

# University of Miami Law Review

---

Volume 61  
Number 3 *Volume 61 Number 3 (April 2007)*  
*SYMPOSIUM The Schiavo Case:*  
*Interdisciplinary Perspectives*

---

Article 7

4-1-2007

## (Mis)Framing *Schiavo* as Discrimination Against Persons with Disabilities

Leslie Pickering Francis

Anita Silvers

Follow this and additional works at: <https://repository.law.miami.edu/umlr>



Part of the [Family Law Commons](#), [Health Law and Policy Commons](#), and the [Medical Jurisprudence Commons](#)

---

### Recommended Citation

Leslie Pickering Francis and Anita Silvers, *(Mis)Framing Schiavo as Discrimination Against Persons with Disabilities*, 61 U. Miami L. Rev. 789 (2007)

Available at: <https://repository.law.miami.edu/umlr/vol61/iss3/7>

This Article is brought to you for free and open access by the Journals at University of Miami School of Law Institutional Repository. It has been accepted for inclusion in University of Miami Law Review by an authorized editor of University of Miami School of Law Institutional Repository. For more information, please contact [library@law.miami.edu](mailto:library@law.miami.edu).

# (Mis)Framing *Schiavo* as Discrimination Against Persons with Disabilities

LESLIE PICKERING FRANCIS, J.D., PH.D.\*

ANITA SILVERS, PH.D.\*\*

I. INTRODUCTION .....	789
II. TERRI SCHIAVO AS A PERSON WITH A DISABILITY .....	791
III. <i>SCHIAVO</i> AND SCIENCE .....	799
IV. THE <i>SCHIAVO</i> CASE IN THE LAW: GUARDIANSHIP, SURROGACY, AND MEDICAL TREATMENT DECISIONS .....	807
V. THE <i>SCHIAVO</i> CASE AND UNDERSTANDING THE GOOD OF PEOPLE WITH INTELLECTUAL DISABILITIES .....	816
VI. CONCLUSION .....	820

## I. INTRODUCTION

The controversial decision to withdraw life-sustaining treatment from Terri Schiavo has been condemned by some disability rights organizations as unconscionable discrimination against people with disabilities.<sup>1</sup> We think that this position is wrong as it applies to the saga of Terry Schiavo<sup>2</sup> and potentially damaging for persons with disabilities in a general sense. Terri Schiavo<sup>3</sup> was a person with a disability.<sup>4</sup> But the contention that the case evidenced disability discrimination relies on assumptions that are deeply problematic in regard to science, guardianship, and surrogate decisionmaking law, and to achieving good for people with serious cognitive disabilities. In this Article, we argue first that

---

\* Ph.D., University of Michigan; J.D., University of Utah; Alfred C. Emery Professor of Law, Professor and Chair, Department of Philosophy, University of Utah.

\*\* Ph.D., Johns Hopkins University; Professor and Chair, Department of Philosophy, San Francisco State University.

1. See, e.g., Brief of Not Dead Yet et al. as Amici Curiae Supporting Appellant and Requesting Reversal at \*1-2, *Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2004) (No. SC04-925), 2004 WL 1713757.

2. See *Schiavo ex rel. Schindler v. Schiavo*, 358 F. Supp. 2d 1161, 1164-1165 (M.D. Fla. 2005); *Schiavo ex rel. Schindler v. Schiavo*, 357 F. Supp. 2d 1378 (M.D. Fla. 2005); *In re Guardianship of Schiavo*, 851 So. 2d 182, 184-86 (Fla. 2d Dist. Ct. App. 2003); *In re Guardianship of Schiavo*, 800 So. 2d 640, 642-43 (Fla. 2d Dist. Ct. App. 2001); *In re Guardianship of Schiavo (Schiavo II)*, 792 So. 2d 551 (Fla. 2d Dist. Ct. App. 2001); *In re Guardianship of Schiavo (Schiavo I)*, 780 So. 2d 176 (Fla. 2d Dist. Ct. App. 2001).

3. In what follows, we have chosen to refer to Terri Schiavo as "Terri Schiavo" for purposes of dignity. To refer to her as "Terri," as many commentaries do encourages infantilization and sentimentalization, rather than regarding her as the disabled woman she was. We owe this point to Laurie Zoloth.

4. See 42 U.S.C § 12102(2)(A)(2006); see also discussion *infra* Part II.

Terri Schiavo was properly viewed as a person with a disability, the half-truth in the critics' view.<sup>5</sup> We then demonstrate the flaws in the critics' view by taking a disability rights perspective to explain the reasons underlying the mistaken scientific, legal, and philosophical claims that *Schiavo* was a case of disability discrimination.

The fundamental contention of advocates that Terri Schiavo was a victim of disability discrimination construes the decision to withdraw life-sustaining treatment as based on a judgment that her quality of life was so poor that her life was no longer worth living.<sup>6</sup> This claim has consistently been advanced by Terri Schiavo's parents on the Web site they created for maintaining her life and, subsequently, for right-to-life advocacy on behalf of people with disabilities.<sup>7</sup> This supposed judgment about quality of life is sometimes erroneously taken to imply a further claim to the effect that her life was less worthwhile, less worthy of protection, or of reduced moral status.<sup>8</sup> If, indeed, the decision to terminate treatment was made on the basis that the quality of her life was poor because of her disability – much less on the basis of the claim that her life was less morally worthwhile because she was a person with a disability – that decision would be problematic from the perspective of both moral theory and disability law. To the contrary, arguments that the *Schiavo* case reflected biased judgments about the quality of life of disabled people rest on assumptions that are not helpful for defenders of the civil rights of the disabled. Our strategy will be to argue that the *Schiavo* case can only be deemed a case of disability discrimination if we make assumptions that are unwarranted and deeply problematic. In

---

5. See Kathy L. Cerminara, *Critical Essay: Musings on the Need to Convince Some People with Disabilities That End-of-Life Decision-Making Advocates Are Not Out to Get Them*, 37 *LOY. U. CHI. L.J.* 343, 374-75 (2006) (claiming that *Schiavo* involved not a person with a disability, but a "not abled" person); see also discussion *infra* Part II.

6. See, e.g., Brief of Not Dead Yet et al. as Amici Curiae Supporting Appellant and Requesting Reversal, *supra* note 1, at \*1-2.

7. "Prominent disability rights advocates, right-to-life proponents and members of both the healthcare and legal professions have long been warning the public of the intrinsic dangers of forcing profoundly disabled people to die by withholding ordinary care – such as enteral nourishment – from them." Pamela F. Hennessey, *We Hate to Say We Told You So*, TERRI SCHINDLER SCHIAVO FOUND., <http://www.terrisfight.org/news.php?id=71> (last visited Jan. 17, 2007).

8. To infer a claim about moral status from an assertion about quality of life requires a further premise: that quality of life is determinative of moral status. Yet these claims are entirely separate. People in severe pain, in impoverished circumstances, or in the deepest clinical depression may be judged to have poor quality of life on many different grounds, but nothing whatsoever follows about their moral status. The distinction between quality of life and moral status is both recognized and blurred in many discussions of disability rights, medical treatment decisions, and aid in dying. For example, the Web site of Not Dead Yet is headlined by the observation that "legalized medical killing is often about a deadly double standard for people with severe disabilities." Notdeadyet.org, <http://www.notdeadyet.org> (last visited Jan. 17, 2007).

so doing, we hope to contribute to the literature that separates opposition to disability discrimination from support for vitalist assumptions about the overriding importance of preserving life.<sup>9</sup>

## II. TERRI SCHIAVO AS A PERSON WITH A DISABILITY

Some have argued that Terri Schiavo was not a person with a disability. Kathy Cerminara, for example, distinguishes people with disabilities from people who are “not abled,” applying the latter term to an individual in permanent or persistent vegetative state (“PVS”).<sup>10</sup> Her contention is that individuals in PVS have no conscious life at all and hence have no reactions to or interests in treatment that affects conscious life.<sup>11</sup> Therefore, Cerminara maintains, individuals in PVS have no abilities whatsoever, as contrasted with individuals with lesser – that is, “dis” – abilities. What is to be concluded about whether an individual in PVS has interests and what those interests are, however – and we agree with much of what Cerminara says on that point<sup>12</sup> – is a different question from whether that individual is a person with disabilities.

Contrary to Cerminara’s claim, an individual in PVS is a living human being who clearly meets the definition of “disability” under the Americans with Disabilities Act (“ADA”): he or she has a physical or mental condition that substantially limits a major life activity.<sup>13</sup> Indeed, someone in PVS would seem to have a severely limiting case of disability as defined in the ADA because PVS is a condition that precludes almost all major life activities, breathing or digesting excepted. As such, a person in PVS meets the legal categorization for people with disabilities. Accordingly, Cerminara’s view is either a recommendation that legal categorizations be changed or not a legal recommendation at all. It would seem odd, however, to continue to categorize those in PVS as “people” – generally a normative category – and to distinguish between

---

9. For an account of how the issues have become intertwined, see Cerminara, *supra* note 5, at 344.

10. *Id.* at 374-75. The more common term here is “persistent vegetative state.” See, e.g., J.J. Fins., N.D. Schiff & K.M. Foley, *Late Recovery from the Minimally Conscious State: Ethical and Policy Implications*, 68 *NEUROLOGY* 304 (2007); J.T. Glacino, *The Vegetative and Minimally Conscious States: Consensus-Based Criteria for Establishing Diagnosis and Prognosis*, 19 *NEUROREHABILITATION* 293 (2004); J.T. Glacino & J. Whyte, *The Vegetative and Minimally Conscious States: Current Knowledge and Remaining Questions*, 20 *J. HEAD TRAUMA REHAB.* 30 (2005); E. Jaul & R. Calderon-Margalit, *Persistent Vegetative State and Dementia in the Elderly*, *INT’L PSYCHOGERIATRICS*, Jan. 19, 2007, at 1-8. We prefer the locution person “in PVS” because it avoids the suggestion that the person is to be identified with the condition.

11. See Cerminara, *supra* note 5, at 350-51.

12. See *infra* Part IV.

13. 42 U.S.C. § 12102(2)(A) (2006).

“disabled,” “not abled,” and “abled” members of this category, as we argue below.

If an individual in PVS is “disabled” under the ADA definition, that person meets the statute’s threshold condition for a claim of discrimination.<sup>14</sup> This observation is, of course, part of the appeal of Cerminara’s contention that someone in PVS is not a person with disabilities. If someone in PVS does not have a disability, that person does not meet the minimum threshold for bringing suit under the ADA.<sup>15</sup> The possibility that every decision to terminate treatment for someone in PVS may be subject to litigation under the ADA and perhaps barred by the ADA as disability discrimination is troubling. This is particularly true for those who believe that treatment withdrawals in such patients are permissible in a wide range of circumstances, especially as a means of respecting what people previously have clearly said about their wishes. Putative protection that overrides peoples’ ideas of their own good easily slides into paternalism.

Despite its appeal, this “non-abled” strategy would seem to be a problematic example of the tail wagging the dog; that is, of judgments about what should be regarded as prohibited conduct under the ADA driving judgments about who may be able to sue on such prohibited conduct. The argument would go as follows: The ADA is not a statute that was intended to block decisions to terminate medical treatment simply because a patient is a person with disabilities. Therefore, a certain patient for whom the decision to terminate treatment might be permissible is not a person with disabilities for purposes of the ADA. But this formulation of the argument is backwards because judgments about what conduct is prohibited under the ADA would seem to be an independent question from judgments about the scope of the definition of disability under the ADA.

Moreover, there are clear examples of what would constitute disability discrimination against an individual in PVS that should be actionable under the ADA. Consider, for example, the decision of a state government to refuse Medicaid payment for the treatment of a person in PVS because of the catastrophic nature of his or her cognitive losses, or a decision by a public entity such as a nursing home to refuse services to such a person on the same grounds. To this extent, proponents of regarding the *Schiavo* case as about disability have it right: Terri Schiavo was a person with a disability, and if the judgment to withdraw the feeding tube had been made solely on this basis, it would have raised questions about whether the door was being inappropriately opened to

---

14. See, e.g., *Sutton v. United Air Lines*, 527 U.S. 471, 477 (1999).

15. *Id.*

non-treatment decisions against cognitively impaired individuals on the basis of disability, as critics still contend.<sup>16</sup>

Thus, identifying Terri Schiavo as a person with a disability, as Samuel Bagenstos argues, opens up the possibility that at least one aspect of the litigation was wrongly decided, namely, the federal district court's judgment rejecting the Schindlers' final contention that the withdrawal of the feeding tube violated the ADA.<sup>17</sup> The legal aspects of the *Schiavo* case were long and complex.<sup>18</sup> The ADA claim appeared only at the very end, just eight days before Terri Schiavo's death, when the Schindlers filed an amended complaint petitioning the federal court to grant a temporary restraining order, issue a declaratory judgment, and grant permanent injunctive relief against the removal of and refusal to reinsert Terri Schiavo's feeding tube.<sup>19</sup> Count six of the Schindlers' amended complaint contended that it was a violation of the ADA to deny "necessary and appropriate rehabilitation services" to a person with substantial disabilities.<sup>20</sup> Count six also alleged that it was a violation of the implementing regulations of the ADA for a guardian to authorize the withdrawal of nutrition and hydration from a person with substantial disabilities.<sup>21</sup>

The federal district court rejected the Schindlers' contentions in count six.<sup>22</sup> Granting for the sake of argument that Terri Schiavo was a qualified person with a disability and that the hospice was a public accommodation for purposes of the ADA, the court concluded that the removal of the feeding tube had not been "on the basis of" a disability.<sup>23</sup> Rather, the hospice's removal of the feeding tube was in response to a Florida court order – just like the earlier removal and reinsertion of the

16. See Notdeadyet.org, *supra* note 8; see also Welcome to the Terri Schindler Schiavo Foundation, (2006), <http://www.terrisfight.org>.

17. Samuel R. Bagenstos, *Judging the Schiavo Case*, 22 CONST. COMMENT. 457, 469 (2005).

18. See cases cited *supra* note 2 (appellate rulings in *Schiavo* case). See also generally Kathy Cerminara & Kenneth Goodman, *Schiavo Case Resources, Key Events in the Case of Theresa Marie Schiavo*, <http://www6.miami.edu/ethics/schiavo/timeline.htm> (providing a comprehensive timeline of *Schiavo*).

19. See Plaintiff's First Amended Complaint for Temporary Restraining Order, Declaratory Judgment, and Preliminary and Permanent Injunctive Relief, *Schiavo ex rel. Schindler v. Schiavo*, 357 F. Supp. 2d 1378 (M.D. Fla. 2005) (No. 8:05-CV-530-T-27TBM) (addressing counts one through five), and 358 F. Supp. 2d 1161 (M.D. Fla. 2005) (No. 8:05-CV-530-T-27TBM) (addressing counts six through ten), 2005 WL 923185 [hereinafter Plaintiff's First Amended Complaint]. This complaint was brought in federal court after An Act for the Relief of the Parents of Theresa Marie Schiavo, Pub. L. No. 109-3, 119 Stat. 15 (2005), granted the Middle District of Florida jurisdiction over any suit brought under federal law challenging the removal of Terri Schiavo's feeding tube. *Schiavo ex rel. Schindler*, 357 F. Supp. 2d at 1378.

20. Plaintiff's First Amended Complaint, *supra* note 19, ¶¶ 77-80.

21. *Id.*

22. *Schiavo ex rel. Schindler*, 358 F. Supp. 2d at 1164-65.

23. *Id.* at 1165.

tube.<sup>24</sup> The court also rejected the Schindlers' reading of the ADA regulations, pointing out that the regulations merely clarified that neither the ADA nor the regulations altered federal law with respect to withdrawal of nutrition and hydration by a guardian.<sup>25</sup>

The Eleventh Circuit affirmed the district court's interpretation and agreed that the hospice had not withdrawn the feeding tube by reason of Terri Schiavo's disability.<sup>26</sup> Additionally, the Eleventh Circuit went further than the district court, opining that the ADA "was never intended to provide an avenue for challenging court orders in termination of treatment decisions" and that it was not a "medical malpractice" statute.<sup>27</sup> The U.S. Supreme Court denied the Schindlers' petition for a stay,<sup>28</sup> and the case ended with Terri Schiavo's death.

In addition to contending that Terri Schiavo should be judged as a person with a disability – a claim with which we agree – Bagenstos argues that the court's treatment of the Schindlers' ultimate efforts to litigate the case under the ADA was too hasty.<sup>29</sup> Bagenstos' view is that the case raised potentially legitimate claims under the ADA, a federal statute, and that the courts should have at least granted the temporary restraining order to allow these claims to be explored further.<sup>30</sup> Bagenstos argues that the judges acted hastily because they were frustrated by the Schindlers' efforts to resurrect claims that had been already settled.<sup>31</sup> Bagenstos contends that the judges instead should have followed either Congress' directions and re-litigated the federal law issues *de novo*, particularly the issues under the ADA, or attacked the constitutionality of the federal statute directly, giving the Schindlers standing to bring suit in federal court within thirty days to re-litigate any federal legal issues raised by the removal of Terri Schiavo's feeding tube.<sup>32</sup>

For this Article's purposes, we set aside the constitutional issues raised by the congressional directive giving federal courts jurisdiction to re-litigate issues already settled in state court.<sup>33</sup> Our goal instead is to consider whether there would have been any substance to an ADA claim beyond the issues of guardianship and surrogate decisionmaking that

---

24. *Id.* at 1164. The court reached a parallel conclusion on the Schindlers' Rehabilitation Act claim, not separately discussed here. *Id.* at 1165-66.

25. *Id.* at 1165 n.4.

26. Schiavo *ex rel.* Schindler v. Schiavo, 403 F.3d 1289, 1294 (11th Cir. 2005).

27. *Id.*

28. Schiavo *ex rel.* Schindler v. Schiavo, 544 U.S. 957 (2005).

29. Bagenstos, *supra* note 17, at 457.

30. *Id.* at 458-459.

31. *Id.* at 471.

32. *Id.*

33. See An Act for the Relief of the Parents of Theresa Marie Schiavo, Pub. L. No. 109-3, 119 Stat. 15 (2005).

had already been litigated in state court.<sup>34</sup> One way to argue that there was substance to an ADA claim would be to read the ADA as a general alteration of the balance of state and federal law with regard to guardianship and surrogacy, affording a federal cause of action because decisions are made with respect to a person with disabilities – rather than affording a federal cause of action based on an allegation that the decisions discriminated against a person with disabilities. If the ADA is read this way, then the federal courts should not have hastily dismissed the ADA claim. The district court’s reasoning on this point was twofold: first, the hospice’s decision to remove the feeding tube was not due to Terri Schiavo’s disability; second, the Schindlers’ reading of the ADA interpretive regulations was mistaken.<sup>35</sup> On the latter point, the district court was clearly correct: the statement that the ADA does not authorize “the representative or guardian of an individual with a disability to decline food, water, medical treatment or medical services for that individual”<sup>36</sup> simply clarifies the principle that the ADA is not to be understood as authorizing non-treatment decisions. This does not, however, imply the converse notion that the ADA requires representatives or guardians to continue treatment. (This implication would be a fallacy: to say that X is not authorized is not to say that not-X is required; not-X could be required, authorized, or not authorized.) Indeed, the preceding section of the regulations clarifies the other side of the question: nothing in the ADA requires a person with disabilities or his or her surrogate decisionmaker to accept services, either.<sup>37</sup>

Another way to argue that there was substance to the ADA claim was to contend that the legal proceedings in the *Schiavo* case had evidenced disability discrimination. This is the more difficult question, whether the Middle District of Florida and the Eleventh Circuit properly resolved the contention that the hospice had acted based on Terri Schiavo’s disability. On this point, each court gave a too-simple answer, an answer which we believe is half-right and half-wrong. The Eleventh Circuit’s simple answer was that the hospice could not have acted on the basis of Terri Schiavo’s disability because the ADA “was never” intended to serve as a basis for challenging non-treatment decisions.<sup>38</sup> The district court’s simple answer was that the hospice had not acted based on Terri Schiavo’s disability because it acted solely in accord with

---

34. See generally *In re* Guardianship of Schiavo (*Schiavo II*), 792 So. 2d 551 (Fla. 2d Dist. Ct. App. 2001); *In re* Guardianship of Schiavo (*Schiavo I*), 780 So. 2d 176 (Fla. 2d Dist. Ct. App. 2001).

35. *Schiavo ex rel. Schindler v. Schiavo*, 358 F. Supp. 2d 1161, 1164-65 (M.D. Fla. 2005).

36. 28 C.F.R. § 35.130(e)(2) (2006).

37. § 35.130(e)(1).

38. *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1289, 1294 (11th Cir. 2005).



a court order, as it had done in the past in both removing and reinserting the tube in response to other court orders.<sup>39</sup>

The Eleventh Circuit's assertion that the ADA "was never" intended to serve as a basis for challenging non-treatment decisions is overly broad. Rather, non-treatment decisions based on disability, which are subject to challenge under the ADA, surely exist; an example would be the challenges raised to initial versions of the Oregon Health Plan.<sup>40</sup> But there is at least a half-truth in the Eleventh Circuit's statement that the ADA was not meant to derange the balance of federal and state law with respect to guardianship and end-of-life decisionmaking.<sup>41</sup> Nothing in the legislative history or interpretive regulations belies this point. Indeed, the Department of Justice's issuance of the final rule interpreting the ADA clarifies that the ADA does not alter federal law regarding medical treatment decisions for persons with disabilities:

Some commenters expressed concern that § 35.130(e), which states that nothing in the rule requires an individual with a disability to accept special accommodations and services provided under the ADA, could be interpreted to allow guardians of infants or older people with disabilities to refuse medical treatment for their wards. Section 35.130(e) has been revised to make it clear that paragraph (e) is inapplicable to the concern of the commenters. A new paragraph (e)(2) has been added stating that nothing in the regulation authorizes the representative or guardian of an individual with a disability to decline food, water, medical treatment, or medical services for that individual. New paragraph (e) clarifies that neither the ADA nor the regulation alters current Federal law ensuring the rights of incompetent individuals with disabilities to receive food, water, and medical treatment.<sup>42</sup>

The reverse is also true, as (e)(1) indicates, namely, nothing in the ADA or the regulations alters federal law regarding the permissibility of persons with disabilities to refuse medical treatment. Although the Department of Justice does not say so, this affected body of federal law also includes the Patient Self-Determination Act,<sup>43</sup> as well as recognition of federal constitutional liberty rights to refuse medical treatment.<sup>44</sup> A crit-

---

39. *Schiavo ex rel. Schindler*, 358 F. Supp. 2d at 1165.

40. Note, *The Oregon Health Care Proposal and the Americans with Disabilities Act*, 106 HARV. L. REV. 1296, 1305-08 (1993).

41. *Schiavo ex rel. Schindler*, 403 F.3d at 1294 ("The ADA was never intended to provide an avenue for challenging court orders in termination of care cases.").

42. Nondiscrimination on the Basis of Disability in State and Local Government Services, 56 Fed. Reg. 35,694 (Dep't of Justice July 26, 1991).

43. 42 U.S.C.A. § 1395cc(a) (2006).

44. See, e.g., *Washington v. Glucksberg*, 521 U.S. 702, 720 (1997) ("We have also assumed, and strongly suggested, that the Due Process Clause protects the traditional right to refuse unwanted lifesaving medical treatment."); *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261

ical component of this federal corpus is that while states are permitted to insist on clear and convincing evidence when non-treatment decisions are made for people who have lost decisionmaking capacity, states are not required to adopt this stringent standard.<sup>45</sup> The ADA should not be read to override this delicate balance of federal law with regard to refusals of medical treatment. What is thus half-right about the Eleventh Circuit's reason in *Schiavo* is that the ADA provides no general reason beyond the possibility of disability discrimination for re-litigating state court decisions with respect to medical decisionmaking. (What is half-wrong is the blanket statement that the ADA never provides grounds for challenging a non-treatment decision.) The mere presence of the ADA, therefore, was not the basis of a claim to raise in *Schiavo* and hence of a federal cause of action for the district court to have examined under the congressional directive granting the federal courts jurisdiction over the case.

The district court reasoned that the hospice was not acting because of Terri Schiavo's disability (and thus not violating the ADA) since it was simply following a state court order.<sup>46</sup> This statement contains a problematic echo of an earlier U.S. Supreme Court decision holding that a hospital did not violate the Rehabilitation Act by following a parents' wish to refuse lifesaving surgery for their disabled infant.<sup>47</sup> Surely an entity otherwise covered by the ADA (the hospice was a public accommodation) cannot avoid the assertion that it is acting on the basis of disability merely by demonstrating that it is following the directions of another party with legal authority (in this case, Michael Schiavo as guardian) who is not covered by the ADA. The ADA must require public accommodations engaged in providing services for people with disabilities to do more than merely accept the reasons they are given by others.

But *Schiavo* was not a case in which the hospice was evading responsibility by following Michael Schiavo's instructions. Rather, the hospice was acting in accord with a court order in a case that had been fully litigated – and re-litigated – under state guardianship and surrogate decisionmaking law.<sup>48</sup> To conclude that in doing so the hospice was acting by reason of Terri Schiavo's disability, the federal district court would either have had to examine whether Florida guardianship law in

---

(1990) (assuming, for the sake of argument that there is a right of competent patients to refuse medical treatment including nutrition and hydration, the state may insist on a clear and convincing evidence standard when such decisions involve incompetent patients).

45. *Cruzan*, 497 U.S. at 284 (a state "may" apply a clear and convincing evidence standard).

46. *Schiavo ex rel. Schindler v. Schiavo*, 358 F. Supp. 2d 1161, 1165 (M.D. Fla. 2005).

47. *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610, 630 (1986).

48. *Schiavo ex rel. Schindler*, 358 F. Supp. 2d at 1165.

general conflicts with the ADA or re-litigate the issues of guardianship law already settled in state court. To do the former would be to read the ADA as changing the present balance of state and federal law with respect to medical decisionmaking. To do the latter would be to re-litigate state law issues, which is not what the congressional directive authorized. Thus, the district court was correct in concluding that the hospice had not violated the ADA because the ADA does not upset fully litigated state court decisions with respect to the appointment of guardians and the making of medical treatment decisions by surrogates. It is worth noting, however, that the district court would have been wrong had it suggested that the hospice could evade ADA responsibility merely because it was following directives reached elsewhere.

Bagenstos seems to contend that the ADA does provide a cause of action to re-examine state law proceedings with respect to guardianship and medical decisionmaking.<sup>49</sup> If there are allegations to the effect that the state law decisions involved discrimination against people with disabilities, Bagenstos is surely right – there would be an issue of disability discrimination to litigate separately from the guardianship decision. The question is whether such an issue was raised in the *Schiavo* case. Bagenstos characterizes the Florida court as having authorized the termination of life-sustaining treatment on the basis of Terri Schiavo's disability: "[T]hat medical condition [Terri Schiavo's impairment] was the sole reason the state courts concluded that she would not choose to receive further feeding and hydration."<sup>50</sup> But this is not exactly correct; the state court decision was based on recommendations of the guardian and the guardian *ad litem* and what the court concluded was clear and convincing evidence of Terri Schiavo's wishes and interests regarding her medical condition.<sup>51</sup> For this to have been an ADA claim, there would need to have been some assertion that these determinations were biased by judgments about Terri Schiavo's disability, not merely that they were judgments that involved a person with a disability. Bagenstos appears to recognize the presence of these additional factors in the court's decision because he further contends that ADA scrutiny would involve examining whether subtle bias against people with disabilities figured into the state courts' handling of the case:

To say that a state judge can insulate from review a decision to withhold a patient's treatment simply by deciding that the patient would have wanted to withhold treatment begs the question. The decision about what the patient would have wanted may well be influenced by

---

49. Bagenstos, *supra* note 17, at 457.

50. *Id.* at 459.

51. *E.g.*, *In re Schiavo*, No. 90-2908GD-003, 2000 WL 34546715, at \*2 (Fla. 6th Cir. Ct. Feb. 11, 2000).

(perhaps unconscious) bias against disability. It is commonplace that non-disabled people entertain much more negative views about the quality and desirability of living life with a disability than do people with disabilities themselves. If a state judge, in the course of deciding what an incompetent patient “would have wanted,” relies on such biased assessments, it is reasonable to treat the judge’s decision as itself discriminatory. Such a decision calls for scrutiny under the disability discrimination laws, and a judge ought not be able to shield his or her decision from such scrutiny simply by deeming the decision to be an exercise of the incompetent patient’s choice.<sup>52</sup>

The problem in Bagenstos’ argument, however, is that the Schindlers advanced no additional reason for thinking that there had been disability discrimination other than reiterating the assertion that Terri Schiavo was not in PVS.<sup>53</sup> Thus, to read the *Schiavo* case as disability discrimination, one must read the ADA as authorizing the federal courts to scrutinize state court guardianship and medical treatment decisions – that is, to second guess the reasoning and safeguards in state law in this area. But as we have argued, the ADA does not do this.

Moreover, as we will argue in the remainder of this Article, the questions that continue to be raised about the resolution of the case under Florida law rest on assumptions that are deeply problematic from the point of view of the civil rights of people with disabilities. The problematic nature of these assumptions suggests that it would be mistaken to revisit the current federal/state balance in these matters or to revamp the ADA as a tool for so doing

### III. SCHIAVO AND SCIENCE

One persistent question that has been raised about the *Schiavo* case concerns Terri Schiavo’s medical condition. Whether the evidence supported the conclusions that she was in PVS and had no chance for recovery is an issue that was contested and re-contested by the Schindlers and continues to be a point of advocacy among right-to-life groups.<sup>54</sup> The evidence about Terri Schiavo’s medical condition and prognosis was repeatedly scrutinized by the Florida courts,<sup>55</sup> which never reached the conclusion that credible evidence supported the questions the Schindlers raised.<sup>56</sup>

The litigation of Terri Schiavo’s medical condition has a lengthy

---

52. Bagenstos, *supra* note 17, at 462-63.

53. See *supra* note 20 and accompanying text.

54. See, e.g., *Medical Affidavits*, TERRI SCHINDLER SCHIAVO FOUND., [http://www.terrisfight.org/mainlinks.php?tablesingle=main\\_terri\\_story&id=7](http://www.terrisfight.org/mainlinks.php?tablesingle=main_terri_story&id=7) (last visited Mar. 7, 2007).

55. See *infra* notes 57-69 and accompanying text. See generally cases cited *supra* note 2.

56. See *infra* notes 57-69 and accompanying text. See generally cases cited *supra* note 2.

history. In 2000, ruling on Michael Schiavo's petition as guardian to remove Terri Schiavo's feeding tube, the Florida trial court concluded "beyond all doubt" that Terri Schiavo was in PVS.<sup>57</sup> The Schindlers filed various motions for relief from the judgment, all of which the appellate court denied.<sup>58</sup> After these rulings, the Schindlers filed an amended petition for relief from the judgment, which introduced new affidavits, including one from a physician stating that Terri Schiavo was not in PVS, that she exhibited purposeful activity, and that new treatments could improve her level of functioning.<sup>59</sup> On this basis, the appellate court remanded the case to the trial court for a determination of whether this new evidence was sufficient to establish that the decision to terminate treatment was no longer equitable.<sup>60</sup> As guidance, the appellate court instructed the trial court to order a new set of medical examinations and to hear expert testimony from at least five physicians, one of whom was new to the case, selected by the parties or appointed by the court if they could not agree, and board certified in neurology or neurosurgery.<sup>61</sup> During the 2001 proceedings, Terri Schiavo's feeding tube was removed and reinserted,<sup>62</sup> the order for new medical examinations resulted in an indefinite stay of the order for removal of the feeding tube.<sup>63</sup>

Finally, in November 2002, the trial court concluded that the medical evidence continued to support the conclusions that Terri Schiavo was in PVS and had no prospects for recovery.<sup>64</sup> Instead of producing testimony from the physician who had given the affidavit on which the Schindlers' appeal relied, the Schindlers produced evidence from two other physicians (a radiologist and a neurologist), Michael Schiavo produced evidence from two physicians (both neurologists), and the court appointed an additional neurologist when the parties were unable to agree on a fifth expert.<sup>65</sup> The trial court placed the greatest weight on its appointed neurologist's conclusions and decided that there was no credible evidence that Terri Schiavo was not in PVS or that treatment was

---

57. Notice to Court Pursuant to Section 415.1055(9), F.S. and Petition/Motion for Intervention at 6, *In re Guardianship of Schiavo*, No. 90-2908GD-003 (Fla. 6th Cir. Ct. Feb. 23, 2005) [hereinafter Notice to Court Pursuant to Section 415.1055(9)], available at <http://www.dcf.state.fl.us/news/petition.pdf>.

58. *In re Guardianship of Schiavo*, 792 So.2d 551, 560 (Fla. 2d Dist. Ct. App. 2001); *In re Guardianship of Schiavo*, 780 So. 2d 176, 177 (Fla. 2d Dist. Ct. App. 2001).

59. *In re Guardianship of Schiavo*, 800 So. 2d 640, 644 (Fla. 2d Dist. Ct. App. 2001).

60. *Id.* at 645.

61. *In re Guardianship of Schiavo*, 851 So. 2d 182, 184 (Fla. 2d Dist. Ct. App. 2003).

62. Cerminara & Goodman, *supra* note 18.

63. *In re Guardianship of Schiavo*, 800 So. 2d at 640.

64. *In re Guardianship of Schiavo*, No. 90-2908-GB-003, 2002 WL 31817960 (Fla. 6th Cir. Ct. Nov. 22, 2002).

65. *Id.* at \*1-2, \*5.

available that held the prospect of improving her condition.<sup>66</sup> The court consequently denied the petition for relief from the judgment, and the Schindlers appealed.<sup>67</sup> In June 2003, the appellate court concluded that the trial court's determination was not an abuse of discretion.<sup>68</sup> Furthermore – and despite its procedural role as an appellate court that does not review evidence *de novo* – the court stated that it would have reached the same evidentiary conclusion as the trial court had made.<sup>69</sup>

In October 2003, the proceedings again reached a breaking point when Terri Schiavo's feeding tube was removed.<sup>70</sup> After intervention by the Florida legislature, then-Florida Governor Jeb Bush ordered replacement of the tube.<sup>71</sup> The court then appointed Jay Wolfson as a new guardian *ad litem* to re-examine the case.<sup>72</sup> Wolfson's December 2003 report to Governor Bush reaffirmed the courts' conclusions regarding Terri Schiavo's medical condition.<sup>73</sup> One of the most contentious medical questions involved the advisability of "swallowing tests" to ascertain whether Terri Schiavo had the capacity to take nutrition orally, an ability not generally possessed by patients in PVS.<sup>74</sup> Regarding the Schindlers' amenability to the performance of such tests, Wolfson's report indicated that the swallowing tests would be desirable if the parties could agree in advance about how the test results might be used.<sup>75</sup> In response to the report, Governor Bush reaffirmed his commitment to protecting Terri Schiavo's right to life and encouraged performance of the swallowing tests and continued therapy.<sup>76</sup> Agreement never ensued, and the swallowing tests were not conducted.<sup>77</sup> One of the experts in the case – Dr. Ronald Cranford, who testified on behalf of Michael Schiavo – has maintained that the swallowing tests were not medically indicated

66. *In re Guardianship of Schiavo*, 851 So. 2d at 185.

67. *Id.*

68. *Id.* at 186.

69. *Id.*

70. See Cerminara & Goodman, *supra* note 18 (Judge Greer ordered feeding tube to be removed October 15, 2003).

71. *Id.* (Bush issued executive order directing reinsertion of feeding tube and appointing a guardian *ad litem* for Terri Schiavo).

72. *Id.* (Dr. Jay Wolfson appointed as new guardian *ad litem* for Terri Schiavo).

73. JAY WOLFSON, A REPORT TO GOVERNOR JEB BUSH AND THE SIXTH JUDICIAL CIRCUIT IN THE MATTER OF THERESA MARIE SCHIAVO 34 (2003), available at <http://abstractappeal.com/schiavo/WolfsonReport.pdf>.

74. James L. Bernat & H. Richard Beresford, *The Controversy over Artificial Nutrition and Hydration*, 66 NEUROLOGY 1618 (2006).

75. WOLFSON, *supra* note 73, at 36-38.

76. Press Release, Florida Governor's Office, Statement by Governor Jeb Bush [Regarding] Guardian *ad Litem*'s Report (Dec. 2, 2003), available at [http://sun6.dms.state.fl.us/eog\\_new/eog/library/releases/2003/December/litem-report\\_12-2-03.html](http://sun6.dms.state.fl.us/eog_new/eog/library/releases/2003/December/litem-report_12-2-03.html).

77. Jay Wolfson, *The Rule in Terri's Case: An Essay on the Public Death of Theresa Marie Schiavo*, 35 STETSON L. REV. 39, 45-46 (2005).

because, although people in PVS can occasionally be trained to swallow, this training increases the risk of aspiration pneumonia and is thus not appropriate medical management for these patients.<sup>78</sup> Neurologists question whether tube feeding reduces the risk of aspiration pneumonia among patients with severe cognitive losses, although this issue remains controversial.<sup>79</sup>

During Terri Schiavo's final days, those opposed to the feeding tube's removal again challenged the determination that she was in PVS.<sup>80</sup> At Governor Bush's direction, the Florida Department of Children and Families petitioned to intervene in the proceedings.<sup>81</sup> The request to intervene was based on an affidavit by Dr. William Cheshire, a neurologist at the Mayo Clinic, who, despite the fact that he had never examined Terri Schiavo before rendering his affidavit, opined that she was not, in fact, in PVS.<sup>82</sup> In addition, the Schindlers filed a last-ditch petition maintaining that Terri Schiavo was responsive, communicated with her mother, and was capable of learning to speak.<sup>83</sup>

During the congressional debates, Senator Frist opined that Terri Schiavo was not in PVS and could improve.<sup>84</sup> He based his opinion on court affidavits and video clips<sup>85</sup> which once played widely on television across the country and are still available on the Internet.<sup>86</sup> Senator Frist's efforts at diagnosis without examination were met with widespread criticism.<sup>87</sup> Additional opponents of the removal of Terri Schiavo's feeding tube included advocates of right-to-life positions who maintained, before and after her death, that she was not in PVS.<sup>88</sup>

---

78. Ronald Cranford, *Facts, Lies and Videotapes: The Permanent Vegetative State and the Sad Case of Terri Schiavo*, 33 J.L. MED. & ETHICS 363, 368 (2005).

79. See, e.g., Bernat & Beresford, *supra* note 74, at 1618-19; Ronni Chernoff, *Tube Feeding Patients with Dementia*, 21 NUTR. CLIN. PRACTICE 142 (2006); Ina Li, *Feeding Tubes in Patients with Severe Dementia*, 65 AM. FAMILY PHYSICIAN 1605 (2002), available at <http://www.aafp.org/afp/20020415/1605.html>.

80. Maya Bell & Ethan Horowitz, *Schiavo's Feeding Tube Pulled, but Fight Goes On: Brain-Damaged Woman's Fate Is Uncertain*, ORLANDO SENTINEL, Mar. 19, 2005, at 1A.

81. Notice to Court Pursuant to Section 415.1055(9), *supra* note 57, at 3.

82. *Id.*

83. Emergency Application for Stay of Enforcement of the Judgment Below Pending the Filing and Disposition of a Petition for a Writ of Certiorari to the Circuit Court of Appeal of the United States for the Eleventh Circuit at 25, *Schiavo ex rel. Schindler v. Schiavo*, 544 U.S. 957 (2005) (No. 04A844).

84. Sheryl Gay Stolberg, *Drawing Some Criticism, Legislators with Medical Degrees Offer Opinions on Schiavo Case*, N.Y. TIMES, Mar. 23, 2005, at A14.

85. Lawrence M. Krauss, *When Sentiment and Fear Trump Reason and Reality*, N.Y. TIMES, Mar. 29, 2005, at F4; Stolberg, *supra* note 84.

86. See *Terri Schiavo Has Died*, CNN.COM, Mar. 31, 2005, <http://www.cnn.com/2005/LAW/03/31/schiavo/index.html>.

87. E.g., George Annas, *"I Want to Live": Medicine Betrayed by Ideology in the Political Debate over Terri Schiavo*, 35 STETSON L. REV. 49, 58 (2005).

88. Here is a typical example:

Following Terri Schiavo's death, the autopsy report confirmed the diagnosis of PVS with significant global brain tissue atrophy consistent with the clinical diagnosis of PVS.<sup>89</sup> The report revealed "marked global anoxic-ischemic encephalopathy resulting in massive cerebral atrophy"<sup>90</sup> and brain weight of 615 grams (less than half the expected weight).<sup>91</sup> By comparison, the weight of Karen Anne Quinlan's brain was 835 grams.<sup>92</sup> Neuropathological and anatomic findings, together with medical records, indicated that Terri Schiavo would not have been able to consume sufficient sustenance by mouth.<sup>93</sup> Further, hypoxic damage in the occipital lobes indicated cortical blindness;<sup>94</sup> Terri Schiavo's inability to process visual images thus put to rest any claims by the Schindler family that she tracked their movements and expressions visually. Finally, the autopsy report also put another claim to rest: because of the implanted thalamic stimulator, MRI exams (requested by the Schindlers to reevaluate Terri Schiavo's diagnosis) would have been medically contraindicated.<sup>95</sup>

Despite the autopsy report, the Schindlers continued to portray Terri Schiavo as though she were not in PVS. For example, in early 2006, their Web site read,

[o]ur family stands by its strong belief that Terri was not in PVS, and we appreciate the many noted neurologists, including Dr. Cheshire who saw Terri just weeks before she died, who agree with our position. We also thank the brave men and women in public office in Florida and Washington, D.C. who nobly stood on the side of life

---

What you find when you examine the medical data and listen to the experiences of those who have spent the most time with Terri over the last decade is that a great deal of evidence belies the contention that Terri is in a PVS. Terri's parents, brother, sister, and numerous other family members and friends who visit her regularly do not believe for a moment that Terri is unaware of her environment or unresponsive. At a press conference organized by the Schindlers on October 24, Terri's mother, father, and eight others all gave accounts of how they see Terri consistently respond to people: She smiles, frowns, or acts sullenly depending on who the person is and what he or she does or says. She reacts quite markedly to music, particularly piano music, which she always especially enjoyed. A certified speech therapist asserted that Terri *does* attempt to verbalize and has been heard saying "yes," "no," "Mommy," and possibly even "Help me."

Robert Johansen, *Killing Terri Schiavo*, CRISIS MAG., Jan. 8, 2004, <http://www.crisismagazine.com/january2004/johansen.htm>.

89. JON R. THOGMARTIN, DIST. SIX MED. EXAM'R OFFICE, REPORT OF AUTOPSY FOR THERESA SCHIAVO (2005), available at [http://www6.miami.edu/ethics/schiavo/pdf\\_files/061505-autopsy.pdf](http://www6.miami.edu/ethics/schiavo/pdf_files/061505-autopsy.pdf).

90. *Id.* at 16

91. *Id.*

92. *Id.*

93. *Id.* at 34.

94. *Id.* at 35.

95. *Id.* at 20.



regardless of one's disability. While their valiant efforts were not able to ultimately save Terri, our family is forever grateful to them for their compassion and for their conviction to do the right thing.<sup>96</sup>

Responding specifically to the autopsy report, they wrote: "We all knew Terri was seriously brain-injured before the IME report. This is nothing new. The IME's report also confirms that TERRI WAS NOT TERMINAL. THAT TERRI HAD NO LIVING WILL, THAT TERRI HAD A STRONG HEART, and THAT TERRI WAS BRUTALLY DEHYDRATED TO DEATH."<sup>97</sup> Much of what the Schindlers have said regarding the autopsy report, such as the observation that Terri Schiavo had a strong heart, is simply irrelevant to the diagnosis of PVS. Most importantly, responses to the autopsy report, such as the one quoted above, indicated either obfuscation of the scientific point or disbelief of science itself.<sup>98</sup>

Disbelief of science is neither new nor unusual in American public life.<sup>99</sup> But it is not good for people with disabilities. Misdiagnoses and recommendations for treatment based on bad science, medical quackery, or outright fraud are not helpful to people with disabilities. In the *Schiavo* case, for example, the request for MRI scans to reconsider the diagnosis of PVS was contraindicated by the implanted thalamic stimulator.<sup>100</sup> Strategies to encourage oral feeding risked aspiration pneumonia.<sup>101</sup> The Schindlers' based their efforts to re-litigate the state court decisions on these problematic scientific assumptions. Senator Frist likewise encouraged congressional intervention based on his opinion that Terri Schiavo was not in PVS.<sup>102</sup> It would not serve the interests of people with disabilities if the ADA were interpreted – or amended – to require courts to treat such pseudo-science on a par with qualified expert testimony and appropriate medical examination.

This is not to say that science has always served people with disabilities well. There is a long and regrettable history of scientific discrimination against people with disabilities,<sup>103</sup> which gives the disabled

---

96. Press Release, Schindler Family, Schindler Family Statement on Medical Examiner's Report (June 16, 2005), available at [http://journalsalnotquaida54.blogspot.com/2005\\_06\\_01\\_journalsalnotquaida54\\_archive.html](http://journalsalnotquaida54.blogspot.com/2005_06_01_journalsalnotquaida54_archive.html).

97. *Id.*

98. Cranford, *supra* note 78, at 370 (Schindlers were "terribly mistaken and ill informed" about Terri Schiavo's true medical condition).

99. See, e.g., CHRIS MOONEY, THE REPUBLICAN WAR ON SCIENCE 14-24 (2005).

100. See Cranford, *supra* note 78, at 364-66.

101. WOLFSON, *supra* note 73, at 27-28; Cranford, *supra* note 78, at 368; see also Thomas E. Finucane & Colleen Christmas, *Aspiration Pneumonia Letter 002*, 344 NEW ENG. J. MED. 1868 (2001).

102. Stolberg, *supra* note 84.

103. See generally DANIEL J. KEVLES, IN THE NAME OF EUGENICS (1995).

good reason to be suspicious of science and of policy in the name of science. Put bluntly, “eugenics” for a time cloaked itself as a science to press for the legitimization of the elimination of people with disabilities.<sup>104</sup> The Nazi program of killing people with disabilities was the worst of these practices.<sup>105</sup> Eugenics even has an extensive role in American law: *Buck v. Bell*, a case in which a disposition to reproduce out of wedlock was deemed as stemming from an inheritable disability and in which Justice Holmes made the infamous comment that “three generations of imbeciles are enough,”<sup>106</sup> has not been overruled to this day despite the state of Virginia’s own resolution of regret.<sup>107</sup> Eugenics has also played an important role in American science; Cold Spring Harbor, historically and to this day a major center for genetics research and education,<sup>108</sup> was the location of the Eugenics Records Office.<sup>109</sup> At present, efforts to allow parents to use prenatal genetic diagnosis and selective abortion for disability are also highly controversial.<sup>110</sup> The idea that diagnosis of a fetus with Down Syndrome is a “medical indication” for abortion, for example, confuses empirical judgments about the chromosomal makeup of the fetus with other likely empirical judgments about the fetus (such as the likelihood of anomalies like heart defects associated with Down Syndrome) and the parents’ judgments made on non-medical grounds about whether they want to carry the fetus to term.<sup>111</sup>

Science also has been associated with the “medicalization” of disability – the idea that disability is always and only about “mis”-fitting

104. *See id.* at 97-128.

105. For overviews of Nazi eugenics, see generally CTR. FOR BIOMED. ETHICS, UNIV. MINN., *WHEN MEDICINE WENT MAD: BIOETHICS AND THE HOLOCAUST* (Arthur L. Caplan ed., 1992), and ROBERT JAY LIFTON, *THE NAZI DOCTORS: MEDICAL KILLING AND THE PSYCHOLOGY OF GENOCIDE* (1986).

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

107. *See* Paul A. Lombardo, *Taking Eugenics Seriously: Three Generations of ??? are Enough?*, 30 FLA. ST. U. L. REV. 191, 196 (2003).

108. Cold Spring Harbor Laboratory, <http://www.cshl.edu> (last visited Jan. 17, 2007).

109. Janet L. Dolgin, *Personhood, Discrimination, and the New Genetics*, 66 BROOK. L. REV. 755, 766 n.67 (2001); Edward J. Larson, *The Meaning of Human Gene Testing for Disability Rights*, 70 U. CIN. L. REV. 913, 915 (2002).

110. *See generally* Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315 (2003); Peter Chipman, *The Moral Implications of Prenatal Genetic Testing*, 2 PENN. BIOETHICS J. 13 (2006), available at [http://www.bioethicsjournal.com/pdf/pbj2.2\\_chipman.pdf](http://www.bioethicsjournal.com/pdf/pbj2.2_chipman.pdf); A.E. Raz, *Disability Rights, Prenatal Diagnosis and Eugenics: A Cross-Cultural View*, 14 J. GENETIC COUNSELING 183 (2005); Christy Roberts, *The Role of Genetic Counseling in the Elective Termination of Pregnancies Involving Fetuses with Disabilities*, 36 J. SPEC. EDUC. 48 (2002).

111. *See* Cara Dunne & Catherine Warren, *Lethal Autonomy: The Malfunction of the Informed Consent Mechanism Within the Context of Prenatal Diagnosis of Genetic Variants*, 14 ISSUES L. & MED. 165, 168 (1998); Larson, *supra* note 109, at 922-24; Lombardo, *supra* note 107, at 217-18.

bodies and not about misfits between bodies and world design.<sup>112</sup> The locomotive difficulties faced by someone with a mobility impairment are at least as much a function of how we have designed our streets, public transportation, and building thresholds – some features of which date back centuries – as they are of how bodies are shaped.<sup>113</sup> To place the onus of change on “correcting” bodies is at least in part to put it in the wrong place. The confusion of scientific judgments with notions of appropriate world design has fed these misconceptions.<sup>114</sup>

These problems with science and the use of science are very real and cannot be ignored. But, these problems are far from showing that there is no difference between science and pseudo-science of the types at issue in *Schiavo*: disbelief of medical imaging, selective videotape editing, and untested therapies such as hyperbaric oxygen chambers.<sup>115</sup> Nor do these problems show that it would be a good thing for people with disabilities to make judgments on the basis of inaccurate information or information limited by refusals to learn what is knowable about a person’s physical condition. We must, of course, guard against confusing science with policy and against using science for improper objectives. Further, we must be especially vigilant in the area of disability policy, given the lamentable history of science in this arena. Yet, it does not follow from this that we should ignore science; rather, we should instead use it wisely.

The Florida courts scrutinized and re-scrutinized the evidence about Terri Schiavo’s medical condition.<sup>116</sup> The Schindlers’ claims that Terri Schiavo was not in PVS or that treatments were available to improve her condition were based on inaccurate science.<sup>117</sup> Thus, science provides no argument that the Florida courts missed anything in *Schiavo*. Indeed, the reverse is true: the Florida courts permitted the Schindlers to propound numerous affidavits from physicians who made claims that simply could not be supported scientifically.<sup>118</sup> *Schiavo* is not, therefore, an illustration of state courts failing to scrutinize science carefully. Suggesting that the case does reflect such a failure itself rests on bad science. *Schiavo* is also not a case that would suggest reassessing whether

---

112. See A. SILVERS, D. WASSERMAN & M. MAHOWALD, *DISABILITY, DIFFERENCE, DISCRIMINATION* (1998).

113. See *id.*

114. See, e.g., Ron Amundson, *Biological Normality and the ADA*, in *AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS* 102-111 (Anita Silvers & Leslie Francis eds., 2000); SILVERS, WASSERMAN & MAHOWALD, *supra* note 112, at 1, 129-131.

115. See generally Cranford, *supra* note 78.

116. See *supra* notes 57-69 and accompanying text.

117. *Id.*

118. *Id.*

federal anti-discrimination law should be available as a corrective to state law in this arena.

#### IV. THE *SCHIAVO* CASE IN THE LAW: GUARDIANSHIP, SURROGACY, AND MEDICAL TREATMENT DECISIONS

Another set of deeply contested issues in the *Schiavo* case concerned guardianship and medical treatment decisions. Some of these issues were particular to the case – such as whether Michael Schiavo’s continued appointment as guardian was appropriate – but others reached more generally to Florida guardianship and surrogacy law. The Schindlers maintained that Michael Schiavo had conflicts of interest, was not acting in Terri Schiavo’s best interest, and should have been removed as guardian.<sup>119</sup> With respect to Florida law more generally, arguments have been advanced that it allows too much leeway for surrogates to authorize termination of treatment decisions in making decisions for incompetent people.<sup>120</sup>

Florida law authorizes courts to appoint guardians for people who lack capacity and allows guardianship designations to be either limited or plenary.<sup>121</sup> Florida law is protective of the civil rights of people with cognitive impairments and thus favors limited guardianship appointments whenever possible.<sup>122</sup> Competent people may name “preneed” guardians to serve in case of incapacity,<sup>123</sup> but courts are not required to follow the statutory presumption that favors such designations if there are clear conflicts of interest<sup>124</sup> or questions of the preneed guardian’s qualifications.<sup>125</sup> Florida also has a Statewide Public Guardianship Office that can accept appointments if no family members, friends, banks, corporations, or others are available to serve.<sup>126</sup> Appointment of a guardian for an incapacitated adult is not required; moreover, if the adult has made effective other arrangements such as the creation of a durable power of attorney, such power may survive the incompetency of the principal.<sup>127</sup> Florida law also provides for the appointment of a

---

119. See, e.g., *In re Guardianship of Schiavo*, 780 So. 2d 176, 179-80 (Fla. 2d Dist. Ct. App. 2001).

120. Posting of Elizabeth Price Foley to Blogs for Terri, [http://www.blogsforterri.com/archives/2005/03/saving\\_terri\\_sc.php](http://www.blogsforterri.com/archives/2005/03/saving_terri_sc.php) (Mar. 4, 2005, 9:23 EST).

121. §§ 744.102(9)(a)-(b), FLA. STAT. (2006).

122. § 744.1012, FLA. STAT. (2006).

123. § 744.3045(1), FLA. STAT. (2006).

124. *Davis v. King*, 686 So. 2d 763, 764-65 (Fla. 5th Dist. Ct. App. 1997).

125. *Butler v. Peacock*, 898 So. 2d 1139, 1141 (Fla. 5th Dist. Ct. App. 2005).

126. § 744.702, FLA. STAT. (2006).

127. *Smith v. Lynch*, 821 So. 2d 1197, 1199 (Fla. 4th Dist. Ct. App. 2002). On January 1, 2007, § 744.331 was amended to provide that an attorney seeking to be appointed by a court for

guardian *ad litem* to represent the interests of the ward in particular legal proceedings.<sup>128</sup> Furthermore, in 2006, the Florida legislature added a provision to guardianship law permitting courts to appoint emergency monitors in cases of apparent immediate danger to the physical or mental health, or property, of a ward.<sup>129</sup>

Under Florida's guardianship law, the court appointed guardian is directed to give preference to people "related by blood or marriage" to the ward<sup>130</sup> and to consider the ward's preferences, if they have been expressed.<sup>131</sup> A person is disqualified from serving as a guardian by continuing business relationships, employment with an entity providing services to the ward, or "any other circumstance in which a conflict of interest may occur."<sup>132</sup> If a conflict of interest occurs between the guardian and the ward, a guardian *ad litem* must be appointed to represent the ward's interests and to petition the court for the guardian's removal.<sup>133</sup> Among other rights, incapacitated persons have the right to be free of neglect and abuse and to receive necessary services and rehabilitation.<sup>134</sup> Relatedly, guardians have the duty to act in the best interest of their wards, particularly as evidenced by the fact that interested parties may petition the court if it appears that the guardian is not acting in the ward's best interest.<sup>135</sup> Guardians may be removed for failure to perform their duties, abuse of their powers, or conflicts of interest.<sup>136</sup>

Florida's current advance directive law was adopted in 1992 and amended most significantly in 1999.<sup>137</sup> The law permits both the desig-

incapacity and guardianship proceedings must have completed a minimum of eight hours of education in guardianship. § 744.331(2)(d), FLA. STAT. (2007).

128. § 744.102(9), FLA. STAT. (2006).

129. § 744.1075(1)(a), FLA. STAT. (2006).

130. § 744.312(2)(a), FLA. STAT. (2006).

131. § 744.312(3)(a).

132. § 744.309(3), FLA. STAT. (2006). Interestingly enough, the statute permits the conflict of interest to be overridden when the proposed guardian is a family member employed by an entity providing services to the ward, the conflict is minimal, and the appointment is clearly in the best interest of the ward. The statute does not provide for other conflicts of interest to be overridden in such circumstances. § 744.309(1).

133. § 744.391, FLA. STAT. (2006).

134. § 744.3215(1), FLA. STAT. (2006). A 2006 amendment added "necessary to maximize the quality of the person's life." H.B. 457, 108th Leg., Reg. Sess. (Fla. 2006), available at [http://www.myfloridahouse.gov/Sections/Documents/loaddoc.aspx?FileName=\\_H0457er.doc&DocumentType=Bill&BillNumber=0457&Session=2006](http://www.myfloridahouse.gov/Sections/Documents/loaddoc.aspx?FileName=_H0457er.doc&DocumentType=Bill&BillNumber=0457&Session=2006).

135. § 744.3715(1), FLA. STAT. (2006).

136. §§ 744.474(2), (3), (11), FLA. STAT. (2006).

137. For a review of the Florida decisions and legislative debates leading to the passage of Florida's advance directive law in 1992, see Meta Calder, *Chapter 765 Revisited: Florida's New Advance Directive Law*, 20 FLA. ST. U. L. REV. 291 (1992). For a discussion of the 1999 amendments, see Alison Cossetti, *End of Life Care in Florida: Should the Law Follow the Lobbyists or the People's Wishes?*, 14 ST. THOMAS L. REV. 13, 19-28 (2001).

nation of healthcare surrogates<sup>138</sup> and the creation of living wills.<sup>139</sup> Living wills are applicable if the patient is terminally ill, in an end stage condition, or in PVS.<sup>140</sup> “End stage condition,” added in 1999, is defined as “an irreversible condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and which, to a reasonable degree of medical probability, treatment of the condition would be ineffective.”<sup>141</sup> In the absence of a living will, designated surrogates may make decisions to withhold or withdraw life-sustaining treatment if the patient meets one of these conditions.<sup>142</sup> If the patient has not designated a surrogate, the statute authorizes healthcare decisions to be made by proxies in the following order: guardian, spouse, adult child (or majority of same reasonably available for consultation), parent, adult sibling (or majority of same reasonably available for consultation), followed by other caring relatives, close friends, or a clinical social worker selected by the facility in which the patient is living.<sup>143</sup> The terminology here is useful: “surrogates” are decisionmakers chosen by the person, and “proxies” are decisionmakers chosen by the operation of law.<sup>144</sup>

Florida’s default proxy list is noteworthy in several respects in relation to the identity of the disputing parties in *Schiavo*. First, it adopts the common view that spouses come before parents and parents before siblings.<sup>145</sup> Second, it limits the involvement of “other” relatives to those who have exhibited special care and concern for the patient.<sup>146</sup> Third, it extends beyond the family to close friends.<sup>147</sup> Finally, it authorizes the selection of proxies for those who have no one – the “unbefriended.”<sup>148</sup> Concerns that may guide these statutory provisions include ensuring that everyone is covered (perhaps a special problem in a state with a large elderly population that has either outlived family and

---

138. § 765.202, FLA. STAT. (2006). A written designation of a surrogate creates a rebuttable presumption of clear and convincing evidence of the principal’s selection of the surrogate. § 765.202(7).

139. § 765.302(1), FLA. STAT. (2006). Living wills create rebuttable presumptions of clear and convincing evidence of the principal’s wishes. § 765.302(3). Disputes are subject to expedited review under § 765.105, FLA. STAT. (2006)

140. § 765.302(1).

141. § 765.101(4), FLA. STAT. (2006).

142. § 765.305(1), FLA. STAT. (2006).

143. § 765.401(1), FLA. STAT. (2006).

144. §765.101(15)-(16).

145. UNIV. HEALTH-CARE DECISIONS ACT §5(b), 9(1B) U.L.A. 111 (1993).

146. For a discussion of the role of families as default proxies, see Leslie P. Francis, *The Role of the Family in Health Care Decisionmaking*, 1992 UTAH L. REV. 861.

147. § 765.401(1)(g).

148. For a discussion of the term “unbefriended,” see PAMELA B. TEASTER ET AL., *WARDS OF THE STATE: A NATIONAL STUDY OF PUBLIC GUARDIANSHIP* (2005), available at <http://www.abanet.org/aging/publications/docs/wardofstatefinal.pdf>.

friends or is geographically distant from family and friends) and selecting those who may be especially caring and knowledgeable about the patient

Default proxies have the same duties as the person's designated surrogate with one important qualification: any decision a proxy makes to terminate life-sustaining treatment must be supported by clear and convincing evidence either that the decision is what the ward would have made or is in the person's best interest.<sup>149</sup> Florida's advance directive law is an addition to patients' rights at common law and specifically does not alter these rights.<sup>150</sup> In a case antedating the adoption of Florida's current statute in 1992, the Florida Supreme Court held that competent patients have the constitutional right to refuse medical treatment, that this right extends to patients after they lose competence and may be exercised by proxies on their behalf, and that the clear and convincing evidence standard applies to such proxy decisions.<sup>151</sup>

Two other aspects of Florida's guardianship and advance directive law are especially relevant to the *Schiavo* litigation. One is the provision that permits any interested person – including family members, healthcare providers, or anyone directly affected by a termination of treatment decision – to seek expedited judicial intervention.<sup>152</sup> This intervention must be based on the belief that the decision is not in accord with the patient's known wishes, the advance directive is ambiguous or the patient's views have changed, the surrogate or proxy was improperly designated, or the surrogate or proxy is not discharging his duties or has abused his powers.<sup>153</sup> The second is the requirement that a court, when appointing a new guardian, must ascertain whether the ward has a valid advance directive for healthcare when appointing a guardian.<sup>154</sup> The court must specify what authority the guardian has over the healthcare surrogate<sup>155</sup> and may limit the authority of the surrogate on the grounds provided in the surrogacy statute.<sup>156</sup>

Part of what made the *Schiavo* litigation difficult from the beginning was the fact that Terri Schiavo had not executed any of the instruments available under Florida law to designate a preferred decisionmaker or to direct her management – medical or otherwise – in

---

149. § 765.401(3).

150. § 765.106, FLA. STAT. (2006).

151. *In re* Guardianship of Browning, 568 So. 2d 4, 11-17 (Fla. 1990).

152. § 744.3715(1), FLA. STAT. (2006).

153. § 765.105, FLA. STAT. (2006).

154. *Id.*

155. § 744.3115, FLA. STAT. (2006).

156. § 765.105.

case of incapacity.<sup>157</sup> This was not surprising because Terri Schiavo was a young adult who was happily married and surrounded by a loving family. *Schiavo* thus involved issues about guardianship and proxy decisionmaking, but did not include the involvement of a designated surrogate.

Shortly after Terri Schiavo's cardiac arrest in 1990, Michael Schiavo was appointed her guardian without contest.<sup>158</sup> Under Florida's proxy consent statute, he thus had priority over her parents, as both her guardian and her spouse.<sup>159</sup> In 1993, the Schindlers made their first effort to have him removed as guardian; John Pecarik was appointed guardian *ad litem* to represent Terri Schiavo's interest in the proceedings.<sup>160</sup> After Pecarik reported that Michael Schiavo had acted appropriately and attentively, the court denied the Schindlers' petition.<sup>161</sup> In 1998, after Michael Schiavo petitioned for removal of the feeding tube, the court again appointed a guardian *ad litem*, Richard Pearse.<sup>162</sup> Pearse's report concluded that Terri Schiavo was in PVS and had no prospect of recovery, that both Michael Schiavo and the Schindlers had potential conflicts of interest, and that a guardian *ad litem* should continue to represent Terri Schiavo's interests in any subsequent legal proceeding.<sup>163</sup> Pearse further reported that Michael Schiavo's claims about his wife's wishes about life-sustaining treatment would have to meet Florida's clear and convincing evidence standard in order for the feeding tube's removal to be legally authorized.<sup>164</sup> In the eventual trial in 2000, the court agreed with the guardian *ad litem* that both Michael Schiavo and the Schindlers had conflicts of interest;<sup>165</sup> however, the court concluded that the decision to remove the feeding tube was supported by clear and convincing evidence based on testimony from several other credible witnesses.<sup>166</sup>

After this ruling, the Schindlers sought to produce new evidence to demonstrate that Michael Schiavo's testimony about Terri Schiavo's

157. See, e.g., *In re Guardianship of Schiavo*, 780 So. 2d 176 (Fla. 2d Dist. Ct. App. 2001).

158. Cerminara & Goodman, *supra* note 18.

159. § 765.401(1), FLA. STAT. (2006).

160. Cerminara & Goodman, *supra* note 18.

161. *Id.*

162. *Id.* (Michael Schiavo petitioned the court to authorize the feeding tube's removal, the Schindlers opposed on grounds that Terri Schiavo would want to remain alive, and the court appointed Richard Pearse, Esq., as second guardian *ad litem*).

163. Report of Guardian *ad Litem* Richard L. Pearse, Jr., at 2, 13, *In re Guardianship of Schiavo*, No. 90-2908GD-003 (Fla. 6th Cir. Ct. Dec. 29, 1998), available at [http://www6.miami.edu/ethics/schiavo/pdf\\_files/122998\\_Schiavo\\_Richard\\_Pearse\\_GAL\\_report.pdf](http://www6.miami.edu/ethics/schiavo/pdf_files/122998_Schiavo_Richard_Pearse_GAL_report.pdf).

164. *Id.* at 11.

165. *In re Guardianship of Schiavo*, No. 90-2908GD-003, 2000 WL 34546715, at \*2 (Fla. 6th Cir. Ct. Feb. 11, 2000).

166. *Id.*



wishes was perjured.<sup>167</sup> The Florida appellate court ruled that this testimony should be heard within the original guardianship proceedings and directed the trial court to reopen the proceedings and consider this evidence.<sup>168</sup> The appellate court further cautioned the Schindlers that they must offer new evidence that made continued enforcement of the trial court's initial order inequitable.<sup>169</sup> The appellate court also made clear that it regarded the conclusion that clear and convincing evidence supported removal of the feeding tube as entirely within the discretion of the trial court.<sup>170</sup> The trial judge subsequently concluded that the Schindlers had not produced new evidence that supported Michael Schiavo's removal as guardian, and the appellate court affirmed this ruling.<sup>171</sup> The appellate court's affirmance did not end the proceedings, however, because the appellate court remanded the case to the trial judge for consideration of affidavits with respect to Terri Schiavo's medical condition.<sup>172</sup> The Schindlers also continued to seek to have the court remove Michael Schiavo as guardian on multiple grounds.<sup>173</sup>

After the Schindlers' various petitions were denied, and the feeding tube was removed in fall 2003, the Florida legislature intervened and directed appointment of a new guardian *ad litem* in the case.<sup>174</sup> The court appointed Jay Wolfson, a professor at the College of Public Health at the University of South Florida.<sup>175</sup> Wolfson's report, issued in December 2003, recommended appointment of an ongoing guardian *ad litem* in light of the controversial nature of the case.<sup>176</sup> The report concluded that the court determinations about Terri Schiavo's condition, prognosis, and wishes were "firmly grounded" in Florida law and satisfied the clear and convincing evidence standard.<sup>177</sup>

In comparison to the evidence concerning Terri Schiavo's medical condition and prognosis, Michael Schiavo's continued service as guardian was not an easy question. The reasons advanced by the Schindlers for his removal – his new relationship and his possible financial bene-

---

167. *In re Guardianship of Schiavo*, 792 So. 2d 551, 555-56 (Fla. 2d Dist. Ct. App. 2001).

168. *Id.*

169. *Id.* at 561.

170. *Id.*

171. *In re Guardianship of Schiavo*, 800 So. 2d 640, 643 (Fla. 2d Dist. Ct. App. 2001).

172. *Id.* at 645.

173. Petition to Remove Guardian and to Appoint Successor Guardian, *In re Guardianship of Schiavo*, No. 90-2908GD-003 (Fla. 6th Cir. Ct. Nov. 15, 2002), available at [http://www6.miami.edu/ethics/schiavo/Nov\\_22\\_2002\\_Petition\\_to\\_remove\\_MS\\_as\\_guardian.html](http://www6.miami.edu/ethics/schiavo/Nov_22_2002_Petition_to_remove_MS_as_guardian.html).

174. H.B. 35-E, 105th Leg., Sess. E § 3 (Fla. 2003), available at [http://www.myfloridahouse.gov/Sections/Documents/loaddoc.aspx?FileName=\\_H0035Ee1.doc&DocumentType=Bill&BillNumber=0035E&Session=2003E](http://www.myfloridahouse.gov/Sections/Documents/loaddoc.aspx?FileName=_H0035Ee1.doc&DocumentType=Bill&BillNumber=0035E&Session=2003E).

175. See Cerminara & Goodman, *supra* note 18.

176. WOLFSON, *supra* note 73, at 3.

177. *Id.* at 34.

fit<sup>178</sup> – are factors of the type that give pause about a guardian’s service. The Schindlers, however, had similar conflicts: If Michael Schiavo stood to gain financially under some resolutions, so did they.<sup>179</sup> And if Michael Schiavo had new family commitments, the Schindlers had ideological commitments that were equally firm. The Florida courts scrutinized and re-scrutinized these issues under Florida guardianship law, with the appointment of three different guardians *ad litem* to provide independent representation of the interests of the ward. None concluded that Michael Schiavo had a conflict of interest that warranted his removal as guardian.<sup>180</sup> One did find that Michael Schiavo’s testimony by itself was not clear and convincing evidence of Terri Schiavo’s wishes, but even that report recommended removing the feeding tube if the court found that the clear and convincing evidence standard was met.<sup>181</sup>

Nor was the determination of Terri Schiavo’s wishes an easy question. As is common in these cases, there were no direct, prospective statements regarding her treatment preferences in the case’s exact circumstances.<sup>182</sup> There were, instead, a variety of reported statements, to a variety of people, in a variety of contexts.<sup>183</sup> The effort to retroactively determine Terri Schiavo’s wishes for her resulting circumstances is, therefore, at best a reconstructive enterprise, relying not only on her statements, but also on evidence about what she enjoyed doing, what choices she made, and what values she held, to mention some of the more important factors in this reconstruction. This is the “substituted judgment” standard – at best a reconstruction by others and not the augmented voice of a person who can no longer speak directly for herself.<sup>184</sup>

Although the Schindlers claimed that these third party statements were hearsay – apparently on the general rubric that reports of statements are hearsay if offered to prove the claim made in the statement (although not hearsay if offered to prove that the statement was made) – Florida recognizes the exception to the hearsay rule that statements are not hearsay if offered as proof of the psychological state of their

---

178. See *supra* note 119 and accompanying text.

179. See Report of Guardian *ad Litem* Richard L. Pearse, Jr., *supra* note 163, at 8.

180. *In re* Guardianship of Schiavo, No. 90-2908GD-003, 2000 WL 34546715, at \*2 (Fla. 6th Cir. Ct. Feb. 11, 2000) (first guardian *ad litem* report); Report of Guardian *ad Litem* Richard L. Pearse, Jr., *supra* note 163 (second guardian *ad litem* report); WOLFSON, *supra* note 73 (third guardian *ad litem* report).

181. Report of Guardian *ad Litem* Richard L. Pearse, Jr., *supra* note 163, at 13.

182. *Id.* at 11.

183. *Id.* at 11-13; *In re* Guardianship of Schiavo, 2000 WL 34546715, at \*3-6.

184. See, e.g., Leslie P. Francis, *Decisionmaking at the End of Life: Patients with Alzheimer’s or Other Dementias*, 35 GA. L. REV. 539, 563 (2001).

maker.<sup>185</sup> Thus, these statements are part of the evidence that may be considered – along with evidence about what she did, her frequency of church attendance, or the amount of time she spent with her husband or her parents, for example – in a reconstruction of what Terri Schiavo would decide at the time of her treatment if she had the ability to speak for herself. For their part, the Schindlers produced evidence touching some of these points, including testimony on the amount of time Terri Schiavo spent with her mother and her mother’s testimony about her marriage.<sup>186</sup> The Schindlers failed to proffer other kinds of evidence – like church attendance, for example. Given all of their efforts to convince the court that Terri Schiavo would not have wanted life-sustaining treatment withdrawn and the relevance of active Catholic faith to the controversy, it seems reasonable to assume that they may not have had further evidence of this kind at the time.

When a proxy makes a decision to terminate life-sustaining medical treatment for an incapacitated person, Florida law requires clear and convincing evidence of either the wishes or the best interest of the patient.<sup>187</sup> Whether the evidence meets this clear and convincing evidence standard is frequently a troublesome question, much like the standard itself,<sup>188</sup> and *Schiavo* certainly was not an exception. Commentators have disagreed on whether the Florida courts applied their standard properly in ascertaining Terri Schiavo’s wishes about life-sustaining treatment.<sup>189</sup> Commentators have also argued that the court’s inquiry should have been broadened beyond evidence about her statements – her hopes with her husband to have a child, the quality of her marriage, and the amount of time she spent with her parents – to evidence about other matters such as her wishes concerning the identification of a proxy decisionmaker.<sup>190</sup> The fact remains, however, that the

---

185. See § 90.803(3)(a)(1), FLA. STAT. (2006); see also *In re Conroy*, 486 A.2d 1209, 1230 n.6 (N.J. 1985) (“[O]ral and written expressions of a person’s reactions or desires fit within the ‘existing state of mind’ exception to the hearsay rule.” (citations omitted)).

186. Report of Guardian *ad Litem* Richard L. Pearse, Jr., *supra* note 163, at 6.

187. See § 765.401(3), FLA. STAT. (2006).

188. See, e.g., John A. Robertson, *Schiavo and Its (In)Significance*, 35 STETSON L. REV. 101, 115 (2005).

189. See Maura A. Flood, *Treatment of the “Vegetative” Patient: The Legacies of Karen Quinlan, Nancy Cruzan, and Terri Schiavo*, 1 J. HEALTH & BIOMED. L. 1, 33-46 (2005) (arguing that the clear and convincing evidence standard was met in *Schiavo*); O. Carter Snead, *The (Surprising) Truth About Schiavo: A Defeat for the Cause of Autonomy*, 22 CONST. COMMENT. 383, 400-01 (2005) (arguing that the clear and convincing evidence standard was not met in *Schiavo*).

190. Robert A. Burt, *Family Conflict and Family Privacy: The Constitutional Violation in Terri Schiavo’s Death*, 22 CONST. COMMENT. 427, 447 (2005). For a discussion of legislative efforts to pursue this possibility in Ohio, see Lois Shepherd, *Terri Schiavo: Unsettling the Settled*, 37 LOY. U. CHI. L.J. 297, 318-19 (2006).

courts examined and reexamined evidence about her medical condition, about her statements and her life, and about what her various guardians *ad litem* had reported.<sup>191</sup>

The process in *Schiavo* involved Florida law and Florida courts making the most careful judgments they could about guardianship and medical treatment for an incapacitated person. The courts applied Florida guardianship law and Florida law about the substantive and evidentiary standards for the withdrawal of life-sustaining treatment.<sup>192</sup> To allow continual challenges to such processes, even after they were brought to careful conclusion, would be to introduce ongoing instability into the guardianship and medical decisionmaking processes. This instability would not be positive for people with disabilities, whose best interest requires resolute, yet carefully scrutinized, decisionmaking. Otherwise, there would be no stability about decisions to continue or to withhold treatment; findings to continue treatment on the basis of substituted judgment would be as subject to ongoing challenge as the actual findings in *Schiavo*.

To conclude that the guardianship issues in *Schiavo* should have been re-litigated under the ADA because Terri Schiavo was a person with a disability would open the door for others to use the ADA as an additional source of challenge to factual or legal issues that have already been litigated in state courts merely because the person involved has a disability. Indeed, any case of guardianship, surrogate decisionmaking, or proxy decisionmaking with respect to healthcare (or any other matter) would be subject to an ADA challenge. Thus, using the ADA to unsettle guardianship and medical decisionmaking processes is problematic for people with disabilities who need conclusive resolution to their cases. Congress did not intend the ADA to be a roving challenge to any decision under state law involving people with disabilities; rather, it was meant as a challenge to discriminatory treatment of people with disabilities.<sup>193</sup> We consider below whether there are reasons for altering this balance of federal and state statutory and constitutional law as a more general matter.

Since *Schiavo* began, Florida has continued to reconsider, refine, and amend its guardianship law.<sup>194</sup> This is as the process should be. In this process, one can expect that Florida will reach many different conclusions in this complex legal arena. Whatever conclusions it reaches,

191. See cases cited *supra* note 2.

192. See, e.g., Jay Wolfson, *The Rule in Terri's Case: An Essay on the Public Death of Theresa Marie Schiavo*, 35 STETSON L. REV. 39 (2005).

193. See *supra* notes 38-45 and accompanying text.

194. See, e.g., Committee Substitute for House Bill 457, H. 2006-178, Reg. Sess. (Fla. 2006) (amending Florida guardianship law), 2006 Fla. ALS 178 (LEXIS).

however, are of course subject to challenge as a matter of federal law. For example, Congress could attempt to use its powers under the Spending Clause or the Commerce Clause to federalize guardianship or medical decisionmaking.<sup>195</sup> Any such efforts, however, would surely be subject to constitutional challenge and would, we think, be unwise for the reasons we outline below.

Florida guardianship and medical treatment law could also be subject to challenge under the Due Process Clause of the Fourteenth Amendment. Several commentators have recognized that to challenge Florida law under the Due Process Clause would require changing the currently accepted framework in this area for balancing state judgments and federal constitutional limitations. For example, Professor Robert Burt has argued that absent a clear statement of the patient to the contrary, either as to treatment wishes or the choice of a surrogate, courts should protect the interests of even a single dissenting family member in ensuring that life-sustaining treatment is not withdrawn.<sup>196</sup> Burt terms this a constitutional right of “family” privacy, but does not specify the degree of relational closeness required for the right.<sup>197</sup> Professor Edward Larson has argued that *Schiavo* complied with current statutory and constitutional law and that Florida statutory law is like the law in most states; he thinks the current constitutional picture should be undone to be more protective of life.<sup>198</sup>

These judgments, however, would inject a set of vitalist values into constitutional law. In the next section, we argue that this imposition rests on a flawed understanding of the welfare of people with intellectual disabilities.

#### V. THE *SCHIAVO* CASE AND UNDERSTANDING THE GOOD OF PEOPLE WITH INTELLECTUAL DISABILITIES

A final explanation of the Schindlers’ position – and of the concerns raised by some advocates on behalf of people with disabilities – rests on the importance of protecting life. One version of this view revolves around vitalism with a voluntarist exception: we must protect life unless the person whose continued life-sustaining treatment is under scrutiny has directly and explicitly stated a set of wishes to the contrary. Another version of the view is vitalism with a best interest exception:

---

195. Congress can impose many regulations on the provision of healthcare through its exercise of the Spending Clause power for Medicare and Medicaid; it can also use its powers under the Commerce Clause to prohibit discrimination in healthcare or to regulate pharmaceuticals.

196. Burt, *supra* note 190, at 439.

197. *See id.* at 450-51.

198. *See* Edward J. Larson, *From Cruzan to Schiavo: Similar Bedfellows in Fact and at Law*, 22 CONST. COMMENT. 405 (2005).

we must protect life unless there is clear evidence that life-sustaining treatment would not be in the person's best interest. An even stronger version of this view – the straight vitalist approach – eschews the exceptions and mandates preservation of life unless life-sustaining treatment would be futile.

From a voluntarist vitalism perspective, the numerous, ongoing challenges to the discontinuation of Terri Schiavo's treatment were justified because the evidence in the case never rose to the standard set for the voluntarist exception. From the best interest vitalism perspective, continued treatment was justified unless there was clear and convincing evidence it was not in Terri Schiavo's best interest. From the straight vitalist view, the continued challenges were justified because continuation of the feeding tube was life-sustaining, regardless of any additional evidence about Terri Schiavo's prognosis, interests, or reconstructed wishes. In this section, we argue that each of these vitalist views rests on accounts of the good for people with intellectual disabilities that evidence a form of paternalism that is problematic. We start with the straight vitalist view.

From the straight vitalist perspective, life-sustaining treatment should be continued for people with intellectual disabilities unless the care would be futile. Life itself is a paramount value for the intellectually disabled despite any other considerations. In its strictest form, this view would dictate the continuation of treatment even if the treatment would be extraordinarily painful or intrusive.<sup>199</sup> This view imposes a value – the importance of life – on formerly competent adults despite any evidence about their prior preferences or current experiences. It is thus a moralistic form of paternalism because it holds that life is a preemptive value for someone despite evidence about interests or preferences. Such moralist paternalism is not beneficial for people with disabilities: it imposes a view of the good on them while ignoring who they actually are in the process.

In best interest vitalism, evidence about a person's best interest could override the value of preserving life. While it might appear that this view would permit the withdrawal of very painful life-sustaining treatment, that conclusion is dependent on the definition of "best inter-

---

199. The "Baby Doe" regulations come close to this view for newborns, requiring continuation of treatment unless the infant is "chronically and irreversibly comatose" or treatment would be "virtually futile" and under the circumstances "inhumane." See 45 C.F.R. § 1340.15 (2006); see also Larry Gostin, *A Moment in Human Development: Legal Protection, Ethical Standards and Social Policy on the Selective Non-Treatment of Handicapped Neonates*, 11 AM. J.L. & MED. 31, 36 n.16 (1985); Loretta M. Kopelman, *Are the 21-Year-Old Baby Doe Rules Misunderstood or Mistaken?*, 115 PEDIATRICS 797, 801 (2005) (criticizing the regulations and arguing that they require treatment against reasonable medical judgment based on the best interest of the infant).

est.” In bioethics, the “best interest” standard is complicated. For example, the New Jersey courts have characterized the standard as an “objective” one.<sup>200</sup> An “objective” standard could conceivably refer to a list of positive values that supposedly apply to everyone, regardless of a person’s particular experiences or circumstances.<sup>201</sup> In other words, courts can make judgments about what certain kinds of people need to survive, but these are simply objective judgments about biological needs. These survival necessities might include needs for nutrition, hydration, protection from the elements, and any instrumental interventions required to keep bodily systems functioning. But it is poorly reasoned not to adapt this list to the particular individual whose condition is under consideration: for example, although humans need protein, people who cannot take oral nutrition cannot eat meat and must receive protein in another form. This much seems clear, but what of the experiences of the particular person, such as pain? In developing its “best interest” standard, New Jersey thought that it should take into account the current experiences of the person, such as experiences of pleasure and pain.<sup>202</sup> At least one commentator has criticized other states for apparent disagreement with this view.<sup>203</sup>

People in PVS, like Terri Schiavo, have no conscious experiences.<sup>204</sup> Thus, no experiences are available that can nuance the objective list, either to support or to modify it. Any determination that continued life-sustaining treatment would or would not have been in Terri Schiavo’s interests, therefore, would have rested on a non-experiential account of her interests – that is, on an account of interests based on a “one size fits all” view. Some courts<sup>205</sup> and commentators<sup>206</sup> have concluded that people in PVS have no interests at all; these theorists hold that experiences, among other factors, are necessary conditions for interests.<sup>207</sup>

A non-experiential account of interests, like the straight vitalist view, is paternalistic. According to such a view, something is in someone’s interests even though it has no connection to his or her exper-

---

200. See *In re Conroy*, 486 A.2d 1209 (N.J. 1985).

201. This view is characterized as an “objective list” theory. See DEREK PARFIT, *REASONS AND PERSONS* 493 (1984).

202. See *In re Conroy*, 486 A.2d at 1233.

203. See Alicia R. Ouellette, *When Vitalism Is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 *IND. L.J.* 1, 10 (2004).

204. Cerminara, *supra* note 5, at 350.

205. See, e.g., *In re Peter*, 529 A.2d 419 (N.J. 1987).

206. See, e.g., JEFF McMAHAN, *THE ETHICS OF KILLING: PROBLEMS AT THE MARGINS OF LIFE* 443-50 (2002).

207. See, e.g., *id.*

iences. It is simply “good” for him or her, even if he or she has no experiential interests that support this judgment. It thus represents a judgment about someone’s good that is unsupported by the subjective life of the person to whom the good supposedly belongs. Using such a non-experiential account of interests in making treatment decisions is not, we contend, good for people with disabilities. It lets a series of judgments about what would be “good” for people to determine what people must have, regardless of their actual experiences, much less anything that might be known about their wishes. It ignores them, in short, in favor of outside judgments about what is good for them. And ignoring who they are is not good for people with disabilities.

At first glance, voluntarist vitalism would appear to avoid this difficulty because it permits a patient’s choices to override the presumption in favor of life-sustaining treatment.<sup>208</sup> But this appearance is illusory for two reasons. First, the vitalist presumption itself assumes that life is good for a person, regardless of anything about the person’s own documented views. The exception for the person’s own documented views then lends a second reason. If the exception is formulated to require that there be an actual statement of what the person wanted for his or her exact circumstances – as it would be if the point of the exception is to grant it only in cases of actual choice – the exception as a practical matter will never be met when patients no longer have the capacity to speak for themselves.<sup>209</sup> The default presumption will then prevail in all cases. The result will once again be the paternalistic imposition of the value of life despite other knowledge of the person who cannot speak for him or herself.

Formulating the voluntarist exception more broadly allows evidence about the person – his or her current experiences and circumstances, together with what is known about his or her prior activities, statements, wishes, and values – to override a presumption in favor of life. It thus tailors a decision to the person, even if the person cannot speak for him or herself.<sup>210</sup> This broader formulation of the voluntarist exception is not paternalistic, and it is the standard that was actually used in *Schiavo*, where the court scrutinized evidence that it found to be

---

208. See, e.g., Dorothy Grover, *Posthumous Harm*, 39 PHIL. QUARTERLY 334, 339 (1989).

209. See generally Alan Meisel, *Suppose the Schindlers Had Won the Schiavo Case*, 61 U. MIAMI L. REV. 733 (2007).

210. We have developed elsewhere the view that being able to formulate one’s good independently is not necessary for a liberal theory of the good, although such theories of the good must be individually scripted and rooted in the person’s own psychological life. See Leslie Francis & Anita Silvers, *Liberalism and Individually Scripted Ideas of the Good: Meeting the Challenge of Dependent Agency*, 33 SOCIAL THEORY & PRACTICE (2007).



clear and convincing with respect to her wishes.<sup>211</sup>

As an example, consider the Schindlers' claims about Terri Schiavo's Catholicism. The Schindlers contended that Terri Schiavo was a Catholic and would have wanted Catholic preservation-of-life values to be used in making decisions about her care.<sup>212</sup> They presented no evidence about her commitment to Catholicism or her commitment to her parents' views about Catholic values during her adult life, however.<sup>213</sup> Had there been evidence of such commitments, there might have been reason to think that Terri Schiavo would have incorporated these Catholic values into her decisionmaking framework. Without such evidence, however, the claim could only be that she should be treated as a Catholic because it is part of her good, without any basis for judging Catholicism to be hers – to be valued subjectively by her or to play an experiential role in her life. As we have argued, externally imposing values that may not be their own on people with disabilities makes them subject to a problematic form of paternalism.

## VI. CONCLUSION

Terri Schiavo was a person with a disability. She was not, however, a victim of disability discrimination. Arguments that the decision to terminate her medical treatment was discriminatory rested on views that should be challenged by advocates for the civil rights of people with disabilities. One set of arguments, that Terri Schiavo was not in PVS, relied on distrust of science. A second set of arguments, which challenged the guardianship and medical treatment decisions made under Florida law, would bring such instability to guardianship and medical treatment decisions that the authorization of treatments that are needed by individuals with disabilities could be compromised. A third set of arguments, that the Florida decisions should be challenged because of the importance of preserving life, rested on a position that would impose a view of the good – that is, impose moralistic or paternalistic judgments about their good – on people with disabilities. *Schiavo* is a disability case, to be sure, but it is misframed if it is viewed as a case of discrimination against a person with disabilities.

---

211. See *supra* notes 181-191 and accompanying text.

212. See *supra* note 186 and accompanying text. See generally cases cited *supra* note 2.

213. See *supra* note 186 and accompanying text.