

SEVERE BRAIN INJURY, DISABILITY, AND THE LAW: ACHIEVING JUSTICE FOR A MARGINALIZED POPULATION

MEGAN S. WRIGHT, NINA VARSAVA, JOEL RAMIREZ, KYLE EDWARDS,
NATHAN GUEVREMONT, TAMAR EZER, AND JOSEPH J. FINS*

ABSTRACT

Thousands of persons with severe brain injury who are minimally conscious or “locked in” are wrongly treated as if they are unconscious. Such individuals are unable to advocate for themselves and are typically segregated from society in hospitals or nursing homes. As a result, they constitute a class of persons who often lack access to adequate medical care, rehabilitation, and assistive devices that could aid them in communication and recovery. While this problem is often approached from a medical or scientific point of view, here we frame it as a legal issue amenable to legal remedies. This Article comprehensively explores and analyzes sources of federal, state, and international human rights law that can be leveraged—both in traditional and novel ways—to improve the lives and protect the rights of persons with severe brain injury. We argue that state laws may be the most promising basis for legal action to ameliorate the clinical marginalization and societal neglect faced by persons with severe brain injury, and to promote their recovery and reintegration into their communities.

I. INTRODUCTION	314
II. EPIDEMIOLOGY OF SEVERE BRAIN INJURY AND DIAGNOSTIC FRAMEWORK OF DISORDERS OF CONSCIOUSNESS	317
III. JUSTICE FOR PERSONS WITH SEVERE BRAIN INJURY UNDER FEDERAL LAW	322
A. <i>United States Constitution</i>	322
1. <i>Due Process</i>	323
2. <i>Equal Protection</i>	325
B. <i>Disability Discrimination Statutes and Case Law</i>	328
1. <i>Section 504 of the Rehabilitation Act</i>	328
2. <i>Americans with Disabilities Act and Olmstead Enforcement</i>	329
C. <i>Affordable Care Act</i>	334
1. <i>Nondiscrimination</i>	334
2. <i>Essential Health Benefits</i>	335
3. <i>Changes to Medicaid</i>	336
D. <i>Statutes and Regulations for Subpopulations of Persons with Severe Brain Injury</i>	339

* Megan S. Wright, J.D., Ph.D. is a Postdoctoral Associate of Medical Ethics at Weill Cornell Medical College and a Research Fellow at the Solomon Center for Health Law and Policy at Yale Law School. Nina Varsava is a J.D. candidate at Yale Law School and a Ph.D. candidate at Stanford University. Joel Ramirez, J.D., is an Associate with Morrison Foerster, San Francisco, CA. Kyle Edwards, D.Phil and Nathan Guevremont are J.D. candidates at Yale Law School. Tamar Ezer, J.D., L.L.M. is a Lecturer in Law, Associate Research Scholar in Law, Schell Visiting Human Rights Scholar, and the former Executive Director of the Solomon Center for Health Law and Policy at Yale Law School. Joseph Fins, M.D., M.A.C.P. is the E. William Davis, Jr., M.D. Professor of Medical Ethics at Weill Cornell Medical College, co-director of the Consortium for the Advanced Study of Brain Injury at Weill Cornell Medical College and Rockefeller University, and the Solomon Center Distinguished Scholar in Medicine, Bioethics, and the Law at Yale Law School. The authors wish to acknowledge the support of the Jerold B. Katz Foundation, the Solomon Center for Health Law and Policy at Yale Law School, and Weill Cornell Medical College, and thank Professor Abbe Gluck for her support and for helping to make this collaboration possible.

1. Veterans with Severe Brain Injury	340
2. Children with Severe Brain Injury and Access to Education	342
a. The Six Principles of the IDEA.....	344
b. The Scope of “Special Education and Related Services”	347
c. What Level of Educational Benefit?.....	348
3. Medicare and Access to Rehabilitation for Beneficiaries with Severe Brain Injury	350
4. Severe Brain Injury and Access to Safe and Effective Drugs and Devices	352
IV. JUSTICE FOR PERSONS WITH SEVERE BRAIN INJURY UNDER STATE LAW	355
A. State Disability Discrimination Law.....	355
1. State Constitutions	355
2. State Statutes.....	357
B. Guardianship Law	363
C. Tort Law.....	365
1. Tort Law and Mental Disability: A Brief Review.....	365
2. Misdiagnosis	367
a. Standard of Care.....	368
b. Grounds for Relief	370
c. Informed Consent	373
V. JUSTICE FOR PERSONS WITH SEVERE BRAIN INJURY UNDER INTERNATIONAL HUMAN RIGHTS LAW.....	376
VI. CONCLUSION	380

I. INTRODUCTION

The care of persons with severe brain injury presents significant clinical, legal, and normative challenges. Such individuals are often unable to advocate for themselves and are typically segregated from society in hospitals or nursing homes. As a result, they constitute a class of persons who often lack access to adequate medical care, rehabilitation, and assistive devices that could aid them in communication and recovery. While this problem is often approached from a medical or scientific point of view, here we frame it as an ethical, and in particular a *legal* issue, which is amenable to legal remedies.

Consider the following examples that are emblematic, but not exhaustive, of the types of clinical and social problems faced by persons with severe brain injury, each of which are illustrative of circumstances where the law might be leveraged to improve the lives of people with severe brain injury. The first two vignettes are drawn from over fifty narratives about patient and family experiences with severe brain injury,¹ while the third is drawn from news coverage

1. These narratives are drawn from extensive interviews, conducted as part of research for the recently published manuscript JOSEPH J. FINS, *RIGHTS COME TO MIND: BRAIN INJURY, ETHICS, AND THE STRUGGLE FOR CONSCIOUSNESS* (2015) [hereinafter FINS, *BRAIN INJURY*]. We have permission to use patients’ names in the first two narratives, and the third example is drawn from the public record.

about the experiences of a person with brain injury under guardianship.²

Margaret (Maggie) Worthen was a senior in college in 2006 when she had a brain stem stroke that left her unconscious. She was ultimately diagnosed as permanently vegetative and discharged to a nursing home, where she received little rehabilitation. Maggie's mother, having witnessed glimmers of behaviors that suggested Maggie had some degree of awareness, was concerned that the vegetative diagnostic label was mistaken and that Maggie was missing out on possibilities for improvement. Consequently, she moved Maggie to a facility for young people with traumatic brain injury. Ultimately, one of Maggie's neurologists referred her to the Consortium for the Advanced Study of Brain Injury (CASBI) at Weill Cornell Medical College and Rockefeller University for additional study.³ Maggie was found to be in the minimally conscious state,⁴ based on bedside evaluation using neuropsychological evaluation and functional neuroimaging.⁵ This diagnostic distinction is significant because it indicates that rather than being permanently unconscious, Maggie was intermittently conscious and had the prospect for further improvement.⁶ Without her mother's advocacy, Maggie might never have received the proper diagnosis, and accordingly might have lost the chance for a better outcome.

Next, consider the case of John Harmon, Jr. who, at the age of thirty-three, sustained a severe brain injury as a result of a car accident.⁷ His doctors predicted that he would be permanently vegetative. Nevertheless, John's condition evolved into the minimally conscious state.⁸ His father reported that John was severely neglected by hospital staff, evidenced, for example, by a severe bed sore which

2. See, e.g., Pam Fessler, *Disabled and Fighting for the Right to Vote*, NPR (Sept. 4, 2016, 6:00 AM), <https://www.npr.org/2016/09/04/492430780/disabled-and-fighting-for-the-right-to-vote>.

3. One of us, Joseph Fins, is co-director of CASBI.

4. See generally FINS, BRAIN INJURY, *supra* note 1 (discussing Maggie's case in more detail); Joseph J. Fins & Nicholas D. Schiff, *In Search of Hidden Minds*, 27 SCI. AM. MIND 44, 44-45 (2016) (discussing disorders of consciousness and Maggie's case); J.T. Giacino et al., *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 NEUROLOGY 349, 349-53 (2002) [hereinafter Giacino et al., *Minimally Conscious State*] (describing the minimally conscious state).

5. FINS, BRAIN INJURY, *supra* note 1, at 252-56; Fins & Schiff, *supra* note 4, at 49-50.

6. Michele H. Lammi et al., *The Minimally Conscious State and Recovery Potential: A Follow-Up Study 2 to 5 Years After Traumatic Brain Injury*, 86 ARCHIVES PHYSICAL MED. & REHAB. 746, 746 (2005).

7. FINS, BRAIN INJURY, *supra* note 1, at 189-91 (Institutional Review Board-approved interview at Weill Cornell Medical College by Jennifer Hersh, Transcript IN351H on August 28, 2008).

8. Giacino et al., *Minimally Conscious State*, *supra* note 4.

would not have developed had John been given proper care.⁹ While he did not demonstrate the normal signs of someone with consciousness and was apparently treated as though he was completely unconscious, John, in fact, possessed some degree of awareness. Nevertheless, he was segregated from the medical mainstream and deprived of the opportunity to be maximally integrated into the nexus of home, family, and community, which could be understood to constitute a violation of the Americans with Disabilities Act (ADA), as affirmed in *Olmstead*.¹⁰ As John's case suggests, the care received by individuals with severe brain injury in chronic care can be suboptimal and place their medical condition and potential for rehabilitation at risk.

Finally, consider the case of David Rector. In 2009, David suffered a stroke, which resulted in a "locked in" state—meaning he was conscious, but with limited motor output.¹¹ He was appointed a conservator, a necessary protection given the severity of his disability. The conservatorship disqualified him from voting, a routine violation of a fundamental right. In 2016, California changed its probate code section about conservatees and voting, however, and conservatees now retain voting rights unless they are unable to communicate "with or without reasonable accommodations, a desire to participate in the voting process."¹² With this legal change, David petitioned for reinstatement of his voting rights, and, with the assistance of electronic voice, was able to say to the court, "I, David Rector, want my voting rights restored, immediately."¹³ After several hearings, the probate judge finally reinstated David's voting rights.¹⁴ Several other states' guardianship laws are not as progressive as California's,¹⁵ and a large proportion of the population of persons with severe brain injury may thus continue to be denied the fundamental right to vote.

As these examples demonstrate, the obstacles individuals and their families must confront after a severe brain injury are not solely medical in nature. Indeed, after surviving a severe brain injury, people navigate a changed world in which the law may play a large part

9. FINS, BRAIN INJURY, *supra* note 1, at 189.

10. *Olmstead v. L.C.*, 527 U.S. 581 (1999).

11. SPECTRUM INST., *Spectrum Institute to File a Class-Action Complaint with the DOJ to Restore the Voting Rights of Thousands with Disabilities in California*, BUS. WIRE (Aug. 22, 2016, 9:00 AM), <https://www.businesswire.com/news/home/20160822005209/en/Spectrum-Institute-File-Class-Action-Complaint-DOJ-to-%C2%A0RESTORE> [<https://perma.cc/V2N5-3VE3>].

12. CAL. PROB. CODE § 1910 (West 2016).

13. Fessler, *supra* note 2.

14. Caroline Modarressy-Tehrani, *The Right to Be Counted: One Disabled Man's Fight to Restore His Right to Vote*, VICE NEWS (Oct. 30, 2016), <https://news.vice.com/story/disability-activist-voting-rights> [<https://perma.cc/6DA6-3WDK>].

15. *Id.*

either in denying or ensuring them necessary resources and full inclusion in society.

Because the most egregious violations of ethics and norms tend to occur in patients with the most severe injuries, much of our focus will be on patients with severe disorders of consciousness. Their struggles take place in the shadows, as the average person may be unaware of the degree to which these individuals are disregarded and their rights violated. The law is not solely an impediment, however, but can also supply the means to aid in the recovery and restoration of citizenship and dignity for persons with severe brain injury. This Article comprehensively explores and analyzes sources of law that can improve the situation of persons with severe brain injury.

In Part II, we describe the epidemiology and diagnostic framework of severe brain injury and, given that many severe brain injuries result in disorders of consciousness, we briefly define these disorders and their clinical implications. In Part III, we identify relevant federal law that applies to persons with severe brain injury and analyze how these laws can be leveraged to advance the status of such persons in civil society. In this Part, we focus on the U.S. Constitution, the ADA, and the Affordable Care Act (ACA), as examples of law that apply to all persons with severe brain injury. We further analyze federal laws that will be applicable only to certain subpopulations, such as children, veterans, Medicare recipients, and those who need access to assistive devices, which are regulated by the Food and Drug Administration (FDA). In Part IV, we identify relevant state law that applies to this population and, using the case of California, illustrate how existing laws can be used or modified to rectify the injustice persons with severe brain injury endure. Such laws include state disability laws, guardianship laws, and tort law. In Part V, we expand our inquiry beyond the United States, examining the relevance of international law and human rights for persons with severe brain injury. We conclude with our assessment of the most promising legal strategies to address the unlawful and unjust treatment of persons with severe brain injury, and call upon legal and medical practitioners to advocate on behalf of this vulnerable and marginalized population.

II. EPIDEMIOLOGY OF SEVERE BRAIN INJURY AND DIAGNOSTIC FRAMEWORK OF DISORDERS OF CONSCIOUSNESS

Patients like Maggie, John, and David can be said to suffer from disorders of consciousness.¹⁶ Disorders of consciousness comprise a

16. Joseph T. Giacino et al., *Disorders of Consciousness After Acquired Brain Injury: The State of the Science*, 10 NATURE REVIEWS NEUROLOGY 99, 99 (2014) [hereinafter Giacino et al., *Disorders of Consciousness*].

range of conditions, including brain death, the vegetative state (VS), the minimally conscious state (MCS), and emergence from the MCS.¹⁷ These are amongst the most severe brain injuries, which nationally account for approximately 2.5 million emergency room (ER) visits.¹⁸ Of these ER visits, 87% (2,213,826) result in discharge (e.g., patients with concussion and milder injuries),¹⁹ 2% (52,844) result in death, and 11% (283,630) require hospital admission.²⁰ It is from this latter category that the incidence of patients with disorders of consciousness are drawn. Overall U.S. prevalence of patients having a disability from traumatic brain injury (TBI) is estimated to be between 3.2 and 5.3 million persons.²¹ The epidemiology of other conditions that can cause brain morbidity and mortality, such as stroke and infectious encephalopathies, would add to this prevalence. For example, 795,000 Americans have a stroke each year, killing 140,000 individuals, resulting in a survivor prevalence of 82% with varying degrees of disability.²²

Most injuries able to cause a disorder of consciousness begin with a coma.²³ Clinically, a coma is an eyes-closed state of unconsciousness. Patients are totally unresponsive to external stimuli and appear asleep.²⁴ They do not have sleep-cycles and patients are unresponsive to their environment.²⁵ Comas are self-limited and typically last two weeks, unless they are prolonged by medication or by an ongoing illness.²⁶ Patients can recover completely from a coma (as following anesthesia or intoxication), progress to brain death,²⁷ or, failing those outcomes, move into the VS.²⁸

17. *Id.*

18. U.S. DEP'T OF HEALTH & HUM. SERVS., CTRS. FOR DISEASE CONTROL & PREVENTION, REPORT TO CONGRESS: TRAUMATIC BRAIN INJURY IN THE UNITED STATES: EPIDEMIOLOGY AND REHABILITATION (2015) [hereinafter CDC REPORT TO CONGRESS].

19. Even "milder" injuries can have long-term health consequences. *See, e.g.,* Daniel H. Daneshvar et al., *Long-Term Consequences: Effects on Normal Development Profile After Concussion*, 22 PHYSICAL MED. REHAB. CLINICS N. AM. 683 (2011).

20. CDC REPORT TO CONGRESS, *supra* note 18, at 2.

21. *Id.*

22. *Stroke Facts*, CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/stroke/facts.htm> [<https://perma.cc/GLM4-LA7V>] (last updated Sept. 6, 2017).

23. *See generally* Giacino et al., *Disorders of Consciousness*, *supra* note 16 (describing the state of the science about disorders of consciousness).

24. *Id.*

25. *Id.*

26. *Id.*

27. Ad Hoc Comm. of the Harvard Med. Sch., *A Definition of Irreversible Coma*, 205 J. AM. MED. ASS'N 85, 87 (1968).

28. JEROME B. POSNER ET AL., PLUM AND POSNER'S DIAGNOSIS OF STUPOR AND COMA 8 (4th ed. 2007).

The VS is the isolated recovery of the autonomic functions of the brain stem without higher cortical function.²⁹ First described in a landmark *Lancet* paper in 1972,³⁰ and brought to prominence in landmark right-to-die cases such as *In re Quinlan*,³¹ *Cruzan v. Director, Missouri Department of Health*,³² and *In re Schiavo*,³³ patients in the VS demonstrate “wakeful unresponsiveness” in which their eyes are open but there is no awareness of self, others, or the environment.³⁴ Vegetative patients have sleep/wake cycles, blinking, eye movements, and even the startle reflex.³⁵ Importantly, they breathe spontaneously without ventilator support.³⁶ The VS is considered *persistent* when it has lasted thirty days and is *permanent* three months after anoxic brain injury or twelve months following TBI.³⁷ Before the VS becomes permanent, there is a window during which patients may surreptitiously move into the MCS.³⁸

The MCS formally entered the medical literature in 2002 through a consensus statement published in *Neurology* under the rubric of the Aspen Criteria.³⁹ Importantly, in contrast to vegetative patients, minimally conscious patients are *conscious*, although this is often not recognized by clinical staff.⁴⁰ Patients in the MCS have “minimal but definite awareness of self or environmental awareness.”⁴¹ Minimally conscious patients may demonstrate intention, attention, and memory.⁴² They may track a family member when they enter the room, say their name, or grasp for an object (like a cup).⁴³

Clinical assessment of the MCS is challenging and prone to error. Dr. Schnakers and her colleagues demonstrated that 41% of patients tested with severe TBI in long-term care thought to be vegetative

29. Giacino et al., *Disorders of Consciousness*, *supra* note 16, at 100.

30. Bryan Jennett & Fred Plum, *Persistent Vegetative State After Brain Damage: A Syndrome in Search of a Name*, *LANCET*, Apr. 1972, at 734, 734.

31. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

32. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

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

34. Jennett & Plum, *supra* note 30.

35. *Id.* at 734.

36. *Id.* at 735.

37. A.A. Howsepian, *The 1994 Multi-Society Task Force Consensus Statement on the Persistent Vegetative State: A Critical Analysis*, 12 *ISSUES L. & MED.* 3, 15 n.38 (1996).

38. Joseph J. Fins, *Neuroethics, Neuroimaging, and Disorders of Consciousness: Promise or Peril?*, 122 *TRANSACTIONS AM. CLINICAL & CLIMATOLOGICAL ASS'N* 336, 339-40 (2010).

39. Giacino et al., *Minimally Conscious State*, *supra* note 4, at 350.

40. See generally FINS, *BRAIN INJURY*, *supra* note 1.

41. Giacino et al., *Disorders of Consciousness*, *supra* note 16, at 100.

42. *Id.* at 99.

43. *Id.* at 100.

were in fact minimally conscious on closer examination.⁴⁴ Others have found similar diagnostic error rates between 20-40%.⁴⁵ In the MCS, behaviors are not reliably reproduced and are episodically demonstrated. When a patient is asked to repeat a behavior seen by family members, they will typically *not* comply with the request, leading practitioners to believe that a family's observations are prompted by wishful thinking or outright denial, when in fact this failure of reproducibility derives from the underlying biology of the MCS. Such clinical confounders—coupled with the nihilism associated with severe brain injury and, in particular, the VS⁴⁶—help explain the diagnostic challenge of distinguishing the VS from the MCS.⁴⁷ When behaviors are reproduced reliably, patients are said to have emerged from the minimally conscious state (MCS-E).⁴⁸

Although technically not a disorder of consciousness, the Locked-in State (LIS) is often considered in kind because it needs to be distinguished from the VS. Persons in the LIS appear vegetative because they have a paucity of motor output while retaining “normal” consciousness. This condition vividly came to public attention through Jean-Dominique Bauby's memoir, *The Diving Bell and the Butterfly*, which he wrote by blinking in code.⁴⁹

There has been no comprehensive epidemiology of the incidence and prevalence of disorders of consciousness, which we view as indicative of this population's marginalization,⁵⁰ the complexity of studying dynamic brain states,⁵¹ the use of metrics which measure behaviors but fail to assess consciousness, and the novelty of the MCS as a

44. Caroline Schnakers et al., *Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment*, 9 BMC NEUROLOGY 35, 37-38 (2009).

45. Keith Andrews et al., *Misdiagnosis of the Vegetative State: Retrospective Study in a Rehabilitation Unit*, 313 BRIT. MED. J. 13, 13-14 (1996); Nancy L. Childs et al., *Accuracy of Diagnosis of Persistent Vegetative State*, 43 NEUROLOGY 1465, 1465 (1993); F.C. Wilson et al., *Vegetative State and Minimally Responsive Patients—Regional Survey, Long-Term Case Outcomes and Service Recommendations*, 17 NEUROREHAB. 231, 231 (2002).

46. Joseph J. Fins, *Constructing an Ethical Stereotaxy for Severe Brain Injury: Balancing Risks, Benefits and Access*, 4 NATURE REV. NEUROSCIENCE 323, 323 (2003); FINS, BRAIN INJURY, *supra* note 1.

47. Giacino et al., *Disorders of Consciousness*, *supra* note 16, at 103.

48. *Id.* at 101.

49. JEAN-DOMINIQUE BAUBY, *THE DIVING BELL AND THE BUTTERFLY: A MEMOIR OF LIFE IN DEATH* (1997).

50. See Joseph J. Fins et al., *Late Recovery from the Minimally Conscious State: Ethical and Policy Implications*, 68 NEUROLOGY 304, 306 (2007) (calling for comprehensive epidemiology).

51. Joseph J. Fins et al., *The Minimally Conscious State: A Diagnosis in Search of an Epidemiology*, 64 ARCHIVES NEUROLOGY 1400 (2007) (discussing the complexity of the methodology of studying changing brain states).

diagnostic category.⁵² With these methodological caveats in mind, the prevalence of the VS in the United States has been estimated to be between 40 and 168 patients per million of the population.⁵³ A more recent European meta-analysis suggests a range of 0.2 to 6.1 vegetative patients per 100,000 of the population.⁵⁴ Estimates of the MCS are complicated by similar methodological concerns and pervasive diagnostic error rates, as well as the unfamiliarity of clinicians with this diagnostic category. Dr. Strauss and his colleagues estimate a prevalence of between 112,000 and 280,000 adult and pediatric patients in the MCS,⁵⁵ but data is limited to dated extrapolations of single state databases.⁵⁶

These errors are clinically, ethically, and normatively significant.⁵⁷ Misdiagnosing a minimally conscious patient as vegetative is clinically significant because pain control and palliation are presumed to be unnecessary because the patient is falsely thought insensate. A diagnostic error is also problematic with respect to prognosis as individuals

52. J. Graham Beaumont & Pamela M. Kenealy, *Incidence and Prevalence of the Vegetative and Minimally Conscious States*, 15 NEUROPSYCHOLOGICAL REHAB. 184, 184 (2005) (discussing methodological challenges); W.S. van Erp et al., *The Vegetative State/Unresponsive Wakefulness Syndrome: A Systematic Review of Prevalence Studies*, 21 EUR. J. NEUROLOGY 1361, 1362-65 (2014) (noting that some studies did not include the MCS).

Determining prevalence rates is confounded by the natural history of these conditions and the behavioral metrics used to assess these conditions. Because of the dynamic nature of these brain states and care decisions, prevalence is not fixed. Patients may evolve from the VS into the MCS, before the VS becomes permanent. Moreover, decisions to withhold or withdraw care can preclude this progression. In addition, because these conditions relate to disorders of consciousness, and *not* behaviors, metrics like the Glasgow Coma and Outcome Scales, which take behaviors as a proxy for consciousness, can under-represent patients who have a discordance between thought and action. This phenomenon has been demonstrated over the past decade through functional neuroimaging which has demonstrated that patients *thought vegetative by behavioral criteria* show responsiveness on brain flares, indicating that they are responding to their environment. See Joseph J. Fins & Nicholas D. Schiff, *Shades of Gray: New Insights into the Vegetative State*, 36 HASTINGS CTR. REP. 8, 8 (2006); Martin M. Monti et al., *Willful Modulation of Brain Activity in Disorders of Consciousness*, 362 NEW ENG. J. MED. 579, 579 (2010).

53. Beaumont & Kenealy, *supra* note 52.

54. W.S. van Erp et al., *supra* note 52, at 1365.

55. David J. Strauss et al., *Life Expectancy of Children in Vegetative and Minimally Conscious States*, 23 PEDIATRIC NEUROLOGY 312, 316 (2000).

56. NAT'L INST. ON DISABILITY, INDEP. LIVING, & REHAB. RES., REHABILITATION ACCESS AND OUTCOME AFTER SEVERE TRAUMATIC BRAIN INJURY, at II, X (2016), <http://medians.mghcpd.org.s3.amazonaws.com/spauldingtbi/rehabilitation-access-and-outcome-after-severe-tbi-briefing-book.pdf> [https://perma.cc/5VBF-BACG]; see also Anbesaw W. Selassie et al., *Incidence of Long-Term Disability Following Traumatic Brain Injury Hospitalization, United States, 2003*, 23 J. HEAD TRAUMA REHAB. 123, 125, 129 (2008); Eduard Zaloshnja et al., *Prevalence of Long-Term Disability from Traumatic Brain Injury in the Civilian Population of the United States*, 23 J. HEAD TRAUMA REHAB. 394, 399 (2008).

57. See generally FINS, BRAIN INJURY, *supra* note 1; Joseph J. Fins, *Bring Them Back*, AEON (May 10, 2016), <https://aeon.co/essays/thousands-of-patients-diagnosed-as-vegetative-are-actually-aware> [https://perma.cc/BD6V-7YB9].

who are in the MCS may be amenable to rehabilitation and to progressive improvement, while patients who are permanently vegetative will not have subsequent recovery.⁵⁸ Trapped and mischaracterized in what is euphemistically described as “custodial care,” these patients can be deemed eligible for neurorehabilitation and the skilled physical therapy that can lead to the recovery of functional independence in up to 21% of the most grievously injured patients.⁵⁹

III. JUSTICE FOR PERSONS WITH SEVERE BRAIN INJURY UNDER FEDERAL LAW

We begin by addressing sources of federal law that can be leveraged to assist persons with severe brain injury in recovering their maximum potential post-injury and then being reintegrated in their communities. We first address possible constitutional claims. We then move on to the more promising remedies available under the ADA. We next briefly address the implications of the ACA for persons with severe brain injury. We conclude this Part by describing sources of law that apply to particular subpopulations of persons with severe brain injury; namely, veterans, children, Medicare beneficiaries, and those who could benefit from access to drugs and devices.

A. *United States Constitution*

Constitutional claims on behalf of persons with severe brain injury could be litigated under the Fourteenth Amendment Due Process Clause or Equal Protection Clause. The benefit of constitutional rights compared to statutory rights, such as those granted under the ADA, is that such rights are guaranteed, rather than subject to politics or economic constraints.⁶⁰ However, any such claims require state action to trigger constitutional review, meaning action by private actors is not subject to Fourteenth Amendment constraints.⁶¹ Additionally, due process claims must be framed in terms of unconstitutional deprivations of life, liberty, or property given that the Constitution is one of negative rights rather than positive rights, so substantive due process

58. Giacino et al., *Disorders of Consciousness*, *supra* note 16, at 12-13.

59. Risa Nakase-Richardson et al., *Longitudinal Outcome of Patients with Disordered Consciousness in the NIDRR TBI Model Systems Programs*, 29 J. NEUROTRAUMA 59, 62-64 (2012).

60. Barry Friedman & Sara Solow, *The Federal Right to an Adequate Education*, 81 GEO. WASH. L. REV. 92, 154-55 (2013); James E. Ryan, *A Constitutional Right to Preschool?*, 94 CALIF. L. REV. 49, 96 (2006) (discussing this in the context of rights to education).

61. LAURA ROTHSTEIN & ANN C. MCGINLEY, *DISABILITY LAW: CASES, MATERIALS, AND PROBLEMS* 25 (5th ed. 2010).

claims asserting, for example, a right to healthcare, rehabilitation,⁶² community-based resources,⁶³ or employment will not be successful. Furthermore, persons with disabilities are not a class that receives heightened scrutiny when courts are reviewing claims of equal protection violations. All of these factors present significant challenges for constitutional claims.

1. *Due Process*

Past federal cases have struck down unlawful treatment of persons with disabilities “by public institutions [and have] accorded disabled people many of the same constitutional rights to due process and equal protection as able-bodied people have.”⁶⁴ In the early 1970s, for example, lower federal courts ruled for children with disabilities with respect to state laws that refused to provide public education for these children.⁶⁵ Courts held that such laws violated both due process and equal protection.⁶⁶ Furthermore, federal courts have also held that states cannot indiscriminately institutionalize persons with mental disabilities because this violates procedural due process.⁶⁷ These cases focused on discriminatory state action that *deprived* persons of *fundamental liberties*.

Persons with disabilities and their advocates may prefer constitutional guarantees of a *right to social goods*, such as healthcare. But, as noted above, the Federal Constitution implicates negative rather than positive rights.⁶⁸ Some scholars have noted, however, that there is a

62. See Megan S. Wright & Joseph J. Fins, *Rehabilitation, Education, and the Integration of Individuals with Severe Brain Injury into Civil Society: Towards an Expanded Rights Agenda in Response to New Insights from Translational Neuroethics and Neuroscience*, 16 YALE J. HEALTH POL’Y L. & ETHICS 233 (2016) (presenting novel legal argument asserting a right to rehabilitation).

63. Such services may be required under the ADA, however. See discussion *infra* Section III.B.2.

64. RICHARD K. SCOTCH, FROM GOOD WILL TO CIVIL RIGHTS: TRANSFORMING FEDERAL DISABILITY POLICY 37 (2d ed. 1984).

65. See, e.g., Pa. Ass’n for Retarded Children v. Pennsylvania, 343 F. Supp. 279, 302 (E.D. Pa. 1972) (holding that state laws that excluded mentally retarded children from public schools violated guarantees of procedural due process and equal protection); Mills v. Bd. of Educ. of D.C., 348 F. Supp. 866, 875 (D.D.C. 1972) (holding that exclusion of children with disabilities from public education violates due process).

66. ROTHSTEIN & MCGINLEY, *supra* note 61, at 6-7.

67. See Wyatt v. Hardin, No. 3195-N, 1975 WL 33692, at *1 (M.D. Ala. Feb. 28, 1975) (asserting that the state cannot indiscriminately institutionalize persons with mental disabilities); see also David Ferleger, *The Constitutional Right to Community Services*, 26 GA. ST. U. L. REV. 763, 763-64 (2010) (discussing constitutional arguments under both due process and equal protection clauses for involuntary confinement/institutionalization of persons with intellectual disabilities).

68. Scholars debate the extent to which this distinction makes sense and argue that the Constitution does afford positive rights. See, e.g., Edward Rubin, *The Affordable Care*

substantive due process-based negative right to health:⁶⁹ “[I]ndividuals have a constitutional right to protect their health. This right, moreover, may include a right both to refuse care and to access care—not at government expense, but without government interference.”⁷⁰

This right is implicated when the government decides “to criminalize or otherwise take certain forms of safe and effective healthcare off the table.”⁷¹ Even when it seems like the government is making such decisions through choices, such as whether state Medicaid funds can be used to pay for certain medical procedures, there is often no state action given that the decision is about subsidizing certain forms of healthcare rather than directly restricting access.⁷² So, should a person with severe brain injury be denied access to adequate medical care, rehabilitation, drugs, or devices on the basis of an adverse medical necessity determination, the state action requirement presents a barrier to constitutional claims asserting the negative right to healthcare.⁷³

Another strategy is to bring a liberty-based “dignity” claim on behalf of persons with severe brain injury.⁷⁴ Leading constitutional scholars have reported that in practice, substantive due process and equal protection claims are often combined in jurisprudence and are “hybrid rights.”⁷⁵ However, asserting these hybrid rights would have to take the form of arguing that the government was infringing a fundamental liberty, and again, aside from unlawful institutionalization, it is difficult to see how this would occur in the case of persons with severe brain injury given that much of what they need involves “access to” certain resources rather than *freedom from* some imposition.⁷⁶

Act, the Constitutional Meaning of Statutes, and the Emerging Doctrine of Positive Constitutional Rights, 53 WM. & MARY L. REV. 1639, 1643, 1688, 1689, 1691 (2012).

69. B. Jessie Hill, *What is the Meaning of Health? Constitutional Implications of Defining “Medical Necessity” and “Essential Health Benefits” Under the Affordable Care Act*, 38 AM. J.L. & MED. 445, 447-48 (2012).

70. *Id.* at 461-62 (describing how the right can be traced to *Jacobson v. Massachusetts*, 197 U.S. 11 (1905), and abortion regulation exceptions for preserving the life or health of the mother).

71. *Id.* at 460.

72. *Id.* at 465. This could change at some point in the future, however, if the government is the sole provider or regulator of healthcare. *Id.* at 467-68.

73. This does not mean that other sources of law cannot be used to assert such rights. See discussion *infra* Sections III.B.1, III.B.2, III.C.

74. Kenji Yoshino, *The New Equal Protection*, 124 HARV. L. REV. 747, 749 (2011).

75. *Id.* at 748-50.

76. The problem with dignity-based claims is that they have really only been successful with respect to negative rights rather than positive rights. Areto A. Imoukhuede, *Education Rights and the New Due Process*, 47 IND. L. REV. 467, 506 (2014); see, e.g., *Tennessee v. Lane*, 541 U.S. 509, 531-33 (2004) (holding that the government unlawfully deprived wheelchair users of access to courts, a fundamental right, by not providing access to the

2. Equal Protection

In order for persons with disabilities to prevail in court when alleging an equal protection violation under the Constitution, there must be a federal, state, or local law that treats them differently from other groups, and the claimant must be able to demonstrate that the law is based on irrational prejudice or animus.⁷⁷ Disability is not considered a suspect classification, and thus equal protection violation claims brought by persons with disabilities do not receive higher levels of scrutiny.⁷⁸

The most instructive case applying equal protection analysis to persons with disabilities is *City of Cleburne v. Cleburne Living Center*.⁷⁹ The issue in this case was that the City of Cleburne's zoning ordinance required a special use permit for a group home for persons with intellectual disabilities.⁸⁰ When the group home applied for such a permit, it was denied. The group home then initiated a lawsuit, alleging that the city's decision was based on discrimination against persons with intellectual disabilities and thus constituted an equal protection violation. An appellate court held for the group home, asserting that intellectual disability was a "quasi-suspect classification and that it should assess the validity of the ordinance under intermediate-level scrutiny."⁸¹ When analyzing the specific issue in this case, the Supreme Court summarized the appellate court's reasoning as follows:

[I]n light of the history of "unfair and often grotesque mistreatment" of the retarded, discrimination against them was "likely to reflect deep-seated prejudice." In addition, the mentally retarded lacked political power, and their condition was immutable. The court considered heightened scrutiny to be particularly appropriate in this case, because the city's ordinance withheld a benefit which, although not fundamental, was very important to the men-

upper floors of a courthouse); *Lawrence v. Texas*, 539 U.S. 558, 578 (2003) (holding that a state's anti-sodomy laws deprived persons of the right to engage in private sexual behavior).

77. See *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 439-40 (1985) ("The Equal Protection Clause of the Fourteenth Amendment commands that no State shall 'deny to any person within its jurisdiction the equal protection of the laws,' which is essentially a direction that all persons similarly situated should be treated alike. . . . The general rule is that legislation is presumed to be valid and will be sustained if the classification drawn by the statute is rationally related to a legitimate state interest. . . . When social or economic legislation is at issue, the Equal Protection Clause allows the States wide latitude" (citations omitted)).

78. *Id.* at 440.

79. *Id.* at 432.

80. *Id.* at 447.

81. *Id.* at 437-38.

tally retarded. Without group homes, the court stated, the retarded could never hope to integrate themselves into the community.⁸²

The Supreme Court held that persons with intellectual disabilities are not a quasi-suspect class, however, based on several reasons. First, persons with such disabilities are different from others, and thus legislators are lawfully able to treat them differently.⁸³ Second, legislators had not been indifferent to persons with such disabilities, passing legislation in the form of the Rehabilitation Act of 1973 and the Education of the Handicapped Act, which were meant to more fully integrate persons with disabilities in society.⁸⁴ Third, persons with intellectual disabilities were not politically powerless.⁸⁵ Finally, the Court was concerned about expanding heightened scrutiny to other types of disabilities.⁸⁶

Nonetheless, the group home still prevailed because the city zoning law that disallowed the group home failed to survive rational basis review.⁸⁷ As the Court wrote, "The short of it is that requiring the permit in this case appears to us to rest on an irrational prejudice against the mentally retarded."⁸⁸ Commentators and some dissenting Justices have argued, however, that a standard of review higher than rational basis was used in this case.⁸⁹

Based on the reasoning in *City of Cleburne*, allegations of equal protection violations on behalf of persons with severe brain injury

82. *Id.* at 438 (citation omitted).

83. *Id.* at 442 ("[T]hose who are mentally retarded have a reduced ability to cope with and function in the everyday world. . . . They are thus different, immutably so, in relevant respects, and the States' interest in dealing with and providing for them is plainly a legitimate one.").

84. *Id.* at 443-44.

85. *Id.* at 445 ("[T]he legislative response, which could hardly have occurred and survived without public support, negates any claim that the mentally retarded are politically powerless in the sense that they have no ability to attract the attention of the lawmakers.").

86. *Id.* at 445 ("[I]f the large and amorphous class of the mentally retarded were deemed quasi-suspect . . . it would be difficult to find a principled way to distinguish a variety of other groups who have perhaps immutable disabilities setting them off from others, who cannot themselves mandate the desired legislative responses, and who can claim some degree of prejudice from at least part of the public at large.").

87. *Id.* at 446 ("Our refusal to recognize the retarded as a quasi-suspect class does not leave them entirely unprotected from invidious discrimination. To withstand equal protection review, legislation that distinguishes between the mentally retarded and others must be rationally related to a legitimate governmental purpose.").

88. *Id.* at 450. Laws based on animus will not survive rational basis review. Yoshino, *supra* note 74, at 760.

89. See, e.g., *City of Cleburne*, 473 U.S. at 458 (Marshall, J., concurring in part and dissenting in part) ("[T]he Court's heightened-scrutiny discussion is even more puzzling given that Cleburne's ordinance is invalidated only after being subjected to precisely the sort of probing inquiry associated with heightened scrutiny.").

would likely fail.⁹⁰ Indeed, legal scholars have argued that the Supreme Court over time has been limiting the power of the Equal Protection Clause of the Fourteenth Amendment.⁹¹

However, given recent Supreme Court jurisprudence, as delineated in *Obergefell v. Hodges*,⁹² equal protection doctrine seems less restrictive. Indeed, in Justice Kennedy's *Obergefell* opinion, he relied on both the Due Process and Equal Protection clauses when finding a fundamental right for same-sex couples to be married, even though gays and lesbians are not a suspect class.⁹³ Justice Kennedy wrote that "new dimensions of freedom become apparent to new generations" and that "new insights and societal understandings can reveal unjustified inequality within . . . fundamental institutions that once passed unnoticed and unchallenged."⁹⁴

Given the evolving and unsettled equal protection doctrine, courts may be open to a heightened level of scrutiny for laws that treat persons with disabilities differently from others, and may be sympathetic to Justice Marshall's arguments (in his *City of Cleburne* concurrence in part and dissent in part) about the situation of persons with intellectual disabilities: "[T]he mentally retarded have been subject to a 'lengthy and tragic history' of segregation and discrimination that can only be called grotesque. . . . State laws deemed the retarded 'unfit for citizenship.'" ⁹⁵ This situation resembles that experienced by persons with disorders of consciousness, as has been documented elsewhere.⁹⁶ An important difference between the "mentally retarded" and persons with disorders of consciousness, however, is that the latter condition is not immutable.

The likelihood of success asserting constitutional claims on behalf of persons with severe brain injury is low given the state action requirement, the constitutional emphasis on negative rights, and the current rational basis review of claims of equal protection violation

90. Even if the claims did not fail, however, one disadvantage of equal protection claims is that the state can always respond by leveling or equalizing down and eliminating entitlements for all rather than including entitlements for more. See Yoshino, *supra* note 74, at 800.

91. See, e.g., *id.* at 748 ("Over the past decades, the Court has systematically denied constitutional protection to new groups, curtailed it for already covered groups, and limited Congress's capacity to protect groups through civil rights legislation." (footnote omitted)); Imoukhuede, *supra* note 76, at 491-92 (describing a move toward liberty-based claims rather than equality-based claims).

92. 135 S. Ct. 2584 (2015).

93. *Id.* at 2604-05.

94. *Id.* at 2596, 2603.

95. *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 461, 463 (1985) (Marshall, J., concurring in part and dissenting in part) (citations omitted).

96. See generally FINS, BRAIN INJURY, *supra* note 1; Wright & Fins, *supra* note 62.

for persons with disabilities. Fortunately, however, other sources of federal law, such as the ADA, are more promising. These laws help interpret the constitutional values of equality and dignity.⁹⁷

B. Disability Discrimination Statutes and Case Law

Given the limits of constitutional claims on behalf of persons with disabilities, statutes with the express purpose of protecting persons with disabilities from discrimination are a more promising avenue for rectifying the unjust treatment of persons with severe brain injury,⁹⁸ who are, by any statutory definition, disabled.⁹⁹ The most important of these statutes are the Rehabilitation Act¹⁰⁰ and the ADA¹⁰¹ and its subsequent amendments,¹⁰² all of which strive to ensure the social equality and dignity of persons with disabilities.

1. Section 504 of the Rehabilitation Act

Section 504 of the Rehabilitation Act of 1973 states: “No otherwise qualified handicapped individual in the United States, as defined in section 7(6), shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”¹⁰³

This section is considered to be the first civil rights statute for persons with disabilities.¹⁰⁴ In fact, Title VI of the Civil Rights Act of 1964¹⁰⁵ was the model for section 504, and “disabled people [benefitted] from the previous efforts and political strength of the broader racial civil rights movement.”¹⁰⁶ One major benefit of linking disability rights with civil rights is that economic cost considerations of fully

97. AHARON BARAK, HUMAN DIGNITY: THE CONSTITUTIONAL VALUE AND THE CONSTITUTIONAL RIGHT 205 (2015) (arguing that dignity is a value, but not a right, in the U.S. Constitution).

98. See ROTHSTEIN & MCGINLEY, *supra* note 61, at 9, 25.

99. See, e.g., 42 U.S.C. § 12102(1) (2012) (“The term ‘disability’ means, with respect to an individual—(A) a physical or mental impairment that substantially limits one or more major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment . . .”).

100. Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355 (1973) (codified as amended at 29 U.S.C. §§ 700-796 (2012)).

101. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (1990) (codified as amended at 42 U.S.C. §§ 12101-12213 (2012)).

102. ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3553 (2008).

103. 29 U.S.C. § 794.

104. SCOTCH, *supra* note 64, at 3.

105. 42 U.S.C. § 2000d (2012).

106. SCOTCH, *supra* note 64, at 142; see also Timothy M. Cook, *The Americans with Disabilities Act: The Move to Integration*, 64 TEMP. L. REV. 393, 410 (1991).

including persons with disabilities in society become less relevant.¹⁰⁷ The major limitation of section 504, however, is that it only applies to entities receiving federal funds, which includes hospitals and healthcare providers that accept Medicare or Medicaid,¹⁰⁸ but excludes much of the private sector.¹⁰⁹

2. *Americans with Disabilities Act and Olmstead Enforcement*

The ADA¹¹⁰ rectified this limitation of section 504.¹¹¹ The goal of the ADA is to prohibit discrimination against and promote the full inclusion of persons with disabilities in society,¹¹² and to this end applies to both the public and private sector.¹¹³ The ADA has both positive duties (to accommodate) and negative duties (to not discriminate).¹¹⁴ Title I of the ADA regulates employment;¹¹⁵ Title II regulates state and local government;¹¹⁶ and Title III regulates public accommodations and commercial facilities.¹¹⁷ Employers, state and local

107. Unlike other groups of marginalized persons, persons with disabilities may require additional resources to achieve equality, and equal treatment may not be sufficient for full integration in society. SCOTCH, *supra* note 64, at 11. As one scholar has noted:

Characterizing access as a civil right had distinct political advantages. To portray access as another government benefit for disabled people . . . would have defined improved access as desirable but not as a social imperative. Allowing disabled people greater participation thus would become an essentially charitable act. In periods of limited resources, which is to say virtually always, it is politically acceptable to limit benevolent acts of charity because of budgetary constraints, traditional practice, or administrative difficulty. Reducing benefits may be legitimate, while violating rights is not.

Id. at 41-42.

108. ROTHSTEIN & MCGINLEY, *supra* note 61, at 353, 655-56.

109. *Id.* at 7-8.

110. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12213 (2012).

111. Nancy Lee Jones, *Overview and Essential Requirements of the Americans with Disabilities Act*, 64 TEMP. L. REV. 471, 475-76 (1991) ("A key rationale used to support the ADA was that it essentially extended into the private sector an existing federal statute.").

112. 42 U.S.C. § 12101(a)(7) ("[T]he Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals . . .").

113. See Robert L. Burgdorf, Jr., "Equal Members of the Community": *The Public Accommodations Provisions of the Americans with Disabilities Act*, 64 TEMP. L. REV. 551, 554-56 (1991) (describing how prior to the ADA, public accommodations that could not discriminate on the basis of other status characteristics could do so on the basis of disability).

114. Linda Hamilton Krieger, *Introduction to BACKLASH AGAINST THE ADA: REINTERPRETING DISABILITY RIGHTS* 5 (Linda Hamilton Krieger ed., 2003).

115. 42 U.S.C. §§ 12111-12117.

116. *Id.* §§ 12131-12165. Indeed, the ADA "reaches virtually every state and local public service regardless of whether the program receives federal financial assistance." ROTHSTEIN & MCGINLEY, *supra* note 61, at 354. State and local governments that receive federal funds are also subject to section 504 of the Rehabilitation Act. *Id.*

117. 42 U.S.C. §§ 12181-12189.

governments, and public accommodations have defenses to ADA implementation of nondiscrimination mandates. One is that making an accommodation would fundamentally alter their program.¹¹⁸ The other is that making an accommodation would be overly financially burdensome and thus “unreasonable.”¹¹⁹ Accordingly, for there to be unlawful discrimination under the ADA, a reasonable accommodation must be possible.¹²⁰

The majority of the lawsuits brought under the ADA are Title I lawsuits regarding employment discrimination,¹²¹ and thus this area of disability law is much more developed than other areas, such as healthcare.¹²² For many persons with severe brain injury, however, Title I is likely less relevant, given that the nature of the disability may prevent the person from being able to work.¹²³ Instead, Title II¹²⁴ and Title III¹²⁵ are more promising sources of law for ending the institutionalization of persons with severe brain injury and increasing access to technologies that will aid in community living,¹²⁶ as together these sections of the ADA regulate the provision of both public and private healthcare.¹²⁷

A central focus of both section 504 of the Rehabilitation Act and the ADA is deinstitutionalizing persons with disabilities who can live in community settings if their needs are accommodated.¹²⁸ An explicit goal of the ADA is for persons with disabilities to have services pro-

118. See *id.* § 12182(b)(2)(A)(iii); see also 28 C.F.R. § 36.303 (2017).

119. See 42 U.S.C. § 12182(b)(2)(A)(iii). These defenses are considered on a case-by-case basis. An example of an unreasonable accommodation in the workplace is requesting to have no contact with co-workers. Ronda K. O'Donnell & Lee C. Durivage, *Undue Hardship*, LEGAL INTELLIGENCER (June 14, 2011, 12:00 AM), <https://www.law.com/thelegalintelligencer/almlID/1202496644549> [<https://perma.cc/CF63-FLYX>].

120. ROTHSTEIN & MCGINLEY, *supra* note 61, at 83.

121. See 42 U.S.C. § 12111.

122. ROTHSTEIN & MCGINLEY, *supra* note 61, at vi. While more developed, this area of law has tended to not be very favorable to disabled plaintiffs. Krieger, *supra* note 114, at 8-10. Congress responded to this by amending the ADA and overriding Supreme Court decisions that narrowly defined disability. See ADA Amendments Act of 2008, Pub. L. No. 110-325, § 2(b), 122 Stat. 3553 (2008). This has not changed much in the employment context. Stephen F. Befort, *An Empirical Examination of Case Outcomes Under the ADA Amendments Act*, 70 WASH. & LEE L. REV. 2027, 2041-43 (2013).

123. We do not write off the relevance of Title I, however, because given appropriate assistive devices and reasonable accommodations, many persons with severe brain injury may be able to work.

124. 42 U.S.C. § 12132.

125. *Id.* § 12182(a).

126. Wright & Fins, *supra* note 62, at 236 (arguing this point).

127. ROTHSTEIN & MCGINLEY, *supra* note 61, at 353. Healthcare facilities are places of public accommodation and are covered by Title III of ADA; if they receive federal grants, they are also covered by section 504 of the Rehabilitation Act. *Id.* at 265.

128. *Id.* at 634.

vided in the most integrated setting possible.¹²⁹ The leading Supreme Court case interpreting Title II of the ADA, *Olmstead v. L.C. ex rel. Zimring*, was a case that asked whether the ADA's nondiscrimination mandate required community-based housing rather than institutionalization.¹³⁰ The Court answered with a "qualified yes," explaining that

Such action is in order when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.¹³¹

Since this case, deinstitutionalization lawsuits have become known as *Olmstead* enforcement cases,¹³² and many consider *Olmstead* to be the disability community's equivalent of *Brown v. Board of Education*.¹³³

Achieving deinstitutionalization and community integration of persons with significant disabilities has proven difficult, however. The most significant barrier to deinstitutionalization is inadequate resources, including "funding, placements, and trained staffing . . . in the community."¹³⁴ If community-based living facilities do not exist, then it is impossible to deinstitutionalize.¹³⁵

While it may seem as though the existing disability rights laws should be modified in some way to address the particular problems facing persons with severe brain injury described above, we believe that the current laws, along with reforms of other bodies of law, are sufficient if applied and enforced to aid in community reintegration of persons with severe brain injury. Indeed, we have argued elsewhere

129. 42 U.S.C. § 12182(b)(1)(B) ("Goods, services, facilities, privileges, advantages, and accommodations shall be afforded to an individual with a disability in the most integrated setting appropriate to the needs of the individual.").

130. 527 U.S. 581 (1999).

131. *Id.* at 587.

132. See *Disabilities*, OBAMA WHITE HOUSE, <https://obamawhitehouse.archives.gov/issues/disabilities> [<https://perma.cc/8XL6-M5G2>] (summarizing *Olmstead* enforcement during the Obama Administration).

133. 347 U.S. 483 (1954); see also Samuel R. Bagenstos, *Justice Ginsburg and the Judicial Role in Expanding "We the People": The Disability Rights Cases*, 104 COLUM. L. REV. 49, 49 (2004).

134. ROTHSTEIN & MCGINLEY, *supra* note 61, at 634.

135. *Id.* As Rothstein and McGinley note about "community services and access to independent living," the most significant problem for advocates is not winning nondiscrimination lawsuits, but instead "funding deficiencies." *Id.* at 9; see also Bagenstos, *supra* note 133, at 59 (explaining that budget cuts have slowed *Olmstead* community integration efforts).

that *Olmstead*¹³⁶ is relevant in the case of persons with disorders of consciousness who are institutionalized in custodial care and that such isolation and segregation is a violation of the *Olmstead* integration mandate if the facilities are public, and can be considered a violation by analogy if the facilities are private.¹³⁷ Furthermore, if such persons do not receive accommodations in the form of access to drugs, devices, and rehabilitation, this may be a violation of the ADA's regulations that require that persons with disabilities be given auxiliary aids and services to assist in communication.¹³⁸

Persons with severe brain injury who are unlawfully institutionalized and denied reasonable accommodations can sue for injunctive relief under Title III of the ADA.¹³⁹ While healthcare providers can always raise fundamental alteration or undue burden defenses,¹⁴⁰ they are unlikely to be successful in this context given that many healthcare facilities already have the necessary technologies—many of which are inexpensive—and just need to consistently make them available to persons with severe brain injury.¹⁴¹

Enforcing section 504 and the ADA remains crucial to ensuring equality and full inclusion for persons with a disability. However, other scholars have noted that “[m]any laws passed by Congress have little or no impact in the absence of stipulated enforcement mechanisms and administrative support.”¹⁴² Indeed, there is currently an extensive ADA enforcement docket.¹⁴³ As one example of *Olmstead*

136. 527 U.S. 581, 607 (1999).

137. Wright & Fins, *supra* note 62, at 271-72 (asserting that the reasoning of *Olmstead* can be applied to Title III cases).

138. 28 C.F.R. § 36.303 (2017). In previous work, some of us have noted that reasonable accommodations or modifications is unclear and vague, especially in the context of disorders of consciousness. Wright & Fins, *supra* note 62, at 269-70; see also Alex B. Long, *Introducing the New and Improved Americans with Disabilities Act: Assessing the ADA Amendments Act of 2008*, 103 NW. U. L. REV. COLLOQUY 217, 228-29 (2008) (describing how even after the passage of the ADAAA, there is still a lack of guidance about what reasonable accommodation means). If given access to reasonable accommodations, persons with severe brain injury may be able to work, and then Title I of the ADA would apply.

139. Wright & Fins, *supra* note 62, at 272-73 (discussing this argument in the context of the MCS, but it is more broadly applicable to persons with severe brain injury).

140. 42 U.S.C. § 12182(b)(2)(A)(iii) (2012).

141. See also Wright & Fins, *supra* note 62, at 270-71, 275-77 (addressing cost counterarguments). Cost is not likely to be an issue because some technologies are rather cheap and because the capital equipment already exists in many facilities. Also, it is not a given that costs will increase, if providing accommodations reduces other large costs. Regardless, cost cannot be a huge consideration ethically. *Id.*; see also Dalia B. Taylor, Note, *Communicating with Vegetative State Patients: The Role of Neuroimaging in American Disability Law*, 66 STAN. L. REV. 1451, 1468-69 (2014) (describing guidance related to cost considerations as applied to this population who needs access to neurotechnologies).

142. SCOTCH, *supra* note 64, at 142.

143. See U.S. Dep't of Justice Civil Rights Div., *ADA Enforcement*, ADA.GOV, https://www.ada.gov/enforce_current.htm [<https://perma.cc/5L35-WHTB>].

enforcement, the Justice Department has found that South Dakota has been violating the rights of persons with disabilities by placing them in nursing homes to receive needed medical care rather than providing care in the community.¹⁴⁴ More importantly for the purposes of this Article, there has been litigation in Massachusetts about the medically unnecessary institutionalization of persons with brain injury in nursing homes.¹⁴⁵ Such litigation was settled, with the state promising to deinstitutionalize this population.¹⁴⁶ However, the settlement had to be amended because the state was unable to fulfill its promise.¹⁴⁷ Little material progress has been made, and persons with severe brain injury continue to be marginalized.¹⁴⁸

We advocate for class action lawsuits on behalf of persons with severe brain injury alleging ADA and *Olmstead* violations, similar to the lawsuit that resulted in a settlement in Massachusetts.¹⁴⁹ However, it may be preferable for future litigation to result in a “judicial opinion that [has] significant precedential value,”¹⁵⁰ perhaps an *Olmstead* equivalent for the severely brain injured, rather than a settlement.¹⁵¹ This is difficult for plaintiffs, however, who initiate lawsuits for immediate remedies rather than symbolic victories and may accept a settlement for less than they could attain through litigation.¹⁵² However, as can be seen in the Massachusetts case, settle-

144. U.S. DEP'T OF JUSTICE CIVIL RIGHTS DIV., UNITED STATES' INVESTIGATION, PURSUANT TO THE AMERICANS WITH DISABILITIES ACT, OF SOUTH DAKOTA'S USE OF NURSING FACILITIES TO SERVE INDIVIDUALS WITH DISABILITIES (2016).

145. *Hutchinson ex rel. Julien v. Patrick*, 636 F.3d 1 (1st Cir. 2011).

146. Final Comprehensive Settlement Agreement at 1-4, *Patrick*, 636 F.3d 1 (No. 07-CV-30084-MAP).

147. See Joint Motion for Preliminary Approval of Amended Settlement Agreement, for Approval of a Notice to the Class, and for Scheduling of a Fairness Hearing, *Patrick*, 636 F.3d 1 (No. 07-CV-30084-MAP); Proposed Order Approving Amended Settlement Agreement, *Patrick*, 636 F.3d 1 (No. 07-CV-30084-MAP) (approving amended settlement agreement).

148. See *Hutchinson v. Patrick: The Litigation and Settlement*, CTR. FOR PUB. REPRESENTATION, <https://web.archive.org/web/20160429143543/www.centerforpublicrep.org/litigation-and-major-cases/brain-injury/the-litigation-hutchinson-v-patrick> [https://perma.cc/E538-XMEF].

149. A class action lawsuit with well-supported named plaintiffs may aid in one problem with litigation on behalf of persons with severe brain injury: the inability to advocate for themselves. See SCOTCH, *supra* note 64, at 12 (describing this in the case of disability generally). It may be difficult to initiate Title III lawsuits, however, given that monetary damages are not possible when private parties file suit. Ruth Colker, *ADA Title III: A Fragile Compromise*, 21 BERKELEY J. EMP. & LAB. L. 377, 378 (2000). Absent such a possibility, there may not be incentive for individuals to bring suit.

150. MARK V. TUSHNET, *THE NAACP'S LEGAL STRATEGY AGAINST SEGREGATED EDUCATION, 1925-1950*, at 61 (1st ed. 1987).

151. See also Wright & Fins, *supra* note 62, at 278-79 (describing the benefits of successful litigation on behalf of persons with MCS, and in particular, that such litigation can force compliance from other actors, who are not parties to lawsuits and want to avoid lawsuits).

152. TUSHNET, *supra* note 150, at 81-82.

ments require ongoing enforcement and may promise more than they can deliver. Finally, even if class action litigation is unsuccessful in obtaining a verdict for the plaintiffs, it may nevertheless motivate the legislature—either state or federal—to take action on behalf of this population.¹⁵³

C. *Affordable Care Act*

When the ACA¹⁵⁴ was passed, many anticipated that this legislation would have far-reaching positive impacts on the lives of persons with disabilities.¹⁵⁵ As some scholars wrote, what the ACA does is “introduce a federally uniform meaning to the concept of coverage, at least in the individual and small group markets, with a particular focus on the integrity of such coverage for persons with disabilities and serious health conditions.”¹⁵⁶ The most important ways in which the ACA influences medical care for persons with disabilities are by increasing the numbers of persons who have health insurance through subsidizing healthcare and expanding Medicaid programs, mandating coverage of certain benefits, and prohibiting discrimination.

The future of the ACA is uncertain, however.¹⁵⁷ At the time of this writing, the ACA has not yet been repealed or amended, although these actions are still a priority for some members of the Republican-controlled Congress. The ACA was instrumental in bringing persons with disabilities out of the shadows, and a repeal is likely to be regressive, pushing persons with disabilities back to the margins of society.

1. *Nondiscrimination*

The ACA prohibits health insurers from discriminating against persons with disabilities and chronic health conditions.¹⁵⁸ Some scholars have noted that in this respect the ACA may do more to

153. Ryan, *supra* note 60, at 97-98.

154. 42 U.S.C. § 18001 (2012).

155. See, e.g., Sara Rosenbaum, Joel B. Teitelbaum & Katherine Hayes, *Crossing the Rubicon: The Impact of the Affordable Care Act on the Content of Insurance Coverage for Persons with Disabilities*, 25 NOTRE DAME J.L. ETHICS & PUB. POL'Y 527, 561-62 (2011). Indeed, some scholars even asserted that the ACA was a piece of legislation that interpreted the Due Process Clause of the U.S. Constitution to guarantee a positive right to healthcare. Rubin, *supra* note 68, at 1701, 1704-05.

156. Rosenbaum, Teitelbaum & Hayes, *supra* note 155, at 530.

157. Jonathan Oberlander, *The End of Obamacare*, 376 NEW ENG. J. MED. 1 (2017) (discussing all of the steps a Trump Administration could take to chip away at the ACA and how Congress will likely repeal it, but what, if anything would replace it, is unknown).

158. Rosenbaum, Teitelbaum & Hayes, *supra* note 155; *Disabilities*, *supra* note 132; Douglas Jacobs & Wayne Turner, *Nondiscrimination and Chronic Conditions—The Final Section 1557 Regulation*, HEALTHAFF.: BLOG (July 20, 2016), <http://healthaffairs.org/blog/2016/07/20/nondiscrimination-and-chronic-conditions-the-final-section-1557-regulation/>.

bring persons with disabilities into society than disability legislation itself.¹⁵⁹ This is because the Rehabilitation Act and the ADA still permit insurers to discriminate against persons with disabilities actuarially as long as they do not refuse to sell insurance to them, while the ACA prohibits this.¹⁶⁰ Insurers cannot deny coverage to persons because they have “preexisting conditions,” for example.¹⁶¹ This matters for persons with severe brain injury because it means that any gaps in insurance coverage will not prevent them from later being insured or having health problems associated with their injury covered by insurance. Given that brain injuries often lead to chronic problems, disability advocates should fight any future changes to the ACA that alter this guarantee of nondiscrimination.

2. *Essential Health Benefits*

The ACA mandates that insurance plans sold on the exchanges provide ten essential health benefits.¹⁶² These essential health benefits have the effect of creating a national health insurance minimum standard, and include the critical category of Rehabilitation and Habilitation—a benefit that was lobbied for, in part, by Gabrielle Giffords, who was afforded extensive rehabilitation after surviving a gunshot wound to the head only because it was covered by workers’ compensation.¹⁶³ It is unclear what the impact of this health benefit will be, however, given that it is unknown what kind of rehabilitative services will be considered essential.¹⁶⁴ The ACA deferred to the Secretary of Health and Human Services (HHS) to define the content of the ten essential health benefits.¹⁶⁵ The Secretary requested a report from the Institute of Medicine, which recommended that these “benefits . . . be modeled after a typical small employer plan,” but ensuring that every category is included and that there is no discrimination.¹⁶⁶ The Secretary of HHS then gave the states discretion to define these benefits by selecting a benchmark insurance plan available in their

159. See, e.g., Rosenbaum, Teitelbaum & Hayes, *supra* note 155, at 562.

160. *Id.*

161. Patient Protection and Affordable Care Act, 42 U.S.C. § 18001 (2012).

162. See *id.* § 18022(b)(1).

163. Lena Groeger, *Giffords May Get Better Brain-Injury Care Than Most of Her Constituents*, PROPUBLICA (Jan. 17, 2012, 9:49 AM), <https://www.propublica.org/article/giffords-may-get-better-brain-injury-care-than-most-of-her-constituents> [<https://perma.cc/XWT2-6GDW>].

164. Joseph W. Boninger, Bruce M. Gans & Leighton Chan, *Patient Protection and Affordable Care Act: Potential Effects on Physical Medicine and Rehabilitation*, 93 ARCHIVES PHYSICAL MED. & REHAB. 929, 930 (2012).

165. *Id.*; see also Rosenbaum, Teitelbaum & Hayes, *supra* note 155, at 555; Hill, *supra* note 69, at 451 (describing the process of defining the essential health benefits).

166. Boninger, Gans & Chan, *supra* note 164, at 930.

state.¹⁶⁷ This lessens the intended uniform health insurance standard. Additionally, physical medicine and rehabilitation is currently a “shortage specialty,” so there may not be enough physiatrists to meet demand.¹⁶⁸

Less obviously important than the required rehabilitation coverage is mandatory coverage for chronic disease treatment. There is an emerging medical consensus that persons with moderate/severe TBI who require rehabilitation can acquire “a lifelong health condition termed chronic brain injury (CBI). CBI impairs the brain and other organ systems and may persist or progress over an individual’s life span. CBI must be identified and proactively managed as a lifelong condition to improve health, independent function and participation in society.”¹⁶⁹ Given this change in understanding and the costs associated with decline, some scholars argue that TBI should be considered a chronic health condition and speculate that disease management can “improve outcomes and reduce costs” by “prevention or delay of complications through early detection and intervention.”¹⁷⁰

There may be opportunities under the ACA to target CBI, particularly through grant/funding mechanisms. But the ACA currently conceptualizes the treatment of chronic conditions as interventions such as diabetes management, smoking cessation, and cancer screenings.¹⁷¹ Therefore, advocates for persons with severe brain injury may need to analogize CBI to these other types of conditions and assert the importance of preventative care in the case of TBI.

3. *Changes to Medicaid*

While repealing some parts of the ACA such as the exchanges and subsidies is likely, it may be more politically difficult to repeal the Medicaid eligibility expansion, given that the states that took advantage of it probably do not want to give up those funds.¹⁷² It remains to be seen how other Medicaid programs affected by the ACA will be impacted should the ACA be repealed.

The ACA created new Medicaid programs and increased funding for existing grant programs. In particular, the ACA contains several

167. *Id.* Many large group plans will already have many of these benefits, except habilitation.

168. *Id.*

169. John D. Corrigan & Flora M. Hammond, *Traumatic Brain Injury As a Chronic Health Condition*, 94 ARCHIVES PHYSICAL MED. & REHAB. 1199, 1199 (2013).

170. *Id.* at 1200.

171. *See, e.g., Health Homes*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/ltss/health-homes/index.html> [<https://perma.cc/SGX9-P5BY>] (describing chronic conditions listed in the statute but noting that other chronic conditions may be approved by CMS).

172. Oberlander, *supra* note 157, at 3.

incentives to help states build better long-term services and supports systems (LTSS). LTSS is defined as “assistance with activities of daily living” provided to “people [who] cannot perform these activities on their own because of a physical, cognitive, or chronic health condition that is expected to continue for an extended period of time, typically ninety days or more.”¹⁷³

Most persons who require LTSS use Medicaid.¹⁷⁴ Although persons with disabilities who need LTSS have always preferred to receive care in their homes or communities, the United States has a long history of institutionalizing such persons instead.¹⁷⁵ When Medicaid was first created, “the only mandatory coverage of long-term services and supports was that provided in skilled nursing facilities.”¹⁷⁶ There began to be a transition to home and community-based services when Congress created waivers for Medicaid,¹⁷⁷ and after *Olmstead*, there was a mandate for states to provide LTSS to persons in the least restrictive environment,¹⁷⁸ but this care is often not available or affordable.

Since the Great Recession, states have cut funding for LTSS,¹⁷⁹ and thus state Medicaid programs are placing persons with disabilities in nursing homes when community- or home-based care would be more appropriate.¹⁸⁰ While states do want to provide care to persons with disabilities in their homes and communities because this is more cost-effective and persons with disabilities would prefer not to be institutionalized,¹⁸¹ there are insufficient community-based facilities (or public funding is not available to pay for care in such facilities).¹⁸² Advocates for persons who need LTSS recommend that state Medicaid programs pay family caregivers so that care can be provided in the home, or provide transportation for people who receive

173. Susan C. Reinhard, Enid Kassner & Ari Houser, *How the Affordable Care Act Can Help Move States Toward a High-Performing System of Long-Term Services and Supports*, 30 HEALTH AFF. 447, 449 (2011).

174. *Id.* at 447.

175. Mary D. Naylor et al., *An Assessment of State-Led Reform of Long-Term Services and Supports*, 40 J. HEALTH POL. POL'Y & L. 531, 537 (2015).

176. Reinhard, Kassner & Houser, *supra* note 173, at 452.

177. *See also id.* (“But in 1981 Congress allowed states to waive certain federal requirements in order to increase their ability to provide home and community-based services to people who would otherwise have to be in a nursing home.”).

178. *See* Naylor et al., *supra* note 175, at 542.

179. The proportion of spending on LTSS to total Medicaid spending is high, so budget cuts focus on LTSS. *Id.* at 533.

180. Reinhard, Kassner & Houser, *supra* note 173, at 449; *see also* Naylor et al., *supra* note 175, at 542-43 (discussing financial barriers to *Olmstead* enforcement and deinstitutionalization).

181. Reinhard, Kassner & Houser, *supra* note 173, at 448.

182. *Id.* at 450.

LTSS outside of the home, so they can remain connected to their communities.¹⁸³

In order to address the problem of over-institutionalizing persons with disabilities, the ACA created the Community First Option, the Balancing Incentives Payment Program, and Medicaid “health homes,” as well as extended the existing Money Follows the Person (MFP) grant. The Community First Option increases the amount of federal funding for Medicaid in states that “offer person-centered home and community-based services.”¹⁸⁴ The Balancing Incentives Payment Program is targeted at states that use nursing homes rather than community- or home-based options to provide LTSS, and increases federal Medicaid funding if states change how they approach long-term care.¹⁸⁵ Medicaid health homes are for persons who have multiple chronic health conditions or at least one chronic health condition and are at risk for another; the program is meant to coordinate care that treats the “whole person.”¹⁸⁶

The MFP grant program existed prior to the ACA,¹⁸⁷ but the ACA extended the length of the grant program and allotted more funding for these “grants that help move people out of institutions or avoid unwanted institutionalization”¹⁸⁸ and “change state policies so that Medicaid funds for long-term care services and supports can ‘follow the person’ to the setting of his or her choice.”¹⁸⁹ An evaluation of MFP reveals that 45 state grants have transitioned over 50,000 Medicaid recipients to the community between 2008 and 2014.¹⁹⁰

183. *Id.*

184. *Id.* at 451; see also *Community First Choice (CFC) 1915 (k)*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/hcbs/authorities/1915-k/index.html> [<https://perma.cc/3QU8-S2ZT>].

185. Reinhard, Kassner & Houser, *supra* note 173, at 451; see also *Balancing Incentive Program*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/ltss/balancing/incentive/index.html> [<https://perma.cc/HCU9-NLXY>].

186. *Health Homes*, *supra* note 171.

187. See Deficit Reduction Act of 2005, Pub. L. No. 109-171, 120 Stat. 4 (2006).

188. Reinhard, Kassner & Houser, *supra* note 173, at 451; see also *Money Follows the Person*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/ltss/money-follows-the-person/index.html> [<https://perma.cc/RG6B-CJKH>].

189. NOELLE DENNY-BROWN ET AL., MATHEMATICA POL’Y RESEARCH, THE RIGHT SUPPORTS AT THE RIGHT TIME: HOW MONEY FOLLOWS THE PERSON PROGRAMS ARE SUPPORTING DIVERSE POPULATIONS IN THE COMMUNITY 2 (2015), <https://www.mathematica-mpr.com/our-publications-and-findings/publications/the-right-supports-at-the-right-time-how-money-follows-the-person-programs-are-supporting-diverse> [<https://perma.cc/4ESD-R3LP>].

190. *Id.* at 3 (citing MELISSA MEDEIROS ET AL., MONEY FOLLOWS THE PERSON DEMONSTRATION: OVERVIEW OF STATE GRANTEE PROGRESS, JANUARY TO DECEMBER 2014 (2015)). It is beyond the scope of this Article to detail all the differences between state Medicaid programs given the immense variability in terms of what services are covered and eligibility requirements.

While funding is still available, states that have not yet applied for such grants or created these programs should do so in order to increase noninstitutional options for providing LTSS to persons with chronic conditions and disabilities. Should states receive funding and create programs, advocates for persons with disabilities should continue to pressure the states to ensure that such programs are high quality, successful, and sustainable.

Given that persons with severe brain injury often need LTSS, which may be paid for by Medicaid, they are likely more susceptible to unnecessary institutionalization, something that the above-described programs attempt to reduce. Advocates for persons with severe brain injury should, therefore, lobby Congress to continue funding these programs, even if the ACA is repealed and replaced. Furthermore, advocates should lobby for TBI and CBI to be considered chronic health conditions for the purposes of establishing a Medicaid health home. Currently, the statute does not mention severe brain injury.¹⁹¹ However, the Centers for Medicare and Medicaid Services has the authority and discretion to permit Medicaid health homes for individuals with other chronic conditions not listed in the statute.¹⁹²

D. Statutes and Regulations for Subpopulations of Persons with Severe Brain Injury

Persons with severe brain injury are a diverse group. Some are school-aged, while others are adults. Some acquired their brain injury while serving in the U.S. Armed Forces. Some could benefit from access to cutting-edge drugs and assistive devices. Some access healthcare through Medicare. Below, we discuss federal statutes and regulations that address certain categories of persons with severe brain injury to determine how these could be leveraged to more fully include persons with severe brain injury in civil society.

In the above Sections, we have discussed rights—constitutional and statutory. However, political theorists and ethicists are increasingly focusing on the importance of *capabilities* as a supplement to *rights*. The political theorist Sridhar Venkatapuram,¹⁹³ drawing upon the work of Martha Nussbaum¹⁹⁴ and Amartya Sen,¹⁹⁵ has noted that

191. See *Health Homes*, *supra* note 171.

192. See *id.*

193. SRIDHAR VENKATAPURAM, *HEALTH JUSTICE: AN ARGUMENT FROM THE CAPABILITIES APPROACH* (2011).

194. MARTHA C. NUSSBAUM, *CREATING CAPABILITIES: THE HUMAN DEVELOPMENT APPROACH* (2013).

195. AMARTYA SEN, *COMMODITIES AND CAPABILITIES* (1999).

rights can only be achieved in a supportive and enabling context that allows individuals the opportunity (and capability) to be healthy and pursue a life plan.¹⁹⁶ For those who have sustained a severe brain injury and who have to adapt and modify their life plan, this requires access to those interventions, drugs, and devices that make adaptation and resilience possible.

In this Section, we begin by continuing to address rights in the context of statutes directed toward the needs of veterans with TBI. But we then address three essential instrumentalities that constitute important means that can enable recovery and promote resilience from severe brain injury, and in the process, promote essential capabilities such as health, bodily integrity, consciousness, affiliation, and control over one's environment.¹⁹⁷ These instrumentalities are education, rehabilitation, and assistive devices.

To address the first intervention of education, we consider how the Individuals with Disabilities Education Act (IDEA) may assist minors with severe brain injury receive an education, which is essential to maximizing capabilities. To address the second intervention of rehabilitation, we will consider how Medicare regulations can dictate the extent and nature of access to rehabilitation, which may be necessary to realize consciousness, which underlies many capabilities. To consider the intervention of devices, we will outline some of the current challenges faced by researchers who are attempting to utilize neuromodulation and deep brain stimulation as a plausible treatment for severe brain injury.

1. *Veterans with Severe Brain Injury*

One special population of persons with severe brain injury is veterans; particularly, veterans of the wars in Iraq and Afghanistan, where the signature war injury is TBI.¹⁹⁸ Some estimate that about 235,000 Armed Forces personnel have sustained a TBI since 2000,¹⁹⁹ and these injuries often require extensive and expensive medical care followed by long-term rehabilitation. In this Section, we survey the actions of Congress and the Department of Veterans Affairs (VA) in

196. Joseph J. Fins, *Health Justice: An Argument from the Capabilities Approach*, 307 J. AM. MED. ASS'N 2106 (2012) (book review).

197. See NUSSBAUM, *supra* note 194.

198. Daisy Yuhas, *Veterans of Iraq, Afghanistan Show Brain Changes Related to Explosion Exposure*, SCI. AM. (Jan. 15, 2016), <https://www.scientificamerican.com/article/veterans-of-iraq-afghanistan-show-brain-changes-related-to-explosion-exposure/> [<https://perma.cc/GA3U-5J7X>].

199. CTRS. FOR DISEASE CONTROL & PREVENTION ET AL., REPORT TO CONGRESS ON TRAUMATIC BRAIN INJURY IN THE UNITED STATES: UNDERSTANDING THE PUBLIC HEALTH PROBLEM AMONG CURRENT AND FORMER MILITARY PERSONNEL 54 (2013).

response to the problems faced by veterans with TBI, and conclude that the VA has not successfully addressed the health needs of veterans with TBI, despite the congressional mandate to do so.

Congress has acknowledged the severity of the social and health problems associated with veterans returning from war through extensive legislation meant to aid the VA in responding to this crisis. Much of this legislation has been broad in focus, and all of the legislation mandates reports to Congress on the VA's progress in meeting the needs of veterans.

One early piece of such legislation was the Veterans Health Programs Improvement Act of 2004, the primary purpose of which was "to increase the authorization of appropriations for grants to benefit homeless veterans, [and] to improve programs for management and administration of veterans' facilities and health care programs."²⁰⁰ As part of this particular legislation, Congress mandated reports about the recruitment and retention of rehabilitation nurses and waiting times for veterans to receive care.²⁰¹ While this legislation is about healthcare broadly, its aims, if realized, also benefit veterans with TBI who need quick access to healthcare and rehabilitation.

Other legislation has focused specifically on the needs of veterans with TBI and their family caregivers. Some of this legislation has called for longitudinal studies on veterans with TBI;²⁰² creation of programs that train family caregivers and also provide technical assistance, respite, lodging, health care, and a stipend for them; and reports on the creation and evaluation of these programs.²⁰³ And in 2008, Congress mandated the creation of a "Comprehensive Plan on Prevention, Diagnosis, Mitigation, Treatment, and Rehabilitation of, and Research on, Traumatic Brain Injury, Post-Traumatic Stress Disorder, and Other Mental Health Conditions," part of which required reports on TBI Centers of Excellence; how much money is spent on TBI; progress and priorities on TBI; and the status of community integration of and rehabilitation for veterans with TBI.²⁰⁴

Most recently, Congress passed the Veterans Access, Choice, and Accountability Act of 2014, allotting money to create a database on patient wait times, outcomes, and quality of care received in VA facil-

200. Veterans Health Programs Improvement Act of 2004, Pub. L. No. 108-422, 118 Stat. 2379 (2004).

201. *Id.* §§ 501(d), 604.

202. John Warner National Defense Authorization Act for Fiscal Year 2007, Pub. L. No. 109-364, § 721, 120 Stat. 2294 (2006).

203. Caregivers and Veterans Omnibus Health Services Act of 2010, Pub. L. No. 111-163, § 203(a), 124 Stat. 1143 (2010).

204. National Defense Authorization Act for Fiscal Year 2008, Pub. L. No. 110-181, § 1618, 122 Stat. 450 (2008).

ities in an attempt to increase transparency.²⁰⁵ Additionally, the Act extended a program to assess “the effectiveness of providing assisted living services to eligible Veterans with traumatic brain injuries to ‘enhance the rehabilitation, quality of life, and community integration of such Veterans.’”²⁰⁶

Given reports that veterans were not receiving adequate care at the VA, however, we were not satisfied that legislation alone was sufficient for veterans to obtain the medical and rehabilitative care they needed. In previous research, we attempted to evaluate the impact of this legislation.²⁰⁷ However, we found that the reports mandated by Congress were inaccessible and/or nonexistent. It would appear that the VA has been utterly unresponsive to Congress’s demand for an accounting of the scope of the problem of veterans with TBI, the actions that the VA has taken to address these veterans’ needs, and the success of such actions, as well as gaps that still need to be addressed.²⁰⁸

Veterans with TBI do not need more legislation. Congress need only properly manage the VA by demanding that the agency fulfill its responsibility to veterans with TBI, as outlined in the legislation described above, and appropriate funds necessary for all of the programs Congress outlined.²⁰⁹

We would now suggest that immense public pressure be brought to bear on Congress and the VA to fulfill the letter and spirit of this extensive legislation and give veterans with severe brain injury the medical care and rehabilitative treatment they need to be more fully integrated in society. Citizens should call their congressional representatives and demand action.²¹⁰

2. *Children with Severe Brain Injury and Access to Education*

The IDEA seeks “to ensure that all children with disabilities have available to them a free [and] appropriate public education that em-

205. Veterans Access, Choice, and Accountability Act of 2014, Pub. L. No. 113-146, 128 Stat. 1754 (2014).

206. U.S. DEP’T OF VETERANS AFF., SUMMARY: VETERANS ACCESS, CHOICE AND ACCOUNTABILITY ACT OF 2014 (“CHOICE ACT”) 2, <https://www.va.gov/opa/choiceact/documents/choice-act-summary.pdf> [<https://perma.cc/CK4D-6LLD>].

207. Michael R. Ulrich et al., *Lincoln’s Promise: Congress, Veterans, and Traumatic Brain Injury*, HASTINGS CTR. (June 21, 2016), <http://www.thehastingscenter.org/lincolns-promise-congress-veterans-and-traumatic-brain-injury/> [<https://perma.cc/VFF3-HHAX>].

208. *Id.*

209. See also COMM’N ON CARE, FINAL REPORT 2, 242 tbl.F-7 (2016), https://s3.amazonaws.com/sitesusa/wp-content/uploads/sites/912/2016/07/Commission-on-Care_Final-Report_063016_FOR-WEB.pdf [<https://perma.cc/94US-678Z>] (reporting that access to health care is a problem for veterans, especially those in rural areas).

210. Our easily accessible prior work also can be distributed on social media. Ulrich et al., *supra* note 207.

phasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.”²¹¹ The Act was originally passed in 1975 as the Education for All Handicapped Children Act after a congressional investigation found that the majority of children with disabilities “were either totally excluded from schools or sitting idly in regular classrooms awaiting the time when they were old enough to ‘drop out.’”²¹² The IDEA creates a kind of contract between the federal government and the states: The federal government offers special-education grants to the states and, in accepting the funding, the states agree to provide a “free [and] appropriate public education” (FAPE) as specified by the Act to all children with an eligible disability.²¹³ Notably for our purposes, in amendments to IDEA passed in 1990, Congress explicitly added TBI as an eligible category of disability.²¹⁴

Special education for individuals with brain injuries poses a number of unique challenges. The United States’ special education system has a variety of pathways for beginning interventions for infants and toddlers with disabilities diagnosed early in life, whose parents often become sophisticated advocates.²¹⁵ By contrast, severe brain injury occurs abruptly and often much later in a child’s education, when inexperienced and overwhelmed parents may struggle to locate the resources necessary to transition their child from the hospital to an appropriate educational environment.²¹⁶ Even after that transition, individuals with acquired brain injuries can suffer from the assumption that “as the child’s outward manifestations of an injury fade, the internal damage is repaired as well.”²¹⁷ This may help to explain why one group of scholars found that less than half of children who experience severe TBI and are still in special education four years later are classified as suffering from TBI: most were classified under the general learning disabilities designation in the IDEA, leading the group to conclude that “because interventions for other handicapping conditions have limited applicability in treating TBI, inappropriate

211. 20 U.S.C. § 1400(d)(1)(A) (2012).

212. *Endrew F. v. Douglas Cty. Sch. Dist.*, 137 S. Ct. 988, 999 (2017) (quoting H.R. REP. NO. 94-332, at 2 (1975)); see also Education for All Handicapped Children Act of 1975, Pub. L. No. 94-142, 89 Stat. 773.

213. Antonis Katsiyannis, Mitchell L. Yell & Renee Bradley, *Reflections on the 25th Anniversary of the Individuals with Disabilities Education Act*, 22 REMEDIAL & SPECIAL EDUC. 324, 324 (2001).

214. 20 U.S.C. § 1401(3).

215. Ronald C. Savage et al., *Paediatric Traumatic Brain Injury: A Review of Pertinent Issues*, 8 PEDIATRIC REHAB. 92, 94 (2005).

216. *Id.* at 94, 95.

217. Rik Carl D’Amato & Barbara A. Rothlisberg, *How Education Should Respond to Students with Traumatic Brain Injury*, 29 J. LEARNING DISABILITIES 670, 678 (1996).

classifications are considered obstacles to effective programming.”²¹⁸ And, looking towards adult life, a systematic review of studies on the transition of students with disabilities from school to post-school activities found that students with acquired brain injuries are a particularly stigmatized and poorly treated group—and recommended “inclusive education” through more partnerships between general and special educators to deliver an integrated educational experience.²¹⁹

a. The Six Principles of the IDEA

For individuals who experience severe brain injury between birth and age twenty-one, the IDEA provides an important but complex tool for accessing appropriate education, transition services, and related resources. Six principles underpin the IDEA: (1) the provision of a FAPE; (2) the appropriate use of experts and tools for the evaluation of a student’s capabilities; (3) a written document called an “individualized education program” (IEP); (4) parent and student participation in decisionmaking; (5) education in the least restrictive environment; and (6) procedural safeguards.²²⁰

i. Free and Appropriate

A primary aspect of a FAPE is that it is free to parents despite the often substantially greater resources necessary to provide appropriate education to students with disabilities. Parents may be reimbursed for the costs of private school education if a court determines that the educational agency “had not made a free appropriate public education available to the child in a timely manner prior to that enrollment,” over which much IDEA litigation takes place.²²¹

ii. Evaluation

Appropriate evaluation under the IDEA requires the use of trained professionals and proper evaluation instruments.

iii. Individualized Education Program

The IEP is “a written statement for each child with a disability” that includes a statement of the child’s current academic and functional performance; “measurable annual goals . . . designed to . . .

218. H. Gerry Taylor et al., *Long-Term Educational Interventions After Traumatic Brain Injury in Children*, 48 REHAB. PSYCHOL. 227, 234 (2003).

219. R. Brian Cobb & Morgen Alwell, *Transition Planning/Coordinating Interventions for Youth with Disabilities: A Systematic Review*, 32 CAREER DEV. EXCEPTIONAL INDIVIDUALS 70, 73, 78 (2009).

220. DISABILITY RIGHTS EDUC. & DEF. FUND, A GUIDE FOR CALIFORNIA PARENTS: SPECIAL EDUCATION DUE PROCESS AND THE RESOLUTION MEETING 2-3 (2008), https://dredf.org/special_education/dueprocess.pdf [<https://perma.cc/MRG3-A49M>].

221. 20 U.S.C. § 1412(a)(10)(C)(ii) (2012).

meet the child's needs"; how progress will be measured; the special services and accommodations to be provided to the child; and post-secondary goals and transition services for training, education, employment, or independent living.²²²

iv. Participation

The IDEA provides for substantial parental involvement in the creation of the IEP through regular IEP meetings and affords a robust due process hearing for parents to challenge eligibility, services, and the sufficiency of the education provided to their children.

v. Least Restrictive Environment

Finally, the IDEA requires that "[t]o the maximum extent appropriate, children with disabilities . . . are educated with children who are not disabled," such that students are only removed from the normal educational environment "when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."²²³

vi. Procedural Safeguards

The IDEA has been characterized as "view[ing] special education law through a strongly proceduralist lens [T]he process by which the IEP is created is of far more importance than the substantive content of the resulting IEP."²²⁴ Indeed, in the seminal Supreme Court case on the IDEA, the Court pointed to the "contrast[]" between "the elaborate and highly specific procedural safeguards" and "the general and somewhat imprecise substantive admonitions contained in the Act," ultimately determining that the focus on process "demonstrates the legislative conviction that adequate compliance with the procedures prescribed would in most cases assure much if not all of what Congress wished in the way of substantive content in an IEP."²²⁵ On one level, this is troubling for failing to endorse any strong substantive standard that schools must meet. Yet, on another level, it provides an important model of robust procedural protections that are largely lacking in other areas for individuals with severe brain injury.

The procedural safeguards section of the IDEA requires states to establish a detailed set of safeguards—including the opportunity for parents to examine all records and participate in all meetings regard-

222. *Id.* § 1414(d)(1)(A)(i).

223. *Id.* § 1412(a)(5)(A).

224. Jon Romberg, *The Means Justify the Ends: Structural Due Process in Special Education Law*, 48 HARV. J. ON LEGIS. 415, 416 (2011).

225. *Bd. of Educ. v. Rowley*, 458 U.S. 176, 205-06 (1982).

ing the evaluation and placement of their child,²²⁶ a provision of notice in the parents' native language,²²⁷ an opportunity for mediation prior to a formal due process complaint and hearing,²²⁸ and the creation of a model form to assist parents in filing a due process complaint.²²⁹ The IDEA provides grants for states to create parent training and information centers,²³⁰ and parents can meet with a disinterested party from such a state center to discuss disputes.²³¹ For parents who decide on mediation, the state must bear the cost of mediation and must maintain a list of qualified mediators.²³²

At a due process hearing, the hearing officer must make a determination of whether the child received a FAPE, considering both substantive factors and any procedural violations that impeded the child's right to a FAPE.²³³ After the hearing, parents have the opportunity to appeal to the state educational agency and, if still aggrieved thereafter, may bring a civil action in U.S. district court.²³⁴ During the due process hearing and appeal, parents are afforded a range of important rights, including "the right to be accompanied and advised by counsel and by individuals with special knowledge or training with respect to the problems of children with disabilit[ies]";²³⁵ "the right to present evidence and confront, cross-examine, and compel the attendance of witnesses";²³⁶ and the right to a written record of the hearing and the hearing officer's decision.²³⁷

Although some have noted the disparities these time- and resource-intensive procedures may create based on socio-economic status,²³⁸ these procedural safeguards provide a far greater opportunity for institutional attention and support than individuals with severe brain injury experience elsewhere in the medico-legal system.

226. 20 U.S.C. § 1415(b)(1).

227. *Id.* § 1415(d)(2).

228. *Id.* § 1415(e)-(f).

229. *Id.* § 1415(b)(8).

230. *Id.* §§ 1471-1472.

231. *Id.* § 1415(e)(2)(B).

232. *Id.* § 1415(e)(2)(C)-(D).

233. *Id.* § 1415(f)(3)(E).

234. *Id.* § 1415(i)(2).

235. *Id.* § 1415(h)(1).

236. *Id.* § 1415(h)(2).

237. *Id.* § 1415(h)(3)-(4).

238. See, e.g., Eloise Pasachoff, *Special Education, Poverty, and the Limits of Private Enforcement*, 86 NOTRE DAME L. REV. 1413 (2011); Joseph Fluehr, Note, *Navigating Without a Compass: Incorporating Better Parental Guidance Systems into the IDEA's Dispute Resolution Process*, 8 DREXEL L. REV. 155 (2015); Erin Phillips, Note, *When Parents Aren't Enough: External Advocacy in Special Education*, 117 YALE L.J. 1802 (2008).

b. The Scope of “Special Education and Related Services”

The IDEA provides for both “special education and related services.”²³⁹ “Related services,” as provided for and defined in the IDEA, contemplates a very wide range of resources, including:

[T]ransportation, and such developmental, corrective, and other supportive services (including speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, school nurse services designed to enable a child with a disability to receive a free appropriate public education as described in the individualized education program of the child, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a child with a disability to benefit from special education²⁴⁰

As this definition suggests, “related services” can be interpreted broadly enough to provide substantial resources to students with severe brain injury. For instance, a court found that the parents of a child with serious behavioral problems arising from a brain injury should be reimbursed for private placement in a rehabilitation facility for brain injury victims because the school’s provision of in-home services failed to confer an educational benefit.²⁴¹ The family succeeded in this case even over the school board’s objection that the facility was a “‘medical’ program for which it was not responsible.”²⁴² In this way, the IDEA serves as an appropriate counterpart to the ADA’s and the Rehabilitation Act’s emphasis on *rehabilitative* services, not just palliative care or, in the educational context, maintenance of the status quo.²⁴³ Similarly, the least restrictive environment requirement mirrors the deinstitutionalization efforts of these statutes, seeking to decrease the separation and isolation of individuals with disabilities.²⁴⁴

239. 20 U.S.C. § 1400(d)(1)(A).

240. *Id.* § 1401(26)(A).

241. *Brown ex rel. Brown v. Wilson Cty. Sch. Bd.*, 747 F. Supp. 436, 445-46 (M.D. Tenn. 1990).

242. *Id.* at 439.

243. See *supra* notes 98-153 and accompanying text.

244. See, e.g., *S.H. v. State-Operated Sch. Dist. of Newark*, 336 F.3d 260, 265 (3d Cir. 2003).

c. What Level of Educational Benefit?

The Supreme Court recently considered an issue that is crucial in clarifying the rights of children with disabilities, in general, and of children with severe brain injury, in particular: What level of educational benefit must school districts provide in order to fulfill the IDEA's requirement of providing a FAPE?²⁴⁵ In the first Supreme Court case to consider the IDEA and the last one to meditate on the definition of a FAPE, the Court held that though an IEP must be "*reasonably calculated* to enable the child to receive educational benefits," Congress did not intend to require "strict equality of opportunity or services" or require schools to "maximize each handicapped child's potential."²⁴⁶ In the wake of that 1982 decision, the courts of appeals have developed different and conflicting standards on what degree of benefit schools must confer: some hold that IEPs must confer "meaningful educational benefit" on students, while others reject this higher standard and hold that schools need only provide "merely . . . 'more than de minimis' " benefit.²⁴⁷

In *Endrew F. v. Douglas County School District*,²⁴⁸ recently decided by the Supreme Court, the parents of a child with autism placed him in private school after he made virtually no progress between third and fifth grade at his public school; the school failed to respond to Drew's increasing behavioral issues and his IEP for fifth grade listed the vast majority of the same goals as his third grade IEP.²⁴⁹ Within months at the new school, which implemented an evidence-based evaluation and program for children with autism, Drew showed substantial progress.²⁵⁰ His improvement suggests that his failure to progress over the preceding years at his original school is attributable to the low expectations and insufficient methods set out in his IEP rather than to incapacity—due to his disability—to benefit from an appropriately tailored education.

The petitioner in *Endrew F.* argued that the IDEA required "schools to provide children with disabilities with substantially equal opportunities to achieve academic success, attain self-sufficiency, and contribute to society,"²⁵¹ and the U.S. government, arguing as amicus curiae in support of the petitioner, urged that a program must be

245. Petition for a Writ of Certiorari at i, *Endrew F. ex rel. Joseph F. v. Douglas Cty. Sch. Dist. RE-1*, 137 S. Ct. 988 (2017) (No. 15-827).

246. *Bd. of Educ. v. Rowley*, 458 U.S. 176, 198, 199, 207 (1982) (emphasis added).

247. Petition for a Writ of Certiorari, *supra* note 245, at 10, 12.

248. 137 S. Ct. 988 (2017).

249. Petition for a Writ of Certiorari, *supra* note 245, at 7.

250. *Id.*

251. Brief for Petitioner at 14, *Endrew F.*, 137 S. Ct. 988 (No. 15-827).

“aimed at significant educational progress in light of the child’s circumstances. . . . [T]his is not a barely more than de minimis standard, and it’s not a maximization standard.”²⁵² The Supreme Court agreed, stating that the educational programs must be “appropriately ambitious in light of [the child’s] circumstances,”²⁵³ and the decision may be very important for children with severe brain injuries whose disabilities may drastically limit the capacity to benefit from special education and services, but for whom long-term and incremental progress is still possible.

The U.S. district court’s decision in *Wenger v. Canastota Central School District* illustrates the difficulties that arise when the ability to benefit educationally due to the severity of brain injury is in question.²⁵⁴ In *Wenger*, after the plaintiff’s son, Steven, experienced severe brain injury in an automobile accident and a later seizure, independent medical evaluators testified that Steven “did not demonstrate signs of obvious auditory processing, purposeful movement, or social awareness, and that his responses appeared to be reflexive rather than responsive.”²⁵⁵ The school’s IEP provided two hours per day of special education, thirty minutes of speech therapy twice per week, and physical therapy once per week—with the IEP goals of “respond[ing] in a consistent manner to visual, auditory, and multisensory stimuli, and . . . achiev[ing] a functional range of motion in his upper and lower extremities.”²⁵⁶ In affirming the sufficiency of this IEP over the complaint of Steven’s father, the court noted that Steven’s “own physician and independent medical evaluators have stated that the severity of [his] condition prevents him from learning and that he is incapable of benefiting from special education.”²⁵⁷ However, the court stressed that at the due process hearing, the “[p]laintiff failed to provide any evidence indicating that Steven would benefit from increased special education and related services.”²⁵⁸ Because the Supreme Court in *Endrew F.* affirmed a more substantial standard for the level of benefit a school district must confer, the ability to present evidence that certain assistive devices or other related services would benefit the child would be particularly meaningful in cases like Steven’s.

252. Transcript of Oral Argument at 20, 21, *Endrew F.*, 137 S. Ct. 988 (No. 15-827) (statement of Irv Gornstein, Counselor to the Solicitor General).

253. 137 S. Ct. at 1000.

254. 961 F. Supp. 416 (N.D.N.Y. 1997), *aff’d in part and vacated in part on other grounds*, 146 F.3d 123 (2d Cir. 1998).

255. *Id.* at 421.

256. *Id.* at 418.

257. *Id.* at 421.

258. *Id.*

3. *Medicare and Access to Rehabilitation for Beneficiaries with Severe Brain Injury*

Here, we focus on determinations of coverage for inpatient rehabilitation for persons with severe brain injury insured through Medicare.²⁵⁹ Many patients with severe brain injury cannot fully achieve their potential without access to rehabilitation. We have previously documented how Medicare coverage policies matter in the context of healthcare provision to persons with severe brain injury and subsequent disorders of consciousness.²⁶⁰ This Section will summarize recent changes to the Medicare Policy Manual and analyze how Medicare regulations provide both obstacles to, and opportunities for, persons with severe brain injury.

The Medicare Policy Manual was recently amended in response to a court challenge. In *Jimmo v. Sebelius*, a group of plaintiffs with chronic health conditions sued HHS in federal court, alleging that Medicare local coverage determinations were being made on the basis of a “rule-of-thumb improvement standard,” rather than on the required criterion of “medical necessity.”²⁶¹ The plaintiffs alleged that Medicare coverage was unlawfully denied if their condition was not expected to improve and that they did not receive *individual determinations* to which they were legally entitled.²⁶² The case survived summary judgment but ultimately was settled.²⁶³ The settlement resulted in many changes to the Medicare Policy Manual, with emphasis on the requirement that coverage determinations be made based on an individual’s particular case, and that the standard used to assess this case is “maintenance” rather than “improvement.”²⁶⁴

259. Many persons with disabilities have Medicare. See Sandra M. Foote & Christopher Hogan, *Disability Profile and Health Care Costs of Medicare Beneficiaries Under Age Sixty-Five*, 20 HEALTH AFF. 242, 245 ex.2 (2001).

260. Joseph J. Fins et al., *Whither the “Improvement Standard”? Coverage for Severe Brain Injury After Jimmo v. Sebelius*, 44 J.L. MED. & ETHICS 182, 182-83 (2016) [hereinafter Fins et al., *Whither the “Improvement Standard”?*]; Wright & Fins, *supra* note 62.

261. Amended Complaint for Declaratory, Injunctive, and Mandamus Relief at 2, 9, *Jimmo v. Sebelius*, No. 5:11-cv-17, 2011 WL 5104355 (D. Vt. Oct. 25, 2011); see also Fins et al., *Whither the “Improvement Standard”?*, *supra* note 260, at 185-86 (describing these allegations).

262. Amended Complaint for Declaratory, Injunctive, and Mandamus Relief, *supra* note 261, at 2; see also Fins et al., *Whither the “Improvement Standard”?*, *supra* note 260, at 185-86. Cf. 20 U.S.C. § 1414(d) (2012) (requiring an individualized assessment of a child with a disability).

263. CTRS. FOR MEDICARE & MEDICAID SERVS., *JIMMO V. SEBELIUS SETTLEMENT AGREEMENT FACT SHEET*, <https://www.cms.gov/medicare/medicare-fee-for-service-payment/NFPPS/downloads/jimmo-factsheet.pdf> [<https://perma.cc/3T7D-RF9Q>].

264. *Id.* at 2; see also Fins et al., *Whither the “Improvement Standard”?*, *supra* note 260, at 186.

While this settlement can be considered a “win” for many persons with chronic conditions, it is not necessarily helpful for persons with disorders of consciousness, given that coverage determinations are based on what physicians think is medically necessary. Given that many physicians are not well-informed about disorders of consciousness, patients with disorders of consciousness may not benefit from these policy changes as it may be difficult to demonstrate that some medical interventions and inpatient rehabilitation are medically necessary.²⁶⁵ However, these changes may help persons with severe brain injury without subsequent disorders of consciousness receive necessary medical care and rehabilitation, especially given that the Medicare Policy Manual now specifies that inpatient rehabilitation cannot be denied solely because a beneficiary is not expected to become fully functionally independent.²⁶⁶

There are, however, recent allegations that Medicare has not fully adhered to all of the terms of the settlement agreement, and in particular, the requirement that it engage in an educational campaign to ensure that those on the front-line making coverage decisions know to apply a maintenance rather than improvement standard.²⁶⁷ Many Medicare beneficiaries allege that they are still unlawfully subject to the rule-of-thumb improvement standard.²⁶⁸ The judge responsible for overseeing the settlement agreement granted a motion for enforcement of the settlement.²⁶⁹

We suggest that Medicare beneficiaries with severe brain injury who are informed of a denial of coverage for an intervention related to their injury appeal such denials to ensure that they are not being subjected to a rule-of-thumb improvement standard, and instead receive an individualized determination. This appeal is appropriate even if a medical necessity standard is being used because it may provide an opportunity to present more evidence that they meet this standard.

We further argue that to more fully aid all persons with severe brain injury—including those with disorders of consciousness—and

265. Fins et al., *Whither the “Improvement Standard”?*, *supra* note 260 at 186-87.

266. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE BENEFIT POLICY MANUAL § 40.1.1 (2017), <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/bp102c07.pdf> [<https://perma.cc/LEG2-AZSJ>]; Fins et al., *Whither the “Improvement Standard”?*, *supra* note 260, at 186.

267. *Judge Orders Medicare Agency to Comply with Settlement in “Improvement Standard” Case and Provide More Education*, CTR. FOR MEDICARE ADVOC. (Aug. 18, 2016), <http://www.medicareadvocacy.org/judge-orders-medicare-agency-to-comply-with-settlement-in-improvement-standard-case-and-provide-more-education/>.

268. *Id.*

269. *Id.*

to prevent arbitrary denials of coverage at the local level given uncertainty about what “medical necessity” means in the context of severe brain injury, the Medicare coverage standard should expand “the definition of ‘reasonable and necessary’ to include monitoring, rehabilitation, and therapy for MCS and view this heightened level of care as a new standard of care.”²⁷⁰ We also would include access to emerging therapies such as drugs and devices in this definition of medical necessity in the context of severe brain injury.²⁷¹

4. *Severe Brain Injury and Access to Safe and Effective Drugs and Devices*

In addition to access to rehabilitation, the restoration of health and function of patients with severe brain injury—and especially disorders of consciousness—will depend upon the development, and ready availability, of novel drugs and devices.²⁷² Drugs and devices are regulated by the FDA, which requires evidence of safety and efficacy prior to approval.²⁷³ The regulation of such drugs and devices is currently in a period of flux, given the recent passage of the 21st Century Cures Act (21st CCA).²⁷⁴ It is thus an opportune time for advocates of those with severe brain injury to attempt to influence the regulatory environment to protect and promote the interest of these patients. In this Section, we will highlight two significant parts of the 21st CCA that are likely to affect the device approval process for persons with severe brain injury who may benefit from devices such as

270. Fins et al., *Whither the “Improvement Standard”?*, *supra* note 260, at 189; *see also* Wright & Fins, *supra* note 62, at 279.

271. Fins et al., *Whither the “Improvement Standard”?*, *supra* note 260, at 189.

272. There are many translational barriers to the development of medical devices, including intellectual property laws and the need to obtain funding to conduct clinical trials to bring the device to market and bridge what has been described as the a “valley of death”—the gap between the basic research funding supplied by the National Institutes of Health and funding from the marketplace. *See generally* Joseph J. Fins, *Deep Brain Stimulation, Free Markets and the Scientific Commons: Is it Time to Revisit the Bayh-Dole Act of 1980?*, 13 NEUROMODULATION J. 153 (2009); Joseph J. Fins & Nicholas D. Schiff, *Conflicts of Interest in Deep Brain Stimulation Research and the Ethics of Transparency*, 21 J. CLINICAL ETHICS 125, 125-26, 130 (2010); Joseph J. Fins et al., *Ethical Guidance for the Management of Conflicts of Interest for Researchers, Engineers and Clinicians Engaged in the Development of Therapeutic Deep Brain Stimulation*, 8 J. NEURAL ENGINEERING 033001, 033003 (2011); Joseph J. Fins, Gary S. Dorfman & Joseph J. Pancrazio, *Challenges to Deep Brain Stimulation: A Pragmatic Response to Ethical, Fiscal, and Regulatory Concerns*, 1265 ANNALS N.Y. ACAD. SCI. 80, 83, 86 (2012); Declan Butler, *Crossing the Valley of Death*, 453 NATURE 840, 842 (2008).

273. 21 C.F.R. § 860.7(c) (2017).

274. 21st Century Cures Act, Pub. L. No. 114-255, 130 Stat. 1033 (2016).

deep brain stimulation, which can aid in the restoration of consciousness or communication—a capability for the realization of rights.²⁷⁵

Although the 21st CCA explicitly states that it makes no changes to the premarket approval standards for medical devices, it directs the FDA to use the “least burdensome appropriate means necessary to demonstrate a reasonable assurance of device safety and effectiveness.”²⁷⁶ While this may increase the number of devices that make it to consumers, devices that are subject to lower standards for approval may not have their intended effect.²⁷⁷ Ensuring efficacy is particularly important when devices pose serious risks to patients. For example, deep brain stimulation is a promising treatment for restoring functional abilities in persons with severe brain injury, but implantation of the device requires invasive neurosurgery. A rigorous assessment of its risks and benefits is thus particularly important.

Another key component of the 21st CCA that is relevant for persons with severe brain injury is an emphasis on patient-focused outcomes.²⁷⁸ The FDA has historically incorporated patient voices into approval processes.²⁷⁹ We think it is important to include patient voices, especially as it relates to conveying information about subjective effects of drugs or devices. But while patients with disorders of consciousness might benefit from increased emphasis on patient experience and needs with respect to drug and device approval, by the very definition of their condition, minimally conscious patients cannot advocate for approval themselves or informally supplement the results of clinical trials by coordinating anecdotal reports of success.²⁸⁰ The burden would thus fall on their caregivers, but only exceptionally proactive and well-informed caregivers may be able to

275. See Wright & Fins, *supra* note 62, at 279-81 (discussing capabilities approach in context of disorders of consciousness).

276. 21st Century Cures Act § 3058(b)(5)(A).

277. Joseph J. Fins et al., *Misuse of the FDA's Humanitarian Device Exemption in Deep Brain Stimulation for Obsessive-Compulsive Disorder*, 30 HEALTH AFF. 302, 302 (2011); Megan S. Wright, Comment, *A Case for Randomized, Double-Blinded, Sham-Controlled Class III Medical Device Trials*, 34 YALE L. & POL'Y REV. 199, 201 (2015) (arguing for higher standards for efficacy in Class III medical device trials).

278. 21st Century Cures Act §§ 3001-04.

279. See generally Nina L. Hunter, Kathryn M. O'Callaghan & Robert M. Califf, *Engaging Patients Across the Spectrum of Medical Product Development: View from the US Food and Drug Administration*, 314 J. AM. MED. ASS'N 2499 (2015) (summarizing the programs in place at the FDA aimed at incorporating patient perspectives).

280. Cf. Marie Thonnard et al., *Effect of Zolpidem in Chronic Disorders of Consciousness: A Prospective Open-Label Study*, 28 FUNCTIONAL NEUROLOGY 259 (2013) (reporting on a study that found no clinical improvements for patients with DOC on zolpidem); Jeffrey L. Shames & Haim Ring, *Transient Reversal of Anoxic Brain Injury—Related Minimally Conscious State After Zolpidem Administration: A Case Report*, 89 ARCHIVES PHYSICAL MED. & REHAB. 386 (2008).

take on this role. We would thus recommend that advocates for patients with severe brain injury encourage the FDA to adopt a formal policy of requiring sponsors to supplement new drug and device applications with patient experience data at every opportunity.

This discussion assumes that researchers are able to recruit persons with severe brain injury as participants in clinical trials of medical devices such as deep brain stimulation. One challenge in this context relates to informed consent to participate in research.²⁸¹ Persons with severe brain injury may be under guardianship due to the severity of their injury. Guardianship removes decisionmaking authority from a person and gives it to his or her guardian, and in the context of consent to research, a guardian would be responsible for providing the consent. The problem, however, is that a significant minority of states restrict the ability of guardians to consent to participation in research on behalf of their wards,²⁸² which means that persons who could benefit from access to clinical trials are denied such access, and scientific progress is hindered.²⁸³ As we have argued elsewhere, states should reform their guardianship laws to permit guardians to decide on behalf of persons with severe brain injury who may regain decisional capacity—after carefully weighing the risks and benefits of participation—to participate in clinical trials that would either contribute to general knowledge about their brain injury or offer the prospect of direct benefit to the person with severe brain injury, and in particular, obviate the need for continued guardianship.²⁸⁴

* * * *

While there are many sources of federal law that could be used to redress the problems facing persons with severe brain injury, the most promising avenues for advocates to pursue are claims under the ADA. If there were class-action lawsuits under the ADA, large numbers of people would benefit. A common problem, however, seems to be lack of enforcement or oversight. Thus, advocates cannot take for granted any legal victories but will have to work to ensure that any legal rights afforded to persons with severe brain injury continue to be protected.

281. 21 C.F.R. § 50.20 (2017).

282. See, e.g., N.D. CENT. CODE § 30.1-28-12 (5-312)(4) (West 2017) (“Notwithstanding general or limited authority to make medical decisions on behalf of the ward, no guardian may consent to psychosurgery, abortion, sterilization, or experimental treatment of any kind unless the procedure is first approved by order of the court.”).

283. See Megan S. Wright, Michael R. Ulrich & Joseph J. Fins, *Guardianship and Clinical Research Participation: The Case of Wards with Disorders of Consciousness*, 27 KENNEDY INST. OF ETHICS J. 43, 63 (2017) (describing this in the context of wards with disorders of consciousness).

284. See *id.*

IV. JUSTICE FOR PERSONS WITH SEVERE BRAIN INJURY UNDER STATE LAW

Much of the legal action around disability discrimination and accommodation occurs at the state level. Indeed, there is a long history of states leading reform efforts to more fully include persons with disability in civil society. For example, states had guide dog and white cane laws prior to passage of section 504 of the Rehabilitation Act of 1973.²⁸⁵

The ADA preempts state disability discrimination laws when the latter grants persons with disabilities fewer rights and protections.²⁸⁶ States can grant residents with disabilities greater protection and more rights than the ADA, however. Because it is not feasible to analyze every states' laws, this Part will begin by focusing on California, a state with disability discrimination law that offers greater protection than the ADA.

We will next consider selected additional sources of state law (guardianship law and tort law) that offer promising tools to improve the situation of persons with severe brain injury in society.

A. *State Disability Discrimination Law*

1. *State Constitutions*

States are free to grant broader protection to persons with disabilities than the minimum protections required by federal law. The state of California provides a promising example of progressive state laws that may be leveraged to rectify legal injustices suffered by persons with severe brain injury.

Given its marginalization, it is unsurprising that this especially vulnerable population is not expressly mentioned in California law. California courts, however, construe state legislation affecting the rights of persons with disabilities broadly, explicitly acknowledging that provisions in such legislation offer more expansive protection than analogous provisions in federal legislation.²⁸⁷ Moreover, the protections afforded to persons with disabilities under California statu-

285. SCOTCH, *supra* note 64, at 28-29.

286. 29 C.F.R. app. § 1630 (2017).

287. See, e.g., *Jensen v. Wells Fargo Bank*, 102 Cal. Rptr. 2d 55, 64 (Ct. App. 2000) (“[T]he Legislature has determined that the definitions of ‘physical disability’ and ‘mental disability’ under the law of this state require a ‘limitation’ upon a major life activity, but do not require, as does the Americans with Disabilities Act of 1990, a ‘substantial limitation.’ This distinction is intended to result in broader coverage under the law of this state than under that federal act.” (alteration in original) (quoting CAL. GOV’T CODE § 12926.1(c) (2000))).

tory law sound in the language of fundamental rights safeguarded by the California constitution.²⁸⁸ Accordingly, even when an individual plaintiff's disability is not explicitly included in statutory language identifying the beneficiaries of protection, California courts construe the text liberally to extend protections to such persons.²⁸⁹

Two provisions of the California constitution guarantee certain fundamental rights to all persons. Article I, Section 1 provides: "All people are by nature free and independent and have inalienable rights. Among these are enjoying and defending life and liberty, acquiring, possessing, and protecting property, and pursuing and obtaining safety, happiness, and privacy."²⁹⁰ The right to personal liberty, the California Supreme Court has stated, is "second only to life itself."²⁹¹ Article I, Section 7 concerns the deprivation of these fundamental rights. It provides: "A person may not be deprived of life, liberty, or property without due process of law, or denied equal protection of the laws"²⁹² The content of these rights follows their federal counterparts. California courts have explained that "[t]he equal protection guarantees of the Fourteenth Amendment and the California Constitution are substantially equivalent and analyzed in a similar fashion."²⁹³

While these two constitutional provisions guarantee rights enjoyed by all persons, the *level* of protection provided depends on the type of harm alleged. California courts have held broadly that classifications that violate fundamental rights, such as the right to personal liberty, are subject to strict judicial scrutiny.²⁹⁴ In *People v. Leng*, the court applied strict scrutiny to find that the state's "use of a non-serious, nonviolent juvenile adjudication to impose a second strike sentence" on a juvenile defendant was a violation of the equal protection of the laws.²⁹⁵ California courts have also found, however, that the "[e]qual protection clause does not require absolute or perfect equality."²⁹⁶ The California constitution does not "direct that statutes necessarily apply equally to all persons," and so it "permits the crea-

288. See, e.g., *In re Hop*, 623 P.2d 282, 286 (Cal. 1981).

289. See, e.g., *Geduldig v. Aiello*, 417 U.S. 484, 498 (1974) (Brennan, J., dissenting) (describing how California courts construe disability statutes).

290. CAL. CONST. art. I, § 1.

291. *In re Hop*, 623 P.2d at 286 (citing *People v. Olivas*, 551 P.2d 375 (Cal. 1976)).

292. CAL. CONST. art. I, § 7.

293. *People v. Leng*, 83 Cal. Rptr. 2d 433, 439 (Ct. App. 1999) (citing *In re Demergian*, 768 P.2d 1069 (Cal. 1989)).

294. *Id.* at 440 (citing *People v. Olivas*, 551 P.2d 375 (Cal. 1976)).

295. *Id.* at 435.

296. *Abel v. Cory*, 139 Cal. Rptr. 555, 559 (Ct. App. 1977).

tion of differences so long as those differences do not amount to an invidious discrimination.”²⁹⁷

Whether rights are framed as deprivations of fundamental liberties or as equal protection violations determines what level of scrutiny the court will apply. As described in greater detail below, we recommend that advocates for persons with severe brain injury style their claims as deprivations of constitutionally guaranteed rights, but not including equal protection violations.

2. *State Statutes*

California law provides fertile ground for seeking protection for the constitutional rights of persons with severe brain injury. The California legislature has repeatedly reaffirmed the state policy that persons with disabilities receive greater protection under California law than under federal law. The California Government Code plainly states that California’s protection of persons with disabilities is at least as broad as the ADA, providing that

[I]f the definition of “disability” used in the federal Americans with Disabilities Act of 1990 would result in broader protection of the civil rights of individuals with a mental disability or physical disability . . . or would include any medical condition not included within those definitions, then that broader protection or coverage shall be deemed incorporated by reference into [the Code].²⁹⁸

Further, because California courts interpret the ADA broadly “to address indifference to or benign neglect of the plight of the disabled,” they recognize that “outright intentional discrimination is not required under [T]itle II of the ADA[]”—nor, consequently, California disability law.²⁹⁹ Thus, “[u]nlawful discrimination occurs” under California law “not just when the disabled are treated differently than the nondisabled[,] [but also when] discriminatory treatment between groups of disabled persons [occurs].”³⁰⁰

Similarly, parts of the California Code require a disability to merely “limit” a life activity, in contrast with the “substantial limitation” required by the ADA.³⁰¹ This deviation reflects a deliberate choice by the California legislature to afford broader protection for persons with disabilities in California than under federal law.³⁰² The

297. *Id.* at 559.

298. CAL. GOV’T CODE § 12926(n) (West 2017) (internal citations omitted).

299. *Black v. Dep’t of Mental Health*, 100 Cal. Rptr. 2d 39, 46 (Ct. App. 2000) (citation omitted).

300. *Id.* at 46.

301. *See, e.g., Diaz v. Fed. Express Corp.*, 373 F. Supp. 2d 1034, 1049 (C.D. Cal. 2005).

302. *Id.* at 1049.

Supreme Court itself has recognized California's policy; specifically, as noted by Justice Brennan in *Geduldig v. Aiello*, California courts "construe[] [disability statutes] liberally in aid of [their] declared purpose to mitigate the evils and burdens which fall on the unemployed and disabled worker and his family."³⁰³

Against this expansive backdrop, the numerous provisions of the California Code providing for the protection of persons with disabilities may readily be construed to apply to persons with severe brain injury. Section 1761 of the California Civil Code defines a "[d]isabled person" to mean "a person who has a physical or mental impairment that substantially limits one or more major life activities."³⁰⁴ That section continues: " 'Major life activities' means functions that include caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working."³⁰⁵ Though this portion of the California Code retains the "substantial" limitation language, severe brain injury easily qualifies as a disability under these definitions.

It is unclear, however, whether severe brain injury would qualify as a physical or mental disability under the California Code. California law, like the laws of many states, reflects a dichotomous classification of physical and mental disabilities.³⁰⁶ This taxonomy is outdated; it does not reflect how modern healthcare practitioners understand disability. The etiology of severe brain injury illustrates the awkwardness of separating physical and mental disabilities. The California Code classifies physiological disfigurement of the brain (affecting neurological functions) as a physiological disorder. A mental impairment, however, is classified as a mental disorder. Severe brain injury rests uncomfortably between these two definitions because it entails significant mental impairments brought on, often, by physical trauma. We encourage lawmakers to update the definitions for disabilities appearing in legislation to better reflect the nondichotomous etiologies and pathologies of disability.

As California law currently stands, however, the *type* of disability under which severe brain injury is classified has important implications. It may be more beneficial for persons with severe brain injury to be classified in California as mentally disabled because one particularly promising vehicle for providing broad protections to persons with severe brain injury is section 4502 of the California Welfare and

303. 417 U.S. 484, 498 (1974) (Brennan, J., dissenting).

304. CAL. CIV. CODE § 1761(g) (West 2017).

305. *Id.* § 1761(g)(2).

306. See CAL. GOV'T CODE § 12926 (West 2017); see also CAL. CIV. CODE § 1761(g).

Institutions Code. That section protects the rights of persons with developmental disabilities, a subclass of mental disabilities.³⁰⁷

Although persons with severe brain injury are unlikely to be classified as developmentally disabled,³⁰⁸ the rights the California Code guarantees to persons with disabilities are merely applications of the constitutional rights of *all* persons. Thus, although persons with severe brain injury are not identified explicitly as recipients of the California Code's protections, they clearly fall within the scope of protection afforded broadly to various classifications of persons with disabilities. The California Welfare and Institutions Code, for example, provides:

Persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other individuals by the United States Constitution and laws and the Constitution and laws of the State of California. An otherwise qualified person by reason of having a developmental disability shall not be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity that receives public funds.³⁰⁹

This protection likely extends to persons with severe brain injury, for as the California Supreme Court recognized in *In re Hop*, “[Section 4502] is but a legislative reaffirmation of a firmly rooted and *independent* constitutional principle which assures that persons will not be deprived of due process or equal protection of law on the basis of developmental disability alone.”³¹⁰

Under the court's rationale, persons with severe brain injury may have a strong claim to all the protections given to persons with developmental disabilities in section 4502 because those protections are manifestations of guaranteed constitutional rights applied to a vulnerable population, and persons with severe brain injury need similar protections. Like persons with severe brain injury, persons with developmental disabilities are often unable to make decisions for themselves; a parent or a conservator make decisions. Conservators

307. CAL. WELF. & INST. CODE § 4502 (West 2017).

308. See *id.* § 4512(a) (defining “developmental disability” to mean “a disability that originates before an individual attains 18 years of age; continues, or can be expected to continue, indefinitely; and constitutes a substantial disability for that individual”). The California Code does, however, include “disabling conditions found to be closely related to intellectual disability or to require treatment similar to that required for individuals with an intellectual disability,” suggesting that persons suffering from severe brain injury before the age of 18 may have more success in qualifying directly for the protections of section 4512. *Id.*

309. *Id.* § 4502(a).

310. 623 P.2d 282, 286 (Cal. 1981) (emphasis added).

are appointed to persons with developmental disabilities and persons with severe brain injury for the same reasons.

In light of this overlap in vulnerabilities, the myriad rights enumerated in section 4502—geared toward safeguarding persons with developmental disabilities from abuse and aiming to facilitate their care—are equally applicable to persons with severe brain injury. These rights are as follows:

1. The right to receive “treatment and habilitation services and supports in the *least restrictive environment*.”³¹¹ These “services and supports” are quite broad.³¹² Further, they should “be directed toward the achievement of the most independent, productive, and normal lives possible.”³¹³ And they *must* “protect the personal liberty of the individual and shall be provided with the least restrictive conditions necessary to achieve the purposes of the treatment, services, or supports.”³¹⁴
2. Rights to “dignity, privacy, and humane care.”³¹⁵ Accordingly, “[t]o the *maximum extent possible*, treatment, services, and supports shall be provided *in natural community settings*.”³¹⁶
3. A right “to prompt medical care and treatment.”³¹⁷
4. A “right to social interaction and participation in community activities,”³¹⁸ as well as “[a] right to physical exercise and recreational opportunities.”³¹⁹
5. The right “to be free from harm” in the course of their treatment.³²⁰ “Harm” is broadly defined, “including unnecessary physical restraint, or isolation, excessive medication, abuse, or neglect.”³²¹ Similarly, patients with developmental disabilities have “[a] right to be free from hazardous procedures.”³²²

311. WELF. & INST. § 4502(b)(1) (emphasis added).

312. “ ‘Services and supports . . . means specialized services and supports *or* special adaptations of generic services and supports directed toward the alleviation of a developmental disability *or* toward the social, personal, physical, *or* economic *habilitation or rehabilitation* of an individual with a developmental disability, *or* toward the achievement and maintenance of independent, productive, and normal lives.’ ” *Id.* § 4512 (emphases added).

313. *Id.* § 4502(b)(1).

314. *Id.*

315. *Id.* § 4502(b)(2).

316. *Id.* (emphases added).

317. *Id.* § 4502(b)(4).

318. *Id.* § 4502(b)(6).

319. *Id.* § 4502(b)(7).

320. *Id.* § 4502(b)(8).

321. *Id.*

322. *Id.* § 4502(b)(9).

6. A right to make life choices, “including, but not limited to, where and with whom they live, their relationships with people in their community, the way they spend their time, including education, employment, and leisure, the pursuit of their personal future, and program planning and implementation.”³²³

All these provisions of the California Welfare and Institutions Code may be beneficial in ensuring that the rights of persons with severe brain injuries are protected. In using statutes like the California Welfare Institutions Code, however, advocates should be mindful of the need to carefully frame the rights of persons with severe brain injury as constitutionally guaranteed *rights* and not statutorily extended social welfare benefits. The former will likely trigger stricter scrutiny.

The famous *Geduldig* case illustrates the point. *Geduldig v. Aiello* involved a challenge to a California disability insurance program that exempted pregnancy-related work loss from coverage.³²⁴ The U.S. Supreme Court held that “consistently with the Equal Protection Clause, a State ‘may take one step at a time, addressing itself to the phase of the problem which seems most acute to the legislative mind. . . . The legislature may select one phase of one field and apply a remedy there, neglecting the others.’ ”³²⁵ “Particularly with respect to social welfare programs,” the Court continued:

[S]o long as the line drawn by the State is *rational*ly supportable, the courts will not interpose their judgment as to the appropriate stopping point. “[T]he Equal Protection Clause does not require that a State must choose between attacking every aspect of a problem or not attacking the problem at all.”³²⁶

Accordingly, the Court concluded, “We cannot agree that [California’s] exclusion of [normal pregnancy] disability from coverage amounts to invidious discrimination under the Equal Protection Clause.”³²⁷

Geduldig was an equal protection case involving the exclusion of the appellee from a California disability insurance program. The question, therefore, was whether withholding benefits extended pursuant to the program was a violation of the Equal Protection Clause. To avoid being subject to deferential rational basis review, advocates for persons with severe brain injury should focus on due process rather than equal protection claims. In the mental disability context,

323. *Id.* § 4502(b)(10).

324. 417 U.S. 484, 484 (1974).

325. *Id.* at 495.

326. *Id.* (emphasis added).

327. *Id.* at 494.

for example, a court held that under the Equal Protection Clause, “statutory classifications that treat similarly situated mentally retarded persons differently with respect to issues affecting their civil commitments are evaluated using rational basis review.”³²⁸ Instead, the rights of persons with severe brain injury should be cast in terms of *absolute* rights guaranteed by the state constitution, not rights relative to other disabled groups.³²⁹

Plaintiffs in California have already successfully used non-equal-protection strategies to rectify inadequate treatment conditions. In 2009, a large class of plaintiffs obtained a favorable settlement for claims brought under the Lanterman Act—codified at section 4502 of the California Welfare and Institutions Code—as well as other state and federal laws.³³⁰ Plaintiffs’ claims focused on the deprivation of rights that the Lanterman Act guaranteed; they did not rely on equal protection grounds. When a California appellate court granted class certification to plaintiffs in 2007, it recited at length the class’s complaint describing the situation faced by persons with developmental disabilities in California: “Thousands of Californians with developmental disabilities are needlessly isolated and segregated from mainstream society in large congregate public and private institutions. Every year hundreds more find themselves at risk of institutionalization due to the lack of appropriate community supports and crisis intervention.”³³¹ Plaintiffs argued that these circumstances “violate[d] [f]ederal and [s]tate law” because section 4502:

[C]reated an entitlement for people with developmental disabilities to an array of services and supports sufficiently complete to meet their needs and choices, to support their integration into the mainstream life of the community and to enable them to approximate the pattern of everyday living available to people without disabilities. . . .³³²

Section 4502 is not discretionary, but a mandate—as is the ADA, which sets a floor for protection under California law, and which the U.S. Supreme Court construed in *Olmstead*³³³ to prohibit the “unjus-

328. *People v. Rosalinda C.*, 168 Cal. Rptr. 3d 294, 303 (Ct. App. 2014).

329. Styling constitutional claims in terms of rights guaranteed, and not an equal claim to benefits, avoids another rationale proffered by the state in *Geduldig*; namely, that “[t]he State has a legitimate interest . . . in distributing [] available resources in such a way as to keep benefit payments at an adequate level for disabilities that are covered, rather than to cover all disabilities inadequately.” 417 U.S. at 496.

330. Proposed Settlement Agreement at 3-4, *Capitol People First v. Dep’t of Developmental Servs.*, 66 Cal. Rptr. 3d 300 (2008) (No. 2002-038715).

331. *Capitol People First*, 66 Cal. Rptr. 3d at 308.

332. *Id.*

333. *Olmstead v. L.C.*, 527 U.S. 581 (1999).

tified institutional isolation of persons with disabilities”³³⁴ Work on behalf of persons with severe brain injuries may similarly draw on mandatory constitutional guarantees to rectify constitutionally insufficient treatment.

B. Guardianship Law

Many persons with severe brain injury lose the capacity to make some types of decisions, and in order to protect them from abuse and to facilitate their care, they may have a guardian or conservator appointed to protect their person, property, or both.³³⁵ Unfortunately, many guardianship laws unduly deprive persons under guardianship of rights and liberties they may still be able to enjoy. This Section will focus on how some states disqualify wards from voting upon appointment of a guardian.

For example, as discussed in the Introduction, David Rector suffered a severe brain injury in 2009 and was appointed a conservator to oversee his person and property; at the time of this appointment, David was disqualified from voting.³³⁶ However, California updated its probate code in 2016 to no longer presume incapacity to vote when a person has a guardian; instead, if people can express a desire to vote, they retain their voting rights.³³⁷ Given this change and David’s recovery to the point where he could communicate with an electronic voice and eye-tracking software, he and his conservator requested the reinstatement of David’s voting rights.³³⁸ The probate judge responsible for David’s case initially refused to reinstate his voting rights absent more evidence that David had the capacity to vote and that his conservator would not be influencing his vote.³³⁹ David and his conservator returned to court, and, given the change in California law, the judge reinstated David’s voting rights.³⁴⁰

While David was able to regain his voting rights, tens of thousands of other Californians under guardianship may not be as civil-

334. *Id.* at 600.

335. Joseph J. Fins & Barbara Pohl, *Guardianship and the Injured Brain: Representation and the Rights of Patients and Families*, in FINDING CONSCIOUSNESS: THE NEUROSCIENCE, ETHICS, AND LAW OF SEVERE BRAIN DAMAGE 246, 246 (Walter Sinnott-Armstrong ed., 2016).

336. Elliot Spagat, *Disabled California Man Seeks to Have Voting Rights Restored*, U.S. NEWS & WORLD REP. (Aug. 23, 2016, 7:28 PM), <https://www.usnews.com/news/politics/articles/2016-08-23/restored-voting-rights-sought-for-california-disabled-people>.

337. CAL. PROB. CODE § 1910 (West 2017).

338. Spagat, *supra* note 336.

339. Order Requesting More Information, Conservatorship of David E. Rector, No. 37-2009-00152179 (Cal. Prob. Ct. Sept. 21, 2016).

340. Order Reinstating Voting Rights, Conservatorship of David E. Rector, No. 37-2009-00152179 (Cal. Prob. Ct. Sept. 21, 2016).

ly minded and knowledgeable about the state of the law, or have the means to fight for their voting rights in court. Furthermore, many other states have not been as progressive as California in updating their guardianship laws to acknowledge the fact that some persons with disabilities, while having a need for guardianship, also retain the capacity to vote.³⁴¹ It is problematic that persons not under guardianship are not asked to demonstrate any capacity to vote while those under guardianship are presumed to lack such capacity. This reality may violate the Voting Rights Act and Title II of the ADA.³⁴²

We offer several suggestions for reforming guardianship law to better address the needs of persons with severe brain injury who have guardians or conservators.³⁴³ First, given that guardianship is a significant liberty infringement, in order for a guardianship appointment to be in the best interests of a person with severe brain injury, the guardian should only have the powers that the person with severe brain injury is not able to exercise. For example, if persons with severe brain injury can still determine whom they want their healthcare provider to be and where they want to live, they should retain this decisionmaking authority even if they may need a conservator of their property.³⁴⁴ Along with this suggestion, the need for guardianship should be regularly evaluated by a judge and investigated by a *guardian ad litem*, and if the need for the guardianship no longer exists, it should be promptly terminated.³⁴⁵

We suggest that states adopt laws like California's new probate code amendment, which preserves as a default voting rights for persons with guardians.³⁴⁶ While some argue that a person who does not have the capacity to vote could (through a presumption that conservatees retain voting rights) have his or her vote manipulated by

341. See BAZELON CTR. FOR MENTAL HEALTH LAW ET AL., A GUIDE TO THE VOTING RIGHTS OF PEOPLE WITH MENTAL DISABILITIES 12-13 (2016), <http://www.bazelon.org/wp-content/uploads/2017/01/voting-rights-guide-2016.pdf> [<https://perma.cc/TL7A-Z2VB>].

342. See, e.g., Complaint at 6, Disability and Abuse Project of Spectrum Inst. v. L.A. Superior Court (U.S. Dep't of Justice, Civil Rights Div., July 10, 2014), <http://disabilityandabuse.org/doj/complaint.pdf> [<https://perma.cc/952F-FYK3>] (alleging that probate judges use literacy tests in violation of the Voting Rights Act of 1965 and do not offer reasonable accommodations to assist persons with disabilities in voting in violation of Title II of the ADA).

343. The scope of our Article excludes a consideration of disability more broadly, but these suggestions to reform guardianship may also aid people with other types of disabilities.

344. The purpose of the guardianship appointment should be to enable the person with severe brain injury to be integrated in civil society to the greatest extent possible. Judges should instruct guardians to make housing decisions with the least restrictive residence in mind. Ideally, it would become standard practice for professional guardians to identify the least restrictive housing options for their wards.

345. See Wright, Ulrich & Fins, *supra* note 283, at 62-63.

346. CAL. PROB. CODE § 1910 (West 2017).

conservators,³⁴⁷ we assert that the procedural safeguards in California's law³⁴⁸ are sufficient to prevent this from occurring on a scale large enough to warrant the opposite presumption from being the law.

We also argue that for those currently under guardianship in California who have the capacity to express a desire to vote, obstacles to the reinstatement of voting rights should be removed. Professional guardians in California should be informed of the change in law and ask their wards if they have a desire to vote, and if they do, the guardians should advocate for reinstatement of voting rights. We also need a public media campaign to inform lay guardians of family members of the change in the law. Probate judges should receive training about the nature of brain injuries and how assistive devices aid in seemingly unconventional communication so that they do not unjustly deny requests for voting rights reinstatement. If lobbying state legislatures to reform guardianship law with respect to voting is unsuccessful, it may be necessary to challenge the constitutionality of the statutes in court or to sue under the ADA.³⁴⁹

C. Tort Law

In this Section, we examine common law tort means of redress for harms to people with severe mental disabilities. We focus on legal rights of people with severe disorders of consciousness in a healthcare setting. In particular, we discuss the limits and potential of claims based on negligence actions of misdiagnosis and failure to obtain informed consent.

1. Tort Law and Mental Disability: A Brief Review

Much of the previous scholarship on tort law and mental disability has been concerned with the applicability of the reasonable person standard for liability to persons with mental disabilities. Under the reasonable person standard, the actions of defendants in negligence cases are evaluated against an objective standard: How would a reasonable person have acted under the circumstances? Courts generally apply the reasonable person standard even where the defendant has

347. See, e.g., Conservatorship of David E. Rector, No. 37-2009-00152179 (Cal. Prob. Ct. Sept. 21, 2016).

348. They must be able to communicate a desire to vote to the satisfaction of a judge. PROB. § 1910.

349. See, e.g., Letter from Elizabeth Johnson, Civil Rights Div., U.S. Dep't of Justice, to Thomas F. Coleman, Legal Dir., Disability & Abuse Project, (May 15, 2015), <http://www.spectruminstitute.org/votingrights/doj-letter-to-spectrum.pdf> [<https://perma.cc/WS82-24HS>] (responding to a request to investigate possible ADA Title II violations because California deprives persons under conservatorship of the right to vote).

a mental disability. Many commentators have criticized this practice as unreasonable and unfair.³⁵⁰ Others, however, have argued that the universal legal standard is favorable to disability rights; insofar as a universal standard implies that persons with mental disabilities are competent and capable of acting responsibly, it might help to destigmatize mental disability.³⁵¹

Scholars have also criticized tort law's approach to disability on other grounds. For example, Sarah Light has argued that tort law offers incentives for confining persons with mental disabilities;³⁵² Anne Bloom and Christy Hetherington Roger have separately examined how tort litigation perpetuates the idea that persons with disabilities are "less than whole," to the detriment of persons with disabilities broadly;³⁵³ and Wendy Hensel has pointed out that tort law's characterization of a disabled life as itself an injury or "wrongful," has detrimental psychological effects on persons with disabilities, and perpetuates negative societal perceptions of disability.³⁵⁴

Other scholars have looked to the common law of torts for possible causes of action to protect the interests of persons with disabilities. Mark Weber, focusing on disability discrimination outside the healthcare context, has found promise in a number of possible torts—including negligence, assault and battery, and especially the related torts of intentional infliction of emotional distress and dignitary harm or injury to "personality interests."³⁵⁵ Steven Schwartz has ex-

350. See, e.g., Johnny Chriscoe & Lisa Lukasik, *Re-Examining Reasonableness: Negligence Liability in Adult Defendants with Cognitive Disabilities*, 6 ALA. C.R. & C.L. L. REV. 1 (2015); Harry J.F. Korrell, *The Liability of Mentally Disabled Tort Defendants*, 19 LAW & PSYCHOL. REV. 1 (1995); Jean Macchiaroli Eggen, *Mental Disabilities and Duty in Negligence Law: Will Neuroscience Reform Tort Doctrine?*, 12 IND. HEALTH L. REV. 591 (2015); Grant H. Morris, *Requiring Sound Judgments of Unsound Minds: Tort Liability and the Limits of Therapeutic Jurisprudence*, 47 SMU L. REV. 1837 (1994); Ian J. Cosgrove, Note, *The Illusive "Reasonable Person": Can Neuroscience Help the Mentally Disabled?*, 91 NOTRE DAME L. REV. 421 (2015); Jacob E. McKnite, Note, *When Reasonable Care Is Unreasonable: Rethinking the Negligence Liability of Adults with Mental Retardation*, 38 WM. MITCHELL L. REV. 1375 (2012).

351. Okianer Christian Dark, *Tort Liability and the "Unquiet Mind": A Proposal to Incorporate Mental Disabilities into the Standard of Care*, 29 T. MARSHALL L. REV. 311, 314 (2004); Stephanie I. Splane, Note, *Tort Liability of the Mentally Ill in Negligence Actions*, 93 YALE L.J. 153, 154, 165-66 (1983).

352. Sarah Light, Note, *Rejecting the Logic of Confinement: Care Relationships and the Mentally Disabled Under Tort Law*, 109 YALE L.J. 381, 381-82 (1999).

353. Anne Bloom & Paul Steven Miller, *Blindsight: How We See Disabilities in Tort Litigation*, 86 WASH. L. REV. 709, 727 (2011); Christy Hetherington, Note, *Rhode Island Facing the Wrongful Birth/Life Debate: Pro-Disabled Sentiment Given Life*, 6 ROGER WILLIAMS U. L. REV. 565, 577-78 (2001).

354. Wendy F. Hensel, *The Disabling Impact of Wrongful Birth and Wrongful Life Actions*, 40 HARV. C.R.-C.L. L. REV. 141, 144 (2005).

355. Mark C. Weber, *The Common Law of Disability Discrimination*, 2012 UTAH L. REV. 429, 437 n.44, 456-66. Weber explains:

amined damage actions broadly as modes to recompense harm to persons with mental disabilities, arguing that such actions offer promising means of improving the care, as well as societal perceptions of, persons with mental disabilities.³⁵⁶

Our aims here are both to fill gaps in what is already a rich literature on tort law and mental disability, and to develop means of redress for harms to persons with severe mental disabilities, where there are not clear and easy precedents in the case law to follow, nor secondary sources to consult for guidance. Accordingly, we focus on an area that is relatively unexamined in the legal literature, but that we believe demands urgent attention: negligence toward persons with severe disorders of consciousness.

2. *Misdiagnosis*

As we discussed in detail in Part II, patients with disorders of consciousness are misdiagnosed as vegetative at a stunningly high rate. As a result of such misdiagnoses, patients with conscious awareness are treated as though they are totally unconscious, and decisions concerning their care are made on that assumption.

Misdiagnoses of VS have dire consequences: people with conscious awareness are subjected to painful and undignified treatment; moreover, their care is based on the false belief that they have no chance of improvement or recovery.³⁵⁷

We argue that many patients who receive misdiagnoses of VS, or premature diagnoses as permanently vegetative, should be entitled to legal relief. Legal claims based on negligence will not only help re-

The intentional infliction cause of action is well suited to instances when someone inflicts severe emotional distress on a person with a disability by exposing that person to continual ridicule, cruel pranks, threats and intimidation, or other abusive treatment. According to the Second Restatement . . . “[t]he extreme and outrageous character of the conduct may arise from the actor’s knowledge that the other is peculiarly susceptible to emotional distress, by reason of some physical or mental condition or peculiarity.” Power disparities also support a finding that behavior is outrageous when the behavior inflicts severe emotional harm on a person with a disability.

Id. at 461-62; see also Jacobus tenBroek, *The Right to Live in the World: The Disabled in the Law of Torts*, 54 CALIF. L. REV. 841 (1966) (examining the potential of tort law to improve the lives of people with disabilities, focusing on tort claims involving the right to service animals, common carrier liability, and white cane laws).

356. Steven J. Schwartz, *Damage Actions As a Strategy for Enhancing the Quality of Care of Persons with Mental Disabilities*, 17 N.Y.U. REV. L. & SOC. CHANGE 651, 655-56, 684 (1989).

357. Giacino et al., *Disorders of Consciousness*, *supra* note 16, at 103; see also Schnakers et al., *supra* note 44, at 1 (“Misdiagnosis [of VS] can lead to grave consequences, especially in end-of-life decision-making.”); Andrews et al., *supra* note 45, at 13 (“The diagnosis of the vegetative state can have a major influence on decision making about the level of care or services provided and may lead to . . . withdrawal of tube feeding.”).

dress the wrongs committed against these patients but should also incentivize positive change in health care practices.³⁵⁸

a. Standard of Care

For a successful claim of negligence, the plaintiff must prove that the defendant owed her a duty of care, that the defendant failed to meet the applicable standard of care, and that the plaintiff was injured as a result.³⁵⁹ If a medical malpractice claim based on negligence is successful, both the patient injured as a result of the negligent conduct and the patient's family members may be entitled to recover.³⁶⁰ Relief includes compensatory damages for physical injury and pain, economic losses, and noneconomic losses.³⁶¹ However, in general, the applicable standard of care in negligence cases involving physicians is taken to be the *ordinary* standard of care.³⁶² Although the definition of this standard differs across jurisdictions,³⁶³ the test generally amounts to an inquiry as to what a reasonable practitioner would have done under the circumstances.³⁶⁴ Additionally, courts rely on expert testimony unless the answer to the inquiry is common

358. While we focus on individual claims here, class actions are a possibility for a group of patients who have received similar negligent treatment from the same medical professional; however, class actions are unlikely to be successful in the medical malpractice context, given the requirements of class certification—in particular, the requirements of numerosity and predominance of common questions over individual issues. *See, e.g.,* *Georgine v. Amchem Prods., Inc.*, 83 F.3d 610, 627 (3d Cir. 1996), *aff'd*, 521 U.S. 591 (1997); *Carroll v. Cellco P'ship*, 713 A.2d 509, 515 (N.J. Super. Ct. App. Div. 1998); *Komocz v. Fields*, 648 N.Y.S.2d 151 (App. Div. 1996); *Kanon v. Brookdale Hosp. Med. Ctr.*, 386 N.Y.S.2d 274 (Sup. Ct. 1975). For a discussion of the topic, see Robert R. Levinson, *The Pitfalls of Commonality, Predominance and Class Action Mass Tort Cases*, 2002 N.J. LAW. 31, 32.

359. *See* Cecily M. Fuhr, *Cause of Action for Medical Malpractice Based on Misdiagnosis of or Failure to Diagnose Cancer*, in 45 CAUSES OF ACTION 2D 205 § 3 (2017); *see also* RESTATEMENT (SECOND) OF TORTS §§ 281, 328A (AM. LAW. INST. 1965); 61 AM. JUR. 2D *Physicians, Surgeons, Etc.* §183 (2017).

360. *See* 61 AM. JUR. 2D *Physicians, Surgeons, and Other Healers* § 342 (2017) (“A spouse may recover any damage that he or she has suffered in the form of loss of services which has resulted from malpractice that has injured the other spouse . . . [t]he loss of consortium is a widely recognized cause that may be brought by the spouse and sometimes by the children or parents of a loved one.”); *see also* *Dahan v. UHS of Bethesda, Inc.*, 692 N.E.2d 1303, 1305, 1306 (Ill. App. Ct. 1998); *Shaweker v. Spinell*, 181 N.E. 896 (Ohio 1932); AM. JUR. 2D *Torts* § 55 (2017).

361. *See* Fuhr, *supra* note 359, § 27.

362. *See, e.g.,* *Cummings v. Jha*, 915 N.E.2d 908, 920 (Ill. App. Ct. 2009) (“[A] physician or surgeon is bound to possess and use reasonable skill, not perhaps the highest degree of skill that one learned in the profession may acquire, but reasonable skill such as physicians in good practice ordinarily use and would bring to a similar case.”); *Pugh v. Swiontek*, 253 N.E.2d 3, 5 (Ill. App. Ct. 1969) (“Where, as in the instant case, there is admittedly a misdiagnosis, the question remains as to whether such misdiagnosis was the exercise of a reasonable medical judgment or a judgment arrived at without the exercise of appropriate care.”).

363. *See* 61 AM. JUR. 2D *Physicians, Surgeons, and Other Healers* § 200 (2017).

364. *See id.* § 186.

knowledge.³⁶⁵ The reasonable practitioner standard presents a major challenge to negligence actions against physicians who have misdiagnosed patients as vegetative. Given the diagnostic difficulties concerning disorders of consciousness and the high rate of misdiagnosis, medical experts are unlikely to testify that a reasonable practitioner would have acted differently; accordingly, courts are unlikely to find that a misdiagnosis of VS constitutes negligence.

However, the malpractice case law shows some willingness of courts to relax the reasonable practitioner standard and to establish new standards of care where the professional norm is insufficient or unclear.³⁶⁶ As Schwartz points out, courts have been more receptive to this move when (1) there is “a related or analogous standard of care to which the court can refer,” or (2) “professionals themselves have articulated definitions of appropriate care.”³⁶⁷

The medical profession has existing standards by which certain medical determinations be made only by practitioners with specialized knowledge, and only by following specific, systematic procedures. For example, the American Academy of Neurology issued Practice Parameters for brain death determinations in 1995 (AANPP), and updated those parameters in 2010.³⁶⁸ These parameters specify necessary qualifications for medical professionals who make brain-death determinations, as well as detailed procedures for the brain-death examination.³⁶⁹ While there is variability among institutions across the country, with many falling short of the AANPP, institutional policies do track the parameters.³⁷⁰ We propose that the same kind of requirements—in particular, specialized knowledge and an official, systematic procedure—should apply to medical determinations and recommendations involving severe disorders of consciousness. A new medical and legal standard can be developed based on the model of the national standard for brain-death determination.

Moreover, many medical professionals and researchers have expressed concern with the problem of misdiagnosis of disorders of consciousness and have in fact proposed new standards of care which, if followed, would reduce rates of misdiagnosis, as well as mitigate the

365. See, e.g., *Weaver v. McKnight*, 97 A.3d 920 (Conn. 2014).

366. Schwartz, *supra* note 356, at 673 (citing *Tarasoff v. Regents of the Univ. of California*, 551 P.2d 334 (Cal. 1976), as an example of a court establishing a new standard of care independent of professional norms); Gerald L. Klerman, *The Psychiatric Patient's Right to Effective Treatment: Implications of Osheroff v. Chestnut Lodge*, 147 AM. J. PSYCHIATRY 409, 415 (1990).

367. Schwartz, *supra* note 356, at 678, 681.

368. Hilary H. Wang et al., *Improving Uniformity in Brain Death Determination Policies Over Time*, 88 NEUROLOGY 562 (2017).

369. *Id.*

370. *Id.*

adverse consequences of misdiagnosis given that some degree of diagnostic error is inevitable. While differentiating VS from MCS presents major challenges,³⁷¹ the medical literature suggests that improved diagnostic accuracy is attainable even given the currently available diagnostic methods. For example, Schnakers has suggested that, “the systematic use of a sensitive standardized neurobehavioral assessment scale may help decrease diagnostic error and limit diagnostic uncertainty”;³⁷² Giacino has published a highly cited set of detailed recommendations, “intended to serve as a reference for clinicians involved in the examination and treatment of patients with severe alterations in consciousness”;³⁷³ and multiple commentators have called for an end to the “therapeutic nihilism” of the medical profession regarding patients with severe disorders of consciousness.³⁷⁴ Plaintiffs bringing negligence causes of action based on misdiagnosis could benefit from appealing to the work that clinicians and researchers have done to articulate improved standards of care; this work might influence what courts take to be the appropriate standard.

b. Grounds for Relief

Assuming plaintiffs can overcome the standard of care test, they could recover (1) for pain and suffering that resulted from their misdiagnoses, and (2) for the loss of chance of a better outcome. Although we focus on damages here, another option for legal relief for one who has been prematurely diagnosed as permanently vegetative, or diagnosed based on insufficient evidence, is an injunction; if successful in such an action, medical professionals would be enjoined from treating the patient as if she were in VS unless and until the diagnosis could be made with more certainty. However, the success of injunction claims in this context might be detrimental to damage claims, since some courts have held that where ex ante injunctive relief is available, it is not necessary to grant ex post damage relief.³⁷⁵

371. Giacino et al., *Disorders of Consciousness*, *supra* note 16; Schnakers et al., *supra* note 44, at 1.

372. Schnakers et al., *supra* note 44, at 2, 4; *see also* Giacino et al., *Disorders of Consciousness*, *supra* note 16; FINS, BRAIN INJURY, *supra* note 1, at 177, 301.

373. Giacino et al., *Minimally Conscious State*, *supra* note 4, at 352.

374. Joseph T. Giacino, *The Vegetative and Minimally Conscious States: Consensus-Based Criteria for Establishing Diagnosis and Prognosis*, 19 NEUROREHAB. 293, 297 (“[T]herapeutic nihilism’ . . . represents the belief that patients with prolonged disorders of consciousness are beyond help, therefore, any effort to intervene is futile and unjustified.”); *see also* FINS, BRAIN INJURY, *supra* note 1; Giacino et al., *Disorders of Consciousness*, *supra* note 16, at 2.

375. *See* Estate of Taylor v. Muncie Med. Inv’rs L.P., 727 N.E.2d 466 (Ind. Ct. App. 2000).

Patients diagnosed as in VS are not given analgesic treatment in situations where conscious patients would be, and moreover, are treated more roughly than conscious patients.³⁷⁶ Furthermore, patients in VS are often not afforded the human interaction or treated with the basic consideration that is expected of medical professionals with respect to conscious patients; many misdiagnosed patients suffer extensively as a result.³⁷⁷ Consequently, patients inaccurately diagnosed as in VS will likely have strong damage claims for compensation for the pain and suffering they experienced as a result of their misdiagnoses.

A misdiagnosis of VS, or premature diagnosis of permanent VS, often means a loss of chance for a better outcome—either because the patient does not receive the treatment and rehabilitation that an MCS patient would receive, or because life support is withdrawn in response to a permanent VS diagnosis. As many clinicians and researchers have noted, the diagnosis of a severe disorder of consciousness “is strongly associated with functional outcome.”³⁷⁸ Jurisdictions differ on their approaches to loss of chance. Many jurisdictions have adopted the proportional approach: the relevant inquiry is “whether the defendant probably caused a reduction in the victim’s chances”; if causation is found, the court grants “compensation for the lost chance in direct proportion to the extent of the lost chance.”³⁷⁹ Lost chance of

376. See, e.g., FINS, BRAIN INJURY, *supra* note 1.

377. See, e.g., *id.* (providing several examples of patients in MCS who experienced severe pain and suffering because they were treated as though they were completely unconscious).

378. Giacino et al., *Disorders of Consciousness*, *supra* note 16, at 1.

379. 61 AM. JUR. 2D *Physicians, Surgeons, and Other Healers* § 340 (2017); see, e.g., *Ford-Sholebo v. United States*, 980 F. Supp. 2d 917 (N.D. Ill. 2013); *Foskey v. United States*, 490 F. Supp. 1047, 1057-58 (D.R.I. 1980) (holding defendant physician liable under loss of chance theory for increased risk of a grand mal seizure in infant patient, which did in fact occur); *Peterson v. Ocean Radiology Assocs., P.C.*, 951 A.2d 606 (Conn. App. Ct. 2008); *Holton v. Mem’l Hosp.*, 679 N.E.2d 1202 (Ill. 1997) (holding that a plaintiff can prove causation under loss of chance theory by showing with reasonable medical certainty that plaintiff’s risk of harm was increased, or effectiveness of treatment decreased, as a result of defendant’s negligence); *N. Tr. Co. v. Louis A. Weiss Mem’l Hosp.*, 493 N.E.2d 6 (Ill. App. Ct. 1986) (finding defendant hospital liable for patient’s injury because its negligent delay in treatment was a substantial factor in bringing about the injury); *Smith v. Washington*, 734 N.E.2d 548 (Ind. 2000); *Wolfe v. Estate of Custer ex rel. Custer*, 867 N.E.2d 589 (Ind. Ct. App. 2007) (holding for plaintiff in negligence action against physician, where plaintiff provided evidence quantifying the increased risk resulting from physician’s conduct); *Roberts v. Ohio Permanente Med. Grp., Inc.*, 668 N.E.2d 480 (Ohio 1996). *But see* *Netto v. Goldenberg*, 640 N.E.2d 948, 953-54 (Ill. App. Ct. 1994) (stating that defendant physician is not liable if plaintiff shows only that physician’s negligence was a substantial factor contributing to plaintiff’s harm). Loss of chance is handled differently depending on the jurisdiction, and some states have adopted loss of chance doctrines that make it particularly challenging for plaintiffs to recover. Under Mississippi law, for example, a plaintiff must prove that if given a proper diagnosis or treatment, she would have had a greater than fifty percent chance of a significantly better outcome. See *Chickaway v. United States*, 990 F. Supp. 2d 650 (S.D. Miss. 2013); *Mem’l Hosp. at Gulfport v. White*, 170 So. 3d 506 (Miss. 2015).

survival is a more specific doctrine that has been adopted in some states, allowing plaintiffs to recover where the chance of a patient's survival was substantially reduced as a result of defendant's negligent conduct.³⁸⁰ Where patients are inaccurately or prematurely diagnosed as permanently vegetative, their chances of recovery might be drastically reduced; moreover, any chance of survival might be eliminated as a result of a premature diagnosis or a misdiagnosis. The loss of chance doctrine is meant to redress precisely this type of harm.

While we have focused on misdiagnosis here, it is also the case that patients can progress from VS to MCS (and emerge from MCS) if given appropriate treatment. Studies have demonstrated that patients often receive improved diagnoses after receiving therapeutic interventions.³⁸¹ Consequently, a loss of chance claim need not be based on misdiagnosis; instead, it could be based on an argument to the effect that the patient's chance of progressing beyond VS was reduced or eliminated as a result of inadequate care.

A possible adverse consequence of a patient receiving an MCS diagnosis is that it might make it difficult or impossible for a surrogate decisionmaker to have life support withdrawn from that patient, even if there is compelling evidence to suggest that the individual would not want to live under the circumstances.³⁸² The current legal standard requires "clear and convincing evidence" of the individual's wishes in order for a request for withdrawal of life support to be granted. While people do often express preferences regarding whether they would want to continue living should they end up in a VS, people are not, in general, knowledgeable about the MCS and the relationship between VS and MCS. Consequently, it would be highly

380. See, e.g., *Roberts*, 668 N.E.2d at 480 (allowing recovery where defendant's conduct reduced chance of survival from twenty-eight percent to zero percent); *McKellips v. Saint Francis Hosp., Inc.*, 741 P.2d 467, 472-74 (Okla. 1987). But see *Joshi v. Providence Health Sys. of Or. Corp.*, 149 P.3d 1164, 1169-70 (Or. 2006) (declining to adopt the lost chance of survival doctrine).

381. FINS, BRAIN INJURY, *supra* 1, at 177.

382. Marybeth Herald argues that the *Wendland* decision, *Conservatorship of Wendland*, 28 P.3d 151 (Cal. 1991), "places a nearly insurmountable burden of proof on the conservator of a person in a minimally conscious state," and goes on to argue that the right to withdraw life support is more important for people in MCS than VS: "[t]he burdens of continued life are far greater for the minimally conscious patient than those in the persistent vegetative state," given that people in MCS, unlike VS, are sentient and aware. Marybeth Herald, *Until Life Support Do Us Part: A Spouse's Limited Ability to Terminate Life Support for an Incompetent Spouse with No Hope of Recovery*, 24 T. JEFFERSON L. REV. 207, 212, 215 (2002); see also Courtenay R. Bruce, Comment, *The Awful Stranger, Consciousness: A Proposed Analytical Framework for Minimally Conscious State Cases*, 1 PHOENIX L. REV. 185, 200 (2008) ("MCS patients are categorically denied the right to withdraw treatment, and evidence suggesting a preference to withdraw treatment will be deemed incredible or insufficient . . ."); Mary Ann Buckley, Comment, In *Re Wendland: Contradiction, Confusion, and Constitutionality*, 11 J.L. & POL'Y 255 (2002).

unusual for someone to indicate preferences specifically for how they wish to be treated in the event that they become minimally conscious.

c. Informed Consent

Surrogate decisionmakers, most often next of kin, have the task of consenting to treatment, or termination of treatment, for patients with severe disorders of consciousness who do not have the capacity to consent themselves.³⁸³ However, often these decisionmakers are not adequately informed to make such decisions. We argue that violations of the legal right to informed consent occur when surrogate decisionmakers are not informed of the difficulty with diagnosing disorders of consciousness and, in particular, the misdiagnosis rates of VS, as well as the chance that the patient, if currently in VS, would regain some degree of consciousness under certain courses of treatment. As one of us has noted elsewhere, often “surrogate decision makers take [loss of consciousness] as an important prognostic sign and use this loss as a prompt to make end-of-life decisions,” perhaps not aware of the likelihood of MCS and associated chance of recovery.³⁸⁴

Patients have a right to informed consent both for undergoing treatment and for refusing treatment.³⁸⁵ While the doctrine of informed consent was traditionally grounded in battery, most informed consent cases today are based on a negligence theory.³⁸⁶ The elements of a tort claim for failure to obtain informed consent are as follows: (1) “that the physician owed a duty to disclose the risk,” (2) “that the physician breached the duty,” (3) “that the patient suffered an injury,” and (4) “that the physician's breach of the duty to disclose was

383. “Unless the patient has a legal guardian appointed, or has designated a surrogate . . . consent is obtained from the next-of-kin.” SUSAN O. SCHEUTZOW, AHILA, PATIENT CARE 11 (1999); see also Kellen F. Rodriguez, *Suing Health Care Providers for Saving Lives: Liability for Providing Unwanted Life-Sustaining Treatment*, 20 J. LEGAL MED. 1, 23 (1999) (“In the majority of states, an appointed surrogate or relative can refuse treatment for an incompetent on the basis of prior statements, life views, personality, or basic values, that is, a ‘substituted judgment’ standard.”).

384. FINS, BRAIN INJURY, *supra* note 1, at 184.

385. See *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 271 (1990) (“[M]ost courts have based a right to refuse treatment either solely on the common-law right to informed consent or on both the common-law right and a constitutional privacy right.”); Andrew J. Broder & Ronald E. Cranford, “*Mary, Mary, Quite Contrary, How Was I to Know?*” *Michael Martin, Absolute Prescience, and the Right to Die in Michigan*, 72 U. DET. MERCY L. REV. 787, 796 (1995) (“[T]he . . . common law right of informed consent encompasses the right of an informed refusal of treatment.”); Ann MacLean Massie, *Withdrawal of Treatment for Minors in a Persistent Vegetative State: Parents Should Decide*, 35 ARIZ. L. REV. 173, 189-90 (1993) (“The necessity that informed consent be given prior to the administration of medical care (absent emergency) is frequently characterized as the basis for the validity of refusal-of-treatment decisions as well.”).

386. SCHEUTZOW, *supra* note 383, at 6.

the proximate cause of the injury.”³⁸⁷ Generally, if a healthcare provider fails to obtain a patient’s informed consent to treatment, the patient “is entitled to compensation for all losses sustained as a direct and natural result of the treatment.”³⁸⁸ While a minority of states judge the duty to disclose based on a physician-oriented standard, asking what a reasonable physician would have disclosed under the circumstances,³⁸⁹ a majority of states employ a reasonable patient standard, asking what information a reasonable person would require in order to make an intelligent decision.³⁹⁰ Where the reasonable patient standard is used, expert testimony by medical professionals is not necessary to demonstrate the information that a physician was required to disclose, since the standard of disclosure is based on what information a reasonable patient under the circumstances would require in order to make an intelligent decision.³⁹¹

The D.C. Circuit set out the patient-oriented standard in *Canterbury v. Spence*, stating that, “whether a particular peril must be divulged [depends on] its materiality to the patient’s decision: all risks potentially affecting the [patient’s] decision must be unmasked.”³⁹² Rejecting the professional-norm standard, the court asserted that, “[r]espect for the patient’s right of self-determination . . . demands a standard set by law for physicians rather than one which physicians may or may not impose upon themselves.”³⁹³ In the words of the Missouri Supreme Court, the requirements of informed consent include that the patient has “a clear understanding of the risks and benefits of the proposed treatment alternatives or nontreatment,” and “a full understanding of the nature of the disease and the prognosis.”³⁹⁴ As the California court of appeals has put it, “[a] physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent con-

387. 61 AM. JUR. 2D *Physicians, Surgeons, and Other Healers* § 151 (2017).

388. Rodriguez, *supra* note 383.

389. See, e.g., *Retkwa v. Orentreich*, 584 N.Y.S.2d 710 (Sup. Ct. 1992).

390. See, e.g., *Canterbury v. Spence*, 464 F.2d 772, 787 (D.C. Cir. 1972); *Dessi v. United States*, 489 F. Supp. 722, 729 (E.D. Va. 1980); *Boyd v. La. Med. Mut. Ins. Co.*, 593 So. 2d 427, 429 (La. Ct. App. 1991); *McKinley v. Stripling*, 763 S.W.2d 407, 410 (Tex. 1989). Some courts have employed a *subjective* patient-oriented standard, asking if the patient in question would have consented if adequately informed. See, e.g., *Scott v. Bradford*, 606 P.2d 554, 559 (Okla. 1979); see also *Ashe v. Radiation Oncology Assocs.*, 9 S.W.3d 119, 121 (Tenn. 1999) (“The majority of jurisdictions having addressed this issue follow an objective standard. A minority of jurisdictions having addressed the issue follow the subjective approach.”).

391. See *Korman v. Mallin*, 858 P.2d 1145, 1149 (Alaska 1993); *Barcai v. Betwee*, 50 P.3d 946, 963 (Haw. 2002); *Bernard v. Char*, 903 P.2d 676, 688 (Haw. Ct. App. 1995), *aff’d*, 903 P.2d 667 (1995).

392. *Canterbury*, 464 F.2d at 786-87.

393. *Id.* at 784.

394. *Cruzan v. Harmon*, 760 S.W.2d 408, 417 (Mo. 1988).

sent by the patient to the proposed treatment.”³⁹⁵ Moreover, in *In re Conroy*, the New Jersey Supreme Court specified that, “the patient must have a clear understanding of the risks and benefits of the proposed treatment alternatives or nontreatment, along with a full understanding of the nature of the disease and the prognosis.”³⁹⁶

Courts have maintained that a surrogate decisionmaker is entitled to (at least) the same medical information that the patient would have required in order to make an appropriate decision concerning treatment. These might include such elements as:

[T]he degree of physical pain resulting from the medical condition, treatment, and termination of treatment, respectively; the degree of humiliation, dependence, and loss of dignity probably resulting from the condition and treatment; the life expectancy and prognosis . . . with and without treatment; the various treatment options; and the risks, side effects, and benefits of each of those options.³⁹⁷

Additionally, the New Jersey Supreme Court specified that “[p]articular care should be taken not to base a decision on a premature diagnosis or prognosis.”³⁹⁸

At the least, medical professionals should be required to communicate the diagnostic uncertainty surrounding disorders of consciousness to the surrogate decisionmakers who are tasked with making decisions regarding patients’ continuing care—decisions which often include whether to continue or withdraw life support.

We believe that under the reasonable person standard, patients with disorders of consciousness and their surrogates need more information from physicians than they are typically given in order to make appropriate medical decisions. Surrogate decisionmakers might reasonably decide differently if they are more fully informed both of the diagnostic difficulties regarding disorders of consciousness and the medical options that exist for people with severe disorders of consciousness. We suggest that parties in this position will often be able to demonstrate that they suffered a harm that would not have occurred but for the failure to disclose, and accordingly should be entitled to legal relief under the doctrine of informed consent.³⁹⁹

The prevalence of misdiagnosis and premature diagnosis of disorders of consciousness is unacceptably high, from both a legal and an ethical perspective. Clinicians and researchers have demonstrated

395. *Salgo v. Leland Stanford Jr. Univ. Bd. of Trs.*, 317 P.2d 170, 181 (Cal. Ct. App. 1957).

396. *In re Conroy*, 486 A.2d 1209, 1222 (N.J. 1985).

397. *Id.* at 1231.

398. *Id.*

399. See *Corrigan v. Methodist Hosp.*, 869 F. Supp. 1202, 1206 (E.D. Pa. 1994).

that this diagnostic error can be mitigated; to the extent that such improvements are possible, standards of care must be adapted accordingly—a change which might require legal intervention. Moreover, while it is perhaps unreasonable to expect very high diagnostic accuracy when it comes to disorders of consciousness, medical professionals have a duty to disclose diagnostic difficulties to the decisionmakers who make treatment and life support decisions on behalf of their loved ones. Ultimately, the optimal result of increased awareness around these ethical and legal issues would not be more lawsuits, but rather improved standards of care for people with severe mental disabilities.

V. JUSTICE FOR PERSONS WITH SEVERE BRAIN INJURY UNDER INTERNATIONAL HUMAN RIGHTS LAW

To fully explore the rights and justice claims of persons with severe brain injury, it is necessary to look beyond current domestic law and consider international best practice and standards. These standards can serve as a guidepost and aspiration for efforts at reform. Care and treatment of persons with severe brain injury raise questions of fundamental human rights recognized in international law.

This Part relies on the Convention of the Rights of Persons with Disabilities (CRPD),⁴⁰⁰ which sets the global standard regarding rights of persons with disabilities, as well as the international bill of human rights,⁴⁰¹ consisting of the Universal Declaration of Human Rights (UDHR),⁴⁰² the International Covenant on Civil and Political Rights (ICCPR),⁴⁰³ and the International Covenant on Social, Economic and Cultural Rights (ICESCR).⁴⁰⁴ The UDHR is not a treaty, but as the foundational document of the human rights regime, it has important “moral authority,” as recognized by the U.S. Supreme Court,⁴⁰⁵ and at least parts of it are considered customary interna-

400. Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, 2515 U.N.T.S. 3 (entered into force May 3, 2008) [hereinafter CRPD].

401. See UNITED NATIONS, OHCHR, FACT SHEET NO. 2: THE INTERNATIONAL BILL OF RIGHTS (1996), <http://www.ohchr.org/Documents/Publications/FactSheet2Rev.1en.pdf> [<https://perma.cc/H9GT-U3GD>].

402. G.A. Res. 217 (III) A, Universal Declaration of Human Rights (Dec. 10, 1948) [hereinafter UDHR].

403. International Covenant on Civil and Political Rights, Dec. 16, 1966, 999 U.N.T.S. 171 (entered into force Mar. 23, 1976) [hereinafter ICCPR].

404. International Covenant on Economic, Social and Cultural Rights, Dec. 16, 1966, 993 U.N.T.S. 3 (entered into force Jan. 3, 1976) [hereinafter ICESCR].

405. *Sosa v. Alvarez-Machain*, 542 U.S. 692, 734 (2004). The Supreme Court has also referenced the UDHR in its analysis. See, e.g., *Dandridge v. Williams*, 397 U.S. 471, 520 n.14 (1970) (citing UDHR, art. 25 “[o]n the issue of whether there is a ‘right’ to welfare assistance”); *Zemel v. Rusk*, 381 U.S. 1, 14 n.13 (1965) (citing UDHR, art. 13 in discussing

tional law.⁴⁰⁶ The CRPD and ICESCR were signed but have not been ratified by the United States.⁴⁰⁷ The ICCPR was both signed and ratified and is legally binding.⁴⁰⁸ As a member of this treaty, the United States reports every few years on its compliance to the U.N. Human Rights Committee, the expert body responsible for monitoring implementation of the ICCPR.⁴⁰⁹ Additionally, the U.N. Human Rights Council, a body of state representatives, regularly reviews each state's human rights record, using peer pressure and shame to induce compliance.⁴¹⁰

In ratifying the ICCPR, however, the U.S. Senate included a declaration that "the provisions of Article 1 through 27 of the Covenant are not self-executing,"⁴¹¹ which aimed to "clarify that the Covenant will not create a private cause of action in U.S. Courts."⁴¹² In reporting to the U.N. Human Rights Committee, the U.S. government explained that this declaration "did not limit the international obliga-

the requirements of due process); *Kennedy v. Mendoza-Martinez*, 372 U.S. 144, 161 n.16 (1963) (noting "the right of every citizen to retain a nationality" in UDHR, art. 15).

406. *Filartiga v. Pena-Irala*, 630 F.2d 876, 882 (2d Cir. 1980) ("This prohibition has become part of customary international law, as evidenced and defined by the Universal Declaration of Human Rights . . ."); David A. Catania, *The Universal Declaration of Human Rights and Sodomy Laws: A Federal Common Law Right to Privacy for Homosexuals based on Customary International Law*, 31 AM. CRIM. L. REV. 289, 300-08 (1994); Richard B. Lillich, *Invoking International Human Rights Law in Domestic Courts*, 54 U. CIN. L. REV. 367, 393 (1985) ("The starting point in ascertaining what international human rights norms have been received into customary international law—and therefore are rules of decisions for domestic courts—commonly is thought to be the Universal Declaration of Human Rights . . ."); Eisuke Suzuki & Suresh Nanwani, *Responsibility of International Organizations: The Accountability Mechanisms of Multilateral Development Banks*, 27 MICH. J. INT'L L. 177, 195 (2005).

407. The CRPD was signed on July 30, 2009, and the ICESCR was signed on October 5, 1977. See *Ratification Status for United States of America*, OHCHR, http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Treaty.aspx?CountryID=187&Lang=EN [<https://perma.cc/L26F-2QMM>]. Under the Vienna Convention on the Law of Treaties, when a state has signed but not ratified a treaty, while it need not take positive steps to comply with its provisions, it is obligated "to refrain from acts which would defeat [its] object and purpose." Vienna Convention on the Law of Treaties, art. 18, May 23, 1969, 1155 U.N.T.S. 331 (entered into force Jan. 27, 1980) [hereinafter Vienna Convention].

408. The ICCPR was signed by President Carter on October 5, 1977 and ratified by Congress on June 8, 1992. See *Ratification Status for United States of America*, *supra* note 407.

409. See ICCPR, *supra* note 403, art. 40. For past U.S. reports to the Human Rights Committee, see *The United Nations Human Rights Treaties*, BAYEFSKY.COM, <http://www.bayefsky.com/docs.php/area/reports/state/184/node/3/treaty/ccpr/opt/0> [<https://perma.cc/5PHQ-8CUX>].

410. See *Basic Facts About the UPR*, OHCHR, <http://www.ohchr.org/EN/HRBodies/UPR/Pages/BasicFacts.aspx> [<https://perma.cc/S66L-V7UC>]; see also *What is the UPR?*, UPR INFO, <https://www.upr-info.org/en/upr-process/what-is-it> [<https://perma.cc/8YTJ-GMNY>].

411. U.S. Reservations, Declarations, and Understandings, International Covenant on Civil and Political Rights, 138 CONG. REC. S4781-01 (daily ed. Apr. 2, 1992).

412. S. EXEC. REP. NO. 102-23, at 19 (1992) (Conf. Rep.).

tions of the United States under the Covenant. Rather, it means that, as a matter of domestic law, the Covenant does not, by itself, create private rights directly enforceable in U.S. courts.”⁴¹³ This leaves open the intriguing possibility of using the ICCPR in conjunction with domestic provisions in litigation.⁴¹⁴ In fact, U.S. courts have referred to the ICCPR as an aid in interpretation.⁴¹⁵ The ICCPR itself requires “an effective remedy” for violations,⁴¹⁶ and the U.N. Human Rights Committee clarified that this includes roles for the executive, legislative, and judicial branches of government.⁴¹⁷

While international human rights law does not serve as a strong basis for litigation, it can be an important anchor for advocacy. In particular, persons with severe brain injury may anchor justice claims to international human rights such as the rights to life,⁴¹⁸ health,⁴¹⁹ benefit from scientific progress,⁴²⁰

413. Human Rights Comm., Rep. on the Initial Reports of States Parties Due in 1993: United States of America, ¶ 8, U.N. Doc. CCPR/C/81/Add.4 (1994).

414. *Id.* The U.S. government further explained that “the fundamental rights and freedoms protected by the Covenant are already guaranteed as a matter of U.S. law, either by virtue of constitutional protections or enacted statutes, and can be effectively asserted and enforced by individuals in the judicial system on those bases,” *id.*, seeming to indicate that constitutional protections and statutes should be interpreted as consistent with the ICCPR.

415. See, e.g., *Roper v. Simms*, 543 U.S. 551, 576 (2005); *Sterling v. Cupp*, 625 P.2d 123, 131 n.21 (Or. 1981).

416. ICCPR, *supra* note 403, art. 2(3)(a).

417. Human Rights Comm., General Comment No. 31, The Nature of the General Legal Obligation Imposed on States Parties to the Covenant, ¶¶ 4, 7, U.N. Doc. CCPR/C/21/Rev.1/Add.13 (2004). Additionally, under the Vienna Convention on the Law of Treaties, a reservation to a treaty is void if it is “incompatible with the object and purpose” of that treaty. Vienna Convention, *supra* note 407, art. 19; see also John C. Yoo, *Globalism and the Constitution: Treaties, Non-Self-Execution, and the Original Understanding*, 99 COLUM. L. REV. 1955, 1959 (1999).

418. As both the ICCPR and CRPD recognize, “every human being has the inherent right to life.” ICCPR, *supra* note 403, art. 6(1); CRPD, *supra* note 400, art. 10; see also UDHR, *supra* note 402, art. 3 (“Everyone has the right to life, liberty and security of person.”).

419. As set out in the ICESCR, human rights law recognizes “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” ICESCR, *supra* note 404, art. 12(1). The CRPD further clarifies that “persons with disabilities have the right to the enjoyment of the highest . . . standard of health without discrimination on the basis of disability.” CRPD, *supra* note 400, art. 25. The CRPD also recognizes a right to “comprehensive habilitation and rehabilitation services and programmes.” CRPD, *supra* note 400, art. 26. The CRPD specifically “[p]rohibit[s] discrimination against persons with disabilities in the provision of health insurance” and the “discriminatory denial of health care or health services.” CRPD, *supra* note 400, art. 25(e), (f).

420. The ICESCR recognizes the right of everyone “[t]o enjoy the benefits of scientific progress and its applications.” ICESCR, *supra* note 404, art. 15(1)(b); see also UDHR, *supra* note 402, art. 27(1). The CRPD elaborates on the state obligation “to undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies.” CRPD, *supra* note 400, art. 4(g). Moreover, it requires states to “promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.” CRPD, *supra* note

education,⁴²¹ freedom of expression,⁴²² community,⁴²³ and equal protection.⁴²⁴

Identifying a human rights issue provides not only the possibility of a legal remedy, but also the mobilizing power of rights. Human rights are much more than the legal framework to which they are linked and also provide a language to articulate and mobilize around justice concerns. Community mobilization complements litigation and can play a critical role in advancing rights protections.⁴²⁵ The Black Lives Matter movement⁴²⁶ and the campaign against solitary

400, art. 26(3). Under the CRPD, states must “undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies” to protect basic rights. CRPD, *supra* note 400, art. 31.

421. The ICESCR encapsulates “the right of everyone to education” for the “full development of the human personality and the sense of its dignity.” ICESCR, *supra* note 404, art. 13(1); *see also* UDHR, *supra* note 402, art. 26 (“Everyone has the right to education. . . . Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms.”). The CRPD mandates “an inclusive education system at all levels and lifelong learning” to enable “development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential” CRPD, *supra* note 400, art. 24(1).

422. The ICCPR recognizes, “[e]veryone shall have the right to freedom of expression,” including “freedom to seek, receive and impart information and ideas of all kinds” ICCPR, *supra* note 403, art. 19(2); *see also* UDHR, *supra* note 402, art. 19 (“Everyone has the right to freedom of opinion and expression; this right includes freedom . . . to seek, receive and impart information and ideas through any media and regardless of frontiers.”). And, under the CRPD, states must “take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion.” CRPD, *supra* note 400, art. 21. The first guiding principle set out by the CRPD is “[r]espect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.” CRPD, *supra* note 400, art. 3(a).

423. The CRPD recognizes the “equal right of all persons with disabilities to live in the community.” States must take measures to ensure their “full inclusion and participation in the community” and “to prevent isolation or segregation.” CRPD, *supra* note 400, art. 19.

424. The ICCPR and UDHR proclaim, “Everyone shall have the right to recognition everywhere as a person before the law.” ICCPR, *supra* note 403, art. 16; UDHR, *supra* note 402, art. 6. People are also entitled to “equal protection of the law.” ICCPR, *supra* note 403, art. 26; UDHR, *supra* note 402, art. 7. The CRPD elaborates, “persons with disabilities have the right to recognition everywhere as persons before the law.” CRPD, *supra* note 400, art. 12(1). Additionally, “all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.” CRPD, *supra* note 400, art. 5(1).

425. One example is the movement for marriage equality. *See How It Happened*, FREEDOM TO MARRY, <http://www.freedomtomarry.org/pages/how-it-happened> (last visited Jan. 24, 2018). For a history of the movement and how campaigning complemented litigation, *see generally Winning the Freedom to Marry Nationwide*, FREEDOM TO MARRY, <http://www.freedomtomarry.org/> (last visited Jan. 24, 2018).

426. In November 2014, Michael Brown’s parents testified before the U.N. Committee Against Torture regarding police brutality and racial profiling in the United States. J.A. Salaam, *Parents of Mike Brown Take the Struggle to United Nations Forum*, FINAL CALL, http://www.finalcall.com/artman/publish/National_News_2/article_101922.shtml [<https://perma.cc/94UE-WLBM>] (last updated Nov. 12, 2014); Deirdre Fulton, *With Heavy Hearts, Activists Carry Human Rights Messages from #FergusonToGeneva*, COM-

confinement⁴²⁷ have used international human rights norms to legitimize and affirm local advocacy and bring global attention to an issue. There is now a vibrant movement working towards the implementation of human rights law, which pairs domestic legal arguments with human rights standards.⁴²⁸ There is also a growing human rights city movement, which endorses international human rights standards and includes cities like Boston, Massachusetts; Washington, D.C.; and, most recently, Mountain View, California.⁴²⁹ These developments may open additional avenues for advocacy for the rights of persons with severe brain injury.

When entered into force in May 2008, the CRPD took a significant step in affirming the dignity of people with disabilities and their standing within the human community. The CRPD asserts that “discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person.”⁴³⁰ However, even within the disability movement, persons with severe brain injuries are largely invisible and marginalized.

VI. CONCLUSION

This Article has described the clinical needs and legal vulnerabilities of persons with severe brain injury. We also identified sources of law that can be used to protect the rights and improve the lives of persons with severe brain injury, assessing which legal strategies are the most promising paths to medical recovery and subsequent community integration. We began by analyzing sources of federal law; we suggested that when it comes to asserting rights-based claims on be-

MONDREAMS (Nov. 11, 2014), <http://www.commondreams.org/news/2014/11/11/heavy-hearts-activists-carry-human-rights-message-fergusontogeneva> [<https://perma.cc/PH5W-T6HX>].

427. *We Can Stop Solitary*, ACLU, <https://www.aclu.org/feature/we-can-stop-solitary> [<https://perma.cc/XDE7-SDYJ>]; *Stop Solitary: Advocacy Campaign Tools*, ACLU, <https://www.aclu.org/other/stop-solitary-advocacy-campaign-tools> [<https://perma.cc/U5RC-JXYV>].

428. See U.S. HUM. RTS. NETWORK, <http://www.ushrnetwork.org/> (last visited Jan. 24, 2018); *The Bringing Human Rights Home Lawyers' Network*, COLUM. L. SCH., <http://www.law.columbia.edu/human-rights-institute/bhrh-lawyers-network> [<https://perma.cc/K8FB-9TSU>].

429. See *National Human Rights Cities Alliance*, U.S. HUM. RTS. NETWORK, <http://www.ushrnetwork.org/our-work/project/national-human-rights-city-network> [<https://perma.cc/38RC-Q5GA>]. There is additionally a U.S. city movement specifically focused on implementing the U.N. Convention on the Elimination of All Forms of Discrimination against Women through city ordinances and resolutions. For a list of involved cities, see THE LEADERSHIP CONFERENCE EDUC. FUND & WOMEN'S INTERCULTURAL NETWORK, CITIES FOR CEDAW: STATUS OF LOCAL ACTIVITIES (2017), <http://citiesforcedaw.org/wp-content/uploads/2017/01/Landscape-Cities-for-CEDAW-Branded-for-Website-January-2017.pdf> [<https://perma.cc/V5WQ-QE3T>].

430. CRPD, *supra* note 400, pmbl. (h). Moreover, the first guiding principle of the CRPD refers to “[r]espect for inherent dignity . . . of persons.” CRPD, *supra* note 400, art. 3(a).

half of persons with severe brain injury at the federal level, the ADA and its amendments are the most promising piece of legislation. It is unclear, however, what the fate of persons with disabilities will be under a Trump Administration. The ADA had bipartisan support and was passed during a Republican administration that had vetoed other civil rights legislation.⁴³¹ Nevertheless, the current federal administration may not prioritize the civil rights of persons with disabilities or *Olmstead* enforcement responsibilities to the same extent as the Obama Administration.⁴³²

With respect to capabilities-based legal strategies at the federal level, we reviewed the role select administrative agencies can play with respect to facilitating access to rehabilitation and medical devices that can aid in fostering recovery from severe brain injury. Many of these strategies would require significant resources, such as organized lobbying. Additionally, given the Trump Administration's attack on the administrative state,⁴³³ the extent to which a focus on regulation will benefit persons with severe brain injury is unclear.

We next analyzed sources of state law that may be used as tools to promote the societal integration of persons with severe brain injury. In a time when the federal government increasingly has been deferring to the states on matters such as healthcare and civil rights,⁴³⁴ advocates may have more success focusing on state and local laws. State statutes that address disability discrimination and provide more protections than the ADA may be particularly promising means to assert rights-based claims. There may also be an opportunity to spread progressive state laws such as California's through cooperative groups like the National Conference of State Legislatures. Furthermore, bringing lawsuits grounded in various tort claims, if successful, may lead to greater awareness of the marginalization of individuals with severe brain injury and favorable legislative change. This latter strategy would likely require significant media exposure to put pressure on the legislature.

We concluded this Article by examining sources of international law. Although the Trump Administration has emphasized isolation-

431. Krieger, *supra* note 114, at 1-2.

432. Indeed, the current administration is retreating from supporting rights-based claims of other marginalized groups. See, e.g., Jeremy W. Peters, Jo Becker & Julie Hirschfeld Davis, *Trump Rescinds Rules on Bathrooms for Transgender Students*, N.Y. TIMES (Feb. 22, 2017), https://www.nytimes.com/2017/02/22/us/politics/devos-sessions-transgender-students-rights.html?_r=0.

433. See Scott Horsley, *Trump Orders Agencies to Reduce Regulations*, NPR (Feb. 24, 2017, 2:11 PM), <http://www.npr.org/2017/02/24/517059327/trump-orders-agencies-to-reduce-regulations>.

434. Even the ACA delegates responsibility to the states through creation of exchanges, selection of a benchmark insurance plan, and Medicaid changes.

ism and international human rights law is not directly applicable in domestic litigation, the language of rights, equality, and dignity for persons with disabilities articulated in international treaties and declarations is both aspirational and inspirational. It provides a goal for full inclusion of persons with disabilities and can be used as an anchor in building a social movement that can sustain law and policy change, or as an interpretive aid in disability discrimination cases. Furthermore, and consistent with our argument that state law may be a more promising avenue for reform than federal law, there is a recent trend of municipalities endorsing human rights standards. Advocates for persons with severe brain injury can draw on these standards in urging their local governments to make changes to promote the full inclusion of persons with severe brain injury in their communities. For example, changes to zoning ordinances would make it easier to create more community-based treatment facilities. Similarly, municipalities could provide financial incentives to organizations to provide such care.

To conclude, there are many sources of law that can be leveraged—both in traditional and novel ways—to ameliorate the clinical and social problems faced by persons with severe brain injury, and to promote their recovery and reintegration into their communities. Here, we have analyzed many of these possibilities, and have attempted to illustrate their relative merits as well as limitations. Given the uncertainty about current federal laws and administrative environment, we recommend increased attention to state law as a basis for legal action that can help create a more just society for persons with severe brain injuries.