

# SURROGATE DECISION-MAKING STANDARDS FOR GUARDIANS: THEORY AND REALITY

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## I. INTRODUCTION

Decisions—we make them every day—hundreds of them in fact, some deliberately, others reflexively. We carefully choose what movie to see, but put little conscious effort into choosing the route to the office. Although even routine decisions require a choice between alternatives (for example, taking the expressway or the secondary roads, the stairs or the elevator) the brain uses past experiences—working memory—to reach such decisions with minimum cognitive effort.<sup>1</sup>

Decisions that require conscious deliberation are another matter. Economists generally explain deliberate decision making by the expected utility theory. According to this theory, a decision is a function of the expected utility of an outcome and the probability of that outcome.<sup>2</sup> Psychologists, however, criticize expected utility theory as too rational and idealistic, arguing that decision makers rarely have complete information upon which to base a decision or the means to accurately predict the outcome.<sup>3</sup>

Psychologists instead focus on the cognitive factors that form a reference point for decisions by “framing” the alternatives. These factors include cognitive biases shaped by past experiences,<sup>4</sup> current emotions and beliefs,<sup>5</sup> and the way

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<sup>1</sup> See Judith A. Ouellette & Wendy Wood, *Habit and Intention in Everyday Life: The Multiple Processes by which Past Behavior Predicts Future Behavior*, 124 PSYCHOL. BULL. 54 (1998).

<sup>2</sup> See generally ANDREU MAS-COLELL ET AL., MICROECONOMIC THEORY (Oxford Univ. Press 1995) (attesting to the importance of analytical convenience and value of the expected utility in guiding decision making and action).

<sup>3</sup> See generally GREGORY ROBINSON-RIEGLER & BRIDGET ROBINSON-RIEGLER, COGNITIVE PSYCHOLOGY: APPLYING THE SCIENCE OF THE MIND 558–60 (2004) (explaining the expected utility theory and discussing its shortcomings).

<sup>4</sup> Both past experiences (including prior losses and gains) and future expectations influence decision making; however, known future outcomes (sure gains) are believed to influence decisions more than past experiences. See E. A. Juliusson et al., *Weighing the Past and the Future in Decision Making*, 17 EUR. J. COGNITIVE PSYCHOL. 561 (2005).

outcome probabilities are presented.<sup>6</sup> Framing theory suggests that we choose an alternative based on our reference point and that changing the reference point through reframing can change our preferences, and ultimately our decision.<sup>7</sup> For example, surrogate decision makers may be more likely to choose life-prolonging procedures for an incapacitated person when the patient's prognosis is framed positively (a doctor's statement that 30 percent of persons in the patient's condition recover) versus a negative frame (that 70 percent of such patients never regain consciousness).<sup>8</sup>

This Article addresses the two theoretical reference points used by the law to frame how guardians should make decisions for incapacitated persons—the substituted judgment standard and the best interest standard.<sup>9</sup> Simply stated, the substituted judgment standard directs the guardian to choose the alternative that the incapacitated person would have chosen if still able to make decisions.<sup>10</sup> The best interest standard, by contrast, directs the guardian to choose the alternative that produces the greatest good or benefit for the incapacitated person.<sup>11</sup>

Neither standard, however, is clear-cut when implemented. For example, when attempting to use substituted judgment, how should a guardian determine

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<sup>5</sup> The role of emotions in decision making was studied by comparing patients with normal intelligence but a decreased ability to feel and express emotions due to lesions in their prefrontal cortex with a group of emotionally healthy participants. See Antonie Bechara & Antonio Damasio, *The Somatic Marker Hypothesis: A Neural Theory of Economic Decision*, 52 GAMES & ECON. BEHAV. 336 (2005). The patients with impaired emotional abilities had significantly decreased decision-making abilities even with respect to routine decisions such as planning their day and choosing activities. *Id.* When the healthy participants were asked to recall a strong emotional event prior to making a decision, the accuracy of their decision was significantly affected. *Id.*

<sup>6</sup> Prospect theory is an alternate theory of decision making that accounts for the values people place on gains and losses instead of the probability of the outcome. See Daniel Kahneman & Amos Tversky, *Prospect Theory: An Analysis of Decision Under Risk*, 47 ECONOMETRICA 263 (1979); see also Martin D. Coleman, *Sunk Cost and Commitment to Medical Treatment*, 29 CURRENT PSYCHOL. 121 (2010) (examining the psychological tendency to continue to invest time, effort, and money in a failing outcome where there are already significant “sunk” costs).

<sup>7</sup> See Dennis Chong & James N. Druckman, *Framing Theory*, 10 ANN. REV. POL. SCI. 103 (2007).

<sup>8</sup> See generally E.A. Akl et al., *Using Alternative Statistical Formats for Presenting Risks and Risk Reductions*, COCHRANE DATABASE OF SYSTEMATIC REVIEWS (2011), available at <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD006776.pub2/full> (researching “the effects of using alternative statistical presentations of the same risks and risk reductions on understanding, perception, persuasiveness and behavior of health professionals, policy makers, and consumers”).

<sup>9</sup> See *infra* notes 71–104 and accompanying text for a synthesis of the decision-making models that have evolved from these standards.

<sup>10</sup> See *infra* notes 71–87 and accompanying text for a discussion of the substituted judgment standard.

<sup>11</sup> See *infra* notes 88–98 and accompanying text for a discussion of the best interest standard.

what the incapacitated person would have chosen? The spectrum of possibilities includes prior written directions, past conversations with the person before incapacitation, current conversations with the incapacitated person, and what the guardian knows about that person's values and preferences.<sup>12</sup> Even when prior written directions exist to guide a guardian, the guardian might reasonably question whether those directions would be different if the incapacitated person had known at the time of writing all of the relevant information about current circumstances.<sup>13</sup>

When attempting to make a decision according to the best interest standard, a guardian may have to navigate divergent opinions about what is best for the incapacitated person. These opinions may come from a variety of sources, including financial advisers, health care providers, the incapacitated person's family members, and close friends.<sup>14</sup> Reasonable minds might differ on whether to define best interest narrowly, by the consequences only to the incapacitated person, or more broadly, to include consequences for significant others that the incapacitated person, if competent, might have considered.<sup>15</sup>

This Article examines the complexities of the substituted judgment and best interest standards and evaluates how effectively they provide a decision-making paradigm for guardians. Because most states have statutes and case law on standards for surrogate health care decisions, this Article focuses primarily on other guardian decisions about the person and property of an incapacitated individual. Part I reviews current statutory standards. Part II presents five decision-making models that synthesize divergent theories about the meaning of the substituted judgment and best interest standards. Finally, Part III analyzes data from our survey about the factors that influence guardian decisions. This analysis includes observations about the extent to which surrogate decision-making theory fits the reality of how guardians make decisions.

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<sup>12</sup> See *infra* notes 107–20 and accompanying text for a discussion of studies that examined the role of these factors in decision making by surrogates; see also *infra* notes 121–175 for a discussion of the role these factors played in surrogate decisions made by respondents to our survey.

<sup>13</sup> For a critical examination of whether past statements are an accurate guide for present surrogate health care decisions, see Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823, 1824–41 (2003); see also Pam R. Sailors, *Autonomy, Benevolence, and Alzheimer's Disease*, 10 CAMBRIDGE Q. HEALTHCARE ETHICS 184, 187–88 (2001) (arguing that preferences stated when competent may not best serve the incapacitated successor self); Karen B. Hirschman et al., *Why Doesn't a Family Member of a Person with Advanced Dementia Use a Substituted Judgment When Making a Decision for That Person?*, 14 AM. J. GERIATRIC PSYCHIATRY 659, 665 (2006) (noting that surrogates for patients with advanced dementia struggle between who their relative is now and who their relative was before the dementia).

<sup>14</sup> See *infra* notes 107–120 and accompanying text for a discussion of studies that examined the role of others' opinions in decision making by surrogates; see also *infra* notes 121–175 and accompanying text for a discussion of the role such opinions played in surrogate decisions made by respondents to our survey.

<sup>15</sup> See *infra* notes 95–98 and accompanying text.

## II. STATUTORY STANDARDS

For the purposes of this Article, we reviewed each jurisdiction's primary adult guardianship statute to identify provisions that give guardians decision-making reference points or standards. To keep the basis of inter-jurisdiction comparison consistent, we excluded from review separate statutes for conservatorships, protective services, veteran's guardianships, public guardianships, and special volunteer guardianship programs. A statutory provision qualified if it could fairly be interpreted as containing substituted judgment language, best interest language, or some combination of the two. We defined substituted judgment language broadly to include any provision that directed a guardian to consider the "desires,"<sup>16</sup> "personal values,"<sup>17</sup> "wishes,"<sup>18</sup> "views,"<sup>19</sup> or "preferences"<sup>20</sup> of the incapacitated person. Statutes were then categorized according to those that contain substituted judgment language (with or without additional best interest language), those that contain only best interest language, and those that are silent. We chose to be over-inclusive in the analysis, counting all guardian provisions with any substituted judgment or best interest language, even if the context of the provision was something less than a stand-alone standard for decision making.

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<sup>16</sup> See, e.g., COLO. REV. STAT. ANN. § 15-14-314(1) (West 2011); GA. CODE ANN. § 29-4-22(a) (West 2007); HAW. REV. STAT. ANN. § 560:5-314(a) (LexisNexis 2006); KAN. STAT. ANN. § 59-3075(a)(2) (Supp. 2010); MASS. GEN. LAWS ch. 190B, § 5-309(a) (2011); N.Y. MENTAL HYG. LAW §§ 81.20–81.21 (McKinney 2006 & Supp. 2012); S.D. CODIFIED LAWS § 29A-5-402 (West 2004); V.I. CODE ANN. tit. 15, § 5-314(a) (Supp. 2010); VA. CODE ANN. § 37.2-1020(E) (2011); W. VA. CODE ANN. § 44A-3-1(e) (LexisNexis 2010); WIS. STAT. ANN. § 54.20(1)(b) (West 2008).

<sup>17</sup> See, e.g., COLO. REV. STAT. ANN. § 15-14-314(1) (West 2011); GA. CODE ANN. § 29-4-22(a) (West 2007); HAW. REV. STAT. ANN. § 560:5-314(a) (LexisNexis 2006); 755 ILL. COMP. STAT. ANN. 5/11a-17(e) (West Supp. 2010) ("ethical values"); KAN. STAT. ANN. § 59-3075(a)(2) (Supp. 2010); MASS. GEN. LAWS ch. 190B, § 5-309(a) (LexisNexis 2011); S.D. CODIFIED LAWS § 29A-5-402 (West 2004); V.I. CODE ANN. tit. 15, § 5-314(a) (Supp. 2010); VA. CODE ANN. § 37.2-1020(E) (2011); W. VA. CODE ANN. § 44A-3-1(e) (2010).

<sup>18</sup> See, e.g., ARIZ. REV. STAT. ANN. § 14-5312(A)(11) (2005); D.C. CODE § 21-2047(a)(6) (2010); N.Y. MENTAL HYG. LAW §§ 81.20–81.21 (McKinney 2006 & Supp. 2012); 20 PA. CONS. STAT. ANN. § 5521(a) (West 2005).

<sup>19</sup> See, e.g., CONN. GEN. STAT. ANN. § 45a-656(b) (West Supp. 2011).

<sup>20</sup> See, e.g., N.J. STAT. ANN. § 3B:12-57(f) (West 2007); N.Y. MENTAL HYG. LAW §§ 81.20–81.21 (McKinney 2006 & Supp. 2012); 20 PA. CONS. STAT. ANN. § 5521(a) (West 2005); WIS. STAT. ANN. § 54.20(1)(b) (West 2008). One state statute does not contain specific substituted judgment terminology but does require input from the incapacitated person when possible. MICH. COMP. LAWS ANN. § 700.5314 (West 2005) ("Whenever meaningful communication is possible, a legally incapacitated individual's guardian shall consult with the legally incapacitated individual before making a major decision affecting the legally incapacitated individual.").

Of the fifty-two jurisdictions examined,<sup>21</sup> twenty-eight have guardianship statutes with no general decision-making standard for guardians.<sup>22</sup> Eighteen have statutes that contain substituted judgment language,<sup>23</sup> most in combination with a best interest component.<sup>24</sup> The statutes in six jurisdictions make reference to best

<sup>21</sup> We reviewed the statutes of all fifty states, the District of Columbia, and the U.S. Virgin Islands.

<sup>22</sup> ALA. CODE §§ 26-2-2 to -55, 26-2A-1 to -160, 26-3-1 to -14, 26-5-1 to -54, 26-8-1 to -52, 26-9-1 to -5, 26-9-7 to -19 (LexisNexis 2009); ALASKA STAT. §§ 13.26.001 to .410 (2010); ARK. CODE ANN. §§ 28-65-101 to -603, 28-66-101 to -124, 28-67-101 to -111 (2011); CAL. PROB. CODE §§ 1400–1490, 1500–1611, 1800–1970, 2100–2893 (2012); DEL. CODE ANN. tit. 12, §§ 3901–3997 (2007 & Supp. 2010); FLA STAT. ANN. §§ 744.101 to .715, 747.01 to .052 (West 2010 & Supp. 2011); IDAHO CODE ANN. § 15-5-101 to -603 (West 2012); IND. CODE ANN. § 29-3-1-1 to -13-3 (West 2010); IOWA CODE ANN. §§ 633.551 to .682 (West 2011); KY. REV. STAT. ANN. §§ 387.010 to .990 (West 2011); LA. CODE CIV. PROCEEDINGS ANN. art. 4542 to art. 4569 (1998 & Supp. 2011); LA. REV. STAT. ANN. §§ 9:1021 to 1034 (2008); ME. REV. STAT. ANN. tit. 18-A, §§ 5-101 to -105, 5-301 to -432 (2012); MD. CODE ANN., EST. & TRUSTS §§ 13-101 to -222, 13-704 to -908 (LexisNexis 2011); MINN. STAT. ANN. §§ 524.5-101 to -502 (West 2002 & Supp. 2011); MISS. CODE ANN. §§ 93-13-1 to -281 (2004 & Supp. 2010); MONT. CODE ANN. §§ 72-5-101 to -638 (2011); NEB. REV. STAT. §§ 30-2601 to -2672 (2008); N.H. REV. STAT. ANN. §§ 464-A:1 to :47 (2011); N.M. STAT. ANN. §§ 45-5-101 to -617 (LexisNexis 2011); N.D. CENT. CODE §§ 30.1-26-01 to -29-31 (West 2011); OKLA. STAT. ANN. tit. 30, §§ 1-101 to 4-904 (West 2011); OR. REV. STAT. §§ 125.005 to .650 (2011); S.C. CODE ANN. §§ 62-5-101 to -435 (2012); TENN. CODE ANN. §§ 34-1-101 to 34-3-109 (2009 & Supp. 2012); TEX. PROB. CODE ANN. §§ 601 to 916 (West 2012); UTAH CODE ANN. § 75-5-101 to -433 (West 2004 & Supp. 2011); VT. STAT. ANN. tit. 14, §§ 2602 to 3081 (West 2010) (however, section 2797 requires a guardian to “manage the estate of his or her ward . . . in a manner most beneficial to the ward,” which could be equated with a best interest standard); WYO. STAT. ANN. §§ 3-1-101 to 3-3-1106 (2011).

<sup>23</sup> ARIZ. REV. STAT. ANN. § 14-5312(A)(11) (2005); COLO. REV. STAT. § 15-14-314(1) (West 2011); CONN. GEN. STAT. ANN. § 45a-656(b) (West Supp. 2010); D.C. CODE § 21-2047(a)(6) (West Supp. 2010); GA. CODE ANN. § 29-4-22(a) (West 2007); HAW. REV. STAT. ANN. § 560:5-314(a) (LexisNexis 2006); 755 ILL. COM. STAT. ANN. 5/11a-17(e) (West Supp. 2011); KAN. STAT. ANN. § 59-3075(a)(2) (Supp. 2010); MASS. GEN. LAWS ch. 190B, § 5-309(a) (2011); MICH. COMP. LAWS ANN. § 700.5314 (West 2002); N.J. STAT. ANN. § 3B: 12-57(f) (West 2007); N.Y. MENTAL HYG. LAW §§ 81.20–81.21 (McKinney 2006 & Supp. 2011); 20 PA. CONS. STAT. ANN. § 5521(a) (West 2005); S.D. CODIFIED LAWS § 29A-5-402 (West 2004); V.I. CODE ANN. tit. 15, § 5-314(a) (Supp. 2010); VA. CODE ANN. § 37.2-1020(E) (2011); W. VA. CODE ANN. § 44A-3-1(e) (LexisNexis 2010); WIS. STAT. ANN. § 54.20(1)(b) (West 2008).

<sup>24</sup> COLO. REV. STAT. ANN. § 15-14-314(1) (West 2011); D.C. CODE § 21-2047(a)(6) (West Supp. 2010); GA. CODE ANN. § 29-4-22(a) (West 2007); HAW. REV. STAT. ANN. § 560:5-314(a) (LexisNexis 2006); 755 ILL. COM. STAT. ANN. 5/11a-17(e) (West Supp. 2010); KAN. STAT. ANN. § 59-3075(a)(2) (Supp. 2010); MASS. GEN. LAWS ch. 190B, § 5-309(a) (West Supp. 2010); N.J. STAT. ANN. § 3B: 12-57(f) (West 2007); 20 PA. CONS. STAT. ANN. § 5521(a) (West 2005); S.D. CODIFIED LAWS § 29A-5-402 (West 2004); V.I. CODE ANN. tit. 15, § 5-314(a) (Supp. 2010); VA. CODE ANN. § 37.2-1020(E) (2005); W. VA. CODE ANN. § 44A-3-1(e) (2010); WIS. STAT. ANN. § 54.20(3)(i) (West 2008).

interest, but without a substituted judgment component.<sup>25</sup> The following discussion further describes the statutory trends within these three groupings.

#### A. *No General Decision-Making Standard*

It is not surprising that more than half of the current guardianship statutes lack a general decision-making standard. Even the original Uniform Probate Code (UPC) did not articulate how guardians should make decisions. The 1969 UPC stated only that a “guardian of an incapacitated person has the same powers, rights and duties respecting his ward that a parent has respecting his unemancipated minor child.”<sup>26</sup> Fourteen of the jurisdictions with no articulated standard contain similar language.<sup>27</sup> Case law is thin on what it means for a guardian to have the same powers, rights, and duties as a parent. The opinions that discuss this language do so in the context of the guardian’s scope of authority rather than the process by which guardians should make decisions.<sup>28</sup> Nonetheless, a customary view is that

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<sup>25</sup> MO. ANN. STAT. § 475.120(2) (West 2009); NEV. REV. STAT. ANN. §§ 159.079, .083 (LexisNexis 2009 & Supp. 2009); N.C. GEN. STAT. ANN. §§ 35A-1241(a)(3), 35A-1251 (West 2009); OHIO REV. CODE ANN. § 2111.14 (LexisNexis 2011); R.I. GEN. LAWS ANN. § 33-15-29 (West 2006); WASH. REV. CODE ANN. § 11.92.043(4) (West Supp. 2012).

<sup>26</sup> UNIF. PROBATE CODE § 5-312 (1969); UNIFORM PROBATE CODE OFFICIAL 1993 TEXT WITH COMMENTS 663 (11th ed. 1993).

<sup>27</sup> ALA. CODE § 26-2A-78(a) (LexisNexis 2009); ALASKA STAT. § 13.26.150(c) (2008); DEL. CODE ANN. tit. 12, § 3922(b) (2007); IDAHO CODE ANN. § 15-5-312 (2009); IND. CODE ANN. § 29-3-8-1(a), (b)(1) (West 2010); LA. CODE CIV. PROC. ANN. art. 4566(A) (Supp. 2011) (“Except as otherwise provided by law, the relationship between interdict and curator is the same as that between minor and tutor.”); LA. REV. STAT. ANN. § 9:1032(A) (2008) (“Except as otherwise provided in this Part, the relationship between an interdict and his curator or continuing tutor is the same as that between a minor and his tutor, with respect to the person and property of the interdict.”); ME. REV. STAT. ANN. tit. 18-A, § 5-312(a) (1998); MD. CODE ANN., EST. & TRUSTS § 13-708(b)(1) (LexisNexis 2001); MONT. CODE ANN. § 72-5-321(2) (2009); NEB. REV. STAT. ANN. § 30-2628(a) (2008); N.M. STAT. ANN. § 45-5-312(B) (LexisNexis 2004); S.C. CODE ANN. § 62-5-312(a) (2009); UTAH CODE ANN. § 75-5-312(2) (1993); WYO. STAT. ANN. § 3-2-201(e) (2009).

<sup>28</sup> See, e.g., *Stubblefield v. Ruvalcaba*, 850 P.2d 674, 677–78 (Ariz. Ct. App. 1993) (finding on appeal that trial court interpreted “same powers, rights and duties respecting his ward that a parent has respecting his unemancipated minor child” too narrowly when it dismissed guardian’s action on behalf of ward for marital dissolution); *Nelson v. Nelson*, 878 P.2d 335, 339–40 (N.M. Ct. App. 1994) (overturning dismissal of guardian’s petition for divorce on behalf of the ward, the court found that the statutory language “same rights, powers, and duties respecting the ward as a parent has respecting a child” grants guardians “exceedingly broad powers,” including “authority to interfere in the most intimately personal concerns of an individual’s life”).

guardians, having similar duties as parents, should act in the incapacitated person's best interest.<sup>29</sup>

A few of the jurisdictions with no general decision-making standard, however, do provide a specific decision-making standard for medical decisions.<sup>30</sup> Of these, some require medical decisions to be made according to a substituted judgment standard if the wishes of the incapacitated person can be ascertained, but if they cannot, the decision is to be made according to the incapacitated person's best interest.<sup>31</sup> Others affirmatively obligate the guardian to follow directions expressed prior to incapacity<sup>32</sup> or, in the negative, not to contravene previously expressed wishes.<sup>33</sup> One jurisdiction—Delaware—directs that in matters of medical consent, the incapacitated person's best interest should come before the personal beliefs of the guardian or those of the incapacitated person.<sup>34</sup>

### B. Best Interest Language

Six states' guardianship statutes contain an express reference to "best interest" in the context of guardian duties but make no reference to substituted judgment.<sup>35</sup> However, none of these statutes provides guidance as to what "best interest" means or what the guardian should consider when determining whether a decision will serve the incapacitated person's best interest. Guardians are simply directed to act, or exercise authority, in or for the best interest of the incapacitated person.<sup>36</sup> When

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<sup>29</sup> Michael Casasanto et al., *A Model Code of Ethics for Guardians*, 11 WHITTIER L. REV. 543, 547 (1989) ("The Best Interest Standard mirrors the view that the guardian's duties are akin to those imposed on a parent.").

<sup>30</sup> See, e.g., ALASKA STAT. §§ 13.26.150(c)(3), (e)(3) (2010); DEL. CODE ANN. tit. 12, § 3922(b)(3) (2007); ME. REV. STAT. ANN. tit. 18-A, § 5-312(a)(3) (1998); MINN. STAT. ANN. § 524.5-313(c)(4)(i) (West Supp. 2011); NEB. REV. STAT. ANN. § 30-2628(a)(3) (2008); N.H. REV. STAT. ANN. § 464-A:25(e) (West Supp. 2011); N.M. STAT. ANN. § 45-5-312(B)(3) (LexisNexis 2004).

<sup>31</sup> See, e.g., ME. REV. STAT. ANN. tit. 18-A, § 5-312(a)(3) (1998); N.M. STAT. ANN. § 45-5-312(B)(3) (LexisNexis 2004).

<sup>32</sup> See, e.g., NEB. REV. STAT. ANN. § 30-2628(a)(3) (2008); N.H. REV. STAT. ANN. § 464-A:25(e) (LexisNexis Supp. 2010).

<sup>33</sup> See, e.g., ALASKA STAT. § 13.26.150(e)(3) (2010); MINN. STAT. ANN. § 524.5-313(c)(4)(i) (West Supp. 2011).

<sup>34</sup> DEL. CODE ANN. tit. 12, § 3922(b)(3) (2007) ("The guardian shall not unreasonably withhold such consent or approval nor withhold such consent or approval on account of personal beliefs held by the guardian or the disabled person, but shall take such action as the guardian objectively believes to be in the best interest of the disabled person.").

<sup>35</sup> MO. ANN. STAT. § 475.120(2) (West 2009); NEV. REV. STAT. ANN. §§ 159.079, .083 (LexisNexis 2009 & Supp. 2009); N.C. GEN. STAT. ANN. §§ 35A-1241(a)(3), 35A-1251 (West 2009); OHIO REV. CODE ANN. § 2111.14 (LexisNexis 2011); R.I. GEN. LAWS ANN. § 33-15-29 (West 2006); WASH. REV. CODE ANN. § 11.92.043(4) (West Supp. 2012).

<sup>36</sup> MO. ANN. STAT. § 475.120(2) (West 2009); NEV. REV. STAT. ANN. §§ 159.079, .083 (LexisNexis 2009 & Supp. 2009); N.C. GEN. STAT. ANN. §§ 35A-1241(a)(3), 35A-

one adds these six jurisdictions to the fourteen jurisdictions that give guardians the “same powers, rights and duties” as a parent<sup>37</sup> it results in a total of twenty jurisdictions that arguably follow a best interest standard. The lack of statutory guidance on the meaning of “best interest” may explain, in part, why there is so little case law on the meaning of the standard. Typically, best interest issues arise in judicial opinions only when the guardian has egregiously breached the standard by neglecting the incapacitated person,<sup>38</sup> or by engaging in self-dealing.<sup>39</sup>

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1251 (West 2009); OHIO REV. CODE ANN. § 2111.14 (LexisNexis 2011); R.I. GEN. LAWS ANN. § 33-15-29 (West 2006); WASH. REV. CODE ANN. § 11.92.043(4) (West Supp. 2012).

<sup>37</sup> See *supra* text accompanying note 27.

<sup>38</sup> See, e.g., *In re B.W.*, No. 04193, 2011 WL 24448373 (Del. Chp. June 3, 2011). In that case, a nursing home petitioned the court to remove the daughter as guardian for her mother because she chronically rejected prescribed treatment recommendations made by the attending physicians. The daughter claimed that the nursing home and the physicians were starving her mother by keeping her on a liquid diet. The daughter also claimed that the court and others were in a conspiracy to harm her mother. The court removed the daughter as guardian because her behavior was detrimental to the ward even though the court believed that the guardian “firmly believes that her actions are in the best interest of the ward.” *Id.* at \*4. In the case *In re Guardianship of Reed*, No. 09AP-720, 2010 WL 369440 (Ohio Ct. App. 10 Dist. Feb. 2, 2010), the court denied a petition by the ward’s daughter to remove the guardian. The petitioner disagreed with the physicians as to what care was best for the ward. The court held that it could remove a guardian, who must act in the best interest of the ward, for neglect of his duty. However, because the guardian was performing his duty, his retention would be in the best interest of the ward. *Id.* at \*5. In the case *In re Guardianship of Clark*, No. 09AP-96, 2009 WL 2102154 (Ohio Ct. App. July 16, 2009), the daughter of the ward petitioned the court to remove the guardian on the grounds that he failed to act in the best interest of the ward. The daughter alleged that the guardian had restricted the daughter’s access to information about her mother’s medical care and severely restricted her right to visit her mother. During the hearing on the petition, evidence showed that the daughter had verbally assaulted and physically intimidated her mother’s healthcare providers and attempted to meddle with her mother’s medications. On appeal, the court held that the guardian’s restrictions on the daughter’s access to information about her mother’s health care and visitation rights were reasonable. *Id.* at \*10. The court upheld the finding of the trial court that the guardian was acting in the best interest of the ward. *Id.* at \*1.

<sup>39</sup> In the case *In re Adler*, No. 1144, 2003 WL 22053309 (Pa. Ct. Com. Pl. Mar. 19, 2003), co-guardians requested judicial approval of gifts to accelerate eligibility for Medicaid. Guardians were the niece and nephew of the ward, who had no children. Court denied approval because the gift was not exclusively for the benefit of the incapacitated person. *Id.* at \*3. According to the court, the “ward receives no benefit from these gifts.” *Id.* at \*5. Although guardians can make gifts that are in the best interest of the ward, any “taint of self-dealing will require a court to deny the request.” *Id.* at \*6. Similarly, in the case *In re Guardianship of Jordan*, 616 N.W. 2d 553 (Iowa 2000), the conservator of a ward who owned a farm arranged to have the farm sold to a corporation that he controlled. The sale was approved by a court as being in the ward’s best interest because sale proceeds would pay off the ward’s nursing home bill and relieve the ward of the costs of maintaining the property. The estate of the ward sued to overturn the sale. On appeal, the court held that the costs of maintaining the property were minimal, and the proceeds of the installment



### C. Substituted Judgment Language

Eighteen jurisdictions incorporate some form of substituted judgment standard into their guardianship statutes.<sup>40</sup> Fourteen of these jurisdictions also mention “best interest.”<sup>41</sup> The most common form of substituted judgment standard is based on language from Section 314(a) of the Uniform Guardianship and Protective Proceedings Act (Uniform Act):

Except as otherwise limited by the court, a guardian shall make decisions regarding the ward’s support, care, education, health, and welfare. A guardian shall exercise authority only as necessitated by the ward’s limitations and, to the extent possible, shall encourage the ward to participate in decisions, act on the ward’s own behalf, and develop or regain the capacity to manage the ward’s personal affairs. *A guardian, in making decisions, shall consider the expressed desires and personal values of the ward to the extent known to the guardian. A guardian at all times shall act in the ward’s best interest and exercise reasonable care, diligence, and prudence.*<sup>42</sup>

This language was added to the Uniform Act in 1997.<sup>43</sup> Nine jurisdictions—Colorado, Georgia, Hawaii, Kansas, Massachusetts, South Dakota, U.S. Virgin Islands, Virginia, and West Virginia—have adopted substantially similar language.<sup>44</sup>

Although the Uniform Act provision encourages guardians to utilize substituted judgment by considering the “expressed desires and personal values of the ward,” it does not make clear how the guardian is to balance this obligation

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sale provided less income than did the rent that ward had previously received. Consequently the sale was not in the ward’s best interest and should never have been approved even though the sale price was fair. *Id.* at 560. Additionally, in *Estate of Griffin*, 611 N.Y.S.2d 743 (Surr. Ct. 1994), the conservator had chosen retirement benefits for the ward that paid a joint, reduced lifetime allowance, providing to the conservator, for her life, the same amount that was paid to the ward, if the conservator survived the ward. The conservator could have selected payment options that would have resulted in greater payments to the ward. The court held that it could authorize a self-dealing transaction if it is in the best interest of the ward, *id.* at 745, but the conservator’s failure to seek prior court approval breached her fiduciary responsibilities to the ward. *Id.* at 746.

<sup>40</sup> See *supra* text accompanying note 23.

<sup>41</sup> See *supra* text accompanying note 24.

<sup>42</sup> UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 314(a) (1997), available at <http://www.law.upenn.edu/bll/archives/ulc/fnact99/1990s/ugppa97.pdf>.

<sup>43</sup> *Id.* § 314 cmt.

<sup>44</sup> See, e.g., COLO. REV. STAT. ANN. § 15-14-314(1) (West 2011); GA. CODE ANN. § 29-4-22(a) (West 2007); HAW. REV. STAT. § 560:5-314(a) (2010); KAN. STAT. ANN. § 59-3075(a)(2) (Supp. 2010); MASS. GEN. LAWS ch. 190B, § 5-309(a) (2011); S.D. CODIFIED LAWS § 29A-5-402 (West 2004); V.I. CODE ANN. tit. 15, § 5-314(a) (Supp. 2010); VA. CODE ANN. § 37.2-1020(E) (2011); W. VA. CODE ANN. § 44A-3-1(e) (LexisNexis 2010).

with the obligation to “at all times . . . act in the ward’s best interest.” The original comment to Section 314(a) did not address this tension:

The ward's personal values and expressed desires, whether past or present, are to be considered when making decisions. Although the guardian only need consider the ward's desires and values "to the extent known to the guardian," that phrase should not be read as an escape or excuse for the guardian. Instead, the guardian needs to make an effort to learn the ward's personal values and ask the ward about the ward's desires before the guardian makes a decision. Subsection (a) requires the guardian to act in the ward's best interest. In determining the best interest of the ward, the guardian should again consider the ward's personal values and expressed desires.<sup>45</sup>

In the current Uniform Laws Annotated, revised commentary to Section 314(a) suggests that, whenever possible, a guardian should give more weight to substituted judgment than best interest:

Although the guardian only need consider the ward’s desire and values to the extent known to the guardian, that phrase should not be read as an “out” for the guardian. Instead, the guardian must make an effort to learn the ward’s personal values and ask the ward about the ward’s desires before the guardian makes a decision. When the guardian is making decisions for the ward, the guardian, wherever possible, should use the substitute decision-making standard . . . . *Only when a guardian is not able to ascertain information about the ward’s preferences and desires should a guardian use a traditional best interest decision-making standard.* In determining the best interest of the ward, the guardian should again consider the ward’s personal values and expressed desires. Instructive to a guardian in understanding substitute decision-making would be the Uniform Health-Care Decisions Act, Section 2(e) and the line of “right to die” cases that discuss the substitute decision-making process.<sup>46</sup>

While the revised commentary to Section 314(a) expresses a clear policy preference for substituted judgment, the language of the Uniform Act remains unchanged and the tension between substituted judgment and best interest unresolved. Four states have provisions substantially similar to Section 314(a) but use slightly different wording—the provision does not require that the guardian shall “at all times” act in the incapacitated person’s best interest, but rather that the

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<sup>45</sup> UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 314 cmt., *available at* <http://www.law.upenn.edu/bll/archives/ulc/fnact99/1990s/ugppa97.pdf>.

<sup>46</sup> UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 314 cmt., 8A U.L.A. 370 (2003) (emphasis added).

guardian “shall otherwise” act in the incapacitated person’s best interest.<sup>47</sup> For example, the relevant part of the Massachusetts statute provides, “[a] guardian, to the extent known, shall consider the expressed desires and personal values of the incapacitated person when making decisions, and *shall otherwise* act in the incapacitated person’s best interest and exercise reasonable care, diligence, and prudence.”<sup>48</sup> A plausible explanation for this difference may be the legislative intent that the guardian should consider best interest only when there are no expressed desires and personal values to support substituted judgment. Unfortunately, none of the statutes of the nine states with Section 314(a)-type language provide guidance as to how the guardian should proceed when substituted judgment and best interest conflict.

Unlike the Uniform Act language, the statutes in the District of Columbia and Illinois provide a clear hierarchical approach to applying substituted judgment and best interest, and unequivocally state a preference for substituted judgment when possible. In the District of Columbia, the guardian shall “[m]ake decisions on behalf of the ward by conforming as closely as possible to a standard of substituted judgment or, if the ward’s wishes are unknown and remain unknown after reasonable efforts to discern them, make the decision on the basis of the ward’s best interests.”<sup>49</sup> Illinois provides even more detailed guidance to the guardian:

Decisions made by a guardian on behalf of a ward shall be made in accordance with the following standards for decision making. Decisions made by a guardian on behalf of a ward may be made by conforming as closely as possible to what the ward, if competent, would have done or intended under the circumstances, taking into account evidence that includes, but is not limited to, the ward’s personal, philosophical, religious and moral beliefs, and ethical values relative to the decision to be made by the guardian. Where possible, the guardian shall determine how the ward would have made a decision based on the ward’s previously expressed preferences, and make decisions in accordance with the preferences of the ward. If the ward’s wishes are unknown and remain unknown after reasonable efforts to discern them, the decision shall be made on the basis of the ward’s best interests as determined by the guardian. In determining the ward’s best interests, the guardian shall weigh the reason for and nature of the proposed action, the benefit or necessity of the action, the possible risks and other consequences of the proposed action, and any available alternatives and their risks, consequences and benefits, and shall take into account any other information, including the views of family and friends, that the

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<sup>47</sup> MASS. GEN. LAWS ch. 190B, § 5-309(a) (2011); S.D. CODIFIED LAWS § 29A-5-402 (West 2011); VA. CODE ANN. § 37.2-1020 (E) (2011); W. VA. CODE § 44A-3-1(e) (2010).

<sup>48</sup> MASS. GEN. LAWS ch. 190B, § 5-309(a) (West Supp. 2010) (emphasis added).

<sup>49</sup> D.C. CODE § 21-2047(a)(6) (2010).

guardian believes the ward would have considered if able to act for herself or himself.<sup>50</sup>

In other jurisdictions that have both substituted judgment and best interest language in their guardianship statutes, it is less clear how the two concepts interrelate. Pennsylvania's statute provides in pertinent part: "It shall be the duty of the guardian of the person to assert the rights and best interests of the incapacitated person. Expressed wishes and preferences of the incapacitated person shall be respected to the greatest possible extent."<sup>51</sup> Similar to the Pennsylvania provision, the New Jersey statute provides, "[A] guardian of the person of a ward shall exercise authority over matters relating to the rights and best interest of the ward's personal needs, . . . a guardian shall give due regard to the preferences of the ward, if known to the guardian or otherwise ascertainable upon reasonable inquiry."<sup>52</sup> Wisconsin requires that a guardian "[a]dvocate for the ward's best interests"<sup>53</sup> and consider, consistent with the functional limitations of the incapacitated person, "[t]he ward's personal preferences and desires with regard to managing his or her activities of daily living."<sup>54</sup>

The remaining four states—Arizona, Connecticut, Michigan, and New York—have substituted judgment language in their statutes, but no express mention of best interest.<sup>55</sup> Guardians in Arizona are to consider the ward's "values and wishes,"<sup>56</sup> while in Connecticut, the conservator is to "ascertain the conserved person's views," and "make decisions in conformance with the conserved person's

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<sup>50</sup> 755 ILL. COMP. STAT. ANN. 5/11a-17(e) (West Supp. 2011).

<sup>51</sup> 20 PA. CONS. STAT. ANN. § 5521(a) (West 2005). On petition by parental guardian to authorize termination of life support for adult son in persistent vegetative state, the Supreme Court of Pennsylvania opined that "where there is enough data for the decision maker to ascertain what the patient would have desired, the decision maker *must* effectuate substituted judgment." *In re Fiore*, 673 A.2d 905, 912 n.11 (Pa. 1996). In such circumstances, according to the court, "a best interest analysis may not be employed," suggesting that in Pennsylvania, the two tests are polar opposites. *Id.* Either the guardian has "enough data" to know what the incapacitated person wants and so applies substituted judgment or the guardian does not and so must use a best interest test. In *Fiore*, the court permitted the guardian to consider "all aspects of [the ward's] personality," indicating a very expansive notion of what factors a guardian can consider to invoke a substituted judgment. *Id.* at 911; see also *infra* notes 79–87 and accompanying text for a discussion of the expanded substituted judgment model.

<sup>52</sup> N.J. STAT. ANN. § 3B:12-57(f) (West 2007); see *In re M.R.*, 638 A.2d 1274, 1280 (N.J. 1994) ("The substituted-judgment and best-interest tests are not dichotomous, but represent points on a continuum of subjective and objective information leading to a reliable decision that gives as much weight as possible to the right of self-determination.").

<sup>53</sup> WIS. STAT. § 54.18(1)(b) (West 2008).

<sup>54</sup> WIS. STAT. § 54.20(1)(b) (West 2008).

<sup>55</sup> ARIZ. REV. STAT. ANN. § 14-5312(A)(11) (2005); CONN. GEN. STAT. ANN. § 45a-656(b) (West Supp. 200410); MICH. COMP. LAWS ANN. § 700.5314 (West 2002); N.Y. MENTAL HYG. LAW §§ 81.20, 81.21 (McKinney 2006 & Supp. McKinney 2011).

<sup>56</sup> ARIZ. REV. STAT. ANN. § 14-5312(A)(11) (2005).

reasonable and informed expressed preferences.”<sup>57</sup> Michigan simply provides that “[w]henever meaningful communication is possible, a legally incapacitated individual’s guardian shall consult with the legally incapacitated individual before making a major decision affecting the legally incapacitated individual.”<sup>58</sup> A guardian in New York is required to “afford the incapacitated person the greatest amount of independence and self-determination . . . in light of that person’s functional level, understanding and appreciation of his or her functional limitations, and personal wishes, preferences and desires.”<sup>59</sup> Each of these statutes encourages guardians to make decisions based on notions of substituted judgment, but none address how the guardian is to make decisions if the values, views, wishes, or preferences of the incapacitated person cannot be obtained.

In 2000, the National Guardianship Association (NGA) adopted standards of practice which include Standard 7—Standards for Decision-Making.<sup>60</sup> Standard 7 defines substituted judgment as “the principle of decision-making that substitutes, as the guiding force in any surrogate decision made by the guardian, the decision the ward would have made when competent.”<sup>61</sup> Standard 7 further provides that “Substituted Judgment is not used when following the ward’s wishes would cause substantial harm to the ward or when the guardian cannot establish the ward’s prior wishes.”<sup>62</sup> If the guardian is unable to ascertain the ward’s “prior or current wishes,” or if “following the ward’s wishes would cause substantial harm to the ward,” then Standard 7 directs the guardian to use the best interest standard.<sup>63</sup>

There is a subtle, but significant, difference between the Uniform Act language and the NGA standard. The Uniform Act language is ambiguous about the relative weight that guardians should give substituted judgment versus best interest. Without the benefit of the revised commentary, a guardian could sensibly conclude that substituted judgment is to be employed only when doing so is also in the incapacitated person’s best interest.<sup>64</sup> In contrast, the NGA standard encourages a guardian to use substituted judgment so long as the decision will not cause substantial harm. In other words, under the NGA approach substituted judgment trumps best interest except in circumstances where the decision would cause substantial harm. The plain meaning of the Uniform Act language suggests that best interest trumps substituted judgment if the two conflict.

On a continuum framed by protection on the one end and self-determination on the other, the most protective standard would be one that favors best interest over substituted judgment when the two conflict. The standard most deferential to self-determination interests would be the hierarchy approach that favors substituted

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<sup>57</sup> CONN. GEN. STAT. ANN. § 45a-656(b) (West Supp. 2010).

<sup>58</sup> MICH. COMP. LAWS ANN. § 700.5314 (LexisNexis 2005).

<sup>59</sup> N.Y. MENTAL HYG. LAW §§ 81.20–81.21 (McKinney 2006 & Supp. 2012).

<sup>60</sup> See NAT’L GUARDIANSHIP ASS’N, *Standard 7: Standards for Decision-Making*, in STANDARDS OF PRACTICE (3d ed. 2007).

<sup>61</sup> *Id.* at 5.

<sup>62</sup> *Id.*

<sup>63</sup> *Id.* at 6.

<sup>64</sup> See *supra* notes 42–48 and accompanying text.

judgment over best interest whenever possible. The NGA approach offers a compromise point somewhere between the two standards as it favors substituted judgment—provided the decision will not result in substantial harm. Consider the following example that demonstrates how these three approaches for balancing substituted judgment and best interest might lead to different decisions:

Esther, a widow with considerable retirement assets, regularly supports environmental organizations that work to save endangered species. On numerous occasions Esther has told Helen, her niece, that she would rather protect endangered species than accumulate possessions or leave a large estate. Helen was recently appointed Esther's guardian after a stroke left Esther cognitively impaired. Helen must decide whether to continue Esther's large annual gifts to environmental organizations, or conserve her assets to pay for the home care that Esther currently receives. If Esther were moved to assisted living, there would likely be enough assets to continue the gifts and pay for her care.

Under the Uniform Act language, Helen might decide that Esther's best interest—continued home care—trumps her wish to make large charitable gifts, and thus choose to reduce or stop the gifts. If Helen follows the hierarchy approach, she might decide to continue the gifts because Esther's wishes are known and unequivocal—it is what Esther would do if she were still able to decide for herself. Helen might also decide to continue the gifts if she follows NGA Standard 7 because the consequence to Esther is something less than substantial harm—she can receive adequate care in an assisted living residence rather than at home.

### III. THE THEORY: SUBSTITUTED JUDGMENT AND BEST INTEREST—FIVE MODELS

Literature devoted to the substituted judgment and best interest standards contains widely divergent opinions about the meaning and application of the standards.<sup>65</sup> To synthesize the spectrum of viewpoints, we have created five representative models labeled: Strict Substituted Judgment,<sup>66</sup> Expanded Substituted Judgment,<sup>67</sup> Strict Best Interest,<sup>68</sup> Expanded Best Interest,<sup>69</sup> and Hybrid Substituted Judgment/Best Interest.<sup>70</sup> For each model we have articulated a decision-making standard and provided examples of how the standard might be applied.

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<sup>65</sup> See *infra* notes 71–104 and accompanying text.

<sup>66</sup> See *infra* notes 71–78 and accompanying text.

<sup>67</sup> See *infra* notes 79–87 and accompanying text.

<sup>68</sup> See *infra* notes 88–94 and accompanying text.

<sup>69</sup> See *infra* notes 95–98 and accompanying text.

<sup>70</sup> See *infra* notes 99–104 and accompanying text.

### A. *Strict Substituted Judgment Model*

#### 1. *Decision-Making Standard*

*Decisions should be based on the incapacitated person's prior directions and expressed wishes.*

The strict substituted judgment model requires the guardian to make decisions based on actual knowledge of what the incapacitated person would have done.<sup>71</sup> Actual knowledge can come from the incapacitated person's prior directions or, when there are no specific directions on point, the guardian can rely on the incapacitated person's reasonably instructive, previously expressed desires.<sup>72</sup> Some argue that when the guardian knows what the incapacitated person wants, the guardian is not making a surrogate decision, but instead reporting a decision already made by the incapacitated person.<sup>73</sup> Proponents contend that strict substituted judgment best protects the autonomy and self-determination interests of the incapacitated person.<sup>74</sup>

The strict substituted judgment model has two shortcomings. First, some argue that substituted judgment is unreliable because an individual's preferences change over time;<sup>75</sup> choices made while competent may not be what a person would direct if it were possible to know the wishes of the later incapacitated

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<sup>71</sup> Ursula K. Braun et al., *Reconceptualizing the Experience of Surrogate Decision Making: Reports vs Genuine Decisions*, 7 ANNALS FAM. MED. 249, 249–52 (2009) (noting the “high evidentiary standards” which must be met for substituted judgment).

<sup>72</sup> Mark R. Tonelli, *Substituted Judgment in Medical Practice: Evidentiary Standards on a Sliding Scale*, 25 J.L. MED. & ETHICS 22, 22–23 (1997) (observing that the various formulations of the substituted judgment standard attempt to “incorporate the relevant aspects of an individual's previously expressed beliefs, values, and goals”).

<sup>73</sup> Braun et al., *supra* note 71, at 252.

<sup>74</sup> See generally RONALD DWORKIN, *LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM* 222–29 (1993) (providing a discussion of how the doctrine of substituted judgment promotes individual autonomy).

<sup>75</sup> See generally Alexia M. Torke et al., *Substituted Judgment: The Limitations of Autonomy in Surrogate Decision Making*, 23 J. GEN. INTERNAL MED. 1514 (2008) (providing an analysis of the unreliability of substituted judgment in the context of health care decision making). Even when the issue concerns property, it would seem the greater the time lag between a prior statement and the surrogate decision, the less certain the guardian can be that the statement reflects what the incapacitated person might want now. Some contend that “conclusively determining whether or not any type of surrogate makes the decisions that an incapacitated person would have made for him or herself is impossible.” Nina A. Kohn & Jeremy A. Blumenthal, *Designating Health Care Decisionmakers for Patients Without Advance Directives: A Psychological Critique*, 42 GA. L. REV. 979, 994 (2008); see also Dresser, *supra* note 13, at 1823 (arguing that a “reliance on advance treatment choice is misguided and morally troubling”).

“successor” self.<sup>76</sup> Second, the more pragmatic criticism of strict substituted judgment is that lack of prior directions or express wishes severely limits what a guardian can do.<sup>77</sup> Mere suspicion or supposition will not suffice; the guardian must have objective evidence of the incapacitated person’s actual intent.

## 2. *Examples*

Actual knowledge of the incapacitated person’s intent can come from prior statements such as:

- “I want my dog, Fluffy, to be taken care of should anything happen to me.”
- “I will pay for the cost of a college education for my niece Melanie at XYZ University.”
- “Never sell my classic 1965 Mustang convertible.”

And, if there are no prior statements right on point, clearly expressed wishes can suffice:

- Jim told his family before he became incapacitated that he was a strong supporter of his church’s youth outreach program. When the church proposed building a youth center, Jim had remarked, “You can count on me to do my part.” Now Jim is incapacitated and the Church has approached his guardian for a donation on Jim’s behalf. The guardian may make the donation under a strict substituted judgment standard because Jim’s desire to financially support the project is reasonably inferred from his earlier general statements.

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<sup>76</sup> See generally *Sailors*, *supra* note 13, at 190–93 (arguing that a radical change in someone’s personal identity can lead to the emergence of a “successor self” that should be protected as if it were a distinct person).

<sup>77</sup> The failure to give prior directions and authority through a power of attorney and advance directives is usually the reason a guardianship must be established for an incapacitated person. Although estimates vary on how many persons have executed health care advance directives, a 2007 poll conducted by AARP found the “overall completion rate of either a living will or a health care proxy document was only 29 percent.” Charles P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, 88 *MILBANK Q.* 211, 221 (2010).



Many persons under a guardianship are not completely incapacitated. They frequently have enough limited capacity to understand a question and express a response. To the extent an incapacitated person can participate in a decision, the guardian can use that expression as the basis for substituted judgment.<sup>78</sup> For example:

- Suppose Cally, age 77, is suffering from early stages of dementia and the court appoints a guardian to handle her extensive assets. Prior to the commencement of the guardianship, Cally had taken several extended cruises with her twenty-eight-year-old granddaughter, Ginny. Cally always paid all the cost of Ginny's cruise. The guardian is approached by Ginny who proposes that she take Cally on a three-week cruise at a cost of \$7,000 each or a total of \$14,000. The cruise quality is comparable to those that she and Cally took in the past. The guardian asks Cally if she would like to go on the cruise with Ginny. Cally, though confused, is clear that she would like to go on the cruise. Under the doctrine of strict substituted judgment, the guardian may approve the expenditure because Cally's current expression of her wishes is consistent with her past decisions and conduct.

### *B. Expanded Substituted Judgment Model*

#### *1. Decision-Making Standard*

*Decisions may be based on the incapacitated person's prior statements, actions, values, and preferences.*

The expanded substituted judgment model provides greater latitude as to the kind of evidence used to ascertain the incapacitated person's preferences and lowers the degree of certainty required before the guardian can act.<sup>79</sup> Under this

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<sup>78</sup> UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 314(a) (1997), available at <http://www.law.upenn.edu/bll/archives/ulc/fnact99/1990s/ugppa97.htm>; *id.* § 314 cmt. (noting that, "the guardian must make an effort to learn the ward's personal values and ask the ward about the ward's desires before the guardian makes a decision"); *see, e.g.*, MICH. COMP. LAWS ANN. § 700.5314 (LexisNexis 2005) ("Whenever meaningful communication is possible, a legally incapacitated individual's guardian shall consult with the legally incapacitated individual before making a major decision affecting the legally incapacitated individual.").

<sup>79</sup> *See* Kathy Cerminara, *Tracking the Storm: The Far-Reaching Power of Forces Propelling the Schiavo Cases*, 35 STETSON L. REV. 147, 165 (2005) ("Evidence of precisely what the patient would have wanted, in the form of written advance directives or oral statements . . . is useful, but it is not required. A decision made pursuant to a substituted judgment standard can be determined by asking what a patient would have wanted based on that patient's values, beliefs, and attitudes."). But ascertaining the preference of an incapacitated person can be difficult. "In making a substituted judgment, a

model, the guardian may look beyond definitive past statements for general statements that reflect the incapacitated person's attitude on a subject.<sup>80</sup> The guardian may also look to past actions, decisions, and even impressions about the incapacitated person's values to discern what the incapacitated person would do under the present circumstances.<sup>81</sup>

The advantage of the expanded substituted judgment model over the strict model is that a guardian is allowed to make reasonable inferences based on what is known about the person, which may produce decisions that more closely approximate what the incapacitated person would choose if still able to make decisions.<sup>82</sup> In theory, this model is appealing because it permits a personally-tailored decision in circumstances where the incapacitated person did not previously express specific expectations or directions. The strength of this model, however, is also its weakness when the guardian does not have background upon which to rely, even in an expanded notion of substituted judgment. For example, a spouse acting as guardian usually has a broad range of past experiences upon which to base surrogate decisions, but a professional guardian typically has had no contact with an incapacitated person before the loss of capacity. The guardian with no personal knowledge of the incapacitated person's prior statements, actions, values, and preferences must either obtain that information from other sources or use a different standard for making the surrogate decision.<sup>83</sup>

Critics of the expanded substituted judgment concept question the reliability of secondary sources of information about the incapacitated person's values and preferences.<sup>84</sup> Even where the guardian has first-hand knowledge of these

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proxy must *interpret, construe, exegete* another person's autonomy from the complex, multi-leveled, shifting text of that person's life." Bart J. Collopy, *The Moral Underpinning of the Proxy-Provider Relationship: Issues of Trust and Distrust*, 27 J.L. MED. & ETHICS 37, 40 (1999).

<sup>80</sup> See *supra* note 51 (discussing the Pennsylvania Supreme Court's interpretation of substituted judgment); see also Naomi Karp & Erica Wood, *Incapacitated and Alone: Healthcare Decision Making for Unbefriended Older People*, 31 HUM. RTS. 20, 22 (2004) (recommending that long-term care facilities and staff should play a greater role in "investigating and conveying resident values and preferences," including developing procedures for "collecting and using resident histories and values information").

<sup>81</sup> Karp & Wood, *supra* note 80, at 22.

<sup>82</sup> See Daniel P. Sulmasy & Lois Snyder, *Substituted Interests and Best Judgments*, 304 J. AM. MED. ASSN. 1946, 1946-47 (2010) (arguing that a "substituted interests" approach, based on a patient's "authentic values and interests" could permit a "best judgment" on behalf of the incapacitated person in circumstances where a patient's preferences are unknown).

<sup>83</sup> See *infra* notes 148-153, 167-175 and accompanying text (reporting that among respondents to our survey, nonfamily guardians more often considered prior written directions, current conversations, and what others told them about the values and preferences of the incapacitated person in order to determine what the incapacitated person would want).

<sup>84</sup> Rebecca Dresser, *Shiavo's Legacy: The Need for an Objective Standard*, 35 HASTINGS CTR. REP. 20, 20 (2005) ("Decisions based on the substituted judgment standard

preferences, some argue that surrogate decision makers are inherently biased by their own perspectives.<sup>85</sup> In addition, opponents of substituted judgment—whether under a strict or expanded model—contend that a guardian cannot be sure that an individual’s past statements reflect what the person might want under present circumstances.<sup>86</sup> Given the importance of present circumstances to a decision, they argue that past pronouncements are little more than guesses as to how one might react in the present.<sup>87</sup>

## 2. Examples

Notwithstanding criticisms of expanded substituted judgment, the following examples illustrate how this model might facilitate a decision that would not be possible under strict substituted judgment:

- Suppose that Millie, an incapacitated person, received a solicitation from the local YWCA to make a gift of \$1,000 to honor her deceased mother. Millie’s mother had been a lifelong member of the YWCA. Millie, a past member for ten years, once gave a \$500 gift to the YWCA. Three years ago Millie gave \$1,000 to the United Way in memory of her mother. The guardian believes that Millie might have approved of a donation to the YWCA to honor her mother, but under a strict substituted judgment standard, the guardian would lack sufficient evidence of that intent to justify making the gift. Under the expanded substituted judgment standard, the guardian can justify the gift as consistent with the totality of Millie’s past conduct and decisions.
- The recently appointed professional guardian for Jane, age 85, was asked to move Jane from her home to a safer living environment. The guardian learned from Jane’s pastor that five years ago Jane helped her best friend sell her house and move to assisted living after the friend was diagnosed with Parkinson’s disease. Jane had remarked to the pastor, “Too many older women continue to live alone in their houses long after it is safe to do so.” If Jane is unable to engage in a current conversation about her residential preferences, the guardian could conclude based on Jane’s past acts and statements that she would approve of a move to an assisted living facility.

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can be influenced by people reporting and interpreting the evidence about patient’s preferences.”); *see also infra* notes 117–120 and accompanying text.

<sup>85</sup> Dresser, *supra* note 84, at 21–22.

<sup>86</sup> *See generally* Dresser, *supra* note 13, at 1823–24 (arguing that precommitment is an “inferior strategy for making end-of-life decisions” and that “a person’s statements about future care can be relevant” but are “just one element of a complex situation”); Sailors, *supra* note 13 (arguing that changed circumstances make an individual’s past statements an unreliable basis for current decision making).

<sup>87</sup> Dresser, *supra* note 13, at 1823.

### C. *Strict Best Interest Model*

#### 1. *Decision-Making Standard*

*Decisions should be based on a comparison of the benefits and burdens from the viewpoint of a reasonable person in the incapacitated person's circumstances.*

The strict best interest model requires the guardian to make decisions that best promote the well-being of the incapacitated person. Rather than attempting to ascertain or project what the incapacitated person would do, the guardian is to make decisions based on what a reasonable person in the incapacitated person's circumstances would do, weighing the burdens and benefits of the proposed course of action.<sup>88</sup> The strict best interest model does not presume that the incapacitated person is a reasonable person or would only act as a reasonable person would; rather, the model attempts to foster decisions that are reasonable because they best promote the well-being of the incapacitated person.<sup>89</sup>

The chief criticism of the strict best interest model is that it is paternalistic—it trades off the self-determination interests of the incapacitated individual for the benefit of protecting that person.<sup>90</sup> However, this trade-off may be unavoidable when substituted judgment is impossible because the desires or attitudes of the incapacitated individual cannot be ascertained.<sup>91</sup> Opinions vary about whether the desires of the incapacitated person, when known, should take priority in guiding a guardian's decision.<sup>92</sup> Proponents of the strict best interest model argue that the incapacitated person's wishes should be followed only when the course of action also is the best to promote the well-being of the incapacitated person.<sup>93</sup>

The strict best interest model is further criticized because it does not necessarily produce a fixed, objective decision. A guardian acting under this standard must determine what is in the incapacitated person's best interest, but different guardians may reach different conclusions under similar circumstances.

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<sup>88</sup> Lawrence A. Frolik, *Is a Guardian the Alter Ego of the Ward?*, 37 STETSON L. REV. 53, 69 (2007) (the best interests test manifests what a reasonable person would do); Loretta Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J.L. MED. & ETHICS 187, 188 (2007) (best interest “guides decision-makers to pick from among options that reasonable persons of good will would consider acceptable”). Best interests can be divided into what is best for the present and what is best for one's life in an overall sense. Sailors, *supra* note 13, at 188.

<sup>89</sup> See Sailors, *supra* note 13, at 188.

<sup>90</sup> See Bruce Jennings, *Freedom Fading: On Dementia, Best Interests, and Public Safety*, 35 GA. L. REV. 593, 605 (2000).

<sup>91</sup> Given that most individuals will not have expressed an opinion on the issue for which a decision has to be made, in many cases the guardian will necessarily have to resort to the best interest test. Cerminara, *supra* note 79, at 165.

<sup>92</sup> See *supra* note 13 and accompanying text.

<sup>93</sup> See generally Sailors, *supra* note 13; Dresser, *supra* note 13 (both arguing that the substituted judgment standard is an unreliable basis upon which to base current surrogate decisions).

Furthermore, the guardian's decision may be influenced by the opinions of others who have an interest in the incapacitated person's welfare, including family members, friends, and professionals such as clergy, health care providers, lawyers, and financial advisers.<sup>94</sup>

## 2. Examples

The following examples illustrate how decisions under a strict best interest model may differ from those made under substituted judgment models:

- The guardian for eighty-five-year-old Oliver must decide whether to transfer the title of his BMW to his sixty-year-old son, Charles. Oliver has moderate dementia and can no longer drive. Records substantiate that Oliver's past practice was to buy a new car every four years and give his old car to his son. The BMW has a present market value of \$20,000. Oliver currently lives in an assisted living facility. His yearly expenses are \$72,000, but his annual income, composed of Social Security and a small pension, is only \$52,000. The shortfall each year is paid from his savings which are currently valued at \$100,000. At this rate, Oliver's savings will be exhausted in a little over 5 years. Despite Charles's protests that Oliver would want him to have the car, the guardian chooses to sell the BMW because that is what a reasonably prudent person in Oliver's circumstances would do to conserve assets for future needs. This choice promotes Oliver's well-being without regard to the interests of anyone else. While a substituted judgment standard might support making the gift of the car to Charles, a strict best interest standard does not.
  
- Betty is a ninety-year-old widow who suffers from emphysema and mild dementia. She lives in a remote area on a lake in a cabin-style home built by her late husband. Her recently divorced granddaughter lives with her as a helpmate and companion. Betty's eldest daughter, Ann, is her guardian. All of the family members are aware of Betty's strong desire to live the remainder of her life at the cabin. She has said many times, "I will live here until they carry me out feet first." Betty's doctor recently ordered oxygen as an assistive therapy for her breathing difficulties. Ann is concerned about the frequent power outages at the cabin and has decided over the objections of Betty, her granddaughter, and other family

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<sup>94</sup> In fact, such input is often encouraged. *See, e.g.*, 755 ILL. COMP. STAT. ANN. 5/11a-17(e) (West Supp. 2011) ("In determining the ward's best interests, the guardian shall weigh the reason for and nature of the proposed action, the benefit or necessity of the action, the possible risks and other consequences of the proposed action, and any available alternatives and their risks, consequences and benefits, and shall take into account any other information, including the views of family and friends, that the guardian believes the ward would have considered if able to act for herself or himself."); *see also* Sulmasy & Snyder, *supra* note 82, at 1946-47.

members, to move Betty to an assisted living facility in town. She believes this is the only decision consistent with Betty's best interest. Under a substituted judgment standard, Ann might choose instead to buy a generator for the cabin, a decision that both reduces the risk to Betty and respects her wish to live at the cabin.

#### *D. Expanded Best Interest Model*

##### *1. Decision-Making Standard*

*Decisions should be based on a comparison of the benefits and burdens from the viewpoint of a reasonable person in the incapacitated person's circumstances, and may include consideration of consequences for significant others if a reasonable person might ordinarily consider such consequences.*

The expanded best interest model recognizes that incapacitated persons do not live in a vacuum and that guardians should be able to consider the consequences a decision would have for people whose interests the incapacitated person would ordinarily consider if competent.<sup>95</sup> Such persons might include the incapacitated person's spouse, children, or other companions. Unlike the strict best interest model, which focuses solely on the consequences to the incapacitated person,<sup>96</sup> the

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<sup>95</sup> See, e.g., *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. Ct. App. 1969). There the court was asked to approve a transplant of a kidney from one brother, who had been incapacitated from birth, to another brother, whose kidneys were failing. *Id.* at 145–46. Although the incapacitated brother could not opine as to whether he might want to donate a kidney, the court nevertheless approved the donation as in the best interest of the incapacitated brother because he would have been emotionally devastated if his brother died. *Id.* at 149. Courts have often used the expanded best interest model under the label of “substituted judgment” in circumstances where there was no evidence upon which a true substituted judgment could be based. In *Ex parte Whitbread*, 2 Meriv. 99, 100–02, 35 Eng. Rep. 878, 878–79 (Ch. 1816), the court granted the niece's request for an increased allowance from the estate of Hinde, her incapacitated uncle, because it believed that this is what “the Lunatic himself would have done.” *Id.* at 102, 35 Eng. Rep. at 879. The court opined that Hinde would likely prefer to support his niece rather than suffer the embarrassment of her poverty. *Id.* The court did not cite any prior statements or acts by Hinde that would support this opinion, but simply concluded that an increased allowance is what Hinde would have done, “if he were in a capacity to exercise any discretion on the subject.” *Id.* at 100 n.a, 35 Eng. Rep. at 878. Additionally, in *In re Daly*, 536 N.Y.S.2d 393 (Sur. 1988), the court approved annual gifts of \$60,000 from the taxable estate of a person who was profoundly disabled because of medical malpractice at birth. Thus, the court could not rely on “subjective intent” and instead had to “employ an objective standard and inquire as to what a reasonable and prudent person would do in the circumstances.” *Id.* at 395.

<sup>96</sup> See *supra* notes 88–94 and accompanying text.

expanded model contemplates that most reasonable persons also consider the impact of their decisions on others for whom they care.<sup>97</sup>

Of course, taking into consideration the interests of others raises the question of whose interests should be considered and how much weight should be given to those interests. A guardian making decisions under an expanded best interest model is still obligated to promote the best interest of the incapacitated person without becoming unduly influenced by the needs of others, no matter how compelling. The primary criticism of the expanded best interest model is that permitting guardians to consider the effect of their decisions on the well-being of others, including themselves, may be the first step on a slippery slope leading to exploitation of the incapacitated person.<sup>98</sup>

## 2. Examples

The following scenarios illustrate guardian decisions that rest on an expanded best interest model—one that contemplates the impact not only on the incapacitated person, but also on individuals whose interests the incapacitated person would likely consider if competent to do so:

- Jed is a seventy-five-year-old widower who moved to a nursing home because of his dementia. Jed owns a nine-year-old golden retriever, Lady, who could not accompany him to the nursing home. Jed's granddaughter, Emily, is very close to her grandfather and to Lady. Emily and her mother cannot keep the dog because their condominium association does not allow pets. Jed's guardian approves expenditures for Lady to live at a rescue shelter where Emily can visit. Although Jed's mental condition has deteriorated to the point where he is unaware of the arrangements made for Lady, the guardian knows it would have been very distressing for Emily if Lady had been euthanized. The guardian believes that doing what a compassionate person would do in Jed's circumstances—if Jed could have made the arrangements himself—is what is in the best interest of Jed, Emily, and Lady.
- Joanne has dementia and can no longer live safely by herself. Her daughter, Beth, a registered nurse, is planning to take a leave of absence so that she can see to her mother's care full time. Beth is also Joanne's

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<sup>97</sup> See *supra* note 95.

<sup>98</sup> In a discussion between author Linda S. Whitton and members of the National Conference of Lawyers and Corporate Fiduciaries, corporate guardians stated that some of their toughest decisions involve expenditures which provide an incidental benefit to family members or companions of the incapacitated person. Examples include requests for funds to go on vacation, do home renovations, and buy a new vehicle. The corporate guardians indicated that they usually seek prior court approval of such expenditures—both to protect the incapacitated person's interests and to protect the guardian from potential liability. Meeting in Washington, D.C., on June 3, 2011.

guardian. Beth would like to use some of her mother's money to convert a family room into a first floor bedroom and bathroom for her mother's use. Beth is concerned that her siblings, all of whom live out of state, will claim Beth is using her mother's money to benefit herself. Beth is seeking court approval to pay for the home modifications. The court may approve these expenditures under an expanded best interest standard. Even though Beth will receive an incidental benefit, the expenditures make it possible for Joanne to avoid institutionalization and to receive care from someone who loves her.

### *E. Hybrid Substituted Judgment/Best Interest Model*

#### *1. Decision-Making Standards*

*1) Decisions should be based on substituted judgment if there is evidence of what the incapacitated person would have wanted; if not, then the decisions should be based on the person's best interest.*

*2) Decisions should be based on substituted judgment if there is evidence of what the incapacitated person would have wanted and the decision also promotes the incapacitated person's best interest. If there is no evidence to support substituted judgment, then the decision should be based on best interest.*

As previously discussed, two predominant approaches have emerged in jurisdictions with both substituted judgment and best interest standards in their guardianship statutes.<sup>99</sup> One is a hierarchical model, which requires the guardian to first employ substituted judgment if there is evidence of what the incapacitated person would want.<sup>100</sup> Under this approach, a guardian is to resort to the best interest standard only when evidence of what the incapacitated person would want is lacking.<sup>101</sup> A criticism of the hierarchical model is that it often fails to address the reality of current circumstances and the relevant interests of incapacitated persons because surrogates rarely know the incapacitated person's precise wishes.<sup>102</sup>

The other model—based on the Uniform Act's language—encourages substituted judgment provided that the decision is also in the incapacitated person's best interest.<sup>103</sup> The guardian must first look to the expressed directions, desires, and values of the incapacitated person as the starting point for decision-making and then craft a decision that promotes the incapacitated person's best interest.<sup>104</sup> Of course, how the guardian interprets substituted judgment and best

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<sup>99</sup> See *supra* notes 40–63 and accompanying text.

<sup>100</sup> See *supra* notes 49, 50 and accompanying text.

<sup>101</sup> See *supra* notes 49, 50 and accompanying text.

<sup>102</sup> Sulmasy & Snyder, *supra* note 82, at 1946–47.

<sup>103</sup> See *supra* notes 42–48 and accompanying text.

<sup>104</sup> See *supra* notes 42–48 and accompanying text.



interest—using the strict or expanded models—will also impact the outcome of the decision-making process.

## 2. *Examples*

The following examples illustrate how guardians make decisions under the hybrid substituted judgment/best interest models and how the decisions might differ depending on the manner in which the model is applied.

- Mary had a long-standing practice of giving each of her three grandchildren an annual gift of \$5,000. After she became incapacitated, four more grandchildren were born. Prior to her incapacity, Mary left instructions to continue the annual gifts. Mary's guardian must now decide whether to continue the annual gifts and, if so, in what amounts. Before Mary's incapacitation, the annual gifts totaled \$15,000. If the guardian now makes annual \$5,000 gifts to all of the grandchildren, the total annual amount will be \$35,000—more than double the past amount. Using a hierarchical substituted judgment/best interest approach, the guardian could decide to continue the \$5,000 annual gifts for each grandchild. Under the Uniform Act language, the guardian would more likely continue the practice of annual gifts, in line with substituted judgment but, in recognition of Mary's need for costly long-term care, reduce the amount of each gift to preserve Mary's capital.
- Ann inherited a classic 1955 pink Thunderbird Convertible from her sister. In her will, Ann leaves the car jointly to her sister's children, Nick and Nora. Ann now has dementia and resides in an assisted living facility. Her guardian wants to stop paying storage costs for the car and must decide on an appropriate solution. Nick has no interest in the car and Nora, although she wants the car, cannot afford to buy out her brother's share. The guardian suggested transferring ownership of the car jointly to Nick and Nora, but Nick refuses this arrangement. Under a hierarchical substituted judgment/best interest approach, the guardian might decide to follow Ann's wishes and not sell the car—especially in light of Nora's pleas that waiting will allow her time to purchase her brother's share. Under the Uniform Act language, the guardian may decide that she must do what promotes Ann's best interest—sell the car now to save storage fees and distribute the proceeds equally to Nick and Nora.

## IV. THE REALITY: HOW GUARDIANS MAKE DECISIONS

Our literature review revealed almost no formalized study of how guardians make decisions. Numerous studies have attempted to ascertain how accurately health care surrogates can predict what still-competent patients would choose in

various health care scenarios.<sup>105</sup> While mixed, the results of these studies suggest that surrogate's predictions often miss the mark.<sup>106</sup> Sifting through studies about surrogate health care decisions, we found two that examined the role of substituted judgment and best interest in the decision-making process. One study was conducted by interviewing thirty family members of patients with advanced dementia.<sup>107</sup> The other was conducted using interviews with fifty surrogate decision makers for older, chronically ill veterans.<sup>108</sup>

In the study conducted with the family members of dementia patients, the interviewer read to the participants the following statement about decision-making standards:

Some people tell us that when they make healthcare decisions for their relative, they choose what they think their relative would have wanted. Other people tell us that when they make healthcare decisions for their relative they choose what is in their relative's best interest. I'd like to find out which of these you use when you make healthcare decisions for your [relative]. Would you say you make decisions based on what he or she would have wanted or based on what is in his or her best interest?<sup>109</sup>

After family members answered this initial question, they were asked follow-up questions to elicit further explanations of how they made decisions.<sup>110</sup> Although 43 percent of the surrogates claimed to use the substituted judgment standard and 57 percent the best interest standard,<sup>111</sup> the responses to follow-up questions revealed that only 7 percent used solely substituted judgment, 57 percent used best interest, and 37 percent used a combination of the standards.<sup>112</sup> The reasons given for using both standards included: 1) there were no prior discussions about health care preferences; 2) unrealistic prior expectations of the patient; 3) the need for family consensus; 4) the need to consider the quality of life for the patient's relatives; and 5) the influence of health care professionals.<sup>113</sup>

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<sup>105</sup> See Kohn & Blumenthal, *supra* note 75, at 996–98 (synthesizing the results of patient-surrogate studies and concluding that (1) surrogates who do not know a patient's wishes often have difficulty predicting what the patient would want; (2) many surrogates refuse to make decisions consistent with known wishes; and (3) surrogates often mistakenly think they know a patient's wishes).

<sup>106</sup> *Id.* at 997–98 (noting that a review of sixteen studies covering nearly 20,000 patient-surrogate comparisons revealed only a 65 percent accuracy rate).

<sup>107</sup> Hirschman et al., *supra* note 13, at 660–61.

<sup>108</sup> Elizabeth K. Vig et al., *Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision-Making*, 54 J. AM. GERIATRICS SOC'Y 1688, 1688–89 (2006).

<sup>109</sup> Hirschman et al., *supra* note 13, at 661 (alteration in original).

<sup>110</sup> *Id.*

<sup>111</sup> *Id.* at 663–64.

<sup>112</sup> *Id.* at 663.

<sup>113</sup> *Id.* at 665–66 (“Over half of the surrogates discussed the need for family consensus on decisions[,]” and many “struggled with the difference between who their relative is today (‘now self’) and who their relative was before the dementia (‘then self’).”).

In the study conducted with surrogate decision makers for chronically ill veterans, all interviewees had previously participated in a controlled trial to promote advance care planning.<sup>114</sup> They were interviewed by telephone and asked to describe: 1) advance care planning conversations with the patient; 2) previous decision-making experiences with the patient; and 3) how they planned to make future health care decisions for the patient.<sup>115</sup> Conversations with the surrogates revealed five bases for past and future decisions. These bases and the percentage of decision makers who applied them were: 1) conversations about the patient's preferences (66 percent); 2) reliance on written documents—no conversation needed (10 percent); 3) shared values and life experience—conversations not necessarily needed (16 percent); 4) the surrogate's own beliefs, values, and preferences (28 percent); and 5) seeking input from others in the surrogate's network, including shared decision making with other family members, clergy, and clinicians (18 percent).<sup>116</sup>

Although 66 percent of the surrogates for chronically ill veterans planned to make future decisions based on conversations with the patient, the interviews revealed that the content of such conversations was often vague.<sup>117</sup> Other participants indicated that they did not need to rely on conversations because they “will ‘just know’ what to do based upon presumed shared values.”<sup>118</sup> The surrogate's values and beliefs also weighed heavily into the decision-making process.<sup>119</sup> The researchers concluded that “[s]ubstituted judgment has a value in promoting patient autonomy during periods of decisional incapacity, but reliance on this standard neither recognizes the surrogate stakeholder's interests nor fits with how many families make decisions.”<sup>120</sup>

#### A. Guardian Survey Design and Methodology

We used the findings from the foregoing studies to arrive at a list of decision-making factors for our Guardian Survey.<sup>121</sup> The survey instructed respondent guardians to indicate how much each of the following factors influenced them when making decisions for an incapacitated person:

- What I think is in the Incapacitated Person's best interest
- What family members of the Incapacitated Person think is in the Incapacitated Person's best interest
- What professionals say is in the Incapacitated Person's best interest

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<sup>114</sup> Vig et al., *supra* note 108, at 1689.

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

<sup>116</sup> *Id.* at 1690–91.

<sup>117</sup> *Id.* at 1690–92.

<sup>118</sup> *Id.* at 1691–92.

<sup>119</sup> *Id.* at 1692.

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

<sup>121</sup> See National Guardianship Summit Guardian Survey, attached *infra* appendix.

- What will create harmony or consensus among the Incapacitated Person's family members
- What I would want in the Incapacitated Person's circumstances
- What I think the Incapacitated Person would want<sup>122</sup>

They indicated these rankings on a Likert scale (1 = not at all; 2 = a little; 3 = somewhat; 4 = quite a bit; 5 = a great deal; NA = not applicable).<sup>123</sup> Two sets of rankings were possible—one for financial and property decisions and one for health care and personal decisions.<sup>124</sup>

If the guardian indicated that “[w]hat I think the Incapacitated Person would want” was a factor in making decisions, then the guardian was asked to further identify all of the following factors that contributed to knowledge of what the incapacitated person would want:

- Conversations with the person before he or she became incapacitated
- Current conversations with the Incapacitated Person
- Written directions given by the person before he or she became incapacitated
- What I know about the values and preferences of the Incapacitated Person
- What others have told me about the values and preferences of the Incapacitated Person<sup>125</sup>

To avoid predisposing respondents' answers, the survey did not explicitly label decision-making factors as furthering substituted judgment or best interest, nor did it indicate which statutory standard was applicable in the respondent guardian's jurisdiction. Nonetheless, three of the general decision-making factors on the survey included the words “best interest.”<sup>126</sup> The phrase “what the incapacitated person would want” was used in lieu of “substituted judgment” as a means of testing whether guardians used substituted judgment when they made decisions for the incapacitated person.<sup>127</sup> The goal of the survey was to ascertain what factors

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<sup>122</sup> See *infra* appendix.

<sup>123</sup> See *infra* appendix. An independent samples t-test was used to compare the means from the Likert scale to determine whether there were statistically significant differences in the responses of guardians from the best interest jurisdiction versus those from the hybrid jurisdictions and in the responses of family member guardians versus nonfamily member guardians. See *infra* notes 136–140, 148–150, 157–159, 167–169 and accompanying text.

<sup>124</sup> See *infra* appendix.

<sup>125</sup> See *infra* appendix. A chi-square significance test was used to compare the yes/no indications for these factors to determine whether there were statistically significant differences in the responses of guardians from the best interest jurisdiction versus those from the hybrid jurisdictions and in the responses of family member guardians versus nonfamily member guardians. See *infra* notes 143–147, 151–153, 162–166, 171–175 and accompanying text.

<sup>126</sup> See *infra* appendix.

<sup>127</sup> See *infra* appendix.

influence guardian decisions and then determine whether those factors differ depending on the jurisdiction's statutory decision-making standard, the guardian's status as a family member or nonfamily member, and the type of decision.

Survey packets were distributed by volunteer attorneys who compiled mailing lists from their adult guardianship client files. They attached mailing labels to pre-prepared survey packets, which included a self-addressed return envelope to permit mailing of the anonymous responses directly to the authors. In addition to the packets sent to private clients, Northern Indiana Adult Guardianship Services distributed packets to individuals who serve as guardians in their volunteer guardianship program. We were informed of the number of packets distributed in each jurisdiction, but did not have access to the recipients' identities.

### B. Survey Response Profile

Of the 114 surveys distributed, 60 were returned, yielding a response rate of slightly over 50 percent. The four participating states represented two types of statutory decision-making standards—the best interest standard in Indiana<sup>128</sup> (forty-one surveys) and the hybrid substituted judgment/best interest standard (hybrid standard)<sup>129</sup> in Georgia,<sup>130</sup> Massachusetts,<sup>131</sup> and South Dakota<sup>132</sup> (nineteen total surveys). The ratio of surveys returned to surveys distributed was approximately 50 percent in each participating state.<sup>133</sup> The number of family member versus nonfamily guardians was almost evenly split in the hybrid states (ten versus nine). In Indiana, the best interest state, almost twice as many family member guardians as nonfamily member guardians participated (twenty-seven versus fourteen). Of the twenty-three nonfamily member guardians who completed the survey, ten identified themselves as volunteers, six as court-appointed, five as professional guardians, and two as attorneys.

Guardians were asked whether they knew the incapacitated person before they were appointed.<sup>134</sup> Not surprising, most family member guardians knew the incapacitated person before appointment (thirty-five out of thirty-seven) and most

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<sup>128</sup> Indiana does not have an explicit statutory best interest standard, but does contain language in its statute indicating that “the guardian of an incapacitated person has, with respect to the incapacitated person, the same responsibilities as those of a guardian of a minor enumerated in subsection (a)(1), (a)(3), and (a)(4) . . . .” IND. CODE ANN. § 29-3-8-1(b)(1) (West 2010). Subsection (a) of that section provides in part that the guardian of a minor has “all of the responsibilities and authority of a parent . . . .” *Id.* § 29-3-8-1(a); see *supra* notes 26–29 and accompanying text for a discussion of the view that the duties of a parent are akin to duties under the best interest standard.

<sup>129</sup> See *supra* notes 42–48 and accompanying text.

<sup>130</sup> GA. CODE ANN. § 29-4-22(a) (West 2007).

<sup>131</sup> MASS. GEN. LAWS ch. 190B, § 5-309(a) (2011).

<sup>132</sup> S.D. CODIFIED LAWS § 29A-5-402 (West 2004).

<sup>133</sup> The return ratios were as follows: Indiana (41/70), Georgia (6/10), Massachusetts (10/17), and South Dakota (3/7).

<sup>134</sup> See *infra* appendix.

nonfamily member guardians did not (twenty-one out of twenty-three). Given the strong correlation between family member status and prior knowledge of the incapacitated person, we did not do a separate analysis of results based on whether the guardian knew the incapacitated person before appointment.

Guardians were also asked to indicate whether they had authority to make decisions about the finances or the property of the incapacitated person as well as whether they had authority to make decisions about the health care or person of the incapacitated individual.<sup>135</sup> Not all guardians had authority to make both types of decisions. Of the sixty respondents, forty-seven had authority to make decisions about finances and property and fifty-four had authority to make decisions about health care and the person.

### *C. Survey Results and Analysis*

The following summary of results is organized first by type of decision—financial/property or health care/personal. Then, for each type of decision, results are analyzed according to the decision-making standard in the guardian’s jurisdiction—best interest or hybrid, and whether the guardian respondent was a family member or nonfamily member.

#### *1. Factors That Influence Financial and Property Decisions*

##### *(a) Best Interest Standard Versus Hybrid Standard*

Table F1 summarizes how guardians ranked the influence of various factors on financial and property decisions. The mean responses from guardians in the best interest jurisdiction (BI) are compared with the mean responses from guardians in the hybrid jurisdictions (SJ/BI). The two factors weighed most heavily by respondents from both jurisdictions were “What I think is in the Incapacitated Person’s best interest,”<sup>136</sup> and “What I think the Incapacitated Person would want.”<sup>137</sup> However, compared to guardians from the hybrid jurisdictions, guardians from the best interest jurisdiction gave significantly more weight to: 1) the views of family members,<sup>138</sup> 2) family harmony and consensus,<sup>139</sup> and 3) what the

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<sup>135</sup> See *infra* appendix.

<sup>136</sup> Although guardians from both jurisdiction types gave this factor significant weight, guardians in the best interest jurisdiction ranked this factor significantly higher ( $5.00 \pm 0$ ) than guardians in the hybrid jurisdictions ( $4.44 \pm 1.04$ ) ( $t(17) = 2.26, p=.037$ ).

<sup>137</sup> A significant majority of both groups responded that this factor influenced their decisions a great deal (BI 70%; SJ 65%).

<sup>138</sup> Guardians in the best interest jurisdiction were significantly more likely to consider what family members of the incapacitated person think is in the incapacitated person’s best interest ( $4.54 \pm 1.10$ ) than guardians in the hybrid jurisdictions ( $3.06 \pm 1.16$ ) ( $t(42) = 4.29, p<.001$ ).

guardian would want in the incapacitated person's circumstances.<sup>140</sup> Guardians from both jurisdictions gave similar weight to the opinions of professionals.<sup>141</sup>

Table F1  
Influence of Factors on Financial and Property Decisions

Factor	BI (Mean)	SJ/BI (Mean)
<i>What I think is in the Incapacitated Person's best interest</i>	5.00	4.44
<i>What family members of the Incapacitated Person think is in the Incapacitated Person's best interest</i>	4.54	3.06
<i>What professionals (such as accountants and investment advisors) say is in the Incapacitated Person's best interest</i>	3.67	3.88
<i>What will create harmony or consensus among the Incapacitated Person's family members</i>	3.91	2.56
<i>What I would want in the Incapacitated Person's circumstances</i>	4.52	2.88
<i>What I think the Incapacitated Person would want</i>	4.69	4.61

<sup>139</sup> Guardians in the best interest jurisdiction were significantly more likely to consider what would create harmony and consensus among family members ( $3.91 \pm 1.35$ ) than guardians in the hybrid jurisdictions ( $2.56 \pm 1.2$ ) ( $t(39) = 3.36, p=.002$ ).

<sup>140</sup> Guardians in the best interest jurisdiction were significantly more likely to consider what they would want in the incapacitated person's circumstances ( $4.52 \pm .871$ ) than guardians in the hybrid jurisdictions ( $2.88 \pm 1.5$ ) ( $t(22.5) = 4.12, p<.001$ ).

<sup>141</sup> The difference between the mean rating by guardians in the best interest jurisdiction (3.67) and the mean rating by guardians in the hybrid jurisdictions (3.88) was not statistically significant.

Table F2 summarizes what percentage of guardians from the best interest jurisdiction (BI) and what percentage from the hybrid jurisdictions (SJ/BI) considered each of the listed factors to determine what the incapacitated person would want. The majority of guardians in both jurisdictions did not consider conversations with the person before he or she became incapacitated,<sup>142</sup> or prior written directions.<sup>143</sup> Although the majority of respondents did not consider prior written directions, a significantly greater percentage of guardians from the hybrid jurisdictions indicated that they did.<sup>144</sup> A majority of guardians from both jurisdictions considered what they knew about the values and preferences of the incapacitated person.<sup>145</sup> But a significantly greater percentage of guardians from the hybrid jurisdictions used current conversations with the incapacitated person<sup>146</sup> and what others told them about the values and preferences of the incapacitated person<sup>147</sup> when assessing what the incapacitated person would want.

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<sup>142</sup> The difference between the percentage of guardians in the best interest jurisdiction who did not consider conversations with the person before he or she became incapacitated (71 percent) and the percentage of guardians in the hybrid jurisdictions who did not consider such conversations (61 percent) was not statistically significant.

<sup>143</sup> Although the majority of guardians in both jurisdiction types did not consider prior written directions, guardians in the hybrid jurisdictions were significantly more likely to consider prior written directions than guardians in the best interest jurisdiction ( $X^2 = 4.68$ ,  $df=1$ ,  $p=.03$ ).

<sup>144</sup> See *supra* note 143.

<sup>145</sup> The difference between the percentage of guardians in the best interest jurisdiction who considered what they knew about the values and preferences of the incapacitated person (81 percent) and the percentage of guardians in the hybrid jurisdictions who considered this factor (89 percent) was not statistically significant.

<sup>146</sup> Guardians in the hybrid jurisdictions were significantly more likely to consider current conversations with the incapacitated person than guardians in the best interest jurisdiction ( $X^2 = 5.86$ ,  $df=1$ ,  $p=.016$ ).

<sup>147</sup> Guardians in the hybrid jurisdictions were significantly more likely to consider what others told them about the values and preferences of the incapacitated person than guardians in the best interest jurisdiction ( $X^2=3.02$ ,  $df=1$ ,  $p=.082$ ).



Table F2  
 Factors that Helped the Guardian Know What  
 the Incapacitated Person Would Want  
 (Financial and Property Decisions)

Factors	BI %	SJ/BI %
<i>Conversations with the person before he or she became incapacitated</i>	29	39
<i>Current conversations with the Incapacitated Person</i>	48	83
<i>Written directions given by the person before he or she became incapacitated</i>	16	44
<i>What the Guardian knows about the values and preferences of the Incapacitated Person</i>	81	89
<i>What others have told the Guardian about the values and preferences of the Incapacitated Person</i>	36	61

*(b) Family Member Guardians Versus Nonfamily Member Guardians*

Table F3 summarizes how family member guardians (FAM) versus nonfamily member guardians (NON) ranked the influence of various factors on financial and property decisions. Perhaps not surprising, family member guardians weighed much more heavily than nonfamily guardians: 1) the views of family members,<sup>148</sup> 2) family harmony and consensus,<sup>149</sup> and 3) what the guardian would want in the incapacitated person's circumstances.<sup>150</sup>

Table F3  
Influence of Factors on Financial and Property Decisions

Factor	FAM (Mean)	NON (Mean)
<i>What I think is in the Incapacitated Person's best interest</i>	4.94	4.43
<i>What family members of the Incapacitated Person think is in the Incapacitated Person's best interest</i>	4.27	2.91
<i>What professionals (such as accountants and investment advisors) say is in the Incapacitated Person's best interest</i>	3.61	4.08
<i>What will create harmony or consensus among the Incapacitated Person's family members</i>	3.73	2.18
<i>What I would want in the Incapacitated Person's circumstances</i>	4.52	2.38
<i>What I think the Incapacitated Person would want</i>	4.71	4.54

<sup>148</sup> Family member guardians were significantly more likely to consider what family members of the incapacitated person think is in the incapacitated person's best interest ( $4.27 \pm 1.28$ ) than nonfamily member guardians ( $2.91 \pm .94$ ) ( $t(42) = 3.24, p=.002$ ).

<sup>149</sup> Family member guardians were significantly more likely to consider what will create harmony or consensus in the family ( $3.73 \pm 1.34$ ) than nonfamily member guardians ( $2.18 \pm 1.08$ ) ( $t(39) = 3.45, p=.001$ ).

<sup>150</sup> Family member guardians were significantly more likely to consider what they would want in the incapacitated person's circumstances ( $4.52 \pm .83$ ) than nonfamily members ( $2.38 \pm 1.33$ ) ( $t(15.89) = 5.39, p<.001$ ).

Table F4 summarizes what percentage of family member guardians (FAM) and what percentage of nonfamily member guardians (NON) considered each of the listed factors to determine what the incapacitated person would want. Three factors were considered more frequently by nonfamily member guardians when making financial or property decisions: 1) prior written directions,<sup>151</sup> 2) current conversations,<sup>152</sup> and 3) what others told the guardian about the values and preferences of the incapacitated person.<sup>153</sup>

Table F4  
Factors that Helped the Guardian Know  
What the Incapacitated Person Would Want  
(Financial and Property Decisions)

Factors	FAM %	NON %
<i>Conversations with the person before he or she became incapacitated</i>	34	29
<i>Current conversations with the Incapacitated Person</i>	51	86
<i>Written directions given by the person before he or she became incapacitated</i>	14	57
<i>What the Guardian knows about the values and preferences of the Incapacitated Person</i>	83	86
<i>What others have told the Guardian about the values and preferences of the Incapacitated Person</i>	29	86

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<sup>151</sup> Nonfamily member guardians were significantly more likely to consider the incapacitated person's prior written directions than family member guardians ( $X^2 = 9.42$ ,  $df=1$ ,  $p=.002$ ).

<sup>152</sup> Nonfamily member guardians were significantly more likely to consider current conversations with the incapacitated person than family member guardians ( $X^2 = 4.95$ ,  $df=1$ ,  $p=.026$ ).

<sup>153</sup> Nonfamily member guardians were significantly more likely to consider what others have told them about the incapacitated person than family member guardians ( $X^2 = 13.2$ ,  $df=1$ ,  $p<.001$ ).

## 2. *Factors That Influence Health Care and Personal Decisions*

### (a) *Best Interest Standard Versus Hybrid Standard*

Table H1 summarizes how guardians ranked the influence of various factors on health care and personal decisions. The mean responses from guardians in the best interest jurisdiction (BI) are compared with the mean responses from guardians in the hybrid jurisdictions (SJ/BI). The comparison between responses from the two types of jurisdictions is almost identical to the comparison of responses for financial and property decisions.<sup>154</sup> The two factors weighed most heavily by respondents from both jurisdictions were “What I think is in the Incapacitated Person’s best interest,”<sup>155</sup> and “What I think the Incapacitated Person would want.”<sup>156</sup> Guardians from the best interest jurisdiction gave significantly more weight than did guardians from the hybrid jurisdictions to: 1) the views of family members,<sup>157</sup> 2) family harmony and consensus,<sup>158</sup> and 3) what the guardian would want in the incapacitated person’s circumstances.<sup>159</sup> Guardians from both jurisdictions gave similar weight to the opinions of professionals.<sup>160</sup> Of note, the mean weight given to the opinions of professionals was higher in both jurisdictions for decisions about the health care and person of the incapacitated individual than for financial and property decisions.<sup>161</sup>

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<sup>154</sup> See *supra* notes 136–141 and accompanying text.

<sup>155</sup> The difference between the mean rating by guardians in the best interest jurisdiction (4.84) and the mean rating by guardians in the hybrid jurisdictions (4.28) was not statistically significant.

<sup>156</sup> The difference between the mean rating by guardians in the best interest jurisdiction (4.53) and the mean rating by guardians in the hybrid jurisdictions (4.83) was not statistically significant.

<sup>157</sup> Guardians in the best interest jurisdiction were significantly more likely to consider what family members of the incapacitated person think is in the incapacitated person’s best interest ( $4.20 \pm 1.22$ ) than guardians in the hybrid jurisdictions ( $3.17 \pm 1.34$ ) ( $t(46) = 2.75, p=.009$ ).

<sup>158</sup> Guardians in the best interest jurisdiction were significantly more likely to consider what would create harmony and consensus among the family members of the incapacitated person ( $3.68 \pm 1.42$ ) than guardians in the hybrid jurisdictions ( $2.28 \pm 1.27$ ) ( $t(44) = 3.40, p=.001$ ).

<sup>159</sup> Guardians in the best interest jurisdictions were significantly more likely to consider what they would want in the incapacitated person’s circumstances ( $4.24 \pm 1.36$ ) than guardians in the hybrid jurisdictions ( $3.24 \pm 1.56$ ) ( $t(53) = 2.41, p=.02$ ).

<sup>160</sup> The difference between the mean rating by guardians in the best interest jurisdiction (4.58) and the mean rating by guardians in the hybrid jurisdictions (4.22) was not statistically significant.

<sup>161</sup> Guardians in the best interest jurisdictions gave the views of professionals a mean rating of 4.58 for health and personal decisions as compared to a mean rating of 3.67 for financial and property decisions. Guardians in the hybrid jurisdictions gave the views of professionals a mean rating of 4.22 for health and personal decisions and a mean rating of 3.88 for financial and property decisions.

Table H1  
Influence of Factors on Health Care and Personal Decisions

Factor	BI (Mean)	SJ/BI (Mean)
<i>What I think is in the Incapacitated Person's best interest</i>	4.84	4.28
<i>What family members of the Incapacitated Person think is in the Incapacitated Person's best interest</i>	4.20	3.17
<i>What professionals (such as doctors and caregivers) say is in the Incapacitated Person's best interest</i>	4.58	4.22
<i>What will create harmony or consensus among the Incapacitated Person's family members</i>	3.68	2.28
<i>What I would want in the Incapacitated Person's circumstances</i>	4.24	3.24
<i>What I think the Incapacitated Person would want</i>	4.53	4.83

Table H2 summarizes what percentage of guardians from the best interest jurisdiction (BI) and what percentage from the hybrid jurisdictions (SJ/BI) considered each of the listed factors to determine what the incapacitated person would want. The majority of guardians in both jurisdictions did not consider conversations with the person before he or she became incapacitated.<sup>162</sup> The majority in the best interest jurisdiction also did not consider prior written directions, while the guardians in the hybrid jurisdictions were evenly split on whether they relied on prior written directions.<sup>163</sup> A majority of guardians in both jurisdictions relied on current conversations with the incapacitated person<sup>164</sup> and on what they knew about the values and preferences of the incapacitated person.<sup>165</sup> Approximately half of the guardians from each type of jurisdiction also relied on what others told them about the values and preferences of the incapacitated person.<sup>166</sup>

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<sup>162</sup> The difference between the percentage of guardians in the best interest jurisdiction who did not consider conversations with the person before he or she became incapacitated (76 percent) and the percentage of guardians in the hybrid jurisdictions who did not consider such conversations (61percent) was not statistically significant.

<sup>163</sup> Guardians in hybrid jurisdictions were significantly more likely to consider prior written directions than guardians in the best interest jurisdiction ( $X^2=5.97$ ,  $df=1$ ,  $p=.015$ ).

<sup>164</sup> The difference between the percentage of guardians in the best interest jurisdiction who considered current conversations with the incapacitated person (58 percent) and the percentage of guardians in the hybrid jurisdictions who considered current conversations (78%) was not statistically significant.

<sup>165</sup> The difference between the percentage of guardians in the best interest jurisdiction who considered what they knew about the values and preferences of the incapacitated person (71 percent) and the percentage of guardians in the hybrid jurisdictions who considered this factor (89 percent) was not statistically significant.

<sup>166</sup> The difference between the percentage of guardians in the best interest jurisdiction who considered what others told them about the values and preferences of the incapacitated person (47 percent) and the percentage of guardians in the hybrid jurisdiction who considered this factor (50 percent) was not statistically significant.

Table H2  
 Factors That Helped the Guardian Know  
 What the Incapacitated Person Would Want  
 (Health Care and Personal Decisions)

Factors	BI %	SJ/BI %
<i>Conversations with the person before he or she became incapacitated</i>	24	39
<i>Current conversations with the Incapacitated Person</i>	58	78
<i>Written directions given by the person before he or she became incapacitated</i>	18	50
<i>What the Guardian knows about the values and preferences of the Incapacitated Person</i>	71	89
<i>What others have told the Guardian about the values and preferences of the Incapacitated Person</i>	47	50

*(b) Family Member Guardians Versus Nonfamily Member Guardians*

Table H3 summarizes how family member guardians (FAM) versus nonfamily member guardians (NON) ranked the influence of various factors on health care and personal decisions. The comparison between responses from the family member and nonfamily member guardians is almost identical to the comparison of responses for financial and property decisions. Family member guardians who made decisions about the health care or person of an incapacitated individual weighed more heavily than nonfamily guardians: 1) the views of family members,<sup>167</sup> 2) family harmony and consensus,<sup>168</sup> and 3) what the guardian would want in the incapacitated person's circumstances.<sup>169</sup>

Table H3  
Influence of Factors on Health Care and Personal Decisions

Factor	FAM (Mean)	NON (Mean)
<i>What I think is in the Incapacitated Person's best interest</i>	4.91	4.24
<i>What family members of the Incapacitated Person think is in the Incapacitated Person's best interest</i>	4.06	3.27
<i>What professionals (such as doctors and caregivers) say is in the Incapacitated Person's best interest</i>	4.54	4.33
<i>What will create harmony or consensus among the Incapacitated Person's family members</i>	3.56	2.14
<i>What I would want in the Incapacitated Person's circumstances</i>	4.49	2.95
<i>What I think the Incapacitated Person would want</i>	4.76	4.43

<sup>167</sup> Family member guardians were moderately more likely to consider what family members of the incapacitated person think is in the incapacitated person's best interest ( $4.06 \pm 1.37$ ) than nonfamily member guardians ( $3.27 \pm 1.16$ ) ( $t(46) = 1.95, p=.058$ ).

<sup>168</sup> Family member guardians were significantly more likely to consider what will create harmony or consensus in the family ( $3.56 \pm 1.52$ ) than nonfamily member guardians ( $2.14 \pm .95$ ) ( $t(38.36) = 3.84, p<.001$ ).

<sup>169</sup> Family member guardians were significantly more likely to consider what they would want in the same circumstances ( $4.49 \pm .92$ ) than nonfamily member guardians ( $2.95 \pm 1.79$ ) ( $t(24.84) = 3.58, p=.001$ ).



Table H4 summarizes what percentage of family member guardians (FAM) and what percentage of nonfamily member guardians (NON) considered each of the listed factors to determine what the incapacitated person would want. The same three factors were considered more often by nonfamily guardians in the context of health care and personal decisions as were considered by those guardians in the context of financial and property decisions:<sup>170</sup> 1) prior written directions,<sup>171</sup> 2) current conversations,<sup>172</sup> and 3) what others told the guardian about the values and preferences of the incapacitated person.<sup>173</sup> The majority of both types of guardians did not rely on past conversations,<sup>174</sup> but did rely on what they knew of the values and preferences of the incapacitated person.<sup>175</sup>

Table H4  
Factors That Helped the Guardian Know What the  
Incapacitated Person Would Want  
(Health Care and Personal Decisions)

Factors	FAM %	NON %
<i>Conversations with the person before he or she became incapacitated</i>	31	24
<i>Current conversations with the Incapacitated Person</i>	51	86
<i>Written directions given by the person before he or she became incapacitated</i>	14	52
<i>What the Guardian knows about the values and preferences of the Incapacitated Person</i>	77	76
<i>What others have told the Guardian about the values and preferences of the Incapacitated Person</i>	29	81

<sup>170</sup> See *supra* notes 151–153 and accompanying text.

<sup>171</sup> Nonfamily member guardians were significantly more likely to consider the incapacitated person's written directions than family member guardians ( $X^2 = 9.33$ ,  $df=1$ ,  $p=.002$ ).

<sup>172</sup> Nonfamily member guardians were significantly more likely to consider current conversations with the incapacitated person than family member guardians ( $X^2 = 6.725$ ,  $df=1$ ,  $p=.01$ ).

<sup>173</sup> Nonfamily member guardians were significantly more likely to consider what others have told them about the incapacitated person than family member guardians ( $X^2 = 14.42$ ,  $df=1$ ,  $p<.001$ ).

<sup>174</sup> The difference between the percentage of family member guardians who did not consider conversations with the person before he or she became incapacitated (69 percent) and the percentage of nonfamily member guardians who did not consider such conversations (76 percent) was not statistically significant.

<sup>175</sup> The difference between the percentage of family member guardians who did rely on what they knew of the values and preferences of the incapacitated person (77 percent) and the percentage of nonfamily member guardians who relied on this factor (76 percent) was not statistically significant.

#### *D. Survey Conclusions*

The National Guardianship Summit Guardian Survey was an exploratory study. To our knowledge, it was the first to investigate what factors influence how guardians make decisions. Specifically, we gathered data to determine whether the decision-making standard, the family status of the guardian, and the type of decision make a difference in the decision-making process. While our sample size was modest—sixty guardians—the results, as analyzed under both an independent samples t-test and a chi-square significance test, yielded statistically significant results. The following conclusions summarize these findings. Further research is warranted to ascertain whether these results will be replicated in another sample and also to investigate what other factors might be material to the surrogate decision-making process.

##### *1. Decision-Making Standard*

The survey results suggest that the statutory decision-making standard in a jurisdiction does influence how guardians make decisions. While all guardians indicated that they give significant consideration to what they think is in the incapacitated person's best interest and what they think the incapacitated person would want, the relative importance of various decision-making factors and the bases for determining what an incapacitated person would want differed significantly with the type of jurisdiction. Guardians in the best interest jurisdiction, for all types of decisions, gave more weight to the views of family members, family harmony and consensus, and what the guardian would want in the incapacitated person's circumstances. For financial and property decisions, guardians from the hybrid jurisdictions were more likely than guardians from the best interest jurisdiction to rely on current conversations with the incapacitated person and on what others told them about the incapacitated person's values and preferences.

The differences based on jurisdiction were less in the context of health care and personal decisions. The majority of guardians in both jurisdictions relied on current conversations with the incapacitated person and on what they knew about the values and preferences of the incapacitated person to determine what the incapacitated person would want. Approximately half of the guardians in both jurisdictions also relied on what others told them about the values and preferences of the incapacitated person. While all guardians looked at similar factors to determine what the incapacitated person would want, the guardians in the best interest jurisdiction also gave significant weight to the views of family members, family harmony and consensus, and what the guardian would want in the incapacitated person's circumstances.

## 2. *Family-Member Status of Guardian*

The survey results suggest that the status of the guardian—family member or nonfamily member—influences how guardians make decisions. For both types of decisions—financial/property and health care/personal—family member guardians gave greater weight to the views of family members, family harmony and consensus, and what the guardian would want in the incapacitated person's circumstances. With respect to factors used to determine what the incapacitated person would want—in other words, factors used to form a substituted judgment—nonfamily member guardians more often considered prior written directions, current conversations, and what others told them about the values and preferences of the incapacitated person.

### *E. Reality and Theory*

Results from the National Guardianship Summit Guardian Survey suggest a number of preliminary conclusions about the five theoretical models for guardian decisions. First, it is unlikely that guardians make decisions using either a strict best interest or a strict substituted judgment model. Nearly all respondents indicated that when they make surrogate decisions they considered both the incapacitated person's best interest and what the incapacitated person would want.

Second, while guardians from the best interest jurisdiction claimed to consider what the incapacitated person would want, they, more than guardians from the hybrid jurisdictions, rated as influential survey factors that were linked to best interest. Guardians in the best interest jurisdiction as well as family member guardians were more likely to give weight to the views of family members, family harmony and consensus, and what the guardians projected the incapacitated person would want in the circumstances. Such considerations reflect what could be understood as expanded best interest—taking into account consequences for significant others that the incapacitated person likely would have considered. Beyond expanded best interest notions, this approach might also be understood as the most protective, as it seeks the broadest range of opinion about what is best for the incapacitated person. On the other hand, consideration of family harmony and consensus, without safeguards, could lead to decisions that favor family members to the detriment of the incapacitated person. Without a clear statutory standard, an almost infinite range of possibilities exist for how a guardian might make a decision under an expanded notion of best interest.

Third, although guardians from both jurisdictions favored using substituted judgment at least in part, the survey responses do not provide much of an explanation for how guardians in the best interest jurisdiction planned to determine what the incapacitated person would want. Most of these guardians appeared to use an expanded notion of substituted judgment based on what the guardian knew about the values and preferences of the incapacitated person; however, the source of this knowledge was unclear. Less than half of the guardians used current conversations with the incapacitated person, and an even smaller percentage

considered past conversations, written directions, and what others told the guardian about the incapacitated person's values and preferences. These results are similar to those found in the study conducted with surrogates for chronically ill veterans.<sup>176</sup> In that study, many of the surrogates presumed to know what the incapacitated person would want but based the belief on factors such as presumed shared values, vague conversations, and the surrogate's own values, beliefs, and preferences rather than on direct evidence of the incapacitated person's desires.<sup>177</sup>

Fourth, guardians in the hybrid jurisdictions, when making decisions, appeared to consider some combination of substituted judgment and best interest factors. The relative importance of substituted judgment appeared greater in the hybrid jurisdictions than in the best interest jurisdiction, as evidenced by more guardian reliance on current conversations, the guardian's knowledge of the incapacitated person's values and preferences, and what others told the guardian about the incapacitated person's values and preferences. In addition, written directions were used by 44 percent of the guardians for financial and property decisions and by 50 percent of the guardians for health care decisions.

## V. CONCLUSION

Guardians have little statutory or case law to guide them on how to make decisions for incapacitated persons. The majority of jurisdictions have no articulated decision-making standard for non-health care decisions but most likely follow a general custom of "best interest." Fourteen jurisdictions have adopted a combination of substituted judgment and best interest standards, but most fail to clarify for guardians the manner in which these standards should be applied.

Theories about the use of substituted judgment and best interest range from a strict substituted judgment approach, which requires that decisions follow the incapacitated person's prior directions, to a strict best interest approach, which dictates that decision makers may only consider actions that will promote the incapacitated person's welfare. The Uniform Act language and the National Guardianship Association (NGA) standard represent hybrid approaches; each recognizes that often no information exists upon which to base a true substituted judgment and that a true substituted judgment, when possible, might sometimes be harmful to the incapacitated person.

Empirical research conducted in best interest and hybrid substituted judgment/best interest jurisdictions revealed that nearly all guardians attempt to consider both standards when they make decisions for an incapacitated person. Survey results, however, showed that guardians in a best interest jurisdiction tended to favor decision-making factors related to best interest, such as the views of family members and what the guardian would want in the incapacitated person's circumstances, and that guardians in the hybrid jurisdictions tended to rely more on decision-making factors related to substituted judgment, such as current

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<sup>176</sup> See *supra* notes 114–120 and accompanying text.

<sup>177</sup> See *supra* notes 114–120 and accompanying text.

conversations with the incapacitated person and what others had told the guardian about the incapacitated person's values and preferences. This research suggests that 1) most guardians use some blend of best interest and substituted judgment standards when they make decisions; 2) statutory decision-making standards influence the way guardians make decisions; and 3) law reform is needed to create statutory standards that provide adequate guidance for guardians. Further empirical research is warranted to determine whether these findings will be replicated and to investigate what other factors may be material to the surrogate decision-making process. Such research would be beneficial both to law reform efforts and development of guardian best practices.

**NATIONAL GUARDIANSHIP SUMMIT  
GUARDIAN SURVEY**

*Thank you for completing this survey about how you make decisions as a Guardian. Please check or circle (where indicated) your responses and return the completed survey by **May 31, 2011**.*

***Note: If you are currently serving (or have served) as Guardian for more than one Incapacitated Person, please base your answers on the most recent Guardianship appointment.***

1. I am:

- currently serving as a Guardian.
- no longer a Guardian but have served as one in the past.

2. Please select the capacity in which you are (were) serving as a Guardian:

- Family member
- Non-family member volunteer
- Other: \_\_\_\_\_

(If “Other,” please indicate in what capacity you came to be appointed as a Guardian—e.g., *professional guardian, public guardian, attorney or social worker appointed by the court, etc.*)

3. Did you know the Incapacitated Person before you were appointed to serve as Guardian?

- Yes  No

If “Yes,” how long did you know the Incapacitated Person before appointment?

- Less than 60 days
- 60 days to 1 year
- Over 1 year

4. Please indicate all types of decisions you have (had) authority to make as a Guardian:

- Decisions about the finances or property of the Incapacitated Person
- Decisions about the health care or person of the Incapacitated Person

5. Did you receive instructions from the court or anyone else about what factors you should consider when you make decisions for the Incapacitated Person?

- Yes
- No

**IF you make FINANCIAL or PROPERTY decisions for the Incapacitated Person . . .**

*(If you do not make these decisions, please skip to question #7).*

6. How much does (did) each of the following influence you when making financial or property decisions for the Incapacitated Person?						
<b>1 = not at all    2 = a little    3 = somewhat    4 = quite a bit</b> <b>5 = a great deal    NA = not applicable</b>						
What <b>I</b> think is in the Incapacitated Person’s <b>best interest</b>	1	2	3	4	5	NA
What <b>family members</b> of the Incapacitated Person think is in the Incapacitated Person’s <b>best interest</b>	1	2	3	4	5	NA
What <b>professionals</b> (such as accountants and investment advisors) say is in the Incapacitated Person’s <b>best interest</b>	1	2	3	4	5	NA
What will <b>create harmony or consensus</b> among the Incapacitated Person’s family members	1	2	3	4	5	NA
What <b>I would want</b> in the Incapacitated Person’s circumstances	1	2	3	4	5	NA
What I think the <b>Incapacitated Person would want</b>	1	2	3	4	5	NA
<input type="checkbox"/> 6a. <b>If “what you think the Incapacitated Person would want” is one of your considerations, please indicate which of the following factors have helped you to know what the Incapacitated Person would want</b> ( <i>Check all that apply</i> ): <ul style="list-style-type: none"> <li><input type="checkbox"/> Conversations with the person before he or she became incapacitated</li> <li><input type="checkbox"/> Current conversations with the Incapacitated Person</li> <li><input type="checkbox"/> Written directions given by the person before he or she became incapacitated</li> <li><input type="checkbox"/> What I know about the values and preferences of the Incapacitated Person</li> <li><input type="checkbox"/> What others have told me about the values and preferences of the Incapacitated Person</li> </ul>						

**IF you make HEALTH CARE or PERSONAL decisions for the Incapacitated Person . . .**

*(If you do not make these decisions, please skip to question #8).*

7. How much does (did) each of the following influence you when making health care or personal decisions for the Incapacitated Person?						
<b>1 = <u>not</u> at all    2 = a little    3 = somewhat    4 = quite a bit</b> <b>5 = a great deal    NA = not applicable</b>						
What <b>I</b> think is in the Incapacitated Person's <b>best interest</b>	1	2	3	4	5	NA
What <b>family members</b> of the Incapacitated Person think is in the Incapacitated Person's <b>best interest</b>	1	2	3	4	5	NA
What <b>professionals</b> (such as accountants and investment advisors) say is in the Incapacitated Person's <b>best interest</b>	1	2	3	4	5	NA
What will <b>create harmony or consensus</b> among the Incapacitated Person's family members	1	2	3	4	5	NA
What <b>I would want</b> in the Incapacitated Person's circumstances	1	2	3	4	5	NA
What I think the <b>Incapacitated Person would want</b>	1	2	3	4	5	NA
<input type="checkbox"/> 7a. <b>If “what you think the Incapacitated Person would want” is one of your considerations, please indicate which of the following factors have helped you to know what the Incapacitated Person would want</b> ( <i>Check all that apply</i> ):						
<input type="checkbox"/> Conversations with the person before he or she became incapacitated						
<input type="checkbox"/> Current conversations with the Incapacitated Person						
<input type="checkbox"/> Written directions given by the person before he or she became incapacitated						
<input type="checkbox"/> What I know about the values and preferences of the Incapacitated Person						
<input type="checkbox"/> What others have told me about the values and preferences of the Incapacitated Person						



8. Please tell us a little about yourself:

Gender:  Male  Female

Age:  18–29  30–49  50–69  70 or older

Please choose the race or ethnicity that best applies to you:

- African American/Black
- White, not Hispanic
- Native American
- Latino/Hispanic
- Asia
- Arab
- Other \_\_\_\_\_

How long you have served as a Guardian?:

- Less than 1 year
- 1-3 years
- Over 3 years

9. Please feel free to share other factors that you consider when you make decisions for the Incapacitated Person:

Return survey in the envelope provided, or mail to:

Professor Linda S. Whitton

Valparaiso University

School of Law

Valparaiso, Indiana

For more information please email: [linda.whitton@valpo.edu](mailto:linda.whitton@valpo.edu)

*Thank you for your participation!*