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### INCAPACITY AND THE INFANCY ILLATION

### Ralph C. Brashier\*

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As the population of elderly Americans swells in coming decades, growing numbers of citizens will experience some degree of cognitive incapacity and require the assistance of surrogate decision-makers. Consequently, the decisions of guardians, conservators, and agents will become increasingly important. Experts have frequently noted that, despite modern reforms, doctrines concerning surrogate decision-making are problematic and often do not result in outcomes that maximize autonomy and promote respect for the unique personhood of the adult with diminished capacity. Unlike other writings that seek to refashion or clarify surrogate decision-making statutes and standards, this Article suggests that a more fundamental problem lies in our inherent, if unwitting, tendency to infantilize the elderly and other adults with diminished capacity. Until we acknowledge and examine our biases and prejudices about age and incapacity, we as surrogate decision-makers will continue to make unfortunate choices for those whom we seek to assist, regardless of definitional changes in decision-making statutes and standards.

### I. INTRODUCTION

The typical American adult assumes that she will always enjoy the right to choose where she will live, how she will pass her days, and with whom she will share her life. Most American

Accordingly, adult persons have a right to exercise autonomous self-determination. They have the right to choose how they live, how they spend their money, and with whom they associate without undue governmental interference.

When viewed as personal power, autonomy takes on added significance to elderly persons, many of whom fear the loss of their independence and their ability to control their own lives. All that many elderly persons have under their control is the prerogative to decide how to live out the rest of their days and how and in what manner they will control their own property. Their ability to exercise this control and to maintain their individual dignity often forms the basis for their self-esteem and their belief in their continuing viability as a person. Thus, the loss of status as an autonomous member of society can intensify any disability that an elderly person may have.

Id. at 328 (footnotes omitted).

<sup>1.</sup> See, e.g., In re Conservatorship of Groves, 109 S.W.3d 317, 327-28 (Tenn. Ct. App. 2003) ("Autonomy, an adult person's right to live life consistent with his or her personal values, is one of the bedrock principles of a free society."). The *Groves* court further stated,

adults do enjoy these freedoms throughout their lives;<sup>2</sup> thus, the odds are that her assumptions will prove true.<sup>3</sup> She knows little or nothing of guardianships and conservatorships<sup>4</sup> and their associated judicial proceedings that can curtail the freedoms of an adult with diminished capacity<sup>5</sup>—a curtailment that, in some ways, can exceed the limitations imposed on convicted felons residing in prison.<sup>6</sup> She has not considered the ways in which an

- 3. Although the vast majority of American adults are never placed under a conservatorship or guardianship, a simple and disturbing fact is that we do not really know just how many adults are placed under a conservatorship or guardianship in the United States each year. See Sally Hurme & Erica Wood, Introduction to the Third National Guardianship Summit: Standards of Excellence, 2012 UTAH L. REV. 1157, 1162 ("We as a nation are essentially working in the dark when describing adult guardianship practice. Data and research are scant to nonexistent. Many courts and states do not know the number of adults under guardianship in their jurisdiction, let alone the demographics.") Hurme and Wood further state, "In 2011, the National Center for State Courts estimated that there are 1.5 million active pending adult guardianship cases—but that this number could, in fact, range from fewer than one million to more than three million." Id.
- 4. Guardianship and conservatorship terminology varies across the country. In some states, a fiduciary may be guardian of the person, guardian of the person's estate, or both. See, e.g., 20 PA. STAT. AND CONS. STAT. ANN. § 5521 (West 2017) (using term "guardian" for person and estate management). In other states, a fiduciary may be conservator of the person and conservator of the person's estate, or both. See, e.g., TENN. CODE ANN. § 34-1-101 (West 2017) (employing term "conservator" for person and estate management of adult); see also LAWRENCE A. FROLIK & ALISON MCCHRYSTAL BARNES, ELDER LAW: CASES & MATERIALS 360 (5th ed. 2011) (noting that "[s]tates use a variety of terms" for the manager of the incapacitated 'person's property). Under the Uniform Probate Code, a guardian serves the person. UNIF. PROB. CODE § 5-102(3) (UNIF. LAW COMM'N 2010). A conservator manages the estate of a protected person. UNIF. PROB. CODE § 5-102(1) (UNIF. LAW COMM'N 2010). This Article generally employs the UPC distinction except when quoting from statutes or cases employing different terminology. Nonetheless, the reader should keep in mind the wide discrepancies that exist in terminology among the states.
- 5. See, e.g., Kristin Booth Glen, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond, 44 COLUM. HUM. RTS. L. REV. 93, 104-06 (2012) (discussing the paradigm of American guardianship law that prevailed throughout most of the twentieth century and that could limit or completely deny basic civil rights to those declared "incompetent").
- 6. See Hedin v. Gonzales (In re Guardianship of Hedin), 528 N.W.2d 567, 573-74 (Iowa 1995) (observing commentator's statement that "[a]lthough the determination of incompetency is in no way a criminal proceeding, the result in terms of the defendant's liberty interests may be very similar. He may be deprived of control over his residence, his associations, his property, his diet, and his ability to go where he wishes" (citing Bobbe Shapiro Nolan, Functional Evaluation of the Elderly in Guardianship Proceedings, 12 L. MED. & HEALTH CARE 210, 214 (1984))); In re Conservatorship of Groves, 109 S.W.3d 317, 329 (Tenn. Ct. App. 2003) (noting that subjects of conservatorship proceedings "face a substantial loss of freedom . . . that resembles the loss of freedom following a criminal

<sup>2.</sup> See id. at 331-32 (noting in conservatorship case that being old is not the same as being disabled and that, in fact, "a vast majority of the elderly are not experiencing a progressive physical or mental decline").

agent with unlimited powers can use a durable power of attorney, without judicial oversight, to control her life. If now and then the possibility of future incapacity flickers across her mind, she quickly pushes it aside. 8

My views, however, differ from those of the typical American adult. As a professor who has taught and written in the field of elder law for over twenty years, 9 my teaching and research have daily impressed upon me that life offers no guarantees of

conviction" (citations omitted)). Despite modern reforms in guardianship and conservatorship law, wards may still find themselves facing limitations that give almost no real possibility of their making "even the most basic decisions for themselves." *Groves*, 109 S.W.3d at 329; see also Jan Ellen Rein, *Preserving Dignity and Self-Determination of the Elderly in the Face of Competing Interests and Grim Alternatives: A Proposal for Statutory Refocus and Reform*, 60 GEO. WASH. L. REV. 1818, 1825 (1992) (observing, in article written near the beginning of the modern reform movement, that a ward under guardianship may have "fewer legal rights than a convict in prison").

- 7. See Carolyn L. Dessin, Financial Abuse of the Elderly: Is the Solution a Problem?, 34 McGeorge L. Rev. 267, 316-17 (2003) (noting that despite its flexibility and potential usefulness as an estate planning tool, the durable power of attorney also raises dangers of agent abuse, especially since the document can give an agent total control of the principal's estate). For an overview of durable powers of attorney, see James H. Pietsch, Alternatives to Guardianship and Supported Decision-Making, in COMPARATIVE PERSPECTIVES ON ADULT GUARDIANSHIP 285, 287-90 (A. Kimberley Dayton ed., 2014) (noting that powers of attorney are "probably the most popular" and frequently used alternative to guardianships and conservatorships); Linda S. Whitton, Durable Powers as an Alternative to Guardianship: Lessons We Have Learned, 37 STETSON L. REV. 7, 52 (2007) [hereinafter Whitton, Durable Powers] ("[T]rustworthiness of the agent, the willingness of third persons to accept the agent's authority, and the cooperation of the incapacitated principal's family are key components to the successful use of durable powers.").
- 8. If she is among the minority who takes precautionary measures in case she should become incapacitated, she may execute a durable power of attorney for health care and a durable power of attorney for estate matters. These are important, often very helpful documents that can enhance the chances that her expressed wishes and continuing autonomy will be respected should she become incapacitated. Nevertheless, powers of attorney placed in the hands of an agent who acts improperly are often far worse than court-supervised guardianships and conservatorships. See Russ ex rel. Schwartz v. Russ, 734 N.W.2d 874, 888 (Wis. 2007) (Abrahamson, C.J., concurring) (noting that the durable power of attorney is "a troublesome document, creating the potential for abuse" by giving an agent "the power to sell the principal's home and any other assets, to make investments, to cancel insurance policies or name new beneficiaries, and even to empty the bank accounts"). In fact, the existence of a durable power of attorney does not preclude the possibility of a future guardianship or conservatorship proceeding. See, e.g., Vernon H. v. Peter H. (In re Protective Proceedings of Vernon H.), 332 P.3d 565, 567-69 (Alaska 2014) (discussing unsuccessful guardianship petition brought by one of proposed ward's fifteen children despite durable power of attorney that proposed ward had given to another child).
- I began teaching an Elder Law survey class in the 1990s—when Elder Law was a relatively new subject in the law school curriculum—at the University of Memphis Cecil C. Humphreys School of Law.

continuing capacity.<sup>10</sup> Having entered my seventh decade of life, I know more than ever that the chance of diminishing capacity increases with old age.<sup>11</sup>

What I fear more than a possible future of incapacity, however, is how the law and those individuals who might become my decision-makers will respond should their intervention be warranted.<sup>12</sup> I know that when an adult becomes incapacitated, too often our judges, lawyers, and surrogate decision-makers focus on the individual's limitations while minimizing the importance of the wishes he previously made known or currently expresses.<sup>13</sup> Moreover, despite statutory admonitions and judicial opinions stating that old age is not the equivalent of incapacity,<sup>14</sup> the unwitting tendency is for judges, lawyers, surrogate decision-makers and everyday folk to act as though old age itself—whether

<sup>10.</sup> See, e.g., RALPH C. BRASHIER, MASTERING ELDER LAW (2d ed. 2015) (discussing major principles of elder law); Ralph C. Brashier, Conservatorships, Capacity, and Crystal Balls, 87 TEMP. L. REV. 1 (2014) [hereinafter Brashier, Crystal Balls] (discussing wills executed by persons under guardianship and conservatorship); Ralph C. Brashier, The Ghostwritten Will, 93 B.U. L. REV. 1803 (2013) (discussing durable powers of attorney and whether a principal's willmaking ability should be delegable).

<sup>11.</sup> See Doug Surtees, Constructing Incapacity: Deconstructing Capacity in Adult Guardianship, in COMPARATIVE PERSPECTIVES ON ADULT GUARDIANSHIP, supra note 7, at 273, 275, 279 (observing that guardianship has long been a primary vehicle for substituted decision-making and that "[t]he majority of persons subjected to substituted decision making regimes are older as opposed to younger"); Glen, supra note 5, at 108-09 (noting that changes in guardianship procedures came in part from work of American Bar Association Commission on Legal Problems of the Elderly and also from work of Commission on Mental and Physical Disability).

<sup>12.</sup> The guardianship, conservatorship, and health-care power-of-attorney statutes of many states often include a priority list of individuals who, in the absence of a designation by the adult who now has diminished capacity, might serve as default substitute decision-makers. *See, e.g.*, UNIF. PROB. CODE § 5-310 (UNIF. LAW COMM'N 2010) (providing priority list for who may be a guardian); UNIF. PROB. CODE § 5-413 (UNIF. LAW COMM'N 2010) (providing priority list for who may be a conservator); UNIF. HEALTH-CARE DECISIONS ACT § 5(b) (UNIF. LAW COMM'N 1994) (providing default list for who may serve as surrogate decision-maker).

<sup>13.</sup> See infra note 79 and accompanying text (noting how a person with a cognitive disability may have preferences that change over time).

<sup>14.</sup> See, e.g., Harvey v. Meador, 459 So. 2d 288, 292 (Miss. 1984) (opining that a person's old age alone is not enough for the imposition of substitute decision-maker for the person, even when "advanced age" is mentioned in statute); *In re* Conservatorship of Groves, 109 S.W.3d 317, 331 (Tenn. Ct. App. 2003) ("The aging process, by itself, is not a disabling condition, and being elderly is not tantamount to being disabled.").

or not accompanied by incapacity—causes one to revert to a childlike state.<sup>15</sup>

This Article suggests that our tendency to conflate adult incapacity and infancy is not inevitable. By acknowledging, examining, and discarding unwarranted biases and prejudices about incapacity and old age, we can take a much-needed initial step towards asking essential questions and making decisions that will better serve the interests of adults with a cognitive incapacity. Through an honest evaluation of why we tend to infantilize adults with diminished capacity, we are more likely to curb unwarranted intrusion into their lives and promote autonomy consistent with their abilities. <sup>20</sup>

<sup>15.</sup> See infra Part III (discussing why people infantilize the incapacitated and elderly); see also Hedin v. Gonzales (In re Guardianship of Hedin), 528 N.W.2d 567, 572 (Iowa 1995) (citing Sheryl Dicker, Guardianship: Overcoming the Last Hurdle to Civil Rights for the Mentally Disabled, U. ARK. LITTLE ROCK L.J. 485, 485-86 (1981)) (noting observation that a person under a guardianship is reduced to the status of a child).

<sup>16.</sup> See infra Part III (discussing reasons we infantilize the elderly).

<sup>17.</sup> For an early and still enlightening discussion of the effects of unacknowledged biases and prejudices in judging and the law, see JEROME FRANK, LAW AND THE MODERN MIND 148-54 (Anchor Books 1963) (1930).

<sup>18.</sup> See infra Part V (discussing questions that should never go unasked in substitute decision-making settings).

<sup>19.</sup> See infra Part V. Terminology concerning individuals with a disability has evolved through the decades. Today, law and society at least pay lip service to the basic principle that proper focus is on the individual, not her disability. Thus an older term such as "disabled person" is now less likely to be used than a term such as "person with a disability." See, e.g., Glen, supra note 5, at 94 n.4 (discussing the importance of nomenclature, stating that "[u]nderstanding and naming a person solely based on her disability—'idiot, incapacitated person'—reduces the person to her disability and makes her an object of the law"). In this Article, I use principally the terms "adult with a cognitive incapacity" or "adult with diminished capacity."

<sup>20.</sup> See infra Part III (discussing modern reform goals of focusing on the individual and seeking to maximize her autonomy and abilities). The modern goal of personcenteredness is discussed further in Leslie P. Francis, *Preface to the Third National Guardianship Summit: Standards of Excellence*, 2012 UTAH L. REV. 1155, 1155 (discussing limited guardianship and noting that ""[r]espect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons' is the very first of the guiding principles of the United Nations Convention on the Rights of Persons with Disabilities" (quoting United Nations Convention on the Rights of Persons with Disabilities art. 3(a), Mar. 5, 2008, 2515 U.N.T.S. 70)); A. Frank Johns, *Person-Centered Planning in Guardianship: A Little Hope for the Future*, 2012 UTAH L. REV. 1541, 1544 ("[N]o statutes, regulations, or standards mandate person-centered guardianship.").

### II. STATUTORY REQUIREMENTS

Modern assisted-decision-making statutes seek to reform an historical lack of respect for wards, conservatees, and principals and have their origins in the last years of the twentieth century. Viewed broadly, one can see in recent reforms a societal desire to ensure that adults with a cognitive incapacity receive due respect for their autonomy, dignity, and uniqueness. These reforms have achieved some of their goals. This is particularly true concerning goals for which legislators can establish highly detailed procedures that a substitute decision-maker must follow. State legislatures have had substantially less success in

<sup>21.</sup> See Nicole M. Arsenault, Start with a Presumption She Doesn't Want to Be Dead: Fatal Flaws in Guardianships of Individuals with Intellectual Disability, 35 LAW & INEQ. 23, 26-32 (2017) (discussing guardianship history from its origins in parens patriae doctrine through symposia of late twentieth and early twenty-first centuries and significant evolution in modern uniform laws).

<sup>22.</sup> Perhaps the best-known statutory exemplars incorporating modern reforms are the uniform laws concerning guardianship, conservatorship, and powers of attorney. Guardianship and conservatorships are covered in the Uniform Guardianship and Protective Proceedings Act (revised in 1997 and now serving as Article 5 of the Uniform Probate Code). See UNIF. PROB. CODE Art. 5 (UNIF. LAW COMM'N 2010). The Uniform Power of Attorney Act was promulgated in 2006. See UNIF. POWER OF ATT'Y ACT §§ 201-217 (UNIF. LAW COMM'N 2006). The Uniform Law Commission website provides maps indicating those jurisdictions that have adopted or are considering adoption of various uniform acts. See Adult Guardianship and Protective Proceedings Jurisdiction Act: Enactment Status Map, UNIFORM L. COMMISSION, http://www.uniformlaws.org/Act.aspx?title=Adult%20 Guardianship%20and%20Protective%20Proceedings%20Jurisdiction%20Act [https://perma.cc/E3C8-PM9V]; Probate Code: Enactment Status Map, UNIFORM L. COMMISSION, http:// www. uniformlaws .org/ Act.aspx?title= Probate%20Code [https://perma.cc/E8EF-ASEF]; Power of Attorney: Enactment Status Map , UNIFORM L. COMMISSION, http:// uniformlaws.org/ Act.aspx?title= Power%20 of%20Attorney [https://perma.cc/8NVH-K9RJ].

<sup>23.</sup> For example, today most state statutory schemes reflect a preference for a limited guardianship over a plenary guardianship, when possible, as a manifestation of the general acceptance that ultimately what is appropriate is the least restrictive alternative for the particular individual in question. *See generally* NINA A. KOHN, ELDER LAW: PRACTICE, POLICY, AND PROBLEMS 142-45, 158 (2014) (providing overview of modern guardianship provisions, and noting statutory availability of limited guardianship and mandatory use in some statutory schemes). The mandates of modern statutory reform, of course, are not always carried out in practice. *See, e.g.*, Lawrence A. Frolik, *Guardianship Reform: When the Best is the Enemy of the Good*, 9 STAN. L. & POL'Y REV. 347, 354 (1998) ("In order for judges to enthusiastically support limited guardianship and other recent reforms, they must appreciate why the underlying values of personal autonomy and independence trump the need for protection.").

<sup>24.</sup> Despite the inclusion of mandatory procedural rules, state approaches to many aspects of guardianship and conservatorship proceedings still vary considerably. *See, e.g.*, A. Kimberley Dayton et al., *Guardianship and Conservatorship*, in 3 ADVISING THE

accomplishing other goals, particularly those aspirational goals that were an important part of the impetus for the reform movement.<sup>25</sup> As is often the case, the letter of the law has been easier to implement than the spirit underlying it.<sup>26</sup>

Unlike older statutory schemes that commonly allowed judges in guardianship and conservatorship cases to sit unchecked like kings on a throne, 27 modern guardianship and conservatorship laws are designed to provide procedural and substantive protections for the person who is the subject of a guardianship or conservatorship petition. 28 Durable power-of-attorney statutes, which first achieved widespread acceptance in the last quarter of the twentieth century, 29 have also evolved in ways that seek to protect a principal from improper acts of an agent. 30

Today's guardianship, conservatorship, and power of attorney laws recognize that individuals have many different abilities and that a particular individual's ability in a particular area may wax and wane along a very broad spectrum throughout life.<sup>31</sup> Indeed, many statutes now focus on "capacity," rejecting

ELDERLY CLIENT § 34:30, Westlaw (database updated June 2017) (noting that not all states require the judge to engage in mandatory fact-finding process underlying a judgment of incapacity; noting also, however, that "[w]ritten findings of fact are critical if an appeal . . . is anticipated").

- 25. *See, e.g.*, Frolik, *supra* note 23, at 354 (noting that limited guardianship has not been a success and observing that judges must be "sold" on the concept, which will require them to appreciate the importance of independence and autonomy).
- 26. *See id.* (discussing prerequisites for courts to internalize the statutory preference for limited over plenary guardianships).
- 27. See Dayton et al., supra note 24, § 34:25 (discussing paternalistic attitude of some judges who "may decide cases as much through 'intuition' than through clearly stated standards and procedures").
- 28. See Glen, supra note 5, at 108-19 (discussing stages and results of guardianship reform).
- 29. See generally Karen E. Boxx, *The Durable Power of Attorney's Place in the Family of Fiduciary Relationships*, 36 GA. L. REV. 1, 4-14 (2001) (providing a history of the durable power of attorney and noting that all states had durable power-of-attorney statutes by 1984).
- 30. See, e.g., UNIF. POWER OF ATT'Y ACT § 114 (UNIF. LAW COMM'N 2006) (providing that agent must act "in accordance with the principal's reasonable expectations to the extent actually known by the agent and, otherwise, in the principal's best interest"; in good faith; and within scope of authority granted).
- 31. See, e.g., In re Conservatorship of Groves, 109 S.W.3d 317, 333 (Tenn. Ct. App. 2003) ("Capacity is not an abstract, all-or-nothing proposition.").
- 32. See, e.g., Richard F. Spiegle & Spencer J. Crona, Legal Guidelines and Methods for Evaluating Capacity, 32 COLO. LAW. 65, 65 (2003) (noting that capacity typically is a

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the older term "competency" for the very reason that, in the past, courts and society often evaluated an individual's competency using a single "on/off switch" approach, disregarding the fact that an individual has any number of abilities, each of which may fluctuate significantly over time. 34

Recognizing the possible variability in an individual's abilities,<sup>35</sup> modern laws therefore contemplate that no fiduciary be permitted to act until either the person represented agrees<sup>36</sup> or a careful determination occurs to ensure that the represented person requires the services of the fiduciary.<sup>37</sup> For example,

legal concept, whereas competency is typically a medical or clinical concept); Kristin Mueller, Note, *The Evolution of Guardianship Law in Iowa: A Search for Fairness and Justice in Guardianship Proceedings*, 45 DRAKE L. REV. 963, 972–73 (1997) (observing trend focusing on capacity rather than competency).

- 33. See Hedin v. Gonzales (In re Guardianship of Hedin), 528 N.W.2d 567, 573 (Iowa 1995) (noting traditional approach under which "states operate under an 'all or nothing' guardianship law, meaning that a person either is fully competent or is not fully competent to handle his or her affairs").
- 34. See Groves, 109 S.W.3d at 334 ("Capacity is . . . situational and contextual, and it may even have a motivational component."). Further elaborating on capacity, the Groves court stated as follows:

[Capacity] may be affected by many variables that constantly change over time. These variables include external factors such as the time of day, place, social setting, and support from relatives, friends, and supportive agencies. It may also be affected by neurologic, psychiatric, or other medical conditions, such as polypharmacy, many of which are reversible with proper treatment. Finally, capacity is not necessarily static. It is fluid and can fluctuate from moment to moment. A change in surroundings may affect capacity, and a person's capacity may improve with treatment, training, greater exposure to a particular type of situation, or simply the passage of time.

Id.

- 35. See, e.g., Evelyn M. Tenenbaum, To Be or To Exist: Standards for Deciding Whether Dementia Patients in Nursing Homes Should Engage in Intimacy, Sex, and Adultery, 42 IND. L. REV. 675, 711-13 (2009) (discussing modern judicial view that seeks to assess "functional competence," rejecting older approach that assessed "competence by making a single, global decision that a person is competent or incompetent").
- 36. Moreover, fiduciary duties cannot be imposed upon a person who does not agree to accept the fiduciary position. *See, e.g.*, UNIF. POWER OF ATT'Y ACT § 113 (UNIF. LAW COMM'N 2006) ("Except as otherwise provided in the power of attorney, a person accepts appointment as an agent under a power of attorney by exercising authority or performing duties as an agent or by any other assertion or conduct indicating acceptance.").
- 37. See, e.g., UNIF. POWER OF ATT'Y ACT § 109(c) (UNIF. LAW COMM'N 2006) ("If a power of attorney becomes effective upon the principal's incapacity and the principal has not authorized a person to determine whether the principal is incapacitated, or the person authorized is unable or unwilling to make the determination, the power of attorney becomes effective upon a determination in a writing or other record by: (1) a physician [or licensed

unless a capable principal has executed an immediately effective durable power of attorney or has explicitly defined the circumstances under which the power of attorney will take effect, the default rules of power-of-attorney statutes often require that someone other than the agent determine whether the principal is incapacitated and thus in need of an agent to act on her behalf.<sup>38</sup> Similarly, guardianship and conservatorship statutes have default provisions that, at least in theory, serve to ensure not only the respondent's procedural and substantive protection at the instigation of a proceeding,<sup>39</sup> but also throughout the proceeding and throughout the existence of a resulting guardianship or conservatorship.<sup>40</sup>

Underlying the reforms in these fiduciary laws is the belief that every human being, whatever her capacities, is a unique individual worthy of respect.<sup>41</sup> Concomitantly, a fundamental aspiration of modern fiduciary reform is to maximize the individual's autonomy consistent with her abilities.<sup>42</sup> Indeed, in

psychologist] that the principal is incapacitated . . . or (2) an attorney at law, a judge, or an appropriate governmental official that the principal is incapacitated . . . . ").

- 38. Thus, when a power of attorney is silent on the determination of a principal's incapacity, a default provision may require that a medical or psychiatric professional determine that the principal is incapacitated before the agent can began to act. UNIF. POWER OF ATT'Y ACT § 109(c). In guardianship and conservatorship proceedings, laws require not only that the respondent be afforded proper notice and the opportunity to be heard, but also may require that the respondent appear at the proceeding or provide good reason for not appearing. Glen, *supra* note 5, at 113-14.
- 39. See Glen, supra note 5, at 108-19 (discussing procedural and decision-making reforms of recent decades).
- 40. But see Arsenault, supra note 21, at 7, 29 ("[T]he reality is that most guardianships go unmonitored after the initial court hearing concludes."); Francis, supra note 20, at 1155-56 (noting that once guardianship is established, states have paid much less attention to its actual operation); Sally Balch Hurme & Erica Wood, Guardian Accountability Then and Now: Tracing Tenets for an Active Court Role, 31 STETSON L. REV. 867, 925-29 (2002) (discussing continuing problems of guardianship monitoring and noting a "host of knotty questions go to the heart of the monitoring issue and bear further examination").
- 41. *But see* Frolik, *supra* note 23, at 354 (observing that many judges will not enthusiastically support modern reforms until they "appreciate... underlying values of personal autonomy and independence").
- 42. Meeting of Legis. Commission's Subcomm. to Study Issues Relating to Senior Citizens and Veterans, Assembl. Con. Res. No. 35, File No. 109, 74th Int. Sess. exh. P-2 (Nev. Feb. 5, 2008) (informational document offered by the Honorable David Hardy, noting that "[m]ore than 30 states . . . have substantially reformed their guardianship statutes in the last 20 years" and "[t]he trend in guardianship reform is [statutorily mandated] greater autonomy for the ward"). Judge Hardy cites as examples of reform legislation the following: "right to counsel, the right to effective notice, standardized forms and petition requirements,

guardianship and conservator laws, if a less intrusive form of assistance is available, modern statutes may specifically require the use of that less intrusive measure in lieu of appointment of a guardian or conservator.<sup>43</sup>

Moreover, even when the individual clearly requires a surrogate decision-maker, under most statutory schemes that decision-maker is guided first by the directions provided by the individual before the need for a fiduciary arose.<sup>44</sup> In the absence of such directions, often the decision-maker is to act in accordance with traditional principles of substituted judgment,<sup>45</sup> basing the decision on what the individual would or probably would have done had she retained the ability to make the instant decision herself.<sup>46</sup>

Importantly, modern statutes often contemplate the individual's continuing participation in the decision-making process even when the individual is represented by a fiduciary.<sup>47</sup> Thus, to the extent that the individual can reliably state a current preference<sup>48</sup> between or among decision-making options, the

the right to be present at hearings, the right to cross-examination, the development of least restrictive alternatives, and the requirement of proof by clear and convincing evidence." *Id.* 

- 43. See KOHN, supra note 23, at 143 (discussing general agreement that today favors use of least restrictive alternative doctrine).
- 44. See Thaddeus Mason Pope, Surrogate Selection: An Increasingly Viable, But Limited, Solution to Intractable Futility Disputes, 3 St. Louis U. J. Health L. & Pol'y 183, 208-14 (2010) (discussing bases on which substituted decision-makers are to make decisions, and noting first responsibility of decision-maker is to implement instructions of person with incapacity). Although the article addresses in particular surrogate decision-making in matters of medical futility, the general discussion concerning bases of substituted decision-making largely reflects the approach demonstrated in most modern American substituted decision-making scenarios.
- 45. *See id.* at 210-12 (noting that surrogate decision-makers are to use substituted judgment, when possible, if the person with incapacity has provided no instructions).
- 46. See id. at 212-14 (discussing use of best interest standard when the adult with incapacity did not provide instructions and decision-maker has no basis for inferring adult's values and preferences); Tenenbaum, *supra* note 35, at 701 (stating that, when adult formerly had no cognitive incapacity, courts traditionally favor use of substituted judgment over a best interests test).
- 47. See, e.g., UNIF. HEALTH-CARE DECISIONS ACT § 2(e) (UNIF. LAW COMM'N 1994) ("An agent shall make a health-care decision in accordance with the principal's individual instructions, if any, and other wishes to the extent known to the agent. Otherwise, the agent shall make the decision in accordance with the agent's determination of the principal's best interest. In determining the principal's best interest, the agent shall consider the principal's personal values to the extent known to the agent.")
  - 48. UNIF. HEALTH-CARE DECISIONS ACT § 2(e).

fiduciary is not free simply to ignore that stated preference.<sup>49</sup> Judges, commentators, and statutes themselves often state that the fiduciary is ultimately to serve the best interests<sup>50</sup> of the individual he represents through the power of attorney, guardianship, or conservatorship. 51 Undergirding this directive is the belief that in most instances the fiduciary will respect the individual's autonomy and serve the individual's best interest<sup>52</sup> first by following the individual's directions (previously given or currently reliably expressed) and, if no such directions exist, second by using principles of substituted judgment.<sup>53</sup> Only when the fiduciary has no direct guidance from the individual and no basis for applying substituted judgment (including some settings in which the application of substituted judgment will clearly result in harm to the individual) is the fiduciary free to make a decision based on an objective determination of the individual's "best interest"—a determination frequently formulated from beliefs about what a "reasonable person" would do.<sup>54</sup>

### III. WHY WE INFANTILIZE ADULTS WITH A **COGNITIVE IMPAIRMENT**

Many adults with diminished capacity—and elderly adults in general—know all too well that society often treats them as

- 49. Unif. Health-Care Decisions Act § 2(e).
- 50. Unif. Health-Care Decisions Act § 2(e).
- 51. Unif. Health-Care Decisions Act § 2(e).
- $52. \ \textit{See}, \textit{e.g.}, \textit{UNIF. PROB. CODE} \ \text{art.} \ \textit{V} \ \textit{prefatory} \ \textit{note} \ (2010) \ (\textit{discussing developments})$ in the areas of guardianship and conservatorship, noting "groundbreaking" support of autonomy in 1982 version, and noting further that 1997 revision provided that "guardianship and conservatorship should be viewed as a last resort, that limited guardianships or conservatorships should be used whenever possible, and that the guardian or conservator should consult with the ward or protected person, to the extent feasible, when making decisions").
- 53. See, e.g., UNIF. POWER OF ATT'Y ACT § 114(a)(1) (UNIF. LAW COMM'N 2006) (providing that agent shall "act in accordance with the principal's reasonable expectations to the extent actually known by the agent and, otherwise, in the principal's best interest").
- 54. For an excellent and detailed investigation of the variations and complexities concerning the two standards, see generally Linda S. Whitton & Lawrence A. Frolik, Surrogate Decision-Making Standards for Guardians: Theory and Reality, 2012 UTAH L. REV. 1491 (examining the intricacies of the substituted judgment and best interest standards); see also Hurme & Wood, supra note 3, at 1170 ("While [the two standards are] seemingly straightforward in definition, the application of either standard is not without difficulty and complexity.").

infants.<sup>55</sup> The reasons for such treatment are many and complex.<sup>56</sup> Moreover, the motives underlying such treatment are often misunderstood and ignored.<sup>57</sup> An observer who carefully studies and considers those motives will quickly conclude, however, that the motives range from genuine concern for the perceived best interest of the individual, on the one hand, to a complete lack of concern for her best interest, on the other.<sup>58</sup>

When a person is elderly *and* has a cognitive disability, as is often the case in settings involving guardianships, conservatorships, and durable powers of attorney, an even greater likelihood arises that one or more fiduciaries or other substitute decision-makers will treat her as a young child.<sup>59</sup> The following discussion suggests a few of the complex and often interconnected reasons for these tendencies and explores some possible motives underlying them.<sup>60</sup>

### A. Altruism

The most generous and pervasive motive underlying our tendency to infantilize the elderly and other adults with a

<sup>55.</sup> This Article concerns infantilization of an adult who becomes cognitively disabled in adulthood, thereafter often requiring supported or substitute decision-making by a guardian, conservator, or agent acting under a durable power of attorney. More often than not, such disability or incapacity develops, if at all, in older rather than younger adults. For a discussion of shortcomings in guardian decision-making for persons with impaired intellectual disability from birth or childhood, see generally Arsenault, *supra* note 21, at 25-33 (noting that guardianship cases most often involve children or the elderly and examining in particular medical decisions by family (sometimes at the suggestion of medical providers) that result in decreased screening and treatment for persons with an intellectual disability existing since childhood).

<sup>56.</sup> See infra notes 61-147 and accompanying text (discussing reasons and motives for infantilizing the elderly and adults with diminished capacity).

<sup>57.</sup> See, e.g., infra notes 104-120 and accompanying text (discussing convenience as a motivation for infantilization of the elderly and adults with diminished capacity).

<sup>58.</sup> See infra notes 61-147 and accompanying text (discussing altruism, assumptions, convenience, ignorance, and self-interest among motives for infantilizing the elderly and adults with diminished capacity).

<sup>59.</sup> Although this Article focuses on the tendency of individual substitute decision-makers to view incapacity and infancy as largely synonymous, the law itself has also historically infantilized wards under guardianship. *See, e.g.*, Rein, *supra* note 6, at 1824-25 (noting that an adult under guardianship is, for purposes of most decisions, treated as a child in the law's eyes).

<sup>60.</sup> Although I provide separate discussion of several reasons for such treatment, these reasons often are not always mutually exclusive. Several of them are in fact almost always interrelated or intertwined.

cognitive disability is a genuine concern for those individuals and a desire to make them feel valued and important. Because we do care about them and consider them important, in conversations with them we may unwittingly simplify our word choices, change our inflection, volume, and speed of delivery, and use words of endearment or encouragement in ways that we would never do in our conversations with other adults. Ironically, our sincere desire to respect the elderly and adults with a cognitive disability may result in unwarranted, unconscious paternalism on our part.

Each ward, conservatee, and principal is unique, of course, and may want and expect different things from a fiduciary or others who engage in surrogate decision-making for her. Nevertheless, what many fiduciaries and surrogate decision-makers perceive as commendable solicitude for the well-being of the adult with diminished capacity often will fail to serve the adult's best interest if their words and actions reflect an implicit assumption of omniscience, no matter how kind their underlying motive.<sup>64</sup>

In sum, fiduciaries and other surrogate decision-makers should take care never to let their good intentions lead them to assume that they inevitably know better than the elder or other adult with a cognitive incapacity what will best serve her interest. Indeed, as discussed in the following subsection, such assumptions can be very dangerous.

### B. Assumptions

If we happen to serve as the respondent's lawyer, a factfinding guardian ad litem for the court, or the judge of a guardianship or conservatorship proceeding, we refuse to assume

<sup>61.</sup> See infra Part IV (discussing elderspeak and generous motives that may lead to it).
62. See infra notes 148-54 and accompanying text (discussing characteristics of

<sup>63.</sup> See, e.g., Pope, supra note 44, at 214, 219 (observing that for various reasons, not all of which are deliberate, "[s]urrogates are frequently inaccurate in implementing patient preferences," and, moreover, substitute decision-makers often are unable to distinguish their own preferences from those of the person on whose behalf they should be acting).

<sup>64.</sup> *See id.* at 215-20 (discussing mediocre performance of substitute decision-makers in medical futility cases).

<sup>65.</sup> See Rein, supra note 6, at 1828 ("It takes an especially conscientious and thorough judge or court investigator to recognize and fend off the misplaced benevolence of some petitions.").

the petitioner's allegations to be completely true and unbiased.<sup>66</sup> We know that respondents are named in such petitions for various reasons, and the reasons asserted in those petitions may not reflect the true motives of a petitioner.<sup>67</sup> For example, we know that petitioners are sometimes more concerned about Mama's money than about Mama herself.<sup>68</sup> We know that some petitions are based more on intra-family squabbles than on true concern for Papa's best interest.<sup>69</sup> We know that sometimes petitioners are seeking to ensure that a respondent-relative lives or acts in accordance with the petitioners' religious, ethnic, or cultural beliefs,<sup>70</sup> regardless of what the respondent appears to want or have wanted.<sup>71</sup>

Armed with this skepticism about the motives of others, we may nevertheless assume that *our own acts* of representing, questioning, and judging will be free from bias and prejudice.<sup>72</sup> Oblivious to our own predilections, we believe that we are proceeding with caution as we remember the modern mandate of

<sup>66.</sup> See, e.g., Anderson v. Lasen (In re Conservatorship of Anderson), 628 N.W.2d 233, 239-41 (Neb. 2001) (noting trial court's concern about daughter's self-interest in becoming conservator).

<sup>67.</sup> See id. (discussing various motives of petitioners that range from those that are well-intentioned to those involving clear conflicts of interest).

<sup>68.</sup> In Anderson v. Lasen, 628 N.W.2d 233, the appellate court noted that the trial court had properly passed over the daughter and son-in-law of an adult with a cognitive incapacity when naming a conservator for the adult. *Id.* at 239-41. Even though the daughter had priority for being named conservator under a state statute, she and her husband had previously made gifts from the adult's estate while acting as agents under a power of attorney that did not permit them to make such gifts. *Id.* at 239. In light of this, the lower court "had a reasonable basis for believing that [daughter's] self-interest in her potential liability as an attorney in fact would conflict with a fiduciary's duty of absolute fidelity to [her father's] welfare and the interests of his estate." *Id.* at 241.

<sup>69.</sup> *See, e.g.*, Wagner v. Wagner (*In re* Estate of Wagner), 367 N.W.2d 736, 737-38, 741 (Neb. 1985) (discussing conservatorship petition filed by several children who disagreed with elderly parent's business decision).

<sup>70.</sup> See, e.g., Conrad v. Atkins (In re Guardianship of Atkins), 868 N.E.2d 878, 880-81 (Ind. Ct. App. 2007) (discussing guardianship case in which mother sought to prevent son's longtime homosexual partner from serving as son's guardian, citing her religious beliefs).

<sup>71.</sup> See, e.g., S.I. v. R.S., 877 N.Y.S.2d 860, 863 (Sup. Ct. 2009) (discussing guardianship petition of respondent's siblings that sought to void health-care power of attorney in respondent's wife, asserting that wife was not acting in accordance with family's religious beliefs).

<sup>72.</sup> See, e.g., In re J.P. Linahan, Inc., 138 F.2d 650, 652-54 (2d Cir. 1943) (warning that judges, like others, must examine their biases and prejudices).

maximizing the respondent's autonomy consistent with her abilities.<sup>73</sup>

In fact, perhaps the gravest danger about assumptions is not that we will assume that the assertions of others are valid, but rather that we will remain unaware of our own assumptions about the elderly and other adults with a cognitive disability.<sup>74</sup> While representing, questioning, judging, and making decisions for or with the assistance of the adult with diminished capacity, are we failing to adequately examine our own prejudices and biases?<sup>75</sup> Are we unwittingly placing ourselves in the shoes of the respondent and thereby confusing what we would want with what she actually wants?<sup>76</sup> Are we unfairly assuming that we know best—or at least that we know better than the respondent—what arrangements will serve her best interest?<sup>77</sup> If the answer to these questions is yes, then we run the risk of devaluing the dignity and autonomy of the adult with diminished capacity and of treating her instead as an infant.

Our unacknowledged assumptions may extend to dichotomous views of "capable" and "incapacitated" adults. Most of us take for granted that the interests, desires, and even fundamental beliefs of a capable adult may change over time.<sup>78</sup>

<sup>73.</sup> See, e.g., In re Fisher, 552 N.Y.S.2d 807, 815 (Sup. Ct. 1989) ("The integrity of the elderly, no less than any other group of our citizens, should not be invaded, nor their freedom of choice taken from them by the state simply because we believe that decisions could be 'better' made by someone else.").

<sup>74.</sup> This obliviousness is not limited to guardians, conservators, and agents. It will often pervade the decisions of attorneys, guardians ad litem, court investigators or visitors, and judges themselves. *See* Dayton et al., *supra* note 24 (discussing biases of judges who may make decisions based more on intuition than on clearly stated standards).

<sup>75.</sup> See id.

<sup>76.</sup> See Pope, supra note 44, at 219 (discussing psychological explanations for substitute decision-makers' frequent inability to distinguish their own wishes from those of the person for whom they are to act).

<sup>77.</sup> See Dayton et al., supra note 24, § 34:24 (warning that "there is always a risk that a difficult or eccentric respondent will be adjudicated 'incompetent' simply because her behavior does not conform to social norms").

<sup>78.</sup> See Ray D. Madoff, Autonomy and End-of-Life Decision Making: Reflections of a Lawyer and a Daughter, 53 BUFF. L. REV. 963, 965-66 (2005) (noting frequent disparity between what people think they would want in the face of illness or incapacity and what they want when they actually face that illness or incapacity); Pope, supra note 44, at 217 (noting that patient wishes concerning end-of-life care change over time). Another wish that may change over time for many adults is how their estate should be distributed under a will or trust. In fact, as I have noted elsewhere, those who bring a conservatorship or guardianship petition against a relative may find that in response the relative will, or at least will attempt to, disinherit them. See Brashier, Crystal Balls, supra note 10, at 1-5 (discussing wills

Yet when the interests, desires, and beliefs of an elder or other adult with a cognitive disability change, we may implicitly assume that she is being unduly influenced, suffering from dementia, or otherwise unable to realize and appreciate the changes in question.<sup>79</sup> Thus, when the ward, conservatee, or principal expresses a wish that does not perfectly square with wishes she expressed before the onset of incapacity, surrogate decision-makers may conclude that the new wishes are not really hers.<sup>80</sup> Family members, for example, may assert openly that "[M]ama would never want *that* if she were in her right mind."<sup>81</sup>

But do we know as much as we think we do? What is the source of this supposed superior knowledge that gives us a moral claim for overriding the decision that an adult with diminished capacity now apparently wants to make? Several assumptions, all of which are spurious, come to mind:

### 1. That we know what they need

When an adult has diminished capacity— especially if she has diminished capacity *and* is elderly—too frequently we assume, implicitly or explicitly, that we "know what she needs,"

executed by person under guardianship or conservatorship). For case examples, see Skelton v. Davis, 133 So. 2d 432, 434 (Fla. Dist. Ct. App. 1961) (observing terms of mother's will, executed following successful curatorship petition brought by two of her daughters, under which "after prayerful deliberation" she revoked earlier, more generous devises to them and bequeathed them only \$100 each, specifically noting that "[o]f course I resent this action on their part"); Tank v. Lange (*In re* Estate of Wagner), 522 N.W.2d 159, 167 (Neb. 1994) (upholding will of woman who disinherited four of her six children after those four children unsuccessfully sought to have a conservatorship imposed upon her following death of her husband); Bottger v. Bottger (*In re* Bottger's Estate), 129 P.2d 518, 521 (Wash. 1942) (observing that mother had become incensed when her children filed guardianship petition against her, and three days later she executed new will).

79. See, e.g., Wagner, 367 N.W.2d at 741 (discussing conservatorship petition filed by several children against octogenarian mother alleging undue influence by her other children after mother made business decision to lease land to third party instead of permitting petitioners to continue to use land at less than fair market value). In Wagner, the court concluded that the mother's decision to "become a better business person" was not evidence that she required a conservator, even if the decision did work to the economic inconvenience of some of her children. *Id.* 

80. See, e.g., Tenenbaum, supra note 35, at 705 (noting that family members may discount the current wishes of a nursing home resident who is incompetent).

81. See, e.g., Wagner, 367 N.W.2d at 741 (discussing "illogical" testimony of petitioner son that his mother's recent business decision over leased land demonstrated her need for a conservator, when in fact that decision would produce a 160% increase in revenue over what her late husband had received by leasing to petitioner).

whether those needs involve housing, medication, social interaction, or anything else relating to her person or finances. 82 If we step back and acknowledge this tendency on our part, we can better recognize and minimize the temptation to substitute what we believe we would want or need were we in her shoes for what she indicates she wants or needs. 83 Moreover, once we take that step back, it becomes easier to remember not only that the law is supposed to serve her best interest, but also that her best

82. Under this approach, the decision-maker asserts (implicitly or explicitly) that he knows what will best serve the interests of the adult with an incapacity, without regard to the adult's known or probable wishes. See, e.g., Nancy J. Knauer, LGBT Issues and Adult Guardianship, in COMPARATIVE PERSPECTIVES ON ADULT GUARDIANSHIP, supra note 7, at 299, 310-11 (discussing decision-making standards and comparing "best interests," "substituted judgment," and the more recent "supported decision-making" standard). The text of this Article discusses primarily the two older, most commonly encountered standards in surrogate decision-making-best interests and substituted judgment. Nevertheless, the overall thrust of the Article is that surrogate decision-makers (1) must cast aside their own biases and prejudices that conflate incapacity and infancy and (2) must make a meaningful inquiry into the wants, needs, and desires of the adult with an incapacity, allowing that adult to make her own decision (perhaps with assistance) whenever possible. See also Alexander A. Boni-Saenz, Sexuality and Incapacity, 76 OHIO ST. L.J. 1201, 1230-33 (2015) (discussing supported decision-making); Nina A. Kohn et al., Supported Decision-Making: A Viable Alternative to Guardianship?, 117 PENN ST. L. REV. 1111, 1113 (2013) ("The use of surrogate decision-making and guardianship . . . is coming under increasing criticism from disability rights advocates and scholars who urge replacing it—or at least supplementing it with a process called 'supported decision-making.""). Professor Kohn and her co-authors state as follows:

As a general matter, supported decision-making occurs when an individual with cognitive challenges is the ultimate decision-maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual's words and behavior to determine his or her preferences. However, some advocates do not use the term "supported decision-making" this broadly. Instead, they reserve the term for situations in which the person being supported has voluntarily entered into the arrangement, and these advocates use terms like facilitated decision-making and co-decision-making to describe other versions of supported decision-making.

Id. at 1120-21.

83. Admittedly, this is not an easy step to take. *See* Tenenbaum, *supra* note 35, at 708 ("It is almost impossible for a substitute decisionmaker to take his or her own values and beliefs out of the decision-making process."); Pope, *supra* note 44, at 219 (noting that surrogates often "cannot distinguish their own preferences from those of the [person for whom they are the substitute decision-maker]" (quoting Sara M. Moorman & Deborah Carr, *Spouses' Effectiveness as End-of-Life Health Care Surrogates: Accuracy, Uncertainty, and Errors of Overtreatment or Undertreatment*, 48 GERONTOLOGIST 811, 812 (2008))); *see also infra* notes 168-99 and accompanying text (discussing questions that the surrogate should ask in the decision-making process).

interest is unlikely to be furthered by a one-size-fits-all pattern based on what we think a "reasonable" person would do. 84

## 2. That we know how to protect them from themselves and others

It is easy to look at an adult with diminished capacity and imagine all of the terrible things that could befall her if we do not intervene in her life. We think, If I let her smoke, she may set her surroundings on fire and burn herself to death. Smoking is bad for her health, anyway. And, speaking of health, I have to watch her diet, rationing or eliminating those unhealthy foods that she would choose for herself. I cannot let her control her finances because there are plenty of evil folks out there just waiting to prey on someone like her. Some of her old friends may also be inclined to put bad ideas into her head, so I better keep them away from her, regardless of how much she seems to enjoy their company. And our concerns go on and on.

What we often fail to do, however, is recognize that by unduly "protecting" her from herself and the world, we once again may largely be ignoring the integrity of her personhood and the explicit direction of modern laws to promote her autonomy where possible. 87

<sup>84.</sup> *See* Rein, *supra* note 6, at 1830 (noting that what a ward would want may differ from what a reasonable prudent person would want).

<sup>85.</sup> See, e.g., In re McDonnell, 266 So. 2d 87, 88-89 (Fla. Dist. Ct. App. 1972) (terminating guardianship order, noting that while ward had made a bad investment and an uncollectible loan and was inclined to drink to the detriment of her health, she was not likely to become the victim of designing persons; moreover, no matter how well-intentioned, ward's daughters simply had not proved that their mother required a guardianship).

<sup>86.</sup> Again, ageism is likely to exacerbate an implicit assumption that an adult with a cognitive incapacity is like a child. See Rein, supra note 6, at 1844 ("Society is unwilling to tolerate in a seventy-or-eighty-year-old person 'the same silly decision' that would go unchallenged if made by an individual in the prime of her life." (quoting Arnold J. Rosoff & Gary L. Gottleib, Preserving Personal Autonomy for the Elderly: Competency, Guardianship, and Alzheimer's Disease, 8 J. LEGAL MED. 1, 30 (1987))); see also Tenenbaum, supra note 35, at 703-08 (discussing likelihood of family objections to needs and desires of nursing home patient suffering from cognitive disability to engage in intimate or sexual relationships with other patients).

<sup>87.</sup> See Rein, supra note 6, at 1835 ("[A] perceived loss of control is a prime factor in producing decline, disorientation, stress, and deterioration of the immune system."); see also infra notes 148-67 (discussing more recent studies linking internalization of infantilizing language among the elderly with substantially shorter life expectancy).

# 3. That we know what they would have wanted had they not become incapacitated

Among the most troubling assumptions asserted by surrogate decision-makers is that they are choosing what the incapacitated person would have chosen for herself had she not become incapacitated.<sup>88</sup> The related doctrine—that of substituted judgment, or making the decision the adult herself would have made before her incapacity<sup>89</sup>—is widely recognized as an important part of guardianship, conservatorship, and power of attorney laws.<sup>90</sup> When the incapacitated person cannot reliably express her wishes or indicate a preference among various options, proper application of the doctrine is often the best way for the decision-maker to respect the continuing personhood of

<sup>88.</sup> See Tenenbaum, supra note 35, at 703-08 (discussing competing theories concerning whether decisions for person with diminished capacity should be based on "who she was" or, instead, "who she is"). The discussion in Tenenbaum's article suggests that a bald-faced assertion by the substitute decision-maker that the decision-maker is acting based on the adult's prior expressions or preferences does not necessarily mean that the decision-maker is acting appropriately. Instead, for a substitute decision-maker to use substituted judgment properly, the decision-maker should consider (1) whether the adult with the cognitive incapacity can currently express her wishes in a reliable fashion and, if she cannot, (2) what evidence supports the decision-maker's assertion that the decision is in accordance with the adult's wishes or probable wishes. See also infra note 89 and accompanying text (discussing "substituted judgment").

<sup>89.</sup> In its broadest sense, the doctrine of substituted judgment provides that the surrogate decision-maker should make decisions based on the known wishes of the adult with a cognitive disability or in accordance with her probable wishes to the extent that those wishes can be reasonably ascertained. See, e.g., Nabity v. Rubek (In re Trust Created by Nabity), 854 N.W.2d 551, 562-63 (Neb. 2014) (quoting Nebraska statute implicitly calling for substituted judgment by health-care agent); Norman L. Cantor, The Relation Between Autonomy-Based Rights and Profoundly Mentally Disabled Persons, 13 ANNALS HEALTH L. 37, 38-41 (2004) (discussing traditional concepts of substituted judgment and questioning whether a surrogate can ever exercise substituted judgment for a person who has never been able to make considered choices about end-of-life medical treatment). In fact, not all states agree on the contours of substituted judgment. Occasionally the traditional view is turned on its head. See, e.g., Wells Fargo Bank v. Keresey (In re Conservatorship of Hart), 279 Cal. Rptr. 249, 264 (Ct. App. 1991) (citing California statute in conservatorship case and stating that "the question in substituted-judgment proceedings is not what the conservatee would do but rather what a reasonably prudent person in the conservatee's position would do"). For a brief history of the origin and use of the substituted judgment doctrine, see Strunk v. Strunk, 445 S.W.2d 145, 148 (Ky. 1969) (citing doctrine's origins in England and noting that the doctrine is sufficiently broad to permit decisions relating to both the person and the property of the adult with diminished capacity).

<sup>90.</sup> See, e.g., KOHN, supra note 23, at 187-89 (discussing decision-making standards for surrogates acting as conservators, guardians, agents, or health-care agents).

the incapacitated individual.<sup>91</sup> Decision-makers sometimes misuse the doctrine, however, to justify a decision that *they* wish to make without genuine regard for whether the decision accurately reflects what the adult with diminished capacity probably would have done or whether she can currently provide a reliable expression of her wishes.<sup>92</sup>

# 4. That we should discount the wishes and preferences they now assert

For an adult with diminished capacity who can reliably express her preferences and wishes, 93 the focus of surrogate decision-makers solely or primarily on what she would have preferred or wished had she not become incapacitated can produce unfortunate results that deny the value of the person she is *now*. 94 By ignoring the preferences and wishes that she currently expresses clearly and reliably, decision-makers are also refusing to admit that, whether from incapacity or otherwise, an individual's wants and needs can change over time—and that she may very well still be in the best position to know her wants and needs. 95

Unless surrogate decision-makers are willing to consider, thoroughly and carefully, the wishes and preferences that the adult with a cognitive disability currently expresses, they run the

<sup>91.</sup> See supra notes 88-89 (discussing substituted judgment).

<sup>92.</sup> See Tenenbaum, supra note 35, at 703-11 (discussing flaws in the use of both substituted judgment and best interest doctrines).

<sup>93.</sup> See, e.g., In re Guardianship of Kowalski, 478 N.W.2d 790, 791, 797 (Minn. Ct. App. 1991) (discussing importance of ward's ability to express her wishes reliably concerning her desire to live with her lesbian partner).

<sup>94.</sup> See Tenenbaum, supra note 35, at 705-07 (observing that a person's preferences may change so substantially after the onset of incapacity that it makes no sense to use substituted judgment based on what were once the person's values). When the person with a cognitive incapacity can and does reliably express wishes or desires that depart from what she once wanted when she was "fully capable," blanket use of substituted judgment or a best interest test seems muddle-headed. On a deeper level, use of either the substituted judgment doctrine or a best interest test in this scenario may reflect our unwitting view of the person as someone who is, in essence, already dead. When the person with a cognitive disability is older, unrecognized bias and prejudice against the elderly may also come into play. See Rein, supra note 6, at 1842-43 (discussing prejudice against the elderly that may include fear of our own death as a factor).

<sup>95.</sup> See, e.g., Kowalski, 478 N.W.2d at 792-93 (observing expert testimony that ward with very serious cognitive impairment could still express her wishes concerning her residence and intimate relationships despite the objections of her blood relatives).

risk of effectively memorializing the person that the incapacitated adult once was and treating the person she has become as an unimportant, barely sentient being. Such treatment is damaging to her sense of self-worth and is likely to intensify the frustration that she may already feel as a result of her cognitive disability.

In sum, incapacity exists in varying degrees along an extremely broad spectrum, 98 and few of us (whether or not declared legally incapacitated) are bound forever by what we feel today. 99 The onset of incapacity does not mean that a person's "real" self has disappeared. 100 Like "capable" adults, elders and other adults with a cognitive incapacity will often experience changing views, desires, and preferences over time. 101 Stated bluntly, when an adult with diminished capacity can clearly and reliably express her current wishes and preferences, a surrogate should not override those wishes and preferences merely because the adult's views were once different. 102

### C. Convenience

In matters affecting our own lives, we often make decisions without particular concern about whether we are well-informed

<sup>96.</sup> Or, in the words of Lawrence Friedman, "[t]he ward is treated as being already half-dead." Lawrence Friedman & Mark Savage, *Taking Care: The Law of Conservatorship in California*, 61 S. CAL. L. REV. 273, 288 (1988).

<sup>97.</sup> See In re Conservatorship of Groves, 109 S.W.3d 317, 328 (Tenn. Ct. App. 2003) (observing in conservatorship case the importance of autonomy to the elderly); Rein, *supra* note 6, at 1834 (observing ill effects on individual resulting from a perceived loss of control).

<sup>98.</sup> See Groves, 109 S.W.3d at 333 ("Capacity is not an abstract, all-or-nothing proposition.").

<sup>99.</sup> *See* Tenenbaum, *supra* note 35, at 705 (discussing change in values that may result following onset of a disability).

<sup>100.</sup> Nor does the fact that a "reasonable" person would make a different decision mean that the decision of the person with a cognitive incapacity is "wrong." *See, e.g., In re* Fisher, 552 N.Y.S.2d 807, 815 (Sup. Ct. 1989) (stating that a belief that someone else could make a better decision is not a sufficient reason to invade elderly person's freedom of choice)

<sup>101.</sup> See Tenenbaum, supra note 35, at 705 (noting the changes that may occur in the values of a person with a disability and citing evidence that even clinicians may "significantly underestimate the quality of life possible after a disability" (quoting Sunil Kothari & Kristi Kirschner, Decision-Making Capacity After TBI: Clinical Assessment and Ethical Implications, in BRAIN INJURY MEDICINE: PRINCIPLES AND PRACTICE 1216 (Nathan D. Zasler et al., eds., 2007))).

<sup>102.</sup> See, e.g., In re Guardianship of Kowalski, 478 N.W.2d 790, 792 (Minn. Ct. App. 1991) (discussing then-existing state statute mandating that court consider the preferences of the respondent in a guardianship proceeding).

or whether the decision will render the best long-term result for us; instead, we make decisions that are convenient or desirable at the moment. In contrast, a surrogate decision-maker's ongoing responsibility for determining what is best for an adult with a cognitive disability is daunting. Careful balancing by a surrogate of what the adult with diminished capacity desires and needs, on the one hand, with the surrogate's ultimate obligation to serve her best interests, on the other, can be time-consuming, costly, and emotionally draining for the surrogate. Not surprisingly, even those surrogate decision-makers who care deeply about the welfare of the adult whom they assist may unwittingly infantilize that adult to justify expedient decisions.

### 1. General convenience

By conflating incapacity and infancy, surrogates can convince themselves (and perhaps others) that their decisions for the adult with diminished capacity are just and proper. They may rationalize that they need not always thoughtfully evaluate actual abilities and wishes of the adult on whose behalf they are to act, especially in light of the potentially mind-numbing number of decisions they must make for the adult. The implicit assumption is that the surrogate decision-maker is somewhat like a parent and can—indeed, must—make some decisions for the adult with a cognitive disability without putting in a great deal of thought or effort, just as a parent sometimes must do for her infant. The

Moreover, surrogates have no magical well from which they can dip unlimited amounts of time. In addition to their

<sup>103.</sup> Moreover, evidence suggests that many surrogate decision-makers have difficulty separating their own preferences from those of the person on whose behalf they should be acting. *See supra* note 92 and accompanying text (noting that decision-makers often make a choice based on what *they* would want).

<sup>104.</sup> See Rein, supra note 6, at 1829 (noting that convenience to the substitute decision-maker and others is one factor motivating petitioners to seek guardianships and conservatorships).

<sup>105.</sup> See id. at 1829 n.42.

<sup>106.</sup> The assumption is not always implicit. *See* Glen, *supra* note 5, at 115–16 (noting that "[t]he 1969 Uniform Probate Code provided that a 'guardian of an incapacitated person has the same powers, rights and duties respecting his ward that a parent has respecting his un-emancipated minor child" and further observing that "fourteen states retain this quite literally *paternalistic* standard" (quoting UNIF. PROB. CODE § 5-312 (West 1969))).

responsibilities to the adult with a cognitive incapacity, often guardians, conservators, and agents have substantial responsibilities to their own families and others. <sup>107</sup> Judges, attorneys ad litem, and guardians ad litem must juggle the demands of other parties in the legal system who demand their time and attention. <sup>108</sup> All of these decision-makers must make many choices quickly and efficiently. Thus, time constraints may exacerbate the tendency to infantilize adults with a diminished capacity. <sup>109</sup>

A decision-maker may also find it inconvenient to consult the adult with diminished capacity about a matter that seems of small consequence to the decision-maker, even when the adult with diminished capacity seems quite concerned over the matter. In such circumstances, the decision-maker can posit that the adult with diminished capacity, like an infant, will quickly forget the matter that seems so important to her in the moment.

In short, when surrogate decision-makers sufficiently infantilize the adult with diminished capacity, they can often maintain a clear conscience while making decisions with much less circumspection.

### 2. Emotional convenience

For the guardian, conservator, or agent of an adult with a cognitive incapacity, the costs associated with promoting the

<sup>107.</sup> See Rein, supra note 6, at 1851-52, 1859-61 (noting economic obligations of adult children that may prevent them from giving all the love and support they might wish to give to their elderly parents).

<sup>108.</sup> In light of these and other pressures, it is not surprising that unrecognized biases and prejudices may greatly influence the outcome of surrogate decision-making. *See infra* notes 72-75, 88-92 and accompanying text (discussing effect of unwitting bias and prejudice).

<sup>109.</sup> Statutory law may also contribute to the infantilization of an adult with a cognitive incapacity. For example, Mississippi's conservatorship laws provide that a person under a conservatorship "shall be limited in his or her contractual powers and contractual obligations and conveyance powers to the same extent as a minor." MISS. CODE. ANN. § 93-13-261 (2016) (emphasis added).

<sup>110.</sup> See supra note 105.

<sup>111.</sup> See, e.g., Strunk v. Strunk, 445 S.W.2d 145, 150 (Ky. 1969) (Steinfeld, J., dissenting) (stating that "[i]t is common knowledge beyond dispute that the loss of a close relative or a friend to a six-year-old child is not of major impact" in case in which adult with diminished capacity had mental age approximating that of a six year-old).

autonomy<sup>112</sup> of the adult with diminished capacity are more than merely time intensive.<sup>113</sup> The costs often will include significant demands on the surrogate decision-maker's own emotions and psyche.<sup>114</sup> Particularly when the surrogate decision-maker is a family member—which is very often the case—the decision-maker may be so emotionally attached to the adult with diminished capacity that the decision-maker cannot make an objective, carefully-reasoned assessment of the adult's needs and expressed wishes.<sup>115</sup> In such cases, the decision-maker may take the easier path of simply "going with his gut" and treating the adult with a cognitive incapacity as an infant, thereby avoiding an emotionally draining inquiry concerning how best to respect and promote her autonomy.<sup>116</sup>

#### 3. Financial convenience

A thorough assessment of the needs and wishes of an adult with a cognitive incapacity often has financial implications far beyond the costs encountered in an actual guardianship or conservatorship proceeding or in the activation of a durable

<sup>112.</sup> See supra Part II (discussing modern statutory requirements regarding assisted decision-making, including the goal of maximizing autonomy consistent with the person's ability).

<sup>113.</sup> The emotional costs may include determining whether the adult with a cognitive incapacity can reliably express her preferences and the role of a best interest standard when her preferences deviate from what a reasonable person would do. *See, e.g.*, Linda S. Whitton, *The Uniform Power of Attorney Act: Striking a Balance Between Autonomy and Protection*, 1 PHOENIX L. REV. 343, 349-50 (2008) [hereinafter Whitton, *Striking a Balance*] (observing that agent must act "according to the principal's reasonable expectations, if known" and stating "[t]hus, to the extent a principal's expectations are known to an agent, the agent may be authorized to engage in transactions that might not meet a 'best-interest' test"). Professor Whitton was Reporter for the Uniform Power of Attorney Act. *Id.* at 344 n.9.

<sup>114.</sup> See KOHN, supra note 23, at 145 (discussing intangible costs associated with the guardianship process).

<sup>115.</sup> See Tenenbaum, supra note 35, at 708 (stating that in substitute decision-making, "[o]ne of the biggest problems is objectivity," and noting further the near impossibility for the decision-maker to disregard his own views in making decisions); Pope, supra note 44, at 219 (observing failure of decision-makers to distinguish their own preference from those of a patient with a cognitive incapacity).

<sup>116.</sup> It is not only guardians, conservators, and agents who may be inclined to rely more on intuition rather than on demanding inquiries that promote autonomy and demonstrate respect for dignity. *See, e.g.*, Dayton et al., *supra* note 24, § 34:25 (noting paternalistic attitude of some judges and observing that such judges "often develop strong biases regarding guardianship generally and in specific cases," ultimately using intuition more than the standards and procedures contemplated by modern statutory reform).

power of attorney.<sup>117</sup> For example, perhaps the adult with diminished capacity expresses a desire for a substantial allowance that she can use as she wishes.<sup>118</sup> Perhaps she asserts her wish to move to a residence that is far more expensive than her current residence. Perhaps she complains often of various ailments and wishes to see a doctor for each complaint.

In such circumstances, a surrogate decision-maker may rationalize that the adult's costly requests do not represent her true wishes, but instead are simply ways to seek more attention from the decision-maker or others. The surrogate decision-maker may thus see little need to "waste" money on the adult's requests. By viewing her requests as infantile "acting out," the decision-maker can also rationalize that what really will serve her best interests is the preservation of her funds.

### D. Ignorance

The preceding discussion—and, indeed, this entire Article—suggests that a principal "innocent" cause of flawed actions by surrogate decision-makers is their often-unwitting conflation of infancy and adult incapacity. This problem exists even when the surrogate undoubtedly cares about the adult with the incapacity and is well-intentioned. Surrogate decision-makers—be they

<sup>117.</sup> See, e.g., Stewart v. Bush ( $In\ re$  Conservatorship of Stallings), 523 So. 2d 49, 52-53 (Miss. 1988)

<sup>118.</sup> See, e.g., id. (discussing and approving an allowance in the form of a checking account for person under conservatorship and over which account the conservator was to have no control). The court in *Stallings* noted as follows:

We begin, therefore, with the underlying reality. Competency is not an either/or. In considering whether a conservatorship should be established, the Chancery Court is inevitably in the relative world of shades of gray. Some persons are so incapable of handling their affairs that a conservator must be charged to do everything. Yet there are many circumstances where it is neither necessary nor desirable that the conservator write a check for every tube of toothpaste or soft drink that the ward may wish to purchase.

Id. at 53 (approving allowance for ward's use as "he or she sees fit").

<sup>119.</sup> See Tenenbaum, supra note 35, at 704-08; Douglas A. Kemerer, How to Manage Manipulative Behavior in Geriatric Patients, AM. NURSE TODAY, Oct. 2016, at 5-1, https://www.americannursetoday.com/manage-manipulative-behavior-geriatric-patients/ [https://perma.cc/U87E-8C6D] (describing elderly patients' capacity for attention-seeking behaviors).

<sup>120.</sup> The financial convenience argument can spill over into self-interest on the part of the substitute decision-maker. *See infra* Part III.E (discussing decisions of the substitute decision-maker based on self-interest).

judges, lawyers, guardians ad litem, <sup>121</sup> conservators, guardians, or agents acting under a power of attorney—simply fail to realize that they are treating the adult with diminished capacity as an infant. <sup>122</sup>

The result of this ignorance is decision-making that flies in the face of both the letter and the spirit of modern guardianship, conservatorship, and power-of-attorney statutes. Although most of the aspirational goals underlying these statutes now have a history of several decades, the statutes have done little to increase awareness of our historical tendency to combine notions about incapacity and infancy. Unless the surrogate decision-maker engages in careful self-reflection of his motivations and attitudes about old age and incapacity, the conflation will likely continue regardless of the decision-maker's familiarity with modern statutory directives. 125

### E. Self-Interest

Most surrogate decision-makers act in good faith. Most surrogates make choices based on altruistic motives. 127

<sup>121.</sup> The term "guardian ad litem" is increasingly being replaced by either "court visitor" or "court investigator." *See* Dayton et al., *supra* note 24, § 34:21 nn.2-3 (discussing the role of the guardian ad litem and modern preference in terminology); Wingspan—Second Nat'l Guardianship Conference, *Recommendations*, 31 STETSON L. REV. 595, 601 (2002) (providing in recommendation number 32 that "[t]he term 'investigator' or 'visitor' be used instead of guardian ad litem" and noting in its comment that "[t]he term 'guardian ad litem' often is confused with the term 'guardian,' thus resulting in misunderstanding of roles and responsibilities").

<sup>122.</sup> See Rein, supra note 6, at 1834 ("[T]he benevolence of others may directly produce dependency, depression and even death." (quoting George J. Alexander, Remaining Responsible: On Control of One's Health Needs in Aging, 20 SANTA CLARA L. REV. 13, 21 (1980))).

<sup>123.</sup> See supra Part II (discussing requirements of modern statutes concerning guardianships, conservatorships, and durable powers of attorney).

<sup>124.</sup> See Rein, supra note 6, at 1824-25 (discussing the view that an incapacitated adult is essentially a child in the law's eyes); see also supra notes 21-26 and accompanying text.

<sup>125.</sup> See infra Part V (suggesting questions to better ensure that the substitute decision-maker respects and promotes the autonomy of the adult with a cognitive incapacity).

<sup>126.</sup> See supra Parts III.A-.C (discussing altruism, erroneous assumptions, personal knowledge, convenience, and ignorance as potential bases for conflating incapacity and infancy).

<sup>127.</sup> See supra Part III.A (discussing altruism as a basis for infantilizing adults with diminished capacity).

Sometimes their decisions spring from erroneous assumptions or from mistaken beliefs that their knowledge confers upon them parent-like responsibility. Like parents of infants, they also may make some decisions based on convenience. In all of these instances, surrogate decision-makers are often unaware of their own biases and prejudices and ignorant of the modern statutory demands regarding fiduciary obligations to the adult with a cognitive incapacity. Is

The role of surrogate decision-makers—a role many surrogates undertake without payment—can be extremely challenging. Well-intentioned decision-makers can and do often make bad decisions. From the stance of the incapacitated adult, however, it may matter little whether the substitute decision-maker's choice springs from good or bad motives. To the adult on whose behalf the decision is made, an erroneous decision concerning her welfare is an erroneous decision. Though such

<sup>128.</sup> See supra Part III.B (discussing erroneous assumptions and mistaken beliefs as bases for infantilizing adults with diminished capacity).

<sup>129.</sup> See supra Part III.C (discussing convenience as a basis for infantilizing adults with diminished capacity).

<sup>130.</sup> In fact, one very important decision-maker often likely to succumb, unwittingly, to internal bias is the judge in the guardianship or conservatorship proceeding. *See* Dayton et al., *supra* note 24, § 34:25 (discussing paternalistic attitude of some judges and noting "[t]hey often develop strong biases regarding guardianship generally and in specific cases," ultimately using intuition more than the standards and procedures contemplated by modern statutory reform).

<sup>131.</sup> See supra Part III.D (discussing ignorance as a basis for infantilizing adults with diminished capacity); see also Dayton et al., supra note 24, § 34.25 (suggesting that some judges, while perhaps not ignorant of the standards and procedures of modern reform statutes, may nevertheless ignore them in favor of intuitive decisions based on bias and prejudice).

<sup>132.</sup> See Russ ex rel. Schwartz v. Russ, 734 N.W.2d 874, 889 (Wis. 2007) (Abrahamson, C.J., concurring) ("[T]he problems involving durable powers of attorney do not arise just from the acts of selfish and conniving agents."). Chief Justice Abrahamson further observes that problems also arise from agent uncertainty as to their powers, and that frequent lack of guidance in statutes and case law compound these problems. *Id.*; see also Tenenbaum, supra note 35, at 704-05 (noting how family members may have "a distorted perception" of the values of their relative who has a cognitive disability).

<sup>133.</sup> See, e.g., In re Guardianship of Braaten, 502 N.W.2d 512, 524 (N.D. 1993) (Vande Walle, C.J., concurring) (recognizing sincere concern of the family for the respondent's well-being in opinion that nonetheless refused family's request for plenary guardianship and conservatorship).

<sup>134.</sup> Modern statutory reform, which favors or mandates limited guardianships and conservatorships over plenary ones and often favors the use of substituted judgment over a best interests test when possible, seeks to reduce the likelihood of such questionable

decisions are unfortunate, society and the law must forgive at least some of the surrogate decision-maker's errors in judgment. No one can guarantee the adult with a cognitive incapacity a record of perfect decision-making by the surrogate.

In contrast to the well-intentioned but imperfect decision-maker is the cunning decision-maker<sup>135</sup> who knowingly acts *in his own interest*.<sup>136</sup> The self-serving surrogate is far more likely than the good faith decision-maker to appear in reported case law<sup>137</sup> as he tries to deny or justify his self-interested actions.<sup>138</sup>

decisions. *See*, *e.g.*, *In re* Guardianship of Mikulanec, 356 N.W.2d 683, 686-87 (Minn. 1984) (discussing statutory reform springing in part from the fear of bad decisions by guardians).

135. Determining what constitutes blatant self-interest may not always be simple. Sometimes a court and the substitute decision-maker may disagree concerning whether the substitute decision-maker's actions are serving the adult with a cognitive incapacity. Sometimes family members of the adult are in such disagreement that a court may feel compelled to appoint a neutral third party as substitute decision-maker. See, e.g., Linda L. v. Collis (In re Guardianship of Catherine P.), 718 N.W.2d 205, 222-23 (Wis. Ct. App. 2006) (appointing neutral guardian and removing daughter as guardian of her mother's person where daughter put "her own self-interests above those of her ward," had failed ward "by refusing to cooperate with the circuit court in obtaining information," had "substantially limited her brother's access to the mother, and had acted in a way causing substantial stress to the mother").

136. See, e.g., DeBoer v. Senior Bridges of Sparks Family Hosp., 282 P.3d 727, 729-30, 732 (Nev. 2012) (discussing abuse of power of attorney by agent who allegedly appropriated principal's money, real property, and other assets); In re Jumper, 984 A.2d 1232, 1236, 1238-39, 1251-54 (D.C. 2009) (discussing guardianship petition filed by beneficiary of elderly person's trust after beneficiary learned that elder had changed her trust terms in ways significantly less beneficial to him); see also Julia Calvo Bueno, Reforming Durable Power-of-attorney statutes to Combat Financial Exploitation of the Elderly, 16 NAELA Q. 20, 20-21 (2003) (pointing to studies suggesting a significant amount of financial abuse occurs through powers of attorney), cited in Deboer, 282 P.3d at 732.

137. See, e.g., Mowrer v. Eddie (In re Guardianship of Mowrer), 979 P.2d 156, 158, 163 (Mont. 1999) (dismissing guardianship petition by niece and her husband against centenarian aunt, noting substantial transfers couple had made to themselves and their family from aunt's assets, observing also misuse of power of attorney by couple, and upholding lower court finding of undue influence by couple). Indeed, the self-serving decision-maker was also among the subjects of media attention that led to a number of the modern reforms in guardianship and conservatorship law. See, e.g., Mikulanec, 356 N.W.2d at 686-87 (noting statutory reform that sprang from "[c]ase studies chronicl[ing] guardians acting as commen to obtain the guardianship and discount wholesalers to dispose of their wards' estates" and also from "a suspicion that guardians are too often less than benevolent").

138. Agents acting under a durable power of attorney are typically free from the constraints of judicial review that (at least according to statute) are to occur periodically for guardianships and conservatorships. Thus, a principal should take extreme care in designating an agent, and should consider privately-imposed constraints in the power of attorney document itself. *See generally* Whitton, *Durable Powers*, *supra* note 7, at 10-38 (discussing how the protectiveness of a power of attorney depends upon the trustworthiness of the agent).

When the facts are fully presented, however, the selfish motives of the substitute decision-maker (who is very often a family member) are revealed. Most commonly the substitute decision-maker who acts primarily in his interest does so for financial reasons. For example, if the substitute decision-maker is an expectant heir or will receive the residue of the estate under the will of the adult with a cognitive incapacity, he may very well line his pockets for increased future benefits by spending less of the financial resources of the adult with a cognitive incapacity on satisfying her needs and wishes. 141

A decision that incidentally benefits the agent, guardian, or conservator is not necessarily at odds with respecting and promoting the autonomy and best interest of the incapacitated adult. For example, if the incapacitated adult reliably expresses an informed preference to sell her home and move to a less expensive residential facility where many of her friends live, her estate may be larger as a result; the substitute decision-maker

<sup>139.</sup> Sometimes these efforts are all too transparent. *See supra* note 81 (discussing Wagner v. Wagner (*In re* Estate of Wagner), 367 N.W.2d 736 (Neb. 1985), in which petitioners asserted as evidence of mother's need for conservator fact that mother decided to stop leasing to them and instead to lease land to a third party for 160% more than petitioners had paid). In *In re* Wagner, the court stated that it is "abundantly clear that one may not have his or her property taken away and placed in the hands of a conservator merely because potential heirs believe that there will be more left for them if the owner of the property is not free to deal with the property as he or she chooses." 367 N.W.2d at 738.

<sup>140.</sup> Not surprisingly, most reported case law concerning fiduciary representation concerns questions about the financial resources of the adult with a cognitive incapacity. *See, e.g., Mowrer*, 979 P.2d at 158 (discussing transfers of principal's property by her agents to themselves and their family members under durable power of attorney).

<sup>141.</sup> See, e.g., Joseph A. Rosenberg, Regrettably Unfair: Brooke Astor and the Other Elderly in New York, 30 PACE L. REV. 1004, 1031-35, 1052-59 (2010) (discussing son's financial abuse as agent under his wealthy mother's power of attorney and how lawyers assisted agent's misconduct). In In re Estate of Raney, 799 P.2d 986, 995-96 (Kan. 1990), a testator disinherited his children who had successfully filed a conservatorship against him. In upholding the will against a charge that it was tainted by testator's insane delusion, the court stated, "Decedent [testator] may have been mistaken in his belief that the conservators were attempting to control his affairs to preserve their inheritance, but their conduct supported his belief, even if it was erroneous." Id. at 996.

<sup>142.</sup> See In re Estate of Scrivani, 455 N.Y.S.2d 505, 510-11 (Sup. Ct. 1982) ("When a fiduciary does not have an interest adverse to that of his ward, a fiduciary is not disqualified solely because he himself may benefit along with his ward from the decision sought to be taken.").

could rightly choose to follow her wishes even if the decision is likely to provide him with a larger inheritance from her estate. 143

In gauging the propriety of the decision made by the agent, guardian, or conservator, it is often helpful, though not always necessary, 144 to examine the motivating factor behind the decision. 145 If the "but for" factor is the surrogate's own gain or benefit—and particularly if the surrogate is a guardian or conservator—then typically he has violated his fiduciary obligation. 146 Seeking to avoid such an allegation, the clever surrogate may find it easier to argue that the adult with a cognitive incapacity, like an infant, had no ability to express her wishes or preferences, and thus that he was simply acting as he believed she would want him to. 147

<sup>143.</sup> See Whitton, Striking a Balance, supra note 113, at 349-50 (discussing mandatory and permissive acts by agent under durable power of attorney, noting that principal may want agent to "carry out donative activities that do not represent any direct 'best-interest' benefit to the principal" and that "might even include transactions that benefit the agent or agent's family").

<sup>144.</sup> Some actions by substitute decision-makers are per se violations of their fiduciary duty, regardless of the decision-maker's motives. *See*, *e.g.*, Saunders v. Thomas (*In re* Estate of Thomas), 853 So. 2d 134, 135-36 (Miss. Ct. App. 2003) (setting aside deeds from ward to conservator, noting that conservator has same fiduciary obligation of loyalty as does a trustee); *In re* Brownell, 447 N.Y.S.2d 591, 593-94 (Del. Cty. Ct. 1981) (observing that conservator's fee for dog care—paid to herself without court approval—breached the fiduciary prohibition against self-dealing, regardless of whether her motive was tainted by fraud or self-interest).

<sup>145.</sup> See, e.g., Neb. Dep't Health & Human Servs. v. Gilmore (In re Guardianship of Gilmore), 662 N.W.2d 221, 226 (Neb. Ct. App. 2003) (noting that sometimes "unscrupulous relatives need supervision" and "[f]requently, a neighbor, an old friend, the child of an old friend, a member of the clergy, a banker, a lawyer, a doctor, or someone else who has been professionally acquainted with the person needing such help will come forward out of simple charity and bring the matter to the attention of the local probate court"). Of course, finding a seemingly appropriate person to serve as guardian can be difficult. In Gilmore, the court put the matter succinctly: "Sometimes, persons in need of a guardian or conservator have no relatives or at least none that care. Sometimes, the relatives of such people are prevented from serving the best interests of the protected person by avarice, greed, self-interest, laziness, or simple stupidity." Id.

<sup>146.</sup> See, e.g., In re Leising, 4 P.3d 586, 587, 590 (Kan. 2000) (suspending lawyer from practice of law where, as conservator and guardian for person with a cognitive incapacity, lawyer misappropriated funds for his own use), reinstatement granted, 175 P.3d 221 (Kan. 2008). But see Whitton, Striking a Balance, supra note 113, at 349-50 (noting that a principal may give her agent broad powers that allow agent to make decisions that primarily serve the agent's interests).

<sup>147.</sup> Sometimes a petitioner will seek a guardianship or conservatorship over another adult to prevent that adult from making a decision that will have an adverse financial effect on the petitioner. *See, e.g.*, Wagner v. Wagner (*In re* Estate of Wagner), 367 N.W.2d 736, 740-41 (Neb. 1985) (concluding that despite petition brought by adult children, no

# IV. CONFLATING INFANCY AND INCAPACITY: ON KILLING WITH KINDNESS

For many years, experts have been telling us that our tendency to infantilize the elderly, even when the tendency springs from generous motives, can harm the elderly. Studies have confirmed what common sense tells us: our words affect those with whom we speak. Moreover, treating the elderly as children can result not only in psychological harm to the elderly, but also in physiological harm.

Perhaps one of the clearest manifestations of our tendency to treat the elderly as infants is the widespread use of "elderspeak." Thus, a young or middle-aged speaker who would never dream of casually calling another young or middle-aged person "sweetie" or "dear" might easily use those terms with an older adult, believing that such usage is kind or encouraging. Such language, however, often carries with it the speaker's implicit assumption that the elder person is, in some ways, as helpless as an infant. Adults with diminished capacity who

conservator was needed for their elderly mother who made land-leasing decision in favor of third party that adversely affected some of the petitioners who had previously used land). An agent, conservator, or guardian may also act in ways to preserve or increase the estate of the person with an incapacity not to benefit that person, but rather to ensure a larger potential inheritance for the agent, conservator, or guardian. *See, e.g.*, Lauren Krohn, *Cause of Action to Establish Involuntary Conservatorship for Estate of Adult Person, in* 6 CAUSES OF ACTION 2D 625, § 4, Westlaw (database updated Mar. 2018) (noting closer scrutiny given to conservatorship petition when inference arises that petitioner is seeking to preserve assets "in order to secure a larger inheritance," and also citing cases supporting proposition).

- 148. See, e.g., John Leland, In "Sweetie" and Dear," a Hurt Beyond Insult for the Elderly, N.Y. TIMES, Oct. 7, 2008, at A1 (discussing the harmful effects of "elderspeak").
  - 149. See id. at A1, A18 (noting studies indicating negative effect of elderspeak).
- 150. See id. (citing study by Yale professor and noting that an elder's negative views of aging may be compounded by the perceived insults of elderspeak, leading to impaired functional health and lower survival rates over time); Camille Peri, What I Wish I'd Known About "Elderspeak": Psychologist Becca Levy, https://www.caring.com/reflections/becca-levy-reflection [https://perma.cc/K4MY-XCDH] (noting that elderspeak can affect the competence and lifespan of elders).
- 151. See Leland, supra note 148, at A18 (discussing prevalence of elderspeak, especially in the field of health care). In addition, researchers have questioned the practice of "speaking needlessly slowly and loudly" to the elderly. See Barry Wigmore, Talking to Old People Like Children Cuts Eight Years Off Their Lives, Says Yale Study, DAILY MAIL (Oct. 8, 2008), http://www.dailymail.co.uk/health/article-1071891/Talking-old-people-like-children-cuts-years-lives-says-Yale-study.html [https://perma.cc/C9QD-NYRZ].
- 152. See Leland, supra note 148, at A1 (noting observation by one elder that people who use elderspeak "think they are being nice . . . but when I hear it, it raises my hackles").
  - 153. See id. at A18.

have a surrogate decision-maker usurping at least some of their autonomy are already in a vulnerable position; thus, the negative effects of elderspeak are likely to be compounded when elderspeak is addressed to them.<sup>154</sup>

Some observers have suggested that health care workers (including doctors)—arguably those individuals who should be most aware of the harmful effects of infantilizing the elderly<sup>155</sup>—are among the most frequent users of elderspeak.<sup>156</sup> If this is so, one can only wonder at the degree of harm substitute decision-makers may unwittingly inflict on adults with a cognitive incapacity outside of the medical arena.

Many elders who are under a guardianship or conservatorship or who need the assistance of an agent under a durable power of attorney are quite able to understand the implicit insult of casual elderspeak addressed to them. <sup>157</sup> A fully capable elder who is the subject of elderspeak may grow livid and inform the speaker that such language is inappropriate and unappreciated. <sup>158</sup> A person aware that she suffers from some degree of cognitive incapacity, however, is perhaps less likely to object clearly and vocally to the elderspeak and more likely to internalize such language, leading to a "negative downward spiral" of "decreased self-esteem, depression, withdrawal and the

<sup>154.</sup> Society tends to infantilize not only the elderly, but also those with disabilities. See Kenneth L. Robey et al., Implicit Infantilizing Attitudes About Disability, 18 J. DEVELOPMENTAL & PHYSICAL DISABILITIES 441, 441-42 (2006) (discussing studies in which individuals unwittingly altered speech in infantilizing manner when dealing with a person with a disability); Jennifer L. Stevenson et al., Infantilizing Autism, DISABILITIES STUD. Q. (2011), http://dsq-sds.org/article/view/1675/1596 [https://perma.cc/89XZ-NXV4]. Stevenson and her co-authors observed that "[s]ociety's overwhelming proclivity for depicting autism as a disability of childhood poses a formidable barrier to the dignity and well-being of autistic people of all ages." Id.

<sup>155.</sup> *See* Leland, *supra* note 148, at A18 (noting that many people do not realize that "it's belittling to call someone [dear]," and that "even among professionals, there appeared to be little movement to reduce elderspeak").

<sup>156.</sup> See id. (noting observations of a University of Kansas associate professor who is a nurse gerontologist). Considering the lack of training that the typical law student receives in working with elderly clients and adults with diminished capacity, one wonders if lawyers are likely to be any more aware of the potential harms of elderspeak.

<sup>157.</sup> See id.

<sup>158.</sup> See id. (observing that one elderly interviewee "sprinkles her conversation with profanities" to indicate to others that "[t]his is someone to be reckoned with"). But see id. (noting that some older individuals do not object to elderspeak and instead view it as a sign of "underlying warmth" or a "way to connect, in a positive way").

assumption of dependent behaviors."<sup>159</sup> In fact, research indicates that individuals with positive attitudes about aging live "on average 7.5 years longer than those with a negative attitude."<sup>160</sup>

Elderspeak is thus yet another form of pernicious infantilization that can exacerbate an elder's negative view of the aging process. Moreover, although the term elderspeak implicates language addressed to the elderly, it appears that the use of such improper, too-familiar language has a negative effect on an adult of any age who suffers a disability. 161 Whether elderly or not, most adults with a cognitive incapacity in fact want what modern laws ostensibly require: to maximize their autonomy<sup>162</sup> consistent with their abilities. 163 Yet if health-care professionals all too often infantilize the adult with a cognitive disability, it should come as no surprise that judges, lawyers, conservators, agents, guardians, and guardians ad litem may also unwittingly adopt infantilizing attitudes and base their decisions on the underlying, if unspoken, premise that incapacity renders a person infant-like. 164

<sup>159.</sup> See id. (discussing findings of Dr. Kristine Williams and other researchers studying how those with mild to moderate dementia react to elderspeak); Wigmore, *supra* note 151 (noting that "[f]or people with mild to moderate dementia, the results of elderspeak were even more alarming" than the results of elderspeak addressed to fully capable elders, and quoting Dr. Williams' statement, "If you know you're losing your cognitive abilities and trying to maintain your dignity, and someone talks to you like a baby, it's upsetting to you").

<sup>160.</sup> See Wigmore, supra note 151 (observing that the 7.5 years increase in life span for those with a positive attitude about aging is larger than the lifespan increase "provided by . . . frequent exercise or not smoking").

<sup>161.</sup> See Robey et al., supra note 154, at 441-42 (discussing study in which college students addressed other adults, whom they believed to have a disability, as children, speaking louder and using more words); Stevenson et al., supra note 154 (noting that adults with disabilities are treated as "childlike entities" who "deserv[e] fewer rights and incur[] greater condescension than [other] adults," and also observing the disturbing stereotype of the "eternal child").

<sup>162.</sup> See Dayton et al., supra note 24, § 34:32 (noting that uniform laws and most states now provide for limited guardianships or conservatorships by statute or practice).

<sup>163.</sup> Moreover, maximum autonomy consistent with ability is perhaps not only what the typical person wants, but also what the typical person needs. *See, e.g.*, MARTIN E.P. SELIGMAN, LEARNED OPTIMISM 168-70 (1991) (citing Yale study indicating that nursing home patients with more choice and control were happier and more active, and discussing study demonstrating that "learned helplessness" is a psychological state that can cause cancer).

<sup>164.</sup> Perhaps truly listening to the elderly is the most generous and genuinely respectful thing we can do in the process of substitute decision-making. *See infra* notes 181-92 and accompanying text (discussing questions that substitute decision-maker should

In short, erroneous assumptions about incapacity, age, and infancy may manifest themselves in spoken words of apparent endearment. Good intentions, however, do not make such usage appropriate. Addressing an adult with a cognitive incapacity in infantilizing terms may contribute to a loss of self-esteem and to an increase in dependent behaviors. As a result, the adult may come to believe that her wishes and preferences are not worthy of consideration. To the extent that such infantilizing language may shorten the life expectancy of an adult with a cognitive incapacity, we would also do well to realize that while infantilizing words may not break bones, even when kindly meant they can kill. 167

### V. THE PARAMOUNT QUESTIONS

To avoid conflating incapacity and infancy, an important initial step is to recognize clearly our own biases and prejudices about incapacity (and old age, when the adult with diminished capacity is elderly). Perhaps we cannot completely eliminate

always ask adult with a cognitive incapacity). In his touching memoir of his life with his mother and especially of her final days, Scott Simon notes that his mother "didn't like being dismissed as adorable or cute by younger people, as if she were a five-year-old...." SCOTT SIMON, UNFORGETTABLE: A SON, A MOTHER, AND THE LESSONS OF A LIFETIME 196 (2015). As her death approaches, she states, "No one really listens to old people. We make people nervous." *Id.* at 18. Later she states from her hospital room that "what is hard" is that "[t]here's a tone in their voice when you get old and people call you 'lovely' ... [l]ike you've become some kind of beautiful, crumbling old statue." *Id.* at 44. Finally, she states, "No one *wants* to listen to old people." *Id.* at 199 (emphasis added).

165. See Leland, supra note 148, at A18.

166. See id.; David Solie, Elderspeak: Annoying and Toxic, DAVID SOLIE: SECOND-HALF LIFE BLOG (July 6, 2016), http://www.davidsolie.com/blog/elderspeak-annoying-and-toxic/[https://perma.cc/M6NW-DZX9].

167. The good news is that the negative impact of elderspeak and infantilizing language apparently can be reduced by educating those who work with the elderly or with adults with cognitive disabilities. *See* Kristine Williams et al., *Improving Nursing Home Communication:* An Intervention to Reduce Elderspeak, 43 GERONTOLOGIST 242, 243, 246-47 (2003), https:// academic.oup.com/gerontologist/ article/43/2/242/636164 [https://perma.cc/HY8Y-TQNP] (discussing results of study designed to educate health care workers about the potential negative effects of elderspeak).

168. Again I emphasize that bias or prejudice can unwittingly taint the choices of various decision-makers in matters relating to guardianships, conservatorships, and powers of attorney. For example, the unconscious assumptions of medical or psychological experts may come into play when they are asked to determine whether an adult is incapacitated for purposes of instituting a guardianship or conservatorship or determining whether a springing durable power of attorney has become effective. *See also* Dayton et al., *supra* note 24, § 34:22 (noting historically that "the use of a single, possibly biased medical report had the

those biases and prejudices, but even mere acknowledgement of our own limitations makes us more likely to see the incapacitated person as a unique individual and not as an archetype we unwittingly hold in our mind's eye.<sup>169</sup>

If we first thoroughly engage in this self-reflective process and if we are then also willing to imagine ourselves in an incapacitated state, we are more likely to understand how infantilization robs the adult with diminished capacity not only of autonomy, but also of self-esteem and dignity. We also realize better that even though she may be incapacitated to some extent, she nevertheless will often be able to reliably express her wishes about who will assist her, where she will live, what activities she will engage in, and with whom she will associate. We begin to discard the notion that we are caring, rational, and "fully capable" adults who know better than the adult with diminished capacity what she needs. When we reach this phase in our own understanding of incapacity, 171 we can then turn our focus to

potential for enormous unfairness to the respondent"). Such a medical report may still have significant adverse repercussions for the respondent even after the statutory reforms of recent decades.

169. Judge Jerome Frank wrote eloquently about the effect of such self-acknowledgment in the following passage from *In re J.P. Linahan*, Inc., 138 F.2d 650, 652-54 (2d Cir. 1943):

In addition to ... social value judgments, every judge, however, unavoidably has many idiosyncratic "learnings of the mind," uniquely personal prejudices, which may interfere with his fairness at a trial. He may be stimulated by unconscious sympathies for, or antipathies to, some of the witnesses, lawyers or parties in a case before him. ... Frankly to recognize the existence of such prejudices is the part of wisdom. The conscientious judge will, as far as possible, make himself aware of his biases of this character, and, by that very self-knowledge, nullify their effect ...; the sunlight of awareness has an antiseptic effect on prejudices. Freely avowing that he is a human being, the judge can and should, through self-scrutiny, prevent the operation of this class of biases. ... As a fact-finder, he is himself a witness—a witness of the witnesses; he should, therefore, learn to avoid the errors which, because of prejudice, often affect those witnesses.

*Id.* at 652-53 (emphasis added). Importantly, Judge Frank's opinion notes that a judge must also examine the attitudes, motives, and biases of witnesses as well as the "real purposes and motives" of lawyers involved in the proceeding. *Id.* at 654.

170. See Tenenbaum, supra note 35, at 709-12.

171. See FRANK, supra note 17, at 153 (stating that "[t]he best we can hope for" is that those who judge "become more sensitive, more nicely balanced, more subject to [their] own scrutiny, more capable of detailed articulation") (emphasis added).

those particularized wants and needs of the incapacitated person, taking into account that person's abilities. 172

The often competing, though sometimes complementary, doctrines of best interest and substituted judgment<sup>173</sup> do not disappear as we engage in this reflective process. Instead, by tempering our natural impulse to choose what we think is best for the adult with diminished capacity<sup>174</sup> (whether we are purporting to act from an objective stance as a reasonable person or from a subjective stance based on what we believe she would want), we employ these doctrines in more enlightened and meaningful ways. We respect more fully the capabilities of the adult with a cognitive incapacity, increasing the likelihood that we will assist in maximizing her autonomy and self-esteem. We no longer assume, for example, that for every adult with a cognitive incapacity a reputable assisted living facility or nursing home (providing three hot meals a day and a climate-controlled room) is a better housing option than the somewhat haphazard circumstances that may exist at the adult's own home. 175 This is so even when a "reasonable" person would choose the assisted living facility or nursing home and even when we would choose the assisted living facility or nursing home for our self. 176

<sup>172.</sup> I am not suggesting that a substitute decision-maker will always be able to rid himself of his biases and prejudices concerning age and incapacity. *See* Tenenbaum, *supra* note 35, at 708 (expressing belief that decision-maker can almost never take his own values and beliefs completely out of the decision-making process); Pope, *supra* note 44, at 219 (citing failure of decision-maker to separate his own preferences from those of person for whom he is making decision). I am suggesting that candid self-awareness of the decision-maker's biases and prejudices can help minimize the intrusiveness of those biases and prejudices in the decision-making process. *See* FRANK, *supra* note 17, at 148 (observing that justice is more likely to be accomplished when a judge recognizes "his own prejudices and weaknesses," and that while a judge cannot eliminate his personality, he can recognize these prejudices and weaknesses).

<sup>173.</sup> See Whitton, Striking a Balance, supra note 113, at 349-50 (noting potential conflicts between substituted judgment and best interest doctrines).

<sup>174.</sup> See supra notes 114-15, 126-34 and accompanying text (discussing tendency for decision-maker to select choices he would want or he thinks best, despite contrary evidence of the preferences or probable wishes of the adult with a cognitive incapacity).

<sup>175.</sup> See Rein, supra note 6, at 1834-36.

<sup>176.</sup> See id. (quoting George J. Alexander, *Remaining Responsible: On Control of One's Health Needs in Aging*, 20 SANTA CLARA L. REV. 13, 21 (1980)) (noting the profound meaning of home, its connection with who one is and how one expresses herself, and its importance for a sense of autonomy and self-control).

To be clear, this Article does *not* suggest that every adult with a cognitive incapacity be left to fend for herself.<sup>177</sup> The Article does emphasize, however, that increased respect for the adult with a cognitive incapacity is likely to contribute to her sense of dignity and self-worth and, further, that increased recognition of our own biases and prejudices will help us better assist those who have a cognitive incapacity.<sup>178</sup>

A one-size-for-all solution is unlikely ever to be appropriate for every adult with a cognitive incapacity. Although individualized solutions can be resource intensive, each adult with a cognitive incapacity deserves at least the opportunity to have her wishes considered. Indeed, the recurrent theme of this Article is that we should tailor assisted decision-making around the individualized wants and needs of *each* adult with a cognitive incapacity and that to do so we must first examine our own preconceptions about elderly and other adults with diminished capacity. Iso

Once we recognize that the adult with diminished capacity can often reliably express her needs and preferences, we are more likely to realize that certain questions should never go unasked regarding any matter of significance to her.<sup>181</sup> The simple, foundational question we must ask the adult with diminished capacity is, "What do you want?" Of course, matters

<sup>177.</sup> For example, if the life of an adult with a cognitive incapacity is endangered by another, a court or other substitute decision-maker might properly refuse to permit that other person from visiting the adult, despite the adult's stated wish to continue to see that other person. *See, e.g.*, Knight v. Knight (*In re* Knight), 317 P.3d 1068, 1070, 1073-74 (Wash. Ct. App. 2014) (discussing petitions by son with power of attorney seeking guardianship for vulnerable mother and a protective order that would prohibit his brother from visiting her, even though mother maintained that she did not want visits to stop).

<sup>178.</sup> See In re J.P. Linahan, Inc., 138 F.2d 650, 653 (2d Cir. 1943) ("[T]he sunlight of awareness has an antiseptic effect on prejudices.").

<sup>179.</sup> This approach may also require the substitute decision-maker to admit that the adult with diminished capacity has indeed become a new and different person whose wishes and desires are worthy of respect. *See, e.g.*, Tenenbaum, *supra* note 35, at 705-06 (discussing theorists' views on personhood before and after "disruption in memory or other psychological connections").

<sup>180.</sup> See FRANK, supra note 17, at 148 ("The honest, well-trained judge with the completest possible knowledge of the character of his powers and of his own prejudices and weaknesses is the best guaranty of justice." (emphasis added)).

<sup>181.</sup> See infra notes 182-87 and accompanying text (discussing questions that decision-maker should ask of person with a cognitive incapacity).

<sup>182.</sup> Cf. Tenenbaum, supra note 35, at 713 (proposing, as first step of test for determining whether a nursing home patient with a cognitive incapacity should be allowed

significantly affecting her life and well-being can run the gamut. For example, perhaps the matter concerns who should serve as her guardian or conservator. Perhaps the matter concerns where she will live. <sup>183</sup> In any event, we should begin by *asking her* what she wants. <sup>184</sup> If she can reliably express her wishes, those wishes should be our starting point for decision-making, and her wishes should be countermanded only with reluctance after careful consideration. <sup>185</sup>

Following her answer to our initial question, often we may have to ask, "Why do you want that?" Our goal with this question is to assure ourselves that she is expressing her wishes in a meaningful, reliable way. We should not be looking for carefully reasoned answers, but rather for answers that demonstrate that she has a basic understanding of the issue and a preference—a preference that is reasonable to her—concerning its resolution. 186

When she answers these questions in an unexpected way, we must not rush to conclude that she can no longer reliably express

to engage in an adulterous or other sexual relationship, that decision-maker "determine whether the resident has the ability to express his or her desires").

183. See, e.g., In re Guardianship of Lanoue, 802 A.2d 1179, 1181 (N.H. 2002) (noting that state statute provides that, unless modified by court order, guardian of ward can select the ward's residence within or without the state).

184. Because a person with a cognitive incapacity may be able to express reliably her wishes and needs in ways that cannot be reconciled with instructions she made before the incapacity, the question should always be asked. *See* Tenenbaum, *supra* note 35, at 705-07 (noting how person with an incapacity may become a totally new and different self following onset of incapacity and may thus also find new and different wishes and needs she never contemplated before the onset of incapacity).

185. See, e.g., In re Medworth, 562 N.W.2d 522, 523-25 (Minn. Ct. App. 1997) (reversing trial court's grant of conservator petition to move conservatee who required 24-hour medical care from her home when record showed conservatee had lived there for many years, had "repeatedly expressed her preference to remain [in that home,]" and was willing to have her assets spent to allow her to remain there); see also Tenenbaum, supra note 35, at 713-14 (opining that adult with cognitive incapacity may be able to express her desires or wishes through behavior even if she can no longer express herself orally).

186. Concerning how guardians might go about demonstrating that they have responsibly fulfilled their roles, see generally Erica Wood, *Guardian Accountability: Key Questions and Promising Practices*, in COMPARATIVE PERSPECTIVES ON ADULT GUARDIANSHIP, *supra* note 7, at 313, 318 ("Perhaps accountable guardians should show they have inquired, and have 'dug deeply' to find out what is and was important to the individual, and have made this a part of their plan of action—essentially that 'attention has been paid' and that it affected the steps the guardian took.").

her wishes.<sup>187</sup> This is so even when we know that her answers are inconsistent with the answers she would have given before the incapacity began. "Capable" adults may experience a significant change in their longest- and most strongly-held beliefs and desires; the same is true of adults with diminished capacity.<sup>188</sup> We as substitute decision-makers must not diminish her personhood by denying her the opportunity to grow and change. If we focus solely on "who she was" prior to incapacity and ignore "who she is" now, we fail to recognize her as a human being fully worthy of respect.<sup>189</sup> A refusal by us to consider her currently expressed preferences comes close to a tacit admission that the person with an incapacity before us now—who continues to live and breathe and to have wants and desires—is essentially dead to us.<sup>190</sup>

As we carefully consider the wants and needs she expresses, we do not renounce our duty to serve her best interest. Rather, when her wishes clash with our expectations, we should remember the limitations of our knowledge and judgment as well as the importance of free will and control to every sentient individual. We can then proceed to a reasoned decision not as patronizing, parent-like figures, but as caring human beings assisting another human being to maximize her happiness and sense of self-worth.<sup>191</sup> In short, we reject the notion that incapacity is infancy.<sup>192</sup>

<sup>187.</sup> See Tenenbaum, supra note 35, at 713-14 (discussing individual's ability to express his or her desires, noting further that "desires need not be communicated orally; they can be communicated through a consistent pattern of behavior").

<sup>188.</sup> See id. at 705.

<sup>189.</sup> See id. at 705-07 (warning that following onset of incapacity, "a person's values and desires may change so much... that it no longer makes sense to base decisions on the person's prior values").

<sup>190.</sup> See supra notes 93-102 and accompanying text (discussing refusal by surrogate decision-maker to consider current wishes of adult with diminished capacity).

<sup>191.</sup> See Tenenbaum, supra note 35, at 713-14 (opining that once adult with incapacity has expressed her wishes, whether orally or by behavior, the next step is for the decision-maker "to determine what critical interests or values might be affected by [allowing the adult to act] on these desires").

<sup>192.</sup> Essentially what I advocate is that the substitute, surrogate, or assisted decision-maker cast aside his own biases and prejudices and carefully examine and respect the continuing capabilities of the adult with a cognitive incapacity. Such an approach would go far towards the accomplishment of a *person-centered philosophy* for decision-making. *See*, *e.g.*, Wood, *supra* note 186, at 319 (describing a "person-centered philosophy" in guardian decision-making).

When the adult with a cognitive incapacity can no longer reliably express her wishes and needs, the surrogate decision-maker will typically turn to principles of substituted judgment. <sup>193</sup> Unfortunately, substituted judgment has come to mean different things depending upon the jurisdiction and the context in which a decision must be made. <sup>194</sup> Many modern statutes—particularly those addressing health-care decisions—clearly contemplate that the substitute decision-maker is to make the decision that the person with an incapacity would have made. <sup>195</sup>

Studies show, however, that often the choices that a surrogate makes are not the choices that the adult with a cognitive incapacity would have made; <sup>196</sup> instead, the decision is often based on what the surrogate would want *for himself*. <sup>197</sup> For example, a surrogate facing a medical decision that could effectively end the life of an adult with diminished capacity might convince himself that—regardless of the wishes the adult expressed when capable—she did not truly contemplate the situation at hand; thus, the surrogate can justify doing what he would want for himself by asserting that he had no helpful guidance from her or, alternatively, that she would have changed her mind and agreed with him had she foreseen the precise circumstances now before her. <sup>198</sup> Such a surrogate is deviating, again perhaps unwittingly, from the probable wishes of the person with a cognitive incapacity. <sup>199</sup> Though his decision is improper,

<sup>193.</sup> See Tenenbaum, supra note 35, at 701 (noting that courts typically favor substituted judgment over a best interests test when the person in question was formerly competent).

<sup>194.</sup> See supra note 89 (discussing substituted judgment and noting that its meaning is not uniform across the states).

<sup>195.</sup> See Pope, supra note 44, at 208-14 (discussing bases of surrogate decision-making).

<sup>196.</sup> See id. at 215-17 (citing empirical studies, including one indicating that surrogate decision-makers predicted patient treatment preferences with only 68% accuracy). Professor Pope further notes that surrogate decision-makers are often unable to distinguish their own wishes concerning treatment from those of the adult for whom they are to act. *Id.* at 219 (discussing psychological factors that might account for this tendency).

<sup>197.</sup> See id. at 219 (noting surrogates' tendency to confuse their own wishes for those of the adult with an incapacity whom they represent); KOHN, *supra* note 23, at 122 (noting studies indicating that surrogates tend to make decisions based on what *they* would want).

<sup>198.</sup> See Madoff, supra note 78, at 965-66 (noting that frequently a person's perceived reaction to a future disability is different from her reaction when she experiences that disability).

<sup>199.</sup> The deviation is not always unwitting. See Nina A. Kohn & Jeremy A. Blumenthal, Designating Health Care Decisionmakers for Patients Without Advance

the deviation is understandable; after all, most of us have a tremendous ability to believe that others want what we want.

Once again, our role in the assisted decision-making process requires us to consider our own assumptions and motives as we consider the wishes of the adult with diminished capacity. When she can no longer reliably express her wishes and yet there are reasons to know what decision she would make if capable, in most instances we should respect that decision. Through concerted efforts to minimize the effects of our prejudices and biases about incapacity and old age, we are much more likely to assist with decision-making in ways that comport with the aspirational goals of modern guardianship, conservatorship, and power of attorney laws. On the conservatorship is a power of attorney laws.

### VI. CONCLUSION

Modern surrogate decision-making statutes, especially those concerning guardianships, conservatorships, and durable powers of attorney, recognize that adults with diminished capacity are individuals whose autonomy is not only to be respected, but also maximized to the fullest degree consistent with their abilities. Modern surrogate decision-making standards are designed to help accomplish this goal. While these improvements in statutes and standards are laudable, they remain largely meaningless if we do not effectively implement them both in judicial proceedings

Directives: A Psychological Critique, 42 GA. L. REV. 979, 996 (2008) ("[M]any surrogate decisionmakers refuse to make decisions consistent with a principal's wishes, even when the surrogates know those wishes and know that ignoring those wishes does not benefit the principal."). Kohn and Blumenthal cite a study in which a third of substitute decision-makers "were willing to consent to the principal's participation in that study despite the fact that participation would not benefit the principal personally" and despite their belief "that the principal would not willingly participate in a medical study..." Id. The authors also cite other research showing "that surrogates often plan to base their decisions about treatment at least partly on their own values." Id. Finally, the authors note that "research shows that surrogate decisionmakers often do not know the wishes of the person on whose behalf they are making decisions, even if they think that they do." Id.

200. But see, e.g., Tenenbaum, supra note 35, at 690-94 (noting that nursing home patients with an incapacity might properly be limited from engaging in sexual activity in public or semi-public parts of nursing home).

201. See FRANK, supra note 17, at 148-49 (discussing effect of bias and prejudice in judicial proceedings). A process of self-reflection by the substitute decision-maker and an effort to ascertain the wishes of the person with an incapacity should be the implied if not express goal of every statutory scheme concerning substitute decision-making.

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involving adults with a cognitive incapacity and in the everyday lives of those adults.

Although surrogate decision-makers who intentionally flout the law receive widespread media attention, most surrogates are good faith actors. Yet this Article has explored how even good faith actors—including judges, lawyers, guardians ad litem, conservators, guardians, and agents—can unwittingly allow their biases and prejudices about incapacity and old age to affect adversely the lives of those with whose best interest they are charged. Misdirected altruism, erroneous assumptions, convenience, and ignorance are among the factors that all too often cause surrogate decision-makers to treat the adult with a cognitive incapacity the same as an infant. The results are decisions that refuse to acknowledge that, like other adults, adults with diminished capacity can grow and change and can often reliably express their needs, wishes, and preferences.

The Article has suggested that, to fulfill the aspirational goals of modern substitute decision-making statutes and standards, we should begin by acknowledging our own biases and prejudices about incapacity and age. When we see clearly the unique personhood of adults with a diminished capacity, we become more willing to listen to their wants and needs and less likely to assume the role of omniscient parent. The habit of infantilizing the elderly and other adults with diminished capacity is neither inevitable nor unbreakable, and with careful self-assessment we can take an important step towards limiting its effect when we serve as surrogate decision-makers.