

# Brain injury, medical progress, and the disability paradox: Towards an *Americans with Abilities Act*

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**Abstract.** It is helpful to think about the needs of patients with moderate to severe brain injury through the lens of disability law. However, there are limitations to current disability law that contribute to ongoing segregation and marginalization of individuals with severe brain injury. Indeed, one of the paradoxes of American jurisprudence is that more clear constitutional protections accrue to those who have definitively immutable conditions. Thus, as neuroscience brings new therapies to those with brain injury, they may become less protected by the constitutional elements of disability law because their conditions have changed and become *mutable*. This is the clinical progress that brain injury professionals all seek to achieve, but ironically these advances could potentially degrade the legal protections of patients who benefit from emerging treatments. In this paper, we will critically examine this paradox at the interface of medicine and the law and suggest that the Americans with Disabilities Act (ADA) could be nicely complemented by legislation we have named the Americans with Abilities Act (AWAA). Instead of focusing on disabilities that need protection, the AWAA seeks to sustain and foster newfound abilities made possible by the fruits of medicine and neuroscience.

**Keywords:** Brain injury, neuroethics, disability law, Americans with Abilities Act, assisted living, vegetative state

## 1. Introduction

It is helpful to think about the needs of patients with moderate to severe brain injury through the lens of disability law, particularly the 1990 Americans with Disabilities Act (ADA) – and its subsequent amendments (ADAAA) – which established a “clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities” (Americans with Disabilities Act, 1990;

ADA Amendments Act, 2008). This legislation was strengthened in the 1999 Supreme Court decision *Olmstead v L.C.* which affirmed the right of individuals with disabilities to receive services in “the most integrated setting appropriate to the needs of the individual” (*Olmstead v. L.C.*, 1999). However, there are limitations to current disability law that contribute to ongoing segregation and marginalization of individuals with severe brain injury. Indeed, one of the paradoxes of American jurisprudence is that more clear constitutional protections accrue to those who have definitively immutable conditions. Thus, as neuroscience brings new therapies to those with brain injury, they may become less protected by the constitutional elements of disability law because their

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conditions have changed and become *mutable*. This is the clinical progress that brain injury professionals all seek to achieve, but ironically these advances could potentially degrade the legal protections of patients who benefit from emerging treatments.

In this paper, we will critically examine this paradox at the interface of medicine and the law and look at ways to reconcile clinical advances with legal protections. While this is a challenge for legal scholarship, this is a good problem to have as it reflects a transformative era of therapeutic possibility. To accommodate clinical promise and some degree of legal peril we have previously suggested that the ADA could be nicely complemented by legislation we have named the Americans with Abilities Act (AWAA) (Shapiro et al., 2022). Instead of focusing on disabilities that need protection, the AWAA seeks to sustain and foster newfound abilities made possible by the fruits of medicine and neuroscience.

## 2. Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is best understood as residing within the lineage of civil rights legislation, with legal scholars such as Tim Cook noting that racial and disability discrimination had common historical roots that marginalized and segregated these populations (Fins, 2015; Cook, 1991). Segregation was instantiated in the 1896 Supreme Court ruling in *Plessy v Ferguson* that allowed the problematic construct of “separate but equal” (*Plessy v. Ferguson*, 1896). This was reversed in 1954 in *Brown v Board of Education* when the Supreme Court mandated racial integration in schools, noting that separate could never be equal (*Brown v. Board of Education*, 1954). This was followed by the landmark civil rights legislation of the 1960s (Civil Rights Act, 1964).

Despite this progress, people with disabilities were not specifically covered by this legislation. They remained segregated in civil society, deprived of the benefits of access and community that other citizens enjoyed. In response, Congress passed the Rehabilitation Act of 1973, the first federal legislation describing the rights of individuals with disabilities. Section 504 established that “No otherwise handicapped individual in the United States ... shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance” (Rehabilita-

tion Act, 1973; Fins & Wright, 2018). And while monumental, the Rehabilitation Act’s purview was limited to entities that received federal funding, so it did not pertain to the private domain.

In response to this shortcoming, Congress passed the ADA, which was signed by President George Herbert Walker Bush in 1990 (Americans with Disabilities Act, 1990). Historians viewed the ADA as a landmark piece of civil rights legislation and perhaps the greatest achievement of the Bush presidency (Meacham, 2016). The ADA (and its subsequent Amendment Act in 2008) defined a disability as “a physical or mental impairment that substantially limits one or more major life activities of such individual; ... a record of such an impairment; or ... [if the individual is] regarded as having such an impairment.” This broad and inclusive definition allowed a multitude of individuals to seek refuge in the new legislation. The ADA outlined equal access to employment (Title I), public entities like most health care institutions (Title II), public and commercial facilities (Title III), and telecommunications (Title IV), amongst other provisions designed to counteract the historic policies that “... isolate and segregate individuals with disabilities” (ADA, 1990). The Equal Employment Opportunity Commission (EEOC), Department of Justice (DOJ), Federal Communications Commission (FCC), Department of Labor (DOL), and Department of Transportation (DOT) each enforce the ADA in their respective domains (Shapiro et al., 2022). As an overarching guideline, the ADA requires that entities provide “reasonable accommodation” or modifications for individuals with disabilities unless it is shown that such changes would “fundamentally alter the nature of the service, program, or activity” (Shapiro et al., 2020; 28 C.F.R. §35.130(b)(7)(i) (2019)). A failure to provide care in the most integrative manner feasible would be an *Olmstead* violation and perpetuate discrimination by maintaining the segregation of people with disabilities.

In 1999, the ADA was upheld by the Supreme Court in *L.C. v Olmstead*. Lois Curtis and Elaine Wilson were two women with developmental and psychiatric disabilities who had been voluntarily hospitalized for treatment in the state of Georgia. After receiving inpatient psychiatric care in a state hospital, they requested transfer to a community facility. Their doctors felt this was safe and medically appropriate. Despite this clinical indication, Curtis and Wilson remained institutionalized against their will, because of the state’s refusal to bear the cost of community care (Shapiro et al., 2020). The Supreme

Court found that this denial of liberty and community integration violated Title II of the ADA. For the majority, Justice Ruth Bader Ginsburg wrote that, in the ADA, “Congress explicitly identified unjustified ‘segregation’ of persons with disabilities as a ‘form of discrimination.’” Furthermore, she noted that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment,” highlighting the mandate for community integration of individuals with disabilities (*Olmstead v LC*, 1999). *Olmstead* became a framework for enforcing violations of the ADA.

Although *Olmstead* was an important legal decision, much work remains to achieve the vision of the ADA. As the late disability activist Justin Dart observed, “Our society is still infected by an insidious, now almost unconscious, assumption that people with disabilities are less than fully human and therefore are not entitled to the respect, the opportunities, and the services and support systems that are available to other people as a matter of right” (Fins, 2015; Dart in Gostin & Beyer, 1993).

### 3. Brain injury and disability law

Dart’s comment about the presumptions made about people with disabilities are especially apt for individuals with severe brain injury, many of whom have undetected or covert consciousness (Schnakers & Monti, 2017; Schiff, 2015). These individuals are often misdiagnosed and relegated to chronic care facilities where they are “warehoused” and receive what is euphemistically (and unacceptably) called “custodial care.” Such marginalization is not acceptable for any population and in this case constitutes malignant neuro-exceptionalism. Institutionalized, these individuals face prolonged separation from family, friends, and their community. In many ways their care is both separate *and* unequal, a situation that would have even violated the holding in the deeply problematic (and properly overturned) *Plessy v Ferguson*.

Furthermore, these patients’ prognoses are often determined by their discharge diagnoses, without proper consideration of the brain’s longitudinal ability to heal (Fins et al., 2016; Thengone et al., 2016). And because access to rehabilitation hinges on criteria of “medical necessity,” this can dictate the provision of care and ignore the reality that “brains

recover by biological mechanisms and not reimbursement criteria” (Fins, 2012; Fins, 2023).

Once patients are sent to “custodial care,” they are distanced from further medical assessments and evaluations, locking in diagnoses which may become inaccurate over time. Thus, their condition remains misunderstood and their treatment (or lack thereof) uninformed. These institutions’ substandard care deprives patients of access to novel interventions that may have the potential to restore functional communication, which we assert violates *Olmstead* and the ADA (Shapiro et al., 2020; Fins et al., 2020; Wright et al., 2018; Wright and Fins 2016).

Denying access to new technologies may also run afoul of the intent of Title IV of the ADA, which regulates access to TTY communication devices for people with hearing impairments (Shapiro et al., 2020; 47 U.S.C. §225). It is likely that the normative intent was not to solely give access to the hearing-impaired community but rather promote functional communication. Nonetheless, this lack of specificity deprives individuals with disabilities access to emerging technologies, as a condition of compliance with the ADA, which could be the subject of litigation to determine legislative intent.

Lack of access to methods that could enable functional communication for this population is normatively and legally deficient and is an *Olmstead* violation. As we have written elsewhere, communication itself is a form of societal integration, as it enables the individual in question access to their community through engaging with those around them (Shapiro et al., 2020; Shapiro et al., 2022). Without emerging neurotechnologies that can foster communication, patients are effectively isolated and unable to convey their needs, desires, and rights. In the case of individuals with covert consciousness, communication becomes an essential means to demonstrate the presence of the self and that they are *there*.

### 4. Medical progress, immutability, and the constitutional paradox

The purpose of neurology and rehabilitation medicine is to restore function and make what appear to be immutable (or unchangeable) conditions mutable. Few would object to this medical goal, pursued with the consent of patients or their surrogates so as not to exert what Foucault called unjustified “biopower” (Foucault, 2012). However, this progress can conflict with a foundational premise

of constitutional law which has traditionally afforded greater protections to those facing discrimination based on immutable characteristics (Clarke, 2015; Waterstone, 2013). Thus, the paradox: improving function may make people with disabilities more vulnerable to discrimination and marginalization if constitutional protections erode.

Historically conditions that are considered immutable have been granted greater legal protection by the courts. The Supreme Court specified heightened levels of protected status or scrutiny of law is appropriate when an affected suspect class has been "... saddled with such disabilities, or subjected to such a history of purposeful unequal treatment, or relegated to such a position of political powerlessness as to command extraordinary protection from the majoritarian political process" (San Antonio Indep. Sch. Dist. v. Rodriguez, 1973). One factor that is considered is whether or not a characteristic is permanent, with immutable conditions such as race afforded greater legal protections (Clarke, 2015). The concept of immutability originated as a categorization of traits deemed an "accident of birth" (Clarke, 2015). These characteristics were determined to be out of the individual's control, for which they could not be held responsible or be blamed. Historically, characteristics like race, gender, and disability have been considered immutable and thus these groups receive heightened protection under the law (City of Cleburne v. Cleburne Living Center, Inc., 473 U.S. 432 (1985); Waterstone, 2013). But what happens when advances in neuroscience, rehabilitation, and medical progress change *disabilities* into *abilities*?

Consider, for example, the potentially transformative capability of deep brain stimulation (DBS) in moderate to severe traumatic brain injury (TBI) to modify disability. One of us (JJF) has recently been involved the CENtral Thalamic Deep Brain Stimulation for the Treatment of Traumatic Brain InjURY study (CENTURY-S), using a Medtronic PC+S device to stimulate the centro-lateral thalamus in this population. Preliminary data in five subjects showed a 10% increase processing speed, as measured by the Trail-Making Test part B (Wong et al., 2022). Quality-of-life self-report measures also highlighted improved attention and executive functioning as did subject and family narratives. Three months after implantation, two participants showed a one-point increase on the Glasgow Outcome Scale-Extended (GOS-E) (Schiff et al., 2019; Fins et al., 2022; Fins et al., 2023).

It is important to note that this use of DBS remains investigational, but its promise raises questions about how advancements in neurotechnology might comport with existing disability law. These patients experienced measurable improvements with the help of a neuroprosthetic device. In semi-structured interviews, subjects and their families reported that these changes had significant implications for their future (Fins et al., 2023).

Despite the remarkable promise of this emerging intervention and the improvements it has wrought, subjects spoke of the challenges that remain to societal integration following this *positively* disruptive technology. They remain disabled but differently so with new aspirations, hopes, and challenges that need to be overcome (Fins et al., 2023). These interviews highlight the paradox of scientific progress. By restoring function, we are potentially putting people in a precarious legal circumstance where they ironically have less constitutional protections because medicine has made their condition mutable. Nonetheless, their statutory protections should remain intact under the ADA and ADAAA.

However, even if individuals are less functionally disabled because of a neuroprosthetic, they still require assistance and accommodations to re-enter society. Consider the example of a patient who had been out of the workforce for a decade or unable to complete school because of a brain injury. Once they get a neuroprosthetic, they may be able to go back to work or school, but they may fall outside of the normal supportive structures that help individuals during life-cycle transitions.

This displacement is a challenge that reflects medical progress. Society and the law have not kept pace with medical advance by either envisioning or designing a supportive infrastructure that sustains people whose progress is out of sync with traditional recovery norms. Despite their restored abilities, these individuals will need help navigating their recoveries. They are legally entitled to this support under existing disability law. The ADA and ADAAA were, however, not designed to sustain the type of longitudinal and dynamic recoveries that are now medically possible for people with moderate to severe brain injury. While medicine has helped to make recovery and reintegration more possible than ever before, the law has lagged behind in helping individuals fully achieve their potential (Shapiro et al., 2022).

## 5. In response: The Americans with Abilities Act (AWAA)

The paradox we have identified can be better appreciated if we adopt a *new* definition of immutability, now circulating in legal scholarship, which views immutability as “not whether a characteristic is strictly unchangeable, but whether the characteristic is a core trait or condition that one cannot or should not be required to abandon” (Clarke, 2015; Obergefell v. Wymyslo, 2013). It is our view that the restoration of a pre-injury self can be understood as a trait that should be preserved and restored. That core is what we would argue is immutable, not functional status.

We think that neuroprosthetics are disruptive and change the self. But in our narrative exploration of the experiences of subjects and families in the CT-DBS study, we have come to understand that it was the injury that was disruptive and the prosthesis that restored essential elements of the self (Schiff et al., 2019; Fins et al., 2022; Fins et al., 2023). That is, the neuroprosthetic reestablished an enduring condition or trait that should not be abandoned.

Understanding therapeutic improvement in this context should not be viewed as making the subject less disabled and hence less protected by constitutional law, but rather as sustaining immutable aspects of personhood that are essential. This formulation of immutability is entirely consistent with the therapeutic *telos* of medicine, supporting the need for continued protection of individuals with disabilities. Despite the promise of this new conceptualization of immutability, current jurisprudence primarily remains operative under the *old* definition of immutability, which legally protects unchanging characteristics.

In response to this potential conceptual challenge to constitutional protections, we have developed the Americans with Abilities Act (AWAA), which seeks to protect the rights of individuals with disabilities whose functional status has improved because of a medical intervention (Shapiro et al., 2022). While we believe constitutional arguments are likely stronger than they may appear, we are advocating for a statutory response as the best way to affirm protections in the face of medical progress. In this way, the AWAA is the natural successor and complement to both the ADA and ADAAMA.

Though these interventions might restore individuals' abilities, they still have ongoing – and different – needs because of their evolving functional status.

The AWAA promotes a legal landscape that fosters the development of services and technologies that promote societal integration for individuals with brain injury, now situated differently because of their improved functional status. In tandem with the ADA and other civil rights law, the AWAA would help preserve and supplement the protections of current disability law and lead to greater societal integration.

A critical aspect of the AWAA is its focus on sustaining essential technical progress. This includes producing drugs and medical devices that promise to restore an individual's functional status, most notably through the development of what is broadly termed assistive technologies (AT). Building on existing policies such as The Orphan Drug Act (ODA) and the Priority Review Voucher (PRV) that helps to foster other technologies, the AWAA would include schema to incentivize increased funding for research and development of AT for individuals with disabilities (FDA Priority Review Voucher Program, 2020). Additionally, through restructuring the existing Centers for Medicare and Medicaid Services (CMS), the AWAA would continue the mission of the ADA by providing increased reimbursement for AT that supports rehabilitation and societal reintegration. These changes are designed to increase access to AT and rehabilitation services that enable capabilities which allow Americans with disabilities to become maximally integrated into their communities (Fins, Knitter, Mukherjee et al., 2023).

By focusing on the needs of the individual, as well as the complex forces that can foster (or impede) device and drug development, the AWAA can help mainstream disability law better take account of, and synergize with, medical progress. And while we have workshopped the development of the AWAA through the prismatic of moderate to severe brain injury, we believe this legal formulation has broader applicability to other conditions that might achieve functional amelioration through the application of emerging technology. As such this offering should be viewed as a thick description of one case application that can serve as a model to revamp disability law.

## 6. Conclusion

For nearly a decade, we have conducted a research seminar in bioethics and brain injury for students at Yale Law School (Shapiro et al., 2023). One of the interesting features of academic scholarship at the intersection of law and medicine is that it makes us

appreciate how these learned professions contribute to the common good using different methods. Benjamin Cardozo, while serving as chief judge of the New York State Court of Appeals, spoke of the indispensability of medicine and the law in society. In an address to the New York Academy of Medicine, he characterized medicine and the law as being “united in common quest, the quest for the rule of order, the rule of health and disease, to which for individuals as a society we give the name of law” (Cardozo, 1929; Lawrence et al., 2019).

Generally, medicine and the law are united in common cause. Rarely, however, their methods can be at cross purposes. In this essay we exposed the ironic discordance between medical progress and disability law and advanced the AWAA as a means to reconcile scientific progress and the pursuit of disability rights. Under our proposed AWAA, individuals can benefit from medical advance and enjoy the ongoing protections of disability law as their improved functional status creates new opportunities and challenges.

### Conflict of interest

None to report.

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