divorce statutes to be in violation of the Contracts Clause focus on the expectations of the policyholder. The decision in the *Whirl-*

12 *Sveen*, *supra* n. 1, at 1821, quoting U.S. Const. art. I, § 10, cl. 1 (internal quotations omitted).

13 *Metro. Life Ins. Co. v. Melin*, 2016 WL 9000457.

14 *Id.* at \*3.

15 *Id.*

16 *Metro. Life Ins. Co. v. Melin*, 853 F.3d 410 (2017).

17 929 F.2d 1318 (8th Cir. 1991).

18 *Id.* at 1322.

19 *Id.* at 1323.

20 *Sveen*, *supra* n. 1, at 1821–1822, citing *Allied Structural Steel Co. v. Spannaus*, 438 U.S. 234, 244 (1978).

21 *Id.* at 1822.

22 *Id.*

*pool* case and the Eighth Circuit's decision regarding *Sveen* are examples. Similarly, the Pennsylvania Supreme Court found that the state's revocation-on-divorce statute as applied retroactively "operated as a substantial impairment of a contractual relationship" because "[s]election of a beneficiary is the entire point of a life insurance policy."<sup>23</sup> The Court then found that the public purpose served and the way in which the statute was drawn were not enough to overcome the "severe, virtually total" contractual impairment by the statute at issue.<sup>24</sup>

On the other side of the debate, a few intertwined themes emerge. One common argument, advanced by the Minnesota District Court in *Sveen*, involves the issue of when the beneficiary's contractual rights actually vest. The Ninth Circuit recently discussed the issue in a case, finding that an Arizona revocation-on-divorce statute as applied to the beneficiary designations of an individual retirement account (IRA) did not violate the Contracts Clause when applied retroactively.<sup>25</sup> In that case, the court focused on the question of whether the former spouse possessed a contractual right with which the retroactive application of the statute would interfere.<sup>26</sup> Answering in the negative, the court found that the crux of the IRA contract was the company's obligation to pay the decedent's designated beneficiary but that "the beneficiary designation itself was not a contractual term."<sup>27</sup> Because the beneficiary designation could be altered up until

the decedent's death, no third-party right to the IRA could vest until the decedent's death. In turn, because the ex-spouse's expectancy interest was extinguished upon divorce, the ex-spouse "never possessed a vested contractual right, [so] she suffered no contractual impairment."<sup>28</sup>

A second argument is that the beneficiary's contractual rights cannot be impaired by the revocation-on-divorce statute because the beneficiary is not a party to the contract at issue. As one court put it, "[The beneficiaries] are merely third-party beneficiaries to the contract . . . . As such, [they] fail to satisfy the threshold requirement of a contract clause claim, namely that there is a contractual relationship."<sup>29</sup>

Other courts distinguish between contractual and donative transfer components of the underlying contract. In a Tenth Circuit case, the court cited a statement issued by the UPC Joint Editorial Board after the *Whirlpool* case was decided stating that the *Whirlpool* decision was "manifestly wrong."<sup>30</sup> The statement indicated that only the donative transfer component of the contract (the beneficiary designation) is affected by revocation-on-divorce statutes but that the contractual component (the requirement that the insurance company pay out the agreed-upon proceeds at the agreed-upon time) is "appropriately . . . protect[ed] against legislative interference."<sup>31</sup> According

23 *Parsonese v. Midland Nat. Ins. Co.*, 550 Pa. 423, 432, 706 A.2d 814, 818 (1998).

24 *Id.*

25 *Lazar v. Kroncke*, 862 F.3d 1186, 1200 (9th Cir. 2017), cert. denied, 138 S. Ct. 2647, 201 L. Ed. 2d 1049 (2018).

26 *Id.*

27 *Id.*

28 *Id.*

29 *In re Estate of DeWitt*, 54 P.3d 849, 859 (Colo. 2002).

30 *Stillman v. Teachers Ins. & Annuity Assn. College Ret. Eqs. Fund*, 343 F.3d 1311, 1322 (10th Cir. 2003).

31 Jt. Editorial Bd. for Unif. Prob. Code, *Statement Regarding the Constitutionality of Changes in Default Rules as Applied to Pre-existing Documents*, 17 Am. College of Trust & Est. Counsel Notes 161 (1991).



to the statement, the donative transfer component “raises no Contracts Clause issue” and “there is never a suggestion that the insurance company can escape paying the policy proceeds that are due under the contract.”<sup>32</sup>

With this background in mind, we turn to the U.S. Supreme Court’s ruling in *Sveen*.

#### IV. *Sveen v. Melin* Majority Opinion

In an opinion written by Justice Elena Kagan, the U.S. Supreme Court ruled 8-1 that the Minnesota revocation-on-divorce statute did not violate the Contracts Clause as applied in the *Sveen* case.<sup>33</sup> The Court ended its analysis after considering the first factor of the test for determining a Contracts Clause violation — whether the law “operated as a substantial impairment of a contractual relationship.”<sup>34</sup> The Court found that the revocation-on-divorce statute at issue does not substantially impair pre-existing contractual relationships, based on the three factors to be considered in making this determination.

First, the Court found that the Minnesota revocation-on-divorce statute does not undermine the contractual relationship and, in fact, often does the opposite.<sup>35</sup> The Court assumed that the majority of policyholders would not want an ex-spouse to benefit from life insurance proceeds, just as they would not want an ex-spouse to benefit under their wills. Accordingly, “the insured’s failure to change the beneficiary after a divorce is more likely the result of neglect than choice.”<sup>36</sup>

Although the Court admitted that the default rule established by the Minnesota revocation-on-divorce statute clearly affects the contract that was made prior to enactment of the statute, it also tends to “support, rather than impair, the contractual scheme.”<sup>37</sup>

Second, the Court found that the Minnesota statute is unlikely to interfere with a party’s reasonable expectations because divorce courts have long had the power to make similar modifications to pre-existing contracts. Because of this broad authority to divide property and alter contractual relationships that exist prior to divorce, including beneficiary designations on life insurance policies, retirement accounts, and similar property, the policyholder has never had a guarantee that the contracts existing prior to divorce will remain unchanged after the event. Accordingly, a policyholder’s “reliance interests are next to nil.”<sup>38</sup>

Third, and perhaps most important for the majority of the Court, the law does not prevent a party from safeguarding or reinstating his or her rights because the policyholder has the ability to undo the default rule with minor effort, simply by sending a letter to the insurance company reaffirming the beneficiary designation that was in place prior to divorce.<sup>39</sup> In multiple cases over the past two centuries, the Supreme Court has held that laws imposing “such minimal paperwork burdens” do not violate the Contracts Clause, even when applied retroactively.<sup>40</sup> The opinion compares the requirement in this case to those related to the recording of a

32 *Id.*

33 *Sveen*, *supra* n. 1. Justice Neil M. Gorsuch filed a dissenting opinion.

34 *Id.* at 1821–1822, citing *Allied Structural Steel Co.*

35 *Id.* at 1823.

36 *Id.*

37 *Id.* at 1822.

38 *Id.* at 1823.

39 *Id.*

40 *Id.*

deed or mortgage or to statutory notice.<sup>41</sup>

Taking this comparison one step further, the Court pointed out that the consequence of failing to reaffirm one's beneficiary designation is not nearly as harsh as forfeiting all rights to a particular piece of property.<sup>42</sup> The insurance company is still required to pay out the policy proceeds, and the contingent beneficiary named on the policy — rather than the primary beneficiary (i.e., the ex-spouse) — becomes the recipient.<sup>43</sup> Although acknowledging that “redirection of proceeds is not nothing,” the Court nonetheless found that, based on precedent, such redirection falls short of a Contracts Clause violation.<sup>44</sup>

## V. Justice Gorsuch's Dissent

Although outnumbered 8-1, Justice Gorsuch made several points in his dissent that are worth discussing. First, he objected to the Court's characterization of the retroactive application of revocation-on-divorce statutes as an insubstantial impairment to the policyholder's contractual rights. As he and Melin put it, “the choice of beneficiary is the whole point” of a life insurance policy.<sup>45</sup> As such, the fact that Minnesota's revocation-on-divorce law acts to change the beneficiary designation presents about as substantial an impairment to the life insurance contract as one could imagine.

The dissent also pointed out a seeming paradox in the majority's reasoning. The purpose of the revocation-on-divorce statute and others like it is to ensure that policyholders who forget to change their beneficiary designations when they get

divorced are protected from their negligence; the assumption is that most policyholders do not pay enough attention to their beneficiary designations to ensure that they match the policyholders' aims at any given time. At the same time, however, the Court assumes that policyholders do pay enough attention to their beneficiary designations to ensure that if they *do* want their ex-spouses to benefit from their policies, they reaffirm that designation in order to carry it forward. According to the dissent, “The statute cannot simultaneously be necessary because people are inattentive to the details of their insurance policies and constitutional because they are hyperaware of those same details.”<sup>46</sup>

Justice Gorsuch also questioned the majority's assumption that most policyholders would prefer the default rule put in place by the revocation-on-divorce statute.<sup>47</sup> He listed various reasons a policyholder may prefer to maintain an ex-spouse as beneficiary of a policy, including “a sense of obligation, remorse, or continuing affection, or to help care for children of the marriage that remain in the ex-spouse's custody.”<sup>48</sup>

Finally, moving to the second part of the Contracts Clause test, the dissent looked to the reasonableness of the Minnesota statute, citing case law indicating that “a substantial impairment is unreasonable when an evident and more moderate course would serve [the state's] purposes equally well.”<sup>49</sup> Justice Gorsuch listed several alternatives that would have been less intrusive to the policyholder, such as (a) a requirement that divorce

41 *Id.* at 1824–1825.

42 *Id.* at 1825.

43 *Id.*

44 *Id.*

45 *Id.* at 1828 (internal quotations omitted).

46 *Id.* at 1830.

47 *Id.* at 1828–1829.

48 *Id.*, quoting Brief for United States as *Amicus Curiae* in *Hillman v. Maretta*, O.T. 2012, No. 11-1221, p. 28.

49 *Id.* at 1829.

courts or divorce attorneys confirm parties' beneficiary designations as part of the divorce process; (b) a requirement that insurance companies "notify policyholders of their right to change beneficiary designations"; or (c) a campaign in which the legislature itself informs policyholders of this right.<sup>50</sup>

## VI. Key Takeaways

For practitioners, including family law, elder law, and estate planning attorneys, the *Sveen* case highlights the importance of encouraging clients to review beneficiary designations whenever a major life event occurs. At least half the states have enacted revocation-on-divorce statutes in some form; the remainder have not. Whatever the default rule in a practitioner's state, it is highly likely that at least some clients would not want that rule (or lack thereof) to affect their estate plans.

From a legislative and advocacy standpoint, the points made in the dissent are worth considering in discussions of the retroactive and prospective application of revocation-on-divorce statutes. For example, the UPC revocation-on-divorce provision and similar statutes rely on historic assumptions about policyholder preferences, but it is unclear whether any empirical evidence backs up these assumptions. It may be wise to gather additional data to objectively ascertain how divorcing spouses actually behave and what their preferences are.

Even if the general assumption about policyholder intent is correct, the *Whirlpool* court suggested that the preference to leave ex-spouses out "is certainly not a universal truth" and such statutes may be just as likely to "effectuate or frustrate

[the policyholder's] intent."<sup>51</sup> To ensure that all policyholders are well served, notice requirements such as those discussed in the dissent may make it more likely that the intent of each individual policyholder is honored. Notice requirements and revocation-on-divorce statutes are not necessarily mutually exclusive options; Virginia's revocation-on-divorce statute, for example, includes a provision that requires divorce decrees to include language alerting the parties that beneficiary designations naming the ex-spouse may be automatically revoked.<sup>52</sup>

Finally, it remains unclear whether the Contracts Clause would prohibit applying this type of law retroactively if the law were enacted after, rather than before, the parties divorced. With the exception of *Stillman*, most cases involving retroactive application of revocation-on-divorce statutes follow the same chronology: the policy is purchased, the statute is enacted, and the parties divorce. Based on the reasoning in *Stillman* and similar cases, it could be argued that because a beneficiary's interests do not vest until the policyholder's death, there would be no Contracts Clause violation even if the revocation-on-divorce statute were enacted after the policyholder's divorce was final. The Supreme Court's decision in *Sveen* does not follow that line of reasoning; therefore, it leaves this particular question unanswered.

51 929 F.2d at 1323.

52 Va. Code Ann. § 20-111.1 (2012). Note, however, that the language gives clearer instructions about revoking a designation for an ex-spouse than it does about maintaining the designation.



**Case Note**  
***Disability Law Center of Alaska v. Davidson***

*By Adriona Horton*

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## I. Introduction

On March 28, 2018, the U.S. District Court for the District of Alaska, in *Disability Law Center of Alaska v. Davidson*<sup>1</sup> denied defendants' motion for summary judgment on plaintiffs' three Title 42 U.S.C. § 1983 claims alleging that defendants were in violation of federal Medicaid law by failing to do the following:

1. Provide adequate notice on how to apply for and access applied behavioral analysis (ABA) therapy under the Alaska early and periodic screening, diagnostic, and treatment (EPSDT) program;
2. Reimburse for ABA under the program; and
3. Provide ABA services under the program with reasonable promptness.<sup>2</sup>

Plaintiffs' cross-motion for summary judgment was granted as to their claim that defendants were required to provide ABA services as part of the state EPSDT program and that the Centers for Medicare & Medicaid Services (CMS) was not authorized to relieve them of that obligation.<sup>3</sup>

## II. Background

State plans for medical assistance under federal Medicaid law must comply with the requirements set out in Title 42 U.S.C. § 1396a.<sup>4</sup> This section specifically references services that must be provided, including "[EPSDT services] ... for individuals who are eligible for the [Medicaid state] plan and who are under the age of 21."<sup>5</sup> EPSDT services must be provided with "reasonable promptness," and people

who are eligible must be informed of the EPSDT program.<sup>6</sup> The Alaska Medicaid State Plan included an EPSDT program, but it did not furnish ABA through the program.<sup>7</sup>

ABA therapy measures and evaluates observable behaviors, and it may help autistic children improve their cognitive function, language skills, and adaptive behaviors.<sup>8</sup> Alaska classified ABA therapy as an intensive active treatment (IAT) and provided it under two of its state Medicaid waiver programs.<sup>9</sup>

On July 7, 2014, CMS issued a bulletin stating that all children with autism spectrum disorder (ASD) are required to receive EPSDT screenings as early as possible.<sup>10</sup> CMS stated, "The role of states is to make sure all covered services are available as well as to [en]sure that families of enrolled children, including children with ASD, are aware of and have access to a broad range of services to meet the individual child's needs ... ." <sup>11</sup>

## III. Claims of Violation of the Medicaid Act

In September 2014, CMS answered questions that were raised by the states regarding the July 7, 2014, bulletin.<sup>12</sup> CMS said that ABA services were not per se mandated for individuals under 21 because ABA is just one treatment for ASD.<sup>13</sup> Because other treatments are avail-

1 2018 WL 1528158 (D. Alaska (March 28, 2018)).

2 *Id.* at \*5, 9.

3 *Id.* at \*9–10.

4 42 U.S.C. § 1396a(a)(10)(A) (2019).

5 *Id.* at § 1396d(a)(4)(B).

6 *Disability Law Center of Alaska, supra* n. 1, at \*1 (quoting J.E. Wong, 125 F. Supp. 3d 1099, 1104 (D. Haw. 2015)).

7 *Id.* at \*1.

8 *Id.* at \*2.

9 *Id.*

10 *Id.*

11 *Id.*

12 *Id.* at \*3.

13 ABA therapy is not specifically required under the EPSDT guidelines, but it is a recognized "treatment modality" for children with ASD.

able, CMS would not endorse or mandate any specific treatment.<sup>14</sup> However, CMS emphasized, “States are expected to adhere to long-standing EPSDT obligations ... including providing medically necessary services available for the treatment of ASD.”<sup>15</sup>

Even though CMS recognized that some states may not have been providing ASD services through their EPSDT programs, CMS indicated that there would be no specific time frame for its review of state compliance with coverage requirements for children with ASD.<sup>16</sup> Nevertheless, states were cautioned that they should complete the task of becoming compliant “expeditiously.”<sup>17</sup> Finally, CMS advised states that ASD-related services should be provided for EPSDT-eligible individuals through the Medicaid state plan, not through state Medicaid waivers.<sup>18</sup>

The defendants in this case were Valerie Davidson in her official capacity as the commissioner of the Alaska Department of Health and Social Services as well as the department itself.<sup>19</sup> In the state’s October 2015 and February 2016 Medicaid waiver program renewal requests, defendants proposed removing IAT services from the two Medicaid waiver programs by January 2017.<sup>20</sup> Defendants then sent a notice on July 1, 2016, to “75 different individuals and/or entities” stating that they anticipated a July 1, 2017, implementation date

for “full application of ABA services in the state of Alaska.”<sup>21</sup> Participants already receiving IAT services under a Medicaid waiver would continue to receive those services during the transition. Children newly eligible for ABA services during this period were assured that defendants were doing all that they could to ensure enrollment.<sup>22</sup> On October 13, 2016, defendants received email from CMS (a) stating that Alaska could delay until July 1, 2017, the removal of IAT services from the Medicaid waiver programs<sup>23</sup> and (b) recommending that Alaska submit these amendments as well as the amendment to the Medicaid state plan to include IAT, and thus ABA, under the EPSDT program at the same time.<sup>24</sup>

The plaintiffs in this case were the Disability Law Center of Alaska, Inc.,<sup>25</sup> and two minors diagnosed with ASD, R.S. and J.S., through their parent, Kikona Savo.<sup>26</sup> On October 14, 2016, plaintiffs alerted the state that it was not in compliance with the Medicaid Act because the defendants’ July 1, 2016, notice did not inform Alaska families how to apply for ABA therapy, thus making the notice insufficient.<sup>27</sup> On October 31, 2016, the state responded that the law did not require it to inform families of “all of the

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Therefore, if a state Medicaid agency determines that ABA therapy is a medically necessary service, it must be provided to eligible individuals. *Id.* at \*2–3.

14 *Id.* at \*3.

15 *Id.*

16 *Id.*

17 *Id.*

18 *Id.*

19 *Id.* at \*1.

20 *Id.* at \*3.

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21 *Id.*

22 *Id.* at \*4.

23 *Id.*

24 *Id.*

25 The Disability Law Center of Alaska is “an independent non-profit law firm providing protection and advocacy for people with disabilities throughout the state” of Alaska. St. of Alaska Gov.’s Council on Disabilities & Spec. Educ., *Disability Law Center of Alaska*, [dhss.alaska.gov/gcdse/Pages/partners/disability-law-center.aspx](https://alaska.gov/gcdse/Pages/partners/disability-law-center.aspx) (accessed Mar. 12, 2019).

26 *Disability Law Center of Alaska*, *supra* n. 1, at \*1.

27 *Id.* at \*5.

possible ABA services available ... and [how] to access those services [for] eligible children under the age of 21.”<sup>28</sup> Plaintiffs responded by commencing suit on November 1, 2016.

Plaintiffs originally asserted three claims against defendants for violation of the Medicaid Act: (1) insufficient notice on how to apply for and access ABA under the Alaska EPSDT program, (2) failure to reimburse for ABA under the program, and (3) failure to provide ABA therapy under the program with reasonable promptness.<sup>29</sup> Plaintiffs moved for summary judgment and a preliminary injunction.<sup>30</sup> The court denied both motions because “plaintiffs had not shown that defendants were required, but failed, to provide ABA therapy under the EPSDT program with reasonable promptness ... .”<sup>31</sup> The court did state that CMS could not ultimately waive the requirement that defendants provide ABA under the Alaska EPSDT program. However, the court also stated that (a) CMS could give Alaska instructions on how to implement the amendments to remove IAT, and thus ABA, from the state’s Medicaid waiver programs and insert IAT under the state EPSDT program and (b) the state could reasonably rely on those instructions.<sup>32</sup>

Defendants submitted proposed amendments to remove IAT from the Medicaid waiver programs on May 2, 2017. CMS sought to delay consideration of these amendments until the amendment to move IAT under the Medicaid state plan was submitted for approval by

July 1, 2017.<sup>33</sup> Defendants did not post draft regulations until August 9, 2017, for the purpose of receiving public comments, and the comment period did not close until October 10, 2017,<sup>34</sup> thus resulting in further delay. The regulations were adopted by defendants on February 2, 2018, and sent off for review by the Alaska Department of Law; however, the regulations attorney failed to complete the review by March 2018.<sup>35</sup> Defendants then moved for summary judgment on plaintiff’s three claims.<sup>36</sup> Plaintiffs cross-moved for summary judgment on whether CMS had legal authority to authorize defendants to deny or delay the provision of ABA under the Alaska EPSDT program and, if so, whether CMS had actually exercised that authority.<sup>37</sup>

#### IV. U.S. District Court, District of Alaska, Decision

The court noted that in order to ultimately prevail under Title 42 U.S.C. § 1983, plaintiffs had the burden of proving that defendants had deprived them of these three rights under federal law: (1) the right to notice of the availability of ABA services under the EPSDT program, (2) the right to be reimbursed for ABA therapy under the EPSDT program, and (3) the right to have ABA therapy provided under the EPSDT program with reasonable promptness.<sup>38</sup> However, the court stated that summary judgment is only applicable “when there are no genuine issues of material fact” and the movant “is entitled to judgment as a matter of law.”<sup>39</sup>

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28 *Id.*

29 *Id.*

30 *Id.*

31 *Id.* at \*6.

32 *Id.*

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33 *Id.*

34 *Id.*

35 *Id.*

36 *Id.* at \*7.

37 *Id.*

38 *Id.*

39 *Id.* The court further noted that summary



Defendants maintained that they were acting with reasonable promptness because they were acting under the instructions of CMS.<sup>40</sup> Although CMS did not give a definite date on which defendants should submit the amendments, defendants pointed out that they were in the process of implementing them.<sup>41</sup> Also, defendants argued that it is appropriate to rely on informal instructions issued by CMS because CMS is the federal agency charged with approving the state's requests for amendments to its Medicaid waiver programs and Medicaid state plan.<sup>42</sup> In addition, the promulgation of regulations associated with these amendments are governed by certain administrative procedures that take time to follow.<sup>43</sup> Defendants argued, therefore, that they could not be in violation of the Medicaid Act because they were acting with reasonable promptness in accordance with CMS instructions.

Plaintiffs argued that the fact that defendants were providing ABA services to some eligible children under the Alaska Medicaid waiver programs did not relieve them of the duty to provide such services to all eligible children under the state's EPSDT program and to do so with reasonable promptness.<sup>44</sup> Restricting pro-

vision of ABA to the waiver programs meant that extremely few Medicaid-eligible children were receiving these services.<sup>45</sup> Plaintiffs also argued that if deference is to be given to any CMS statements, it should be given to the July 2014 bulletin mandating states to begin providing appropriate treatments (including ABA) for children with ASD under state EPSDT programs as expeditiously as possible.<sup>46</sup> Finally, plaintiffs argued that that while it may have been reasonable to wait until July 2017 to amend the Medicaid state plan, it was unreasonable to delay providing ABA therapy under the state's EPSDT program indefinitely.<sup>47</sup>

Given the conflicting factual arguments concerning the reasonableness of the state's delay in providing ABA services through its EPSDT program, the court found that a genuine issue of material fact existed regarding the question of reasonable promptness; thus, the court could not decide on the motions for summary judgment raised by either party.<sup>48</sup> Although a rational fact finder could justify that the defendants had not violated the reasonable promptness provision, the fact finder could also justify that the defendants had violated the provision.<sup>49</sup> The court further held that it could not grant defendants' motion for summary judgment on the issue of whether the state had furnished adequate notice because conflicting factual claims concerning this issue existed as well. However, the court did grant the plaintiffs' cross-motion for summary judgment on the issue of whether CMS had authority to allow defendants to deny

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judgment is generally not available when the law involves an issue of reasonableness but that summary judgment might be appropriate in such cases if the issue of reasonableness becomes one of law because "the undisputed facts leave no room for a reasonable difference of opinion." (quoting *In re Software Toolworks Inc.*, 50 F.3d 615, 621–622 (9th Cir. 1994), quoting *West v. State Farm Fire & Cas. Co.*, 868 F.2d 348, 350 (9th Cir. 1989)).

40 *Id.* at \*7.

41 *Id.*

42 *Id.* at \*8.

43 *Id.*

44 *Id.*

45 *Id.*

46 *Id.* at \*9.

47 *Id.*

48 *Id.* at \*10.

49 *Id.*

provision of ABA services under the Alaska EPSDT program and held that CMS could not authorize the state to refuse to provide ABA therapy through its EPSDT program.<sup>50</sup>

## V. Conclusion

All three defendants' motions for summary judgment were denied.<sup>51</sup> Plaintiffs were entitled to partial summary judgment that CMS cannot authorize defendants to deny ABA therapy under the Alaska EPSDT program. Plaintiffs' cross-motions for summary judgment were also denied.<sup>52</sup> The decision in this case supports the position that states that have elected to participate in the Medicaid program must be prepared as a practical

matter to provide services identified under the federal statute as mandatory because not even CMS can authorize states not to comply with such statutory provisions.

Following the issuance of the court's decision, the parties entered into a settlement agreement that provided for the inclusion of behavioral health services, including medically necessary treatments for autism, under the Alaska EPSDT program beginning July 1, 2018.<sup>53</sup> The settlement agreement further included remedial provisions that resolved the issue of notice, and it was incorporated into the final judgment order signed by Judge H. Russel Holland on August 1, 2018.<sup>54</sup>

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50 *Id.* at \*10.

51 *Id.*

52 *Id.*

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53 Settlement Agreement, No. 3:16-cv-00277-HRH, Docket No. 57 (filed July 26, 2018).

54 Judgment, No. 3:16-cv-00277-HRH, Docket No. 58 (filed Aug. 1, 2018).



