Olmstead Enforcements for Moderate to Severe Brain Injury: The Pursuit of Civil Rights Through the Application of Law, Neuroscience, and Ethics

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Our Article considers what the legal system can do to identify and support the recovery and reintegration of persons with severe brain injury, suffering from disorders of consciousness. We explore the possibility of marshaling law to advocate for this cohort of patients, who are currently overlooked by the medical and legal systems. Despite their potential for recovery, many of these individuals remain segregated in nursing homes, where they do not receive adequate medical care, much less the rehabilitation that might permit the restoration of functional communication, which is so central to their reintegration to the nexus of their homes and families. Deprived of these medical interventions, these patients are further isolated and segregated from civil society. We view this situation as unethical and as a violation of the American with Disabilities Act. To remedy this violation of law, we explore the application of Olmstead enforcements to patients with severe brain injury. We trace the legal evolution of disability law and Olmstead enforcements, deriving from the leading United States Supreme Court case regarding deinstitutionalization and community reintegration, Olmstead v. L.C. ex rel. Zimring. Our Article highlights how Olmstead could be used in an effort to desegregate and reintegrate those with hidden consciousness back into their communities.

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I. INTRODUCTION

Don Herbert sustained a severe brain injury on December 29, 1995. A Buffalo, New York, fireman, he was fighting a house fire when he was struck by a beam and left unconscious in the attic. With his oxygen mask ajar, he had to be rescued and brought to safety. He received critical care and briefly regained consciousness, only to have it slip away in early 1996. His wife, Linda Herbert, was left alone to care for their four children. Plaintively, she wrote major medical centers across the country asking for help, for guidance, and for care.

2. Id.
After none replied, Don was moved to a nursing home to receive what is euphemistically called “custodial care.”

Linda kept her vigil and raised their children, despairing all that had been lost, but never losing hope. Then, in 2003, an earnest physiatrist came to Don’s nursing home and took an interest in his recovery. For nearly a decade, Don had basically been ignored. But now this new doctor prescribed an experimental cocktail of medications, including Ritalin, Prozac, and a Parkinson’s drug, among others, in order to stimulate Don’s brain out of its stupor.

And then the unexpected happened. Don woke up and regained consciousness. An aide at the nursing home called Linda and told her to come in right away. She immediately called her youngest son, Nicky, and told him to call his dad. Nicky was stunned. He had not spoken to his dad for years. Moreover, why should he call his dad? Every time he had visited the home, his dad laid there unresponsive and inert.

But now Linda implored her son to make the call. Don had awakened and was holding on to this side of sentience by a thread. She did not want to lose him again and wanted the voice of his “Little Buddy” Nicky to keep him among the living. So Nicky called his dad and heard his voice for the first time in years. Don was self-aware and surprised, thinking that Nicky was still an infant. How could he be talking with him? Nicky responded by asking how old he thought he was and Don paused. Nicky replied that he was now thirteen, to which Don responded with a vernacular: “Holy shit.”

Linda soon arrived and so did a host of friends and former colleagues. Don had sustained cortical blindness from the hypoxia he experienced in the fire and so could not see who was in the room, but he recognized the voices of those assembled. He knew who he was and had a father’s lament, worried that he had abandoned his family.

4. See generally BLAKE, supra note 1 (noting Donny received rehabilitation treatment from physiatrist, Dr. Jamil Ahmed).
5. See id. at 179.
6. See generally id. (noting that despite Donny’s initial promise in returning to consciousness, he later struggled with his memory and ability to speak).
7. Id. at 199.
and had “been gone a long time.” It was a remarkable day, as one of us noted, like Joyce’s depiction in *Ulysses* of Leopold Bloom’s adventures in Dublin. A life in a microcosm.

But it was short-lived. Don was never as good as that day. He died of complications of pneumonia before he could undergo further study of his brain function. This was a major loss for his family and for the study of severe brain injury and disorders of consciousness (DoC), conditions like the vegetative and minimally conscious states.

Over the past two decades, neuroscience has learned quite a bit about these brain states, mechanisms of brain recovery, resilience, and ways to assess and treat these conditions. New pharmaceutical interventions and technologically assisted communication devices have allowed some individuals with DoCs to regain an ability to communicate that once seemed lost forever.

It has been a golden age for advancements in our knowledge, but sadly one that has not been matched by improved access to care and respect for the rights of these patients. A recent evidence-based review of the state of the science of disorders of consciousness presented an unfortunate paradox. While there are more interventions and treatments for these patients, access to desperately needed rehabilitation days has decreased over the past fifteen years, and the rate of misdiagnosis for patients with disorders of consciousness remains staggeringly high.

We think this is an untenable and unjust situation that deserves a remedy. These patients are incredibly vulnerable and on the margins of consciousness and society. They deserve better.

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The law provides a solution. In this Article, we consider patients like Don Herbert and reflect on what the legal system can do to identify and support their potential for recovery. We consider the possibility of mustering disability law to advocate for the covertly and liminally conscious and others with moderate-to-severe brain injury. Primarily, we explore the application of *Olmstead* enforcements,
deriving from the leading United States Supreme Court case regarding deinstitutionalization and community reintegration, *Olmstead v. L.C. ex rel. Zimring,* to those suffering from brain injury.

In *Olmstead,* the Supreme Court upheld the Americans with Disabilities Act of 1990 (ADA), holding that the Act provides a mechanism to gain access to services that would help disabled patients better integrate back into their families, homes, and communities. The Court held that reintegration "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 . . . , and [community] placement can be reasonably accommodated, taking into account the resources available." We consider whether the court’s decision in *Olmstead* provides a mechanism to help better integrate patients with moderate-to-severe brain injury into their families, homes, and communities by increasing access to rehabilitation and assistive technologies so that they may make their first steps toward community reintegration.

Patients like Don Herbert should give us pause. Where was he during his decade away, his hiatus from his family and friends? That he returned, his personhood and memory intact, suggests that he could have been helped long before a decade’s absence, if only someone had the will to try. Mrs. Herbert had worked in vain to gain the assistance of the best of American medicine only to have been uniformly ignored. We suggest that, aided by the proper legal arguments, she might have been more successful.

While it is too late for Don Herbert, there are others with brain injuries, many of whom linger undiagnosed in nursing homes, who remain in desperate need of advocacy. This is the problem we seek to address and to remedy through legal advocacy using disability law and the application of *Olmstead* enforcements.

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12. *See id.* at 587-98.
13. *Id.* at 587.
We posit that existing disability law can be applied and enforced to aid in the reintegration of patients with moderate-to-severe brain injury back into society. The law can be used to demand services for this population when they are not already provided by hospitals or long-term care facilities. These services can include access to assistive communication devices, pharmaceuticals, and increased rehabilitation. The goal of these interventions is to help reintegrate individuals back into society, consistent with the ADA’s mandate for integration.

The reintegration that is essential for this population is not necessarily a physical reintegration but rather a cognitive one, made possible by the restoration of functional communication. This can finally enable patients to more fully communicate with their healthcare providers, caregivers, and loved ones. For patients who are unable to communicate because of a disorder of consciousness, the restoration of functional communication is akin to the gap in the sidewalk for someone with a disability that compromises their mobility. For patients with brain injury who are unable to communicate, their “ramp is the restoration of functional communication, which makes reintegration into its cognate—community—possible. When we restore voice to these patients we bring them back into the room and the conversation.”

In *Olmstead*, while the court specifically considered whether institutionalization of individuals with intellectual disabilities violated the ADA, its reasoning and holding applies to those who are covertly or liminally conscious.17 These people are not integrated into the community if they are kept in isolated, segregated care and not given access to functional communication (referring generally to neuroprosthetic and rehabilitative technologies). We contend that the failure to provide functional communication devices constitutes unlawful discrimination and violates *Olmstead*.

Part I introduces the nomenclature, nosology, and biology of patients with moderate-to-severe brain injury who would benefit from

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greater access to rehabilitation and assistive communication devices. We primarily consider patients with DoCs and those who are covertly and liminally conscious, all of whom might benefit from Olmstead enforcements.

Part II turns to the history of the American disability rights movement, highlighting the legacy of advocacy, seminal disability rights legislation, and the passage of the Americans with Disabilities Act. This history helps us to appreciate the applicability of established disability law to a novel population, which was not necessarily envisioned when the ADA was drafted in 1990.

Part III focuses on deinstitutionalization and the Supreme Court case Olmstead. Part IV considers typical Olmstead enforcement actions from both a state and federal perspective.

Part V argues that Olmstead should be applied to patients with moderate-to-severe brain injury in order to secure access to proper medical care, rehabilitation, and assistive devices. We conclude by exploring what we mean when we discuss community reintegration, invoking the adage “Nothing About Us Without Us.”

II. **Severe Brain Injuries: An Evolution of NOSOLOGY**

Those with moderate-to-severe brain injury present unique clinical, ethical, and legal challenges. Whether these individuals are unconscious in the vegetative state or liminally so in the minimally conscious state, patients with DoCs are often unable to advocate for themselves and are typically segregated from society in long-term care facilities. This Part describes DoCs.

A. **Disorders of Consciousness**

Disorders of consciousness refers to a range of conditions, including the vegetative state (VS), the minimally conscious state

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19. See generally RCTM, supra note 15 (noting that patients with severe brain injuries present unique challenges because they are seen as hopeless and are therefore largely excluded from lifesaving care, benefits, and legal protections).


(MCS), and emergence from the MCS.\textsuperscript{22} These are among the most severe brain injuries.\textsuperscript{23} Despite this, there is little epidemiological information concerning their prevalence, a marker of the societal neglect of these conditions and the marginalization of these individuals.\textsuperscript{24} The best \textit{estimate} of the prevalence of the VS in the United States is between 40 and 168 patients per million of the population.\textsuperscript{25} Another study estimated the prevalence of MCS to be between 112,000 and 280,000.\textsuperscript{26} However, these are likely low assessments based on databases ill-equipped to make these projections.\textsuperscript{27}

Most injuries leading to a DoC are characterized by an initial loss of consciousness.\textsuperscript{28} If this loss of consciousness is prolonged, it can evolve into a coma, an eyes-closed state of unconsciousness and unresponsiveness.\textsuperscript{29} Comas are self-limited, lasting for up to two weeks unless they are prolonged by medication or by an intercurrent illness.\textsuperscript{30} Patients in comas may eventually recover completely (such as after anesthesia), progress to brain death, or transition into the VS or the MCS.\textsuperscript{31}

The VS is the isolated recovery of the autonomic functions of the brain stem without higher cortical function.\textsuperscript{32} Vegetative individuals demonstrate "wakeful unresponsiveness," in which their eyes are open but there is a total lack of awareness of self, others, or the environment.\textsuperscript{33} Vegetative patients have sleep-wake cycles and

\begin{itemize}
\item \textsuperscript{22} Joseph T. Giacino et al., \textit{Disorders of Consciousness After Acquired Brain Injury: The State of the Science}, 10 NATURE REV. NEUROLOGY 99, 100-01 (2014).
\item \textsuperscript{23} \textit{Id}. at 99-100.
\item \textsuperscript{24} \textit{See} Joseph J. Fins et al., \textit{supra} note 14, at 305-06.
\item \textsuperscript{26} David J. Strauss et al., \textit{Life Expectancy of Children in Vegetative and Minimally Conscious States}, 23 PEDIATRIC NEUROLOGY 312, 316 (2000).
\item \textsuperscript{27} Joseph J. Fins et al., \textit{The Minimally Conscious State: A Diagnosis in Search of an Epidemiology}, 64 ARCHIVES NEUROLOGY 1400, 1400-01 (2007).
\item \textsuperscript{28} \textit{See generally} Giacino et al., \textit{supra} note 21 (describing the state of the science about disorders of consciousness).
\item \textsuperscript{29} \textit{See} Giacino et al., \textit{supra} note 22, at 99-101.
\item \textsuperscript{30} \textit{Id}. at 99, 107-08.
\item \textsuperscript{31} \textit{See} JEROME B. POSNER ET AL., PLUM AND POSNER’S DIAGNOSIS AND TREATMENT OF STUPOR AND COMA 6-9 (5th ed. 2019).
\item \textsuperscript{32} \textit{See} Jennett & Plum, \textit{supra} note 20, at 734-35.
\item \textsuperscript{33} \textit{Id}. at 734.
random eye movement and are able to breathe spontaneously without ventilator support because they have an intact brain stem.34

In the 1972 formulation by Jennett and Plum, the VS was persistent.35 In 1994, this paradigm was revised by the Multi-Society Task Force on PVS,36 which helped govern the diagnostic criteria for vegetative patients for decades. The VS was considered persistent when it lasted thirty days and permanent if it lasted for three months after anoxic brain injury or twelve months following traumatic brain injury (TBI).37 Of course, the milestones articulated in the reports assumed that patients were properly assessed and accurately diagnosed.38

Patients may transition from the VS into a higher functional state, termed the minimally conscious state.39 The MCS formally entered the medical literature in 2002, after a consensus statement published in Neurology under the rubric of the Aspen Criteria.40 In contrast to vegetative patients, those in the MCS are conscious, although this is often not recognized.41

MCS individuals show fluctuating but reproducible signs of awareness.42 While these patients are capable of manifesting emotional and behavioral responses, these behaviors occur sporadically,43 complicating detection of awareness. Minimally conscious “patients might show intermittent or inconsistent verbal output, object use, response to verbal command, or purposeful communicative gestures (such as eye movements).”44 MCS patients

34. See id. at 735.
35. Id. at 736-37.
37. MSTF Part II, supra note 36, at 1574-75.
38. See generally id. (noting data and numbers in article are assuming correct diagnoses).
39. It is also possible for patients to recover from a diagnosis of CVS to progress into MCS. See Giacino et al., supra note 22, at 99-101.
40. See Giacino et al., supra note 21.
41. See generally RCTM, supra note 15 (noting that due to large rates of misdiagnosis, many patients are presumed to be unconscious, though they may be conscious).
42. See Giacino et al., supra note 21, at 350.
43. Id.
may demonstrate memory, inattention, and focus. Their eyes may track a family member, and sometimes these individuals are able to say people’s names or grasp for objects. Recovery from the MCS is defined by the emergence of some sort of reliable functional communication or use of objects. When behaviors are reproduced consistently, patients have emerged from the MCS.

Clinical assessment of the MCS remains challenging and prone to error. One study found that forty-one percent of patients with severe TBI in long-term care, who were diagnosed as vegetative, were actually minimally conscious. Others have found similar diagnostic error rates between twenty and forty percent. Diagnoses are difficult because an individual’s behaviors in the MCS are not reliably reproduced and are episodically demonstrated. For instance, when a patient is asked to repeat a behavior seen by family members, they will typically not comply with the request. This results in practitioners believing that the family’s observations are unreliable, prompted by wishful thinking or denial, when in fact this failure of reproducibility derives from the underlying nature of the condition. Furthermore, recovery from MCS is open-ended and unpredictable, with no reliable time course.

Medical understanding of DoCs is constantly evolving. Just a few years ago, assessment of consciousness was entirely made based on bedside behavioral determinations. Now, physicians use a

45. See Giacino et al., supra note 21, at 351.
46. Id.
47. See Giacino et al., supra note 22, at 101.
48. Id.
49. Caroline Schnakers et al., Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment, 9 BMC NEUROLOGY 35, 35 (2009) (highlighting that up to forty percent of MCS patients are misdiagnosed as vegetative).
51. Andrews et al., supra note 50, at 15.
52. See Fins, supra note 16.
54. See id. at 749.
more mechanistic and circuit-based diagnostic approach. The JFK-Johnson Coma Recovery Scale-Revised, a neuropsychological examination best undertaken multiple times, remains the gold standard for assessment.

Investigators are becoming aware of the discordance that may exist between what is evaluated at the bedside and what is actually happening within the patient’s brain. This presents the challenge of covert consciousness, or non-behavioral MCS, where patients who clinically appear to be vegetative are able to volitionally imagine doing tasks on neuroimaging with the appropriate activation of brain regions. These patients who appear behaviorally unaware may actually have covert consciousness, or what Schiff has subsequently described as “[C]ognitive [M]otor [D]issociation (CMD),” a state where motor output does not necessarily reflect covert cognitive processing.

Rehabilitation-oriented interventions aid in recovering consciousness. The goal of rehabilitation is some form of restoration of the ability to communicate, coupled with demonstration of functional competency. For others with higher levels of function, rehabilitation assists with the challenges of daily life. Because those in the MCS may be amenable to rehabilitation and progressive improvement, while patients who are diagnosed as chronically vegetative are less likely to subsequently receive rehabilitation, a diagnostic error can be devastating. Nearly seventy percent of

56. Id. at 2021-29.
58. For more background on neuroimaging, see generally Zachary E. Shapiro, Note, Truth, Deceit, and Neuroimaging: Can Functional Magnetic Resonance Imaging Serve as a Technology-Based Method of Lie Detection?, 29 HARV. J.L. & TECH. 527 (2016) (explaining that functional MRIs allow scientists to measure an individual’s brain activity).
62. See Anbesaw W. Selassie et al., Incidence of Long-Term Disability Following Traumatic Brain Injury Hospitalization, United States, 2003, 23 J. HEAD TRAUMA REHAB.
patients with TBI who receive inpatient rehabilitation are able to recover consciousness, and just over twenty percent will regain functional independence. However, rehabilitation will not be provided if the diagnosis seems to obviate any potential for recovery.

There is a plethora of emerging technology that may be able to help those with DoC. Technological modalities include neuroprosthetics, including communication boards or similar devices; deep brain stimulation (DBS); and pharmaceutical interventions, as well as advances in neuroimaging.64 These technologies may aid in restoring communication, as well as making an accurate diagnosis. While many of these interventions remain investigational, we have argued in the past that modalities that can augment consciousness and restore communication should be available to patients with DoC through clinical trials.65 More access would also expand translational research, resulting in more discovery and robust data.

While it is possible to spontaneously recover from a coma or VS to a MCS, prognosis is improved by rehabilitation-oriented treatments.66 Because rehabilitation can also help assess a patient's diagnostic state, such techniques prevent premature withdrawal of life support. Furthermore, rehabilitation may enable patients to inform their caregivers whether they are experiencing pain, allowing these individuals to better participate in their own care.67 Perhaps most importantly, rehabilitation can enable DoC patients to finally communicate with their loved ones.68


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

64. See generally Caroline Lawrence et al., Brain-Computer Interfaces and the Right to Be Heard: Calibrating Legal and Clinical Norms in Pursuit of the Patient’s Voice, 33 HARV. J.L. & TECH. 167 (2019).

65. See Fins, supra note 8, at 295.


67. Id.

68. Id.
However, DoC patients often lack access to rehabilitation that might allow them to recover consciousness and regain function.\textsuperscript{69} There are many reasons for this.\textsuperscript{70} One is the extraordinary misdiagnosis rate between thirty and forty percent for those in the MCS.\textsuperscript{71} Furthermore, there is no predictable time course for these patients, as individuals with DOC “may need a longer period of time to declare themselves than other critically ill patients . . . . In a setting where decisional constructs operate in days and weeks, and not months, it becomes too easy to mistake the failure to improve quickly as an indication that no improvement will be possible.”\textsuperscript{72}

Another issue concerns inpatient rehabilitation admission criteria and health insurance funding constraints.\textsuperscript{73} For example, admission to rehabilitation facilities or reimbursement standards sometimes require that a patient be minimally conscious upon discharge, or they may use an unlawful “improvement standard.”\textsuperscript{74} Many individuals with severe brain injury and DoC cannot satisfy these criteria even though some of these same patients, if given rehabilitation, could recover consciousness in time.\textsuperscript{75}

These factors contribute to a situation where many DoC patients are simply left institutionalized in chronic care facilities.\textsuperscript{76} These facilities are often under-resourced, understaffed, and overburdened.\textsuperscript{77} They are not well-suited to provide long-term proper rehabilitative care to DoC patients. Many lack the state-of-the-art tools that can assist in diagnosing fleeting signs of conscious awareness or lack trained staff who can provide the skilled physical therapy that can lead to the recovery of functional independence in up to twenty-one percent of patients.\textsuperscript{78} Others do not provide access to assistive communication devices, or even to low cost options such as word

\textsuperscript{69} Id.
\textsuperscript{70} Id. at 245-47.
\textsuperscript{71} See Schnakers et al., supra note 49, at 1.
\textsuperscript{72} Joseph J. Fins, Affirming the Right to Care, Preserving the Right to Die: Disorders of Consciousness and Neuroethics after Schiavo, 4 PALLIATIVE & SUPPORTIVE CARE 169, 170-74 (2006).
\textsuperscript{73} See Wright & Fins, supra note 66, at 247.
\textsuperscript{74} Id.
\textsuperscript{75} Id.
\textsuperscript{76} Id. at 271.
\textsuperscript{77} See generally RCTM, supra note 15 (noting that because patients are thought to be unconscious and hopeless, they lack proper care).
\textsuperscript{78} See Nakase-Richardson et al., supra note 63, at 62-64.
boards or eye trackers, which can help some patients regain functional communication. Thus, many individuals with DoC remain trapped in “custodial care,” even if they could benefit from a more community-focused placement.79

These diagnostic access issues resulted in a multi-society consensus statement on the standard of care for these patients.80 In 2018, an evidence-based review of existing literature highlighted that more than twenty percent of patients considered permanently vegetative might actually recover consciousness. 81 This helped prompt the development of the new AAN (American Academy of Neurology) /ACRM (American Congress of Rehabilitation Medicine) /NIDILRR (National Institute on Disability, Independent Living, and Rehabilitation Research), Practice Guideline: Disorders of Consciousness, 82 which represented an important shift in the standard of care. The Guideline was the product of a multiyear, interdisciplinary effort to improve healthcare for patients with DoC and was the product of “rigorous application of evidence-based criteria to the available literature” concerning patients with DoC.83 Notably, the new Guideline recommended reclassifying the permanent vegetative state to the chronic vegetative state (CVS), referring to any patient who has been vegetative for three months after anoxic injury and twelve months after traumatic brain injury.84 This was a major development for bioethics and the law.85

This is important because the VS has long been associated with futility and the right to die. While the VS diagnosis was first described by Jennett and Plum in a landmark Lancet paper,86 it was brought to legal prominence in cases concerning the right to die, such as In re Quinlan,87 Cruzan v. Director of Missouri Department of Health,88

79. See Wright & Fins, supra note 66, at 237.
80. See generally Giacino et al., supra note 9 (providing recommendations of care based on new guidelines issued by the American Academy of Neurology).
81. Id. at 451.
82. Id. at 450-57.
83. See Fins & Bernat, supra note 10, at 471.
85. See Fins & Bernat, supra note 10, at 472-74.
86. See Jennett & Plum, supra note 20.
and *In re Guardianship of Schiavo*. While a full discussion of this history is beyond the scope of this Article, it is important to note that through these cases, the VS became closely associated with the right to die. Indeed, the “futility of the VS became the moral and legal warrant to remove Quinlan’s respirator. Thereafter, the VS was linked to the right to die.” This link of futility has been overgeneralized to all severe brain injury.

In the past, one of us has written about the culture of prevailing nihilism concerning the chance of recovery for patients with severe brain injury. Therapeutic nihilism leads to “the belief that patients with prolonged [DoCs] are beyond help, therefore, any effort to intervene is futile.” This nihilism is an unfortunate relic of the right-to-die movement, arising after the prominence of the cases mentioned previously, in which individuals in the VS had no prospect for recovery. Scholars have warned society not to overgeneralize lessons from these right-to-die cases, as doing so runs the risk of denying hope to patients and families and contributes to nihilism that marginalizes those with DoC. While we want to be clear in our support for a right to die for patients, we still decry that the hard-won right to die has come at the expense of a right to care for patients who might be helped.

This nihilistic approach presents an ongoing problem for individuals with DoCs, who often appear to be diagnostically

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91. See RCTM, supra note 15, at 102-03.
92. See Fins & Bernat, supra note 10, at 472.
95. See Fins, supra note 93, at 323-35.
96. See Giacino, supra note 94.
97. See Fins, supra note 72, at 170.
similar to those in the VS. Nihilism contributes to premature recommendations to withhold or withdraw care and to the reduction in access to therapeutic and diagnostic interventions.

B. Constructing a Category

It is instructive to think about patients with covert and liminal consciousness as an informal class, made up of several different types of patients with brain injuries. Indeed, thinking about the subset of patients in this manner cuts against traditional diagnostic labeling and allows us to employ a classification that is more inclusive of all who can benefit from increased rehabilitative services and communication devices.

The covertly conscious includes several groups of DoC patients. First, it includes those initially diagnosed as vegetative, but who have subsequently improved and whose higher state of consciousness has not yet been recognized. The covertly conscious also includes patients who were simply misdiagnosed as vegetative when they were actually minimally conscious.

Another group included among the covertly conscious are individuals who undergo a state change from appearing behaviorally vegetative to being minimally conscious once they have received certain pharmaceuticals (such as amantadine or zolpidem) or neurostimulation. They are best recognized as being MCS patients with under-activated, but intact, neural networks. These individuals appear behaviorally vegetative before treatment but are actually minimally conscious, in a state of potentiality. While their consciousness may depend on external interventions, these individuals must be accounted for, as they could be brought into the

99. Id. at 156-57.
100. Id. at 154-55.
101. Id. at 165-66.
102. See Fins, supra note 90, at 605.
103. See Fins & Bernat, supra note 10, at 472.
104. See, e.g., Christine Brefel-Courbon et al., Clinical and Imaging Evidence of Zolpidem Effect in Hypoxic Encephalopathy, 62 ANNALS NEUROLOGY 102, 102-05 (2007).
105. See, e.g., Giacino et. al., supra note 22, at 101-04.
107. Even with intervention, these individuals may continue to appear vegetative, and would thus fall in the final category discussed above. See Fins, supra note 90, at 605.
community and out of their own heads through medical intervention.\textsuperscript{108}

An overlapping subset of patients are covertly conscious individuals with CMD.\textsuperscript{109} For people with CMD, behavioral examination will be unable to reveal an accurate diagnosis, as these individuals can have largely intact neural networks but remain unable to manifest signs of consciousness on a behavioral examination.\textsuperscript{110} While these neural networks cannot be detected with behavioral examination, evidence of consciousness can be found through neuroimaging when patients follow volitional commands.\textsuperscript{111}

Another class of patients are the liminally conscious, whose consciousness could be recognized were it not expressed only intermittently or inconsistently.\textsuperscript{112} This intermittent evidence of consciousness leads to an especially high risk that these patients will be overlooked and denied access to communication devices or rehabilitative therapy.\textsuperscript{113} These patients may have the ability to communicate if provided with assistive devices and rehabilitation.\textsuperscript{114}

Going forward, we will describe this putative class with the acronym C&LC, referring to the covertly and liminally conscious. For these individuals, consciousness is present but may not have been accurately diagnosed or consistently detected.\textsuperscript{115} For these reasons, the C&LC will continue to be treated as though they lack consciousness, helping lead to nihilism concerning prospects for recovery.\textsuperscript{116} This reduces the chance of receiving rehabilitation and can even trigger premature end-of-life decisions to withdraw or withhold life-sustaining therapy.\textsuperscript{117} However, the C&LC are not lost causes. Through application of the latest diagnostic and therapeutic modalities, it is possible to determine whether an individual who seems behaviorally unconscious actually has covert consciousness.\textsuperscript{118}

\begin{thebibliography}{9}
\bibitem{108} See Giacino et al., \textit{supra} note 22, at 110.
\bibitem{109} See Schiff, \textit{supra} note 60, at 1414-15.
\bibitem{110} \textit{Id}.
\bibitem{112} See Giacino et al., \textit{supra} note 22.
\bibitem{113} See Wright & Fins, \textit{supra} note 66, at 245-46.
\bibitem{114} \textit{Id}.
\bibitem{115} \textit{Id}.
\bibitem{116} \textit{Id}.
\bibitem{117} \textit{Id}.
\bibitem{118} See \textit{id}.
\end{thebibliography}
This can best be done by employing the Coma Recovery Scale-Revised, neuroimaging, and other non-behavioral assessment tools, in addition to revalidating the initial diagnosis or performing some form of neuro-intervention.\(^{119}\)

There is an ethical imperative to help the C&LC through accurate diagnosis and intervention so that they might manifest their consciousness. These individuals are at their most vulnerable: unable to advocate for themselves while being at the mercy of their caregivers, who could provide assistance in communication and rehabilitation if only they recognized the hidden signs of consciousness. As one of us has noted, "[g]iven that consciousness is an irreducible component of personhood, the use of these additional modalities [to restore consciousness] contributes to respect for persons."\(^{120}\) Without recognition of their consciousness, caregivers are playing an unintentional part in denying C&LC patients access to communication and community. Without the ability to communicate, these individuals will remain trapped in their heads, unable to interact with the outside world, prevented from accessing interventions that could help improve their quality of life, all while remaining unable to communicate with their caregivers and loved ones.

While there is a clear ethical imperative to bring C&LC patients out of their head and reintegrate them into the community to the greatest extent possible, there may also be a defined legal obligation to do so. Given the misdiagnosis rate discussed previously, there can be no doubt that some number of patients diagnosed as vegetative are C&LC.\(^{121}\) Without access to rehabilitation and communication aides, these individuals will be left isolated, unable to communicate with their healthcare providers, caregivers, or loved ones. Such a situation is not only untenable from an ethical perspective but also may represent a violation of the ADA.

The ADA, and the court cases interpreting this legislation—specifically *Olmstead*—apply to persons with liminal and covert consciousness.\(^{122}\) The C&LC satisfy the statutory requirements for

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121. See Schnakers et al., *supra* note 49.
122. See Wright & Fins, *supra* note 66, at 266-67.
being considered disabled, as they possess mental and physical impairments that substantially limit their lives.

For these individuals, such as Don Herbert, the Olmstead precedent might have provided an effective mechanism to advocate for increased resources and better treatment. In fact, keeping C&LC patients segregated in “custodial care” without access to auxiliary aids or services that can enable them to communicate likely represents a violation of both Olmstead and the ADA.

C. Paradigm Shifts and Covert Consciousness

To appreciate the significance of C&LC for clinical practice and disability law, it is instructive to turn to the philosopher of science, Thomas S. Kuhn. In his landmark work *The Structure of Scientific Revolutions*, Kuhn challenged the mainstream view of advancement in “normal science,” arguing that while scientific progress is typically viewed as “development-by-accumulation” of theories and data, a more accurate description is that conceptual continuity in science is periodically interrupted by periods of revolutionary science. These groundbreaking advances trigger what Kuhn termed “paradigm shifts,” recognized in hindsight as scientific revolutions.

These paradigm shifts are triggered by explosive new theories, which radically alter the previous conception of the scientific world, causing a new model of thinking to replace the old one. As examples, Kuhn highlights the Copernican Revolution and the displacement of Newtonian Physics by Einstein’s Theory of Relativity. Both changed astronomy and physics, forever shifting thought from the old

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123. *Id.* at 267-68.
127. *See id.* at 2, 10-11.
128. *See id.* at 84-85.
129. *See generally id.* (referencing transformative theories that have dramatically altered scientific research and thinking).
model to a new paradigm that updated and replaced established epistemology.  

Not to overstate our case, but we now approach a similar Kuhnian cusp in the conceptualization of brain injury, covert and liminal consciousness, and civil and disability rights. Standing at this threshold, we can appreciate how scientific advance brings new legal and normative obligations, heretofore obscured by the equation of severe brain injury with a right to die versus a right to care. Central to this evolution is the place of disability rights in our understanding of the moral status of this population.

In order to appreciate this paradigm shift, we need to trace the history of disability rights and legislation. In the following Part, we will explore the history of the disability rights movement in America. This is essential in understanding why the ADA and *Olmstead* should apply to the C&LC, even though they were not specifically considered when the legislation was first drafted. Nor could they have been, as the scientific developments that defined our legal obligations to these patients were still decades away. But now that we know of their plight, we cannot look away. Indeed, the law needs to lean into the problem and embrace the rights of these individuals as the next chapter in the advance of civil rights.

III. THE DISABILITY RIGHTS MOVEMENT IN AMERICA

A. History

In colonial America, people with disabilities were largely hidden from the public. They remained at the mercy of their families and were often disowned or left to die. In the 1820s, there was a societal shift toward organized, institutionalized care, later termed "warehousing." Institutions were founded on a "protective isolation model," which tried to protect individuals with disabilities from the "hardships of society." Building on a notion of beneficence, the

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130. See generally id. (noting that certain scientific discoveries often invalidate previous ways of thinking).


132. Id.

133. Id.
"warehouses" were largely custodial in nature. Unfortunately, this practice also allowed patients to be abused and neglected.

Care took on renewed importance after World War II, as many veterans returned home with disabilities. In 1948, a cross-disciplinary study was established in order to research disability ergonomics. The study identified numerous barriers—like lack of ramps, poor maintenance of walkways, and a dearth of visual and hearing communication aids—which effectively kept individuals with disabilities from full participation in society. This study helped lead to the American National Standard Institute's (ANSI) Barrier Free Standard called ANSI A117.1 Making Buildings Accessible to and Usable by the Physically Handicapped in 1961, which drew from the findings of the disability ergonomics studies. The ANSI Barrier Free Standard, which represented the first codification of disability accommodations, quickly became the global model for technical standards for accessible features.

1. Legislation

The civil rights movements of the 1960s resulted in landmark pieces of legislation. Title VI of the Civil Rights Act of 1964 prohibited discrimination on the basis of race, color, religion, sex, and national origin throughout federally funded programs. While this was a tremendous victory, this legislation failed to protect Americans with disabilities.

In 1972, former Vice President and then-Senator Hubert Humphrey pushed to have Congress amend the Civil Rights Act to

134. Id.
135. Id.
137. See id. at 44.
138. See id. at 61, 83.
139. See id.
include the disabled as a protected class. As Senator Humphrey’s
grandchild was diagnosed with Down syndrome, he was acutely
aware of the impact that legislative protection could have. However, proponents of the Civil Rights Act feared that opening up
the bill to Senate amendments might undo important progress. Humphrey ultimately agreed to incorporate the disability antidiscrimination protection into section 504 of his proposed Rehabilitation Act of 1972.

After President Nixon refused to sign the Rehabilitation Act of
1972, it was reintroduced as the Rehabilitation Act of 1973. Framing the Rehabilitation Act as one that would help workers with disabilities to reenter the workforce, termed “vocational rehabilitation,” Humphrey helped garner bipartisan support for the bill. President Nixon signed the Rehabilitation Act of 1973 on September 26, 1973. The Department of Health, Education, and Welfare (HEW) was tasked with drafting and enacting the legislation.

The key provisions were sections 501, 503, 504, and 508. Section 501 required affirmative action and nondiscrimination in federal agency employment for any impaired federal workers. Section 503 required a similar program for any federal contractors with contracts larger than $10,000, while section 508 guaranteed equal or comparable access to technological information and data.

142. Id.
143. Id.
144. Id.
145. Id.
146. Id.
147. Id.
148. Id.
149. Id.
150. Id.
Section 504, drawing from the language from title VI of the Civil Rights Act of 1964, extended civil rights to people with disabilities.\textsuperscript{154}

Nearly all the main provisions of the Rehabilitation Act of 1973, except section 504, were turned into regulations by federal agencies.\textsuperscript{155} Section 504 states: “No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his [or her] 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.”\textsuperscript{156} HEW’s position was that section 504 was simply a public policy statement that did not require implementation.\textsuperscript{157}

In \textit{Cherry v. Mathews}, HEW argued that it was not legally bound to issue any regulations regarding section 504.\textsuperscript{158} Five months after the start of the \textit{Cherry} suit, the United States District Court for the District of Columbia ruled for the plaintiff, directing HEW to draw up the section 504 regulation.\textsuperscript{159} However, HEW Secretary David Mathews ultimately refused to sign the regulation, and he was held in contempt of court.\textsuperscript{160} As there would be a new administration in two days following President Carter’s inauguration, the court agreed to wait for the new HEW Secretary, Joseph Califano, to take office.\textsuperscript{161}

During this time, public support for the section 504 regulation had been growing. On March 18, 1977, the American Coalition of Citizens with Disability (ACCD), a collaboration between many disability advocacy groups, issued an ultimatum to Secretary Califano: sign the section 504 regulations as written by April 4, 1977, or the ACCD would act. The date came and went with no action from Califano.\textsuperscript{162}

The next day, hundreds of people with disabilities and their allies staged sit-ins at HEW offices across the country.\textsuperscript{163} The “504 Sit-
In[s]" were deliberately modeled after the protests of the Civil Rights movement, complete with protestors singing anthems such as "We Shall Overcome."\(^{164}\) The protests helped to dispel popular notions of people with disabilities as weak objects of pity.

Sit-ins in San Francisco and Washington, D.C., lasted nearly a month.\(^{165}\) Indeed, the protestors did not move until Secretary Califano signed the section 504 regulation.\(^{166}\) Four years after the Rehabilitation Act had been passed, all of its provisions were finally implemented.\(^{167}\)

2. Independent Living

Concurrently, the Independent Living Movement was taking off. In 1972, Edward Roberts established the Center for Independent Living in Berkeley, California, using funds from the Rehabilitation Administration.\(^{168}\) This was the first center for independent living in the country.\(^{169}\)

Across the country in Staten Island, New York, the parents and families of residents of the Willowbrook State School, a state-supported institution for special needs children, filed a class action lawsuit against the school over rampant abuse and neglect of residents.\(^{170}\) Final judgment on the Willowbrook case was passed in 1975, but it took nearly two decades for all of the designated "Willowbrook" class to be moved into suitable community housing.\(^{171}\) Following a television exposé,\(^{172}\) the Pennhurst State School and Hospital in Spring Hill, Pennsylvania, were sued on behalf of former and current residents.\(^{173}\) Building off the Willowbrook case, the United States District Court for the Eastern

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164. See id.
165. See id.
166. See id.
167. See id.
169. Id. at 60.
170. Id. at 326-28.
171. Id. at 326-29.
District of Pennsylvania held that “[o]nce admitted to a state facility . . . residents have a constitutional right to be provided with minimally adequate habilitation under the least restrictive conditions consistent with the purpose of the commitment.”\(^\text{174}\)

Outside of government, the disability rights movement found a foothold in student activism. In 1988, students of Gallaudet University, a federally chartered university for the education of deaf and hearing-impaired students, hosted a weeklong protest demanding the appointment of a deaf university president.\(^\text{175}\) Heavy media attention brought a new wave of attention to the struggles of students with disabilities.\(^\text{176}\)

**B. The ADA**

The stage was set to turn activism into lasting change through new legislation that would address the limited scope of the Rehabilitation Act of 1973. The initial form of the ADA drew heavily from section 504 and was introduced two months after the Gallaudet protests.\(^\text{177}\) Drafters began to drum up grassroots support for the ADA, and disability organizations and activists nationwide advocated on its behalf.

By 1990, the ADA had passed in the Senate with bipartisan support but was stuck in the House of Representatives. In response, on February 7, 1990, activist Justin Dart took out a full-page ad in the *Washington Post* delineating a “Magna Carta” of demands and rights, along with “[a m]essage to Congress from . . . [the] 43 [m]illion Americans with [d]isabilities.”\(^\text{178}\)

1. **Passage**

The ADA was sponsored by Democratic Senator Tom Harkin of Iowa and subsequently cosponsored by forty-four Democrats and

\(^{174}\) *Id.* at 1319.

\(^{175}\) *See* PELKA, supra note 168, at 90-92.

\(^{176}\) *Id.* at 91.

\(^{177}\) *Id.* at 92.

nineteen Republicans.\(^{179}\) In March, with the bill stalled,\(^{180}\) the “Wheels of Justice Campaign” was launched.\(^{181}\) This protest helped prompt Congress to pass the ADA on May 22, 1990, by a wide margin.\(^{182}\)

In its final stages, the ADA was popular with the general public and had the backing of both the executive and legislative branches, as well as agencies.\(^{183}\) During the legislative process, the ADA was amended twenty-two times, notably to include the human immunodeficiency virus (HIV) on the list of infectious diseases,\(^{184}\) to more clearly define the term “disability,” and to offer a plan for providing entities with technical assistance.\(^{185}\)

2. Purpose

The ADA sought to reshape “attitude[es], communication, transportation, policy and physical barriers” to desegregate those previously isolated from society as a result of their disability.\(^{186}\) On July 26, 1990, President George H.W. Bush signed the ADA into law, noting that the Act is “powerful in its simplicity” and characterizing the goals as “independence, freedom of choice, control of their lives, [and] the opportunity to blend fully and equally into the rich mosaic of the American mainstream.”\(^{187}\) Some maintain that the passage of the ADA was one of the most enduring accomplishments of the Bush presidency.\(^{188}\)


\(^{180}\) Magna Carta, supra note 178.

\(^{181}\) Id.


\(^{184}\) This gives employers a right to reassign those with HIV to jobs not involving the handling of food.

\(^{185}\) See Final Push, supra note 182.

\(^{186}\) ADA—Findings, Purpose, and History, supra note 183.


The ADA focused on three findings: (1) "disabilities in no way diminish a person’s right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination;" 189 (2) "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;" 190 and (3) "the Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency." 191

Congress envisioned the ADA as a stepping stone for those with disabilities to fully integrate into society and placed a heavy emphasis on the role of discrimination in preventing that integration. The ADA as passed in 1990 aimed to promote integration in all areas of public life, while advancing equal opportunity, if not necessarily equal outcomes. 192

3. Organizational Structure

Congress divided the ADA into five titles to accomplish the far-reaching goals set out in this new legislation.

a. Title I: Equal Employment Opportunity for Individuals with Disabilities

Title I understands employment as a means for integration into society and is devised to help people with disabilities access similar job opportunities and benefits available to the general public. 193 Specifically, employers must provide reasonable accommodations to qualified applicants or employees. 194 A reasonable accommodation is any modification or adjustment to a job or the work environment that will enable an employee with a disability to participate and perform essential job functions. 195 This also covers accessibility in the

190. Id. § 12101(a)(2).
191. Id. § 12101(a)(7).
192. See ADA—Findings, Purpose, and History, supra note 183.
194. Id. § 12112(b)(5)(A)-(B).
195. See id. § 12111(9).
application process.\textsuperscript{196} This title applies to all employers with fifteen or more employees and is regulated by the U.S. Equal Employment Opportunity Commission.\textsuperscript{197}

b. Title II: Nondiscrimination on the Basis of Disability in State and Local Government Services

Title II takes aim at ensuring state and local governments are inclusive of those with disabilities. It prohibits discrimination in all programs, activities, and services of public entities.\textsuperscript{198} This title applies to all state and local governments, along with their departments and agencies, and public or state run healthcare facilities.\textsuperscript{199} It also clarifies the requirements of section 504 of the Rehabilitation Act of 1973 for public transportation systems.\textsuperscript{200}

c. Title III: Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities

Title III promotes equality by ensuring that individuals with disabilities can access public accommodations equal to those without disabilities. As such, it prohibits private places of public accommodation from discriminating against individuals with disabilities.\textsuperscript{201}

This title dictates minimum standards for accessibility for construction or alterations of public facilities.\textsuperscript{202} It requires public accommodations to remove existing barriers when it can be done without significant hardship.\textsuperscript{203} This title, which applies to private healthcare providers, instructs businesses to make “reasonable modifications” to better serve people with disabilities and requires that businesses effectively communicate with customers possessing

\textsuperscript{196} Id. § 12112(b)(6).
\textsuperscript{197} Id. § 12111(5).
\textsuperscript{198} Id. § 12132.
\textsuperscript{199} Id. § 12131(1).
\textsuperscript{200} Id. § 12163.
\textsuperscript{201} Examples include privately owned, leased, or operated facilities, such as hotels, restaurants, retail merchants, doctors’ offices, private schools, daycare centers, sports stadiums, movie theaters, and more.
\textsuperscript{202} 42 U.S.C. § 12182(b).
\textsuperscript{203} Id. § 12182.
hearing, vision, or speech disabilities.\textsuperscript{204} Like title II, this is regulated and enforced by the Department of Justice (DOJ).\textsuperscript{205}

d. Title IV: Telecommunications

Title IV considers the ways that communications can exclude disabled members of society and amends title II of the Communications Act of 1934.\textsuperscript{206} Specifically, it requires telephone and internet companies to provide a nationwide system of telecommunications relay services to enable those with speech or hearing disabilities to communicate over telephones.\textsuperscript{207}

e. Title V: Miscellaneous Provisions

Title V covers miscellaneous provisions that do not fall within the purview of titles I-IV. This title provides a list of conditions not to be considered as disabilities.\textsuperscript{208} These include homosexuality and bisexuality,\textsuperscript{209} compulsive gambling, kleptomania, pyromania, pedophilia, and disorders resulting from current use of illegal drugs.\textsuperscript{210} This informs subsequent analysis of how to define disability in the context of the ADA.

4. Defining “Disability”

The definition of disability in the ADA was meant to be broad and not limited to currently understood disabilities. The ADA does not have an exhaustive list of disabilities, even though it does clarify, in part, conditions and behaviors that are not to be considered disabilities.\textsuperscript{211}

In defining a covered disability, the ADA copied the 1973 Rehabilitation Act’s three-prong definition for “handicapped individuals.”\textsuperscript{212} The sole modification was the substitution of the term

\textsuperscript{204} Id. § 12182(b)(2)(A)(ii).
\textsuperscript{206} 47 U.S.C. § 225.
\textsuperscript{207} Id.
\textsuperscript{208} 42 U.S.C. § 12211.
\textsuperscript{209} Id. § 12211(a).
\textsuperscript{210} Id. § 12211(b).
\textsuperscript{211} See id. §§ 12210, 12211.
"disability" for the term "handicapped." Under the ADA, an individual disability is "(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment."

Following the statute's enactment, the Equal Employment Opportunity Commission issued guidance and regulations reaffirming this broad reading, clarifying that an individual rejected from a job because of the "myths, fears, or stereotypes" associated with disabilities would be covered under the regarded-as prong whether or not the employer's or other covered entity's perception were shared by others in the field.

The ADA protects individuals from discrimination when that individual is known "to have a family, business, social or other relationship or association" with an individual who has a known disability. For example, this prevents an employer from discriminating against someone with caregiving responsibilities or making "unfounded assumptions" about insurance requirements. Thus, protection is not limited to people with disabilities themselves or to those with conditions that medically affect daily life.

Nor has disability law remained static, as legislative refinement has shaped how the ADA functions to improve the lives of those with disabilities and how the statute defines disability. Most notably, the ADA Amendments Act of 2008 (ADAAA) clarified that the term disability ought to be broadly construed, with a few modifications expanding its scope.

First, the revised statute rejects the reading of "substantially limits" that forced litigants to demonstrate that they "have an impairment that prevents or severely restricts the individual from doing activities that are of central importance to most people's daily lives."
lives." Instead, "the primary object of attention" is now "whether entities covered under the ADA have complied with their obligations" under the statute.

Secondly, the ADAAA provides an illustrative list of major life activities that courts were previously obliged to deduce on a case-by-case basis. The activities listed "include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working." The result is that some individuals can qualify for coverage without detailing limits on their daily activities.

IV. DEINSTITUTIONALIZATION AND OLMSTEAD

A central focus of the disability rights movement has been deinstitutionalizing persons with disabilities. The leading U.S. Supreme Court case interpreting this mandate is Olmstead, which asked whether the ADA's nondiscrimination mandate required community-based housing rather than institutionalization.

In this 1999 case, the respondents Lois Curtis and Elaine Wilson, who were both institutionalized with mental disabilities, fought to secure state-funded, community-based treatments and supports, while the petitioners, state healthcare officials, pleaded a defense of inadequate funding. The U.S. Supreme Court considered whether or not the antidiscrimination provision of title II of the ADA required states to provide community-based treatment rather than placement in institutions, deciding for the respondents.

Olmstead has had profound implications for institutionalized persons with disabilities, and the enforcement of Olmstead has turned into a nationwide effort to protect civil and disability rights. To better understand the impact and evolution of Olmstead, it is important to learn more about its procedural posture and to consider the reaction to Olmstead when the decision was issued.

219. Id. § 2(b)(4) (quoting Toyota Motor Mfg., Ky., Inc. v. Williams, 534 U.S. 184, 198 (2002)).
220. Id. § 2(b)(5).
223. Id. at 587 (majority opinion).
224. Id. at 593-94.
A. **Lead Up to Olmstead**

Respondents were both diagnosed with mental health conditions and intellectual disabilities and were in and out of the State’s mental health hospitals, which were ill-equipped to provide adequate supports.\(^{225}\) The two sought community-based programs that would allow them to get care without being confined. While their doctors agreed that the patients no longer met the State’s requirements for involuntary confinement, requests for release were turned down by the hospital and State. Both women remained confined for years due to long waitlists and the State’s lack of ability to accommodate their needs in a community-based setting.

B. **Procedural History**

In 1995, Lois Curtis enlisted the Atlanta Legal Aid Society to file suit against Tommy Olmstead, the Commissioner of Georgia’s Department of Human Resources, together with the Superintendent of Georgia Regional Hospital at Atlanta, and the Executive Director of the Fulton County Regional Board. Curtis alleged that the defendants continued to confine her at the Georgia Regional Hospital despite her doctor’s determination that she no longer needed institutionalized treatment.\(^{226}\) She alleged that such unnecessary confinement constituted unlawful discrimination in violation of title II of the ADA and regulations requiring public entities to administer services, programs, and activities “in the most integrated setting appropriate to the needs of qualified individual with disabilities.”\(^{227}\) She demanded that Georgia place her in a community-based program. In 1996, Wilson intervened.\(^{228}\)

Defendants argued that they did not violate the ADA because denial of community placement was due to inadequate funding, not discrimination. The United States District Court for the Northern

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\(^{226}\) Id.


District of Georgia rejected this defense, holding that unnecessary segregation is a form of illegal discrimination per se and that such discrimination cannot be defended on grounds of inadequate funding.\footnote{Id. at *3.} It also concluded that an immediate transfer, even if inconvenient, would not fundamentally alter Georgia's program.\footnote{Id. at *4.} The district court granted summary judgment for the plaintiffs and ordered the State to transfer Curtis and Wilson to a community-based treatment program.

Georgia appealed, and the United States Court of Appeals for the Eleventh Circuit affirmed.\footnote{Olmstead, 138 F.3d at 895.} The Eleventh Circuit gave controlling weight to the title II integration regulations, after finding direct support from the plain language of the ADA, the statutory scheme of title II, and the legislative history.\footnote{Id at 896-97.} Given authority by Congress to promulgate regulations, the U.S. Attorney General issued an integration regulation in 28 C.F.R. § 35.130(d) to mandate that public entities provide services in the most integrated manner.\footnote{Id at 902.} Under that integration regulation, Georgia had violated title II by institutionalizing patients for whom an integrated community placement would be appropriate.\footnote{Id.}

The court allowed a cost defense only in "the most limited of circumstances."\footnote{Id at 899.} According to 28 C.F.R. § 35.130(b)(7), when the accommodations "would fundamentally alter the nature of the service, program, or activity,"\footnote{28 C.F.R. § 35.130(b)(7)(i) (1997).} the State would not have a duty to provide integrated services.\footnote{See Olmstead, 138 F.3d at 905.} A cost defense was appropriate only when the additional expenditures to accommodate these two women's needs would be "so unreasonable given the demand of the State's mental health budget" that such services would amount to a fundamental alteration of the system.\footnote{Id.} To develop the facts concerning fundamental alteration, the Eleventh Circuit remanded

\footnotesize{\begin{itemize}
  \item \footnote{Id. at *3.}
  \item \footnote{Id. at *4.}
  \item \footnote{Olmstead, 138 F.3d at 895.}
  \item \footnote{Id at 896-97.}
  \item \footnote{Id at 902.}
  \item \footnote{Id.}
  \item \footnote{28 C.F.R. § 35.130(b)(7)(i) (1997).}
  \item \footnote{See Olmstead, 138 F.3d at 905.}
  \item \footnote{Id.}
\end{itemize}}
the case to consider whether the plaintiffs' requests would "fundamentally alter the nature of the service, program, or activity."

On remand, the district court found that the extra expenditures of accommodating two women in an integrated community program were not unreasonable in relation to Georgia's overall mental health budget. The U.S. Supreme Court granted certiorari to review the judgment and in 1999 issued the opinion in *Olmstead*.

C. Supreme Court's Decision

The U.S. Supreme Court decision had four subparts: Part I, II, III-A and III-B. The majority, announced by Justice Ginsburg and joined by Justices Stevens, O'Connor, Souter, and Breyer, articulated a three-factor test in Parts I, II, and III-A. The test provided that under title II of the ADA, states are required to provide persons with disabilities with integrated treatments when (1) the State's treatment professionals decide that such placement is appropriate, (2) the integrated placement is not opposed by the affected persons, and (3) the placement is a reasonable accommodation, taking into consideration the State's available resources and the needs of others with mental disabilities.

In Part III-B, a plurality of Justices Ginsburg, O'Connor, Souter, and Breyer concluded that 28 C.F.R. § 35.130(b)(7) permitted a cost-based defense. The Eleventh Circuit instruction to evaluate the expenditures of accommodating two specific people against the State's entire mental health budget was flawed, however, as it would arguably prevent the State from ever prevailing. Instead, the State should consider the care for a large, heterogeneous population with mental disabilities and whether immediate relief would be inequitable, if the relief were displacing persons at the top of waiting list. This plurality remanded the case for consideration of relief, given the State's available resources and the needs of persons with diverse disabilities.

239. *Id.;* 28 C.F.R. § 35.130(b)(7).
241. *Id* at 587.
242. *Id.*
243. *Id* at 603-04 (plurality opinion).
244. *Id.*
245. *Id* at 604.
246. *Id* at 607.
On one hand, a majority of justices agreed that unjustified and inappropriate segregation of people with disabilities in institutions constituted discrimination under title II of the ADA. Justice Kennedy, believing such conduct was not per se discrimination, expressed the view that it was “relevant and instructive” that Congress had identified the “isolat[ion] and segregat[ion]” of disabled persons as a form of discrimination.

On the other hand, the Court wrestled with what should constitute a “fundamental alteration,” how much responsibility the State should have in creating or providing community-based programs, and how much discretion the State would receive for its cost analysis. Both the majority’s opinion in Part III-B and Justice Kennedy’s concurrence suggested a cautious attitude.

1. Unjustified Segregation is Discrimination: The Majority’s Opinion

Justice Ginsburg, writing for the majority, recognized that this case was about the “proper construction of the antidiscrimination provision” in title II of the ADA. The relevant legislative regulation was the “integration regulation” at 28 C.F.R. § 35.130(d). The DOJ and Georgia argued for different constructions of these regulations. The DOJ argued that undue institutionalization qualified as discrimination “by reason” of one’s disability, while Georgia insisted that institutionalization was not discrimination, as no comparison class received preferential treatment.

The Court sided with the DOJ after finding support in the legislative history, as well as in the mandatory language from the Rehabilitation Act and the Developmentally Disabled Assistance and Bill of Rights Act. Congress had explicitly recognized unjustified segregation and isolation of individuals with disabilities as a “form of discrimination.”

247. *Id.* at 587 (majority opinion).
248. *Id.* at 613-14 (Kennedy, J., concurring) (quoting 42 U.S.C. § 12101(a)(2)).
249. *Id.* at 603-04 (plurality opinion).
250. See *id.* at 610 (Kennedy, J., concurring).
251. *Id.* at 587 (majority opinion).
252. *Id.* at 592.
253. *Id.* at 597 n.9.
254. *Id.* at 598.
255. *Id.* at 598-602.
discrimination.” The majority concluded that unjustified isolation “is properly regarded as discrimination based on disability.”

This opinion reflected two important decisions. First, it emphasized that placing individuals who can benefit from less restrictive programs into segregated institutions “perpetuates unwarranted assumptions” that those persons are “incapable or unworthy of participating in community life.” Second, the opinion highlighted that institutional isolation can severely diminish quality of life by hampering key components of existence like family relations, educational advancement, and cultural enrichment.

2. State’s Defense

The Court went on to question to what extent the State must create, change, or expand its community-based programs to comply with the “integration provision” of title II. The majority, including Justice Kennedy, were wary of possible backlash, since to guarantee compliance with the mandate, states might be tempted to substantially decrease institutional settings, or even to terminate institutional treatments altogether.

The majority clarified that the ADA would not condone termination of institutional settings for those who were “unable to handle or benefit from community settings,” as title II limited protection against segregation only to “qualified individuals” who met eligibility requirements. To determine eligibility, the State could generally rely on the reasonable assessments and judgments of its own professionals, but community-based treatment would not be imposed on patients who opposed it.

In Part III-B, a plurality wanted to expand the scope of the state’s “fundamental alteration” defense to partially address the concern that the “integration provision” could go too far. The plurality disfavored the Eleventh Circuit’s narrow approach because

256. Id. at 600; see 42 U.S.C. § 12101(a)(2).
257. Olmstead, 527 U.S. at 597.
258. Id. at 600.
259. Id. at 601.
260. Id. at 601-02.
261. Id.
262. Id. at 602.
263. Id.
264. Id. at 602-04 (plurality opinion).
the expenditure in placing a small number of persons in the community-based program would rarely cause a fundamental alteration of the system.\textsuperscript{265} Even if the cost of transitioning one person from institutions to community programs was less, in aggregate the State could still experience "increased overall expenses by funding community placements without being able to take advantage of the savings associated with the closure of institutions."\textsuperscript{266} The plurality concluded that if the State could show that it had a "comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated," the State would meet the demands of title II.\textsuperscript{267}

3. Dissent

Justice Thomas dissented, and Chief Justice Rehnquist and Justice Scalia joined.\textsuperscript{268} The dissent disagreed with the majority's reading of the concept of "discrimination" in title II.\textsuperscript{269} They urged that discrimination should require a showing of disparate treatment when compared to members of a different group "by reason of" a statutorily described characteristic—in this case, "disability."\textsuperscript{270} The comparison group must be people who were similarly situated but were not members of the same protected class, as suggested by the majority.\textsuperscript{271} Mere disparate treatment between the comparison group and the statutorily protected group was not enough; one had to show that the disparate treatment was "by reason of" the disability.\textsuperscript{272}

Justice Thomas believed that in altering the traditional meaning of "discrimination," the majority was equating institutional isolation with segregation.\textsuperscript{273} He considered the textual evidence that the

\textsuperscript{265} Id.

\textsuperscript{266} Id. at 604 (quoting Brief for United States as Amicus Curiae Supporting Respondents, \textit{Olmstead}, 527 U.S. 581 (No. 98-536), 1999 WL 149653).

\textsuperscript{267} Id. at 605-06.

\textsuperscript{268} Id. at 615 (Thomas, J., dissenting).

\textsuperscript{269} Id. at 624.

\textsuperscript{270} See id. at 617.

\textsuperscript{271} Id. at 616.

\textsuperscript{272} Id. at 623-24, 626 (quoting 42 U.S.C. § 12132).

\textsuperscript{273} Id. at 620.
majority relied upon to be too vague and accused the majority of affirmatively imposing a standard of care that could not track the plain and ordinary meaning of "discrimination." 274

D. Reaction to Olmstead

The decision in Olmstead inspired significant reaction by the public, the government, and the academic community. Activism began quickly, as Olmstead "prompted advocates for the disabled to file other lawsuits, . . . helped them win lower-court judgments[,] and . . . put new pressure on states." 275 After the ADA passed, activists turned their attention toward ensuring access to in-home and community-based care. 276 The decision in Olmstead marked a crucial step toward this goal by creating the legal framework to support and demand community-based care for those with disabilities. 277 The disability rights community praised Olmstead, 278 lauding it as the Brown v. Board of Education of disability rights. 279

A month after the Olmstead decision, President Bill Clinton’s Secretary of the Department of Health and Human Services (HHS), Donna E. Shalala, praised the decision. 280 In January 2000, the Health Care Financing Administration distributed a letter to state Medicaid

274. Id. at 622-24.
directors emphasizing the need for change in the wake of \textit{Olmstead} and providing recommendations for ensuring compliance.\textsuperscript{281} The letter emphasized that the decision applied to “all individuals with disabilities protected from discrimination by title II of the ADA”\textsuperscript{282} and directed states to consider all those who could be receiving care in the community,\textsuperscript{283} including individuals with mental and physical disabilities and those living in nursing homes.\textsuperscript{284}

Despite Texas’s opposition to the petitioner in \textit{Olmstead} while George W. Bush was Governor, as President, Bush supported \textit{Olmstead} with Executive Order 13217\textsuperscript{285} and The New Freedom Initiative for People with Disabilities.\textsuperscript{286} His administration also instituted programs to support community living, including Money Follows the Person (MFP), a grant program through HHS.\textsuperscript{287} The program provided states with Medicaid funding to support individuals living in their communities.\textsuperscript{288}

However, minimal progress was made toward deinstitutionalization.\textsuperscript{289} The National Disability Rights Network reviewed the practices of the DOJ and HHS in the ten years following \textit{Olmstead} and found that HHS relied too heavily on short-term incentives, without monitoring enforcement, while the DOJ had not engaged in sufficient enforcement.\textsuperscript{290}
By contrast, the Obama Administration began a period of aggressive enforcement. In 2009, President Obama announced the Year of Community Living to commemorate the *Olmstead* decision.\(^{291}\) President Obama also directed the Civil Rights Division of the DOJ to increase *Olmstead* enforcements.\(^{292}\) From 2009 to 2016, Obama’s DOJ was involved in fifty *Olmstead* integration cases,\(^ {293}\) continued to support MFP, and expanded the program through the Affordable Care Act (ACA) in 2010.\(^ {294}\) HHS affirmed support of *Olmstead* and the ADA through the Community Living Initiative\(^ {295}\) and also established the Administration for Community Living to address disability policy and programs.\(^ {296}\) In 2014, HHS and the DOJ jointly issued a “Dear Colleague” letter providing guidance to ensure that new Department of Labor rules regarding minimum wage and overtime protections to home-care workers were implemented in accordance with the ADA and *Olmstead*.\(^ {297}\)

The Senate’s Committee on Health, Education, Labor, and Pensions considered the state of *Olmstead* in 2010 and again in 2012.\(^ {298}\) The hearings provide insight into Congress’s views on


\(^{292}\) See id.


\(^{298}\) The ADA and Olmstead Enforcement: Ensuring Community Opportunities for Individuals with Disabilities: Hearing Before the S. Comm. on Health, Educ., Lab., &
Olmstead enforcement and the ADA. The first Senate hearing was held on June 22, 2010.\textsuperscript{299} The hearing included testimony from six witnesses\textsuperscript{300} and statements from six senators.\textsuperscript{301} Speakers repeatedly indicated that Olmstead applied to all categories of disabilities.\textsuperscript{302} Witnesses in the hearing referenced a number of different types of disabilities, including physical disabilities, developmental disabilities, and learning disabilities.\textsuperscript{303} Assistant Attorney General Thomas Perez clarified that “[t]he Olmstead decision makes clear that States have an obligation to provide services to individuals with disabilities in the most integrated setting appropriate to their needs.”\textsuperscript{304}

On June 21, 2012, the Senate Committee convened again in a hearing called “Olmstead Enforcement Update: Using the ADA to Promote Community Integration.”\textsuperscript{305} At this hearing, Mr. Perez asserted that “Olmstead is more than simply where you live, it is also how you live, and that is what we are working on.”\textsuperscript{306} Speakers again referenced individuals with a variety of different disabilities, including developmental, intellectual, mental, and physical


\textsuperscript{299} Id.

\textsuperscript{300} Witnesses included Thomas E. Perez, Assistant Attorney General of the Civil Rights Division of the Department of Justice; Cindy Mann, Director of the Center for Medicaid and State Operations of the Department of Health and Human Services; Robert Bernstein, Executive Director of the Bazelon Center; Nancy Thaler, Executive Director for the National Association of State Directors of Development Disabilities Services; and Kelly Buckland, Executive Director of the National Council on Independent Living. Id. at III (Table of Contents).

\textsuperscript{301} Id. at II (Committee Members). The Senators included Tom Harkin of Iowa; Michael B. Enzi of Wyoming; Jeff Merkley of Oregon; Al Franken of Minnesota; Kay R. Hagan of North Carolina; and Robert P. Casey, Jr. of Pennsylvania.

\textsuperscript{302} Id. at 6 (statement of Thomas E. Perez, Assistant Att’y Gen., C.R. Div., U.S. Dep’t of Just.) (“The Olmstead decision applies to all people with disabilities, not simply people with certain kinds of disabilities.”).

\textsuperscript{303} See id. at 6, 9, 36 (statement of Jeffrey Knight of Frederick, Md.).

\textsuperscript{304} Id. at 10 (statement of Thomas E. Perez, Assistant Att’y Gen., C.R. Div., U.S. Dep’t of Just.).


\textsuperscript{306} Id. at 4 (emphasis added) (statement of Thomas E. Perez, Assistant Att’y Gen., C.R. Div., U.S. Dep’t of Just.).
disabilities. They specifically mentioned veterans, those in nursing homes, and an infant who had a brain injury.307

The Olmstead decision also sparked academic discussions about the implications of the Court's ruling that unjustified segregation of persons with disabilities is a form of discrimination. There seemed to be a general consensus that the Olmstead decision would have far-reaching implications for a much broader audience than individuals with mental disabilities. Indeed, in the wake of Olmstead, suggestions for novel applications emerged.308 One author suggested that Olmstead could lead to a reevaluation of state policies that lock up defendants being evaluated for competency to stand trial and insanity.309 Others considered whether Olmstead could lead to a reconsideration of institutional mental disability law.310

V. OLMS TED FEDERAL AND STATE ENFORCEMENTS

A. Typical Olmstead Enforcement

The majority of Olmstead enforcement cases are brought through federal courts.311 Title II of the ADA provides, inter alia, that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”312 As the United States Court of Appeals for the Second Circuit explained:

To establish a violation of [t]itle II, [a plaintiff] must show that: (1) [they are] a “qualified individual with a disability,” (2) [the accused institution] is subject to the ADA, and (3) [they are], “by reason of such

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307. Id. at 3, 11 (statement of Henry Claypool, Principal Deputy Adm’r, Admin. for Cmt. Living).
311. Plaintiffs must demonstrate standing under Article III of the U.S. Constitution. However, the ADA expressly provides a cause of action under the Integration Mandate, See Reid v. Hurwitz, 920 F.3d 828, 834 (D.C. Cir. 2019) (citing Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581, 594 n.6 (1999)).
disability, . . . excluded from participation in or . . . denied the benefits of the services, programs, or activities of a public entity, or . . . subjected to discrimination by any such entity.”

Once the first two prongs are met, the reason for disparate treatment comes under scrutiny. The specific aids, services, programs, and settings to which an individual is entitled from a public entity closely tie into the benefits, if any, that would derive from accessing them. For example, public entities may not “[p]rovide a qualified individual with a disability with an aid, benefit, or service that is not as effective in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as that provided to others.” Similarly, these services, programs, and activities must be administered “in the most integrated setting appropriate to the needs of qualified individuals with disabilities,” defined as one that “enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.”

1. Plaintiffs

Although Olmstead dealt with the issue of mental health, the holding is not limited to individuals with mental disabilities, as courts agree that Olmstead applies to all disabilities under the ADA. Furthermore, while the plaintiffs in Olmstead were institutionalized individuals, the holding also protects individuals at risk of institutionalization.

315. Id. § 35.130(d).
316. Id. pt. 35 app. B.
317. See Day v. District of Columbia, 894 F. Supp. 2d 1, 5 (D.D.C. 2012) (“Although the plaintiffs in Olmstead had exclusively mental disabilities . . . its holding also applies to individuals with physical disabilities.”); M.R. v. Dreyfus, 663 F.3d 1100, 1102 (9th Cir. 2011) (involving a plaintiff with both physical and mental disabilities); Radaszewski ex rel. Radaszewski v. Maram, 383 F.3d 599, 613 n.5 (7th Cir. 2004) (holding that Olmstead applied to persons with disabilities in general); Grooms v. Maram, 563 F. Supp. 2d 840, 852 (N.D. Ill. 2008); Davis v. Shah, 821 F.3d 231, 264 (2d Cir. 2016) (holding that New York could not deny services to certain disabled beneficiaries if doing so would place them at a substantial risk of institutionalization).
318. See, e.g., Fisher v. Okla. Health Care Auth., 335 F.3d 1175, 1181-82 (10th Cir. 2003) (holding that Olmstead is not limited to institutionalized individuals); Pashby v. Delia, 709 F.3d 307, 322 (4th Cir. 2013) (holding that Olmstead protections included “‘persons at serious risk of institutionalization or segregation’” (quoting Statement of the Dep’t of Just.
While the first prong of the Supreme Court’s test focuses on “qualified individual[s] with a disability,” *Olmstead* enforcement actions in federal courts are often brought on behalf of qualified individuals with disabilities.\(^{319}\) For example, actions are usually brought by the DOJ and the HHS Office of Civil Rights (OCR).\(^{320}\) Class action lawsuits are another common vehicle for bringing *Olmstead* claims challenging “systemic” violations of the integration mandate.\(^{321}\) Lastly, organizations may also bring actions on behalf of qualified individuals, such as in the case of individuals with “intellectual and developmental disabilities.”\(^{322}\)

One study found that between 1999 and 2011, there were 131 *Olmstead* and related cases filed, and ninety of those cases were resolved through court rulings and settlements.\(^{323}\) Almost sixty percent of those cases were filed on behalf of plaintiffs who were diagnosed with intellectual disabilities or mental illness, while plaintiffs with physical disabilities filed twenty-nine percent of cases. We estimate that those with TBI initiated less than four percent of cases.\(^{324}\)
2. Defendants

Title II of the ADA covers any State entity that receives federal funding.\textsuperscript{325} Courts have interpreted this provision to cover state hospitals as well as state prisons.\textsuperscript{326} Courts have held that title II applies when the relevant public entity "administer[s] . . ., plan[s] . . ., and allocate[s] resources" for the accused State service, program, or activity related to a plaintiff's claims, even if the plaintiff's care is received in a privately operated facility.\textsuperscript{327} Furthermore, courts look beyond state statutes and regulations when determining whether a facility constitutes an "institution."\textsuperscript{328}

3. Establishing Injury

As the U.S. Supreme Court explained, the third prong of the test is satisfied by a violation of the integration mandate of the ADA,\textsuperscript{329} which "requires that when a state provides services to individuals with disabilities, it must do so 'in the most integrated setting appropriate to their [sic] needs.'"\textsuperscript{330} To establish a violation, a plaintiff must show that (1) "the State's treatment professionals determine that such placement is appropriate," (2) "the affected persons do not oppose such treatment," and (3) "the placement can be reasonably accommodated."\textsuperscript{331} A violation requires a denial of a service by reason of disability, meaning that there must be some service requested by an individual that is then denied by the defendant.\textsuperscript{332} Furthermore, \textit{Olmstead} does not require every disability to be treated equally.\textsuperscript{333}

\textsuperscript{325} See Henrietta D. v. Bloomberg, 331 F.3d 261, 272 (2d Cir. 2003).
\textsuperscript{326} See Pa. Dep't of Corr. v. Yeskey, 524 U.S. 206, 209-10 (1998) (holding that state prisons were subject to title II of the ADA).
\textsuperscript{327} Disability Advocs., Inc. v. Paterson, 598 F. Supp. 2d 289, 317 (E.D.N.Y. 2009).
\textsuperscript{328} Pashby v. Delia, 709 F.3d 307, 322-23 (4th Cir. 2013) (holding that a court could reasonably conclude that an adult care home was an institution).
\textsuperscript{330} Disability Advocs., Inc. v. Paterson, 653 F. Supp. 2d 184, 190 (E.D.N.Y. 2009) (quoting 28 C.F.R. § 35.130 (2009)).
\textsuperscript{331} \textit{Olmstead}, 527 U.S. at 607 (plurality opinion).
\textsuperscript{333} Id. at 97 ("Eight circuit decisions, ADA legislative history, case law interpreting the Rehabilitation Act, and post-ADA legislative action all favor holding that the ADA does not require equal benefits for different disabilities."); Weyer v. Twentieth Century Fox Film Corp., 198 F.3d 1104, 1117 (9th Cir. 2000).
4. Affirmative Defenses

The most significant hurdle to an Olmstead action is known as the "fundamental alteration" defense.\(^{334}\) Under the ADA, to remedy a violation of title II, "[a] public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity."\(^{335}\) For example, "failure to provide Medicaid services in a community-based setting may constitute a form of discrimination,"\(^{336}\) but requiring a "separate service or one not already provided by the state" may constitute a fundamental alteration.\(^{337}\)

B. State Olmstead Plans

While the majority of Olmstead claims are brought in federal court, states can violate the ADA by providing services to individuals with disabilities in institutional settings when those individuals could be placed into a community-based setting.\(^{338}\) However, the U.S. Supreme Court acknowledged that states are not obligated to provide services at any and all costs.\(^{339}\) Rather, if a "State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace . . . the reasonable-modifications standard [of the ADA integration mandate] would be met."\(^{340}\)

A full discussion of all issues related to state Olmstead plans and enforcement is beyond the scope of this Article. However, an understanding of law related to state Olmstead plans and enforcement will help us understand how to best mobilize Olmstead to improve the lives of individuals with moderate-to-severe brain injury.

\(^{334}\) See Olmstead, 527 U.S. at 592.
\(^{336}\) Fisher v. Okla. Health Care Auth., 335 F.3d 1175, 1182-84 (10th Cir. 2003).
\(^{337}\) Id. at 1183 (interpreting Olmstead as not imposing the ADA’s nondiscrimination requirement to services not provided by an institution).
\(^{338}\) Olmstead, 527 U.S. at 587-88.
\(^{339}\) Id. at 603-04 (plurality opinion).
\(^{340}\) Id. at 605-06 (emphasis added).
1. State Plans

An *Olmstead* plan is the lens through which the State may evaluate its success in providing services to individuals with disabilities. These plans describe the goals of community-based care, assess the capabilities of personnel and organizations, and identify barriers to integration and areas for improvement. States are granted significant freedom in developing *Olmstead* plans, and HHS has recognized that no single plan will be perfect for all states.\(^{341}\) Currently, more than forty-three states have developed written *Olmstead* plans.\(^{342}\) Because the states choose how to develop their plans, and given that a successfully implemented plan contemplates the specific needs of the states’ particular communities, *Olmstead* plans vary considerably in their scope, depth, and issues of focus.

States are not granted absolute latitude, however, as the DOJ has specified that a “working plan must do more than provide vague assurances of future integrated options or describe the entity’s general history of increased funding for community services and decreased institutional populations.”\(^{343}\) Accordingly, there are a few fundamental requirements with which states must comply.\(^{344}\)

An *Olmstead* plan must, at minimum, analyze the extent to which the State provides services to individuals with disabilities in the most integrated settings possible.\(^{345}\) It should also identify practices or policies that could hinder transition from segregated to integrated settings.\(^{346}\)

A comprehensive plan cannot simply be aspirational. Plans must contain concrete and reliable commitments to increase opportunities for individuals with disabilities to be served in integrated settings.\(^{347}\) Implementation must be considered, and plans need specific,

\(^{341}\) Dear Director, *supra* note 281.


\(^{343}\) DOJ Title II Statement, *supra* note 318.

\(^{344}\) *Id.*

\(^{345}\) *Id.*


\(^{347}\) *Id.*
“reasonable timeframes,” combined with “measurable goals.” The plan must specify the resources necessary to fulfill each commitment. Critically, an “effectively working” Olmstead plan must prove successful in actually moving individuals out of institutional settings and into the community. Otherwise, a state cannot mount a successful fundamental alteration defense.

Notwithstanding the DOJ’s requirements, states retain broad flexibility under Olmstead. To aid states in creating their plans, federal agencies have published guidance on Olmstead compliance.

2. State Litigation

The DOJ Civil Rights Division utilizes an array of administrative and legal tools to enforce Olmstead. These methods include direct investigations of states, preparing and issuing “Letters of Finding,” reporting on the results and conclusions of investigations, and making settlement agreements with states to correct illegal policies and practices. One of the most frequently employed methods of enforcement is litigation.

The vast majority of Olmstead litigation is brought in federal court, whether or not the DOJ is involved. Indeed, a substantial

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348. DOJ Title II Statement, supra note 318.
349. See id.
350. Id.
351. See MOSELEY, supra note 346, at 8.
number of lawsuits fairly categorized as "Olmstead litigation" either are federally initiated by the DOJ or actions where the DOJ has intervened. The National Disability Rights Network’s most recent compilation of cases indicates that of 141 suits and findings letters brought or issued since the Supreme Court decided Olmstead in 1999, the DOJ was involved in thirty-nine. The National Disability Rights Network’s docket notes that only five of the 141 actions were suits filed in state court. A Westlaw search of cases citing Olmstead produces only fifty-three cases filed in state court, as compared to 667 cases filed federally.

C. Recent Olmstead Enforcements

Although Olmstead enforcements increased under the Obama Administration, the Trump Administration took a different approach. It became difficult to track changes, as the DOJ’s list of closed Olmstead investigations was only updated sporadically. We found that Olmstead enforcements under the Trump Administration decreased dramatically, with only one action filed since 2016.

355. See id.; see also DOJ Olmstead Enforcement by Case or Matter, ADA.GOv, https://www.ada.gov/olmstead/olmstead_cases_list2.htm (listing Olmstead enforcement cases in which the DOJ has either initiated or intervened in).

356. PRIAULX, supra note 354, at 7 ("Cases in which the U.S. Department of Justice has been involved in any capacity are indicated with this symbol 'J' next to the case name."). The number thirty-nine was reached by counting the thirty-six cases in the docket’s Table of Contents that are marked by the symbol "J," adding a case that was (presumably) mislabeled with a "J" instead of a "j," and adding two cases with clear reference to DOJ intervention that were nevertheless unmarked by either a “J” or a “j.”


358. We acknowledge the limitations of a Westlaw search: every lawsuit filed does not result in an opinion accessible through a database, Westlaw’s coverage of state court documents varies, and the “cited by” feature can be an inexact method of detecting cases.


There were several indications that the Trump Administration was disinterested in pursuing *Olmstead* enforcements. On December 21, 2017, the DOJ retracted guidance that it had issued in 2016 regarding *Olmstead* enforcements. The 2016 guidance was intended to supplement DOJ guidance from 2011. The 2011 guidance remains in effect and is available on the ADA website.

According to then-Attorney General Jeff Sessions, the 2016 guidance was retracted, along with twenty-four other guidance documents, as part of a policy to end “the long-standing abuse of issuing rules by simply publishing a letter or posting a web page.” The U.S. Commission on Civil Rights criticized this decision.

Given the rollback of DOJ guidance, it is unlikely that the Trump Administration would have supported an expansion of the integration mandate. Avenues for action under the Trump Administration included private litigation and modification of the ADA. Chai Feldblum has asserted that she is in favor of amending the ADA. Sam Bagenstos has suggested that one option for future litigation is suits to enforce provisions of the Medicaid Act, though this litigation presents its own challenges. What is clear is that

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362. Id.

363. DOJ Title II Statement, supra note 318.


365. Id.


plaintiffs considering *Olmstead* claims cannot necessarily count on the DOJ to intervene to support the action.

VI. *OLMSTEAD ENFORCEMENTS AND BRAIN INJURY*

With an understanding of typical state and federal *Olmstead* enforcement actions, we can now consider the application of *Olmstead* to individuals with moderate-to-severe brain injury and DoC. We will focus on the application of *Olmstead* to the C&LC\(^3\) who may be amenable to improvement, yet are unable to access needed rehabilitation treatment due to their placement or diagnoses.\(^3\)

As noted, many with moderate-to-severe brain injury do not receive adequate rehabilitative treatment or assistive communication devices, even when they might be able to benefit from such interventions. In part, this is because an accurate diagnosis, necessary to understand what type of rehabilitation and devices could be useful, remains elusive. Indeed, as many as forty percent of those in the vegetative state following TBI are misdiagnosed, which is mistaking patients who are conscious as unconscious.\(^3\)

The combination of high misdiagnosis and prolonged recoveries conspires against those whose prognosis has not yet become clear.\(^3\) Improper diagnosis prevents patients with an otherwise encouraging outlook from receiving necessary outcome-enhancing rehabilitation. Determinations of futility can quickly follow even preliminary diagnoses.\(^3\) The advent of new modalities to more effectively diagnose and ameliorate these conditions, coupled with the knowledge that brain states are dynamic, makes access to proper diagnostic and rehabilitation therapy essential.\(^3\)

Many of these patients are housed in institutional care facilities, such as nursing homes or long-term care centers. As discussed

\(^3\) This group, termed the covert and liminally conscious, is detailed in subpart II.B.

\(^3\) Megan S. Wright et al., *supra* note 3, at 331-34; see also RCTM, *supra* note 15, at 5-8.

\(^3\) See Schnakers et al., *supra* note 49.


\(^3\) See generally RCTM, *supra* note 15 (noting that people associate severe brain injuries with minimal chances of recovery and nihilism).

previously, a central focus of disability rights laws has been reintegration of persons with disabilities into community settings.\textsuperscript{375} Community integration has been shown to have numerous benefits.\textsuperscript{376} The lack of integration for this population is not only ethically troubling but also a violation of their civil rights and constitutes unlawful discrimination due to disability, in violation of the ADA and the holding of \textit{Olmstead}.\textsuperscript{377}

A. Previous Applications of \textit{Olmstead} and Brain Injury

Plaintiffs with brain injuries are not uncommon among \textit{Olmstead} claims, though few claims specifically focus on DoCs. For example, in \textit{Crabtree v. Goetz}, the United States District Court for the Middle District of Tennessee granted a preliminary injunction to prevent the State from imposing drastic cuts to home healthcare services that would have likely forced the plaintiffs to be institutionalized on the basis of their disabilities, which included cerebral palsy, traumatic brain injury, Alzheimer’s, Parkinson’s, and stroke.\textsuperscript{378}

Individuals with brain injuries have prevailed in \textit{Olmstead} claims. For example, a “mentally alert and fully aware” woman “paralyzed from the chest down” with “a diagnosis of quadriplegia” was granted preliminary injunctive relief for in-home based healthcare services provided to others through Florida’s Traumatic Brain Injury/Spinal Cord Injury Waiver (TBI/SCI Waiver) program.\textsuperscript{379} The individual was characterized as “completely dependent on others to help her perform most of her activities of daily living,” requiring “ten to twelve hours a day of in-home assistance to remain in the community.”\textsuperscript{380} Two additional quadriplegic individuals received a similar preliminary injunction in \textit{Cruz v. Dudek}.\textsuperscript{381} More recently, a quadriplegic inmate with a frontal lobe brain injury, who was

\begin{itemize}
\item \textsuperscript{375} See Scotellaro, \textit{supra} note 308, at 737, 739-41.
\item \textsuperscript{376} \textit{Id.} at 738.
\item \textsuperscript{377} \textit{Id.}
\item \textsuperscript{378} No. Civ.A. 3:08-0939, 2008 WL 5330506, at *3 (M.D. Tenn. Dec. 18, 2008); see also M.R. v. Dreyfus, 697 F.3d 706, 720 (9th Cir. 2012) (granting preliminary injunction against State for violating the ADA by cutting the budget for home healthcare services).
\item \textsuperscript{379} Haddad v. Arnold, 784 F. Supp. 2d 1284, 1289, 1308 (M.D. Fla. 2010).
\item \textsuperscript{380} \textit{Id.} at 1290.
\item \textsuperscript{381} Cruz v. Arnold, No. 10-23048-CIV-UNGARO (S.D. Fla. Nov. 24, 2010) (granting preliminary injunction).
\end{itemize}
confined to his bed for approximately seventeen years, was granted a partial preliminary injunction, requiring that he be provided with access to "socialization" and "prison programming."\(^{382}\)

*Olmstead* cases have included plaintiffs who combine mental and physical impairments. In Illinois, a physically and mentally impaired plaintiff survived a motion to dismiss regarding a claim to continue intensive home-based care once the plaintiff aged out of a particular waiver program.\(^{383}\) The case relied in large part on another, *Radaszewski ex rel. Radaszewski v. Maram*, wherein the plaintiff underwent surgery, radiation, and chemotherapy to treat brain cancer and then suffered a mid-brain stroke, rendering him in need of "one-on-one care by a registered nurse 24 hours per day in order to survive."\(^{384}\) Ultimately, the State was permanently enjoined from reducing the plaintiff’s in-home care.\(^{385}\) Such cases lead us to believe that *Olmstead* can be appropriately applied to the C&LC. They also provide guideposts to design the most effective *Olmstead* action.

1. Appropriate Placements and Treatments

"*Olmstead* makes it clear that persons should not be in institutional isolation unjustifiably."\(^{386}\) In determining whether a placement is "unjustifiable," the State can "rely upon the assessments of its professionals."\(^{387}\) As discussed, when an individual is "unable to handle or benefit from community settings," the State is under no obligation to provide these.\(^{388}\)

Courts heavily weigh a prognosis of "no recovery" and have affirmatively factored this into the determination of whether guardians or relatives can decline life-preserving medical treatment on behalf of chronically vegetative patients.\(^{389}\) Recent studies reporting the possibility of late recovery for patients with covert


\(^{384}\) 383 F.3d 599, 601-02 (7th Cir. 2004).

\(^{385}\) Radaszewski v. Maram, No. 01-C-9551 (N.D. Ill. May 9, 2008) (granting permanent injunction).


\(^{387}\) Id.


\(^{389}\) See generally In re Guardianship of Schiavo, 780 So. 2d 176 (Fla. Dist. Ct. App. 2001) (holding that family members can terminate life-prolonging medical procedures for patient who remained in the vegetative state for ten years).
consciousness could be construed to change the balance of whether certain services or placements should be provided.\textsuperscript{390} Other studies have suggested that neuroimaging can offer predictors of recovery.\textsuperscript{391} These factors raise questions about whether and what additional services would benefit the C&LC rather than being “unjustified.” However, \textit{Jimmo v. Sibelius} indicates that maintenance of function, not an improvement standard, is operative.\textsuperscript{392}

Research about a “reeducation” theory of neurogenesis and synaptic pruning in patients who have recovered from DoCs\textsuperscript{393} also raises questions about whether isolation and lack of proper medical care “cause ... p[atients] to experience unnecessary regression, deterioration, isolation, and segregation.”\textsuperscript{394} The plaintiffs in \textit{Hutchinson ex rel. Julien v. Patrick}\textsuperscript{395} made this argument when advocating for a class of individuals with “serious brain injuries that substantially impair basic life skills and require ongoing rehabilitation and support” to be provided “services in the most integrated setting appropriate to their needs.”\textsuperscript{396} The case reached a settlement, requiring the state “to expand community services ... for Medicaid-eligible individuals with acquired brain injuries” subject to certain logistical requirements, in which the United States District Court for the District of Massachusetts appropriately characterized the plaintiffs as the prevailing parties.\textsuperscript{397} The argument for C&LC patients could echo those of the \textit{Hutchinson} plaintiffs, although Massachusetts has undermined the settlement through inaction.\textsuperscript{398}

If continued research suggests that certain treatments, rehabilitation, and communication devices can help increase a patient’s chance of recovery, there may be a greater obligation to provide them. This is especially true if these services can be framed as already being provided by the State or facility. Indeed, given recent

\textsuperscript{390} See Thengone et al., supra note 372.
\textsuperscript{393} See Wright & Fins, supra note 66, at 250-51.
\textsuperscript{395} Hutchinson ex rel. Julien v. Patrick, 636 F.3d 1, 6 (1st Cir. 2011).
\textsuperscript{396} Amended Class Action Complaint, supra note 394, at 1, 3.
\textsuperscript{397} See Hutchinson, 636 F.3d at 6.
\textsuperscript{398} See id. at 9 (arguing that the State is not bound by a formal consent decree).
findings about the MCS, possible communication with seemingly vegetative patients who are not behaviorally reactive, and the possibility of recovery from chronically vegetative patients, it is more important than ever to ensure that efforts be made to correctly diagnose this population and then increase their ability to communicate. This could allow them to finally rejoin the community in some fashion, rather than remaining segregated. If failing to provide certain reasonable services—such as assistive communication devices—would actively contribute to the likelihood that a patient would stay institutionalized, permanently unconscious, and deprived of a greater chance to recover and transition to a more integrated setting, this could constitute discriminatory exclusion. We are convinced that this situation violates the holding of Olmstead and that Olmstead enforcements apply to the provision of rehabilitation and treatments that promote the recovery of attainable functional communication. So assisted, these individuals can be reintegrated into the nexus of social relations.

B. Charting a Path Forward

Olmstead requires the medical and legal community to revisit the question of what setting and care is appropriate for the C&LC. Title III of the ADA is applicable to those with covert or liminal consciousness, as they possess physical and mental impairments that substantially limit their major life activities. It is illegal for private entities providing public accommodations, such as long-term care facilities, hospitals, nursing homes, and healthcare providers, to engage in discrimination, and the ADA requires that "[g]oods, 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." Federal regulations have supplemented these requirements.

Olmstead's reasoning concerning the effects of isolation and segregation and their link to discrimination applies to the C&LC. Like

399. See, e.g., Monti et al., supra note 111, at 582-83.
401. See id. § 12181(7)(F).
402. Id. § 12182(a).
403. Id. § 12182(b)(1)(B).
the plaintiffs in *Olmstead*, when brain-injured but conscious persons are "isolated [and] in custodial care," they are segregated because they are kept separate from the broader community.405 Compounding this injury, patients are often not given access to drugs and devices that would aid in recovering functional communication. The lack of ability to communicate, even though some of these patients would be able to do so with assistance, further segregates the C&LC. Importantly, failure to provide these directly increases their risk of institutionalization and thus constitutes unlawful discrimination in violation of the ADA.406

Persons with severe brain injury who are unjustifiably kept separated from their communities and denied reasonable accommodations, which could allow them to communicate, can rely on *Olmstead* to sue for injunctive relief or increased services under the ADA. While healthcare providers can raise fundamental-alteration or undue-burden defenses,407 these arguments are not terribly persuasive, as many healthcare facilities already have the necessary technologies to assist DoC patients in communication and simply need to consistently make them available to persons with brain injury.408 While neuroprosthetics were not mentioned specifically in the text of the ADA, such communication aids should be classified as "[o]ther similar services and actions" under the catchall provision concerning necessary services and aids.409 Indeed, scholars writing about the ADA have highlighted that "the specific requirements [of the ADA's reasonable accommodation requirements] may vary as technological advances occur."410 Services and auxiliary aids are

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405. See Wright & Fins, *supra* note 66, at 272.
406. *Id.* at 267, 271-72.
407. 42 U.S.C. § 12182(b)(2)(A)(iii). It is important to note, however, that healthcare providers are often ignorant of their legal duties under the ADA to their patients with disabilities. Nicole D. Agaronnik et al., *Knowledge of Practicing Physicians About Their Legal Obligations When Caring for Patients with Disability*, 38 HEALTH AFFS. 545, 550-51 (2019).
legally required in order "to ensure effective communication with individuals with disabilities."[411]

Further:

The type of auxiliary aid or service necessary to ensure effective communication will vary in accordance with the method of communication used by the individual . . . . A public accommodation should consult with individuals with disabilities whenever possible to determine what type of auxiliary aid is needed to ensure effective communication . . . provided that the method chosen results in effective communication . . . [A]ids and services must be provided in accessible formats, in a timely manner, and in such a way as to protect . . . privacy and independence.[412]

Accompanying these regulations is guidance that "[i]mplicit in this duty to provide auxiliary aids and services is the underlying obligation of a public accommodation to communicate effectively with customers, clients, patients, companions, or participants who have disabilities affecting hearing, vision, or speech."[413] This guidance seems to mandate that treatment providers for individuals with brain damage face an obligation to provide access to a low-cost communication device or to pharmaceuticals that could assist communication. Without these interventions, communication will remain impossible.

Crucially, not all individuals with DoCs must be provided with rehabilitation, removed from custodial care, or given auxiliary assistive communication devices. For instance, vegetative patients may be unable to use any communication device and thus would not benefit. As the majority in Olmstead noted, "nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings."[414] For individuals correctly diagnosed as vegetative, rehabilitation might not be possible.

However, in light of the staggering rates of misdiagnosis,[415] it is clinically and ethically imperative that diagnosis is validated, even
when initial assessment was conducted at a respected academic medical center. Furthermore, diagnosis should be retested and revalidated longitudinally. This is especially important given evolving temporal parameters for recovery.416 It is also quite possible that a patient’s state can only be ascertained through interventions.417 Methods like speech therapy or drug trials have the potential to reveal crucial diagnostic information.418 Under the new Practice Guideline, this has become the standard of care.419

For the C&LC, segregated care in a long-term facility may not be the most appropriate setting, especially if that facility lacks assistive communication devices to aid in restoring voice. The lack of such modalities represents a violation of Olmstead and the ADA, especially if the State could make reasonable modifications that would result in greater community integration through an enhanced ability to communicate.420

On the higher end of the scope of these reasonable modifications is moving a patient to community-based treatment rather than an institutional setting. In keeping with Olmstead, what is considered reasonable would vary in accordance with the latest medical research.421 For instance, while vegetative individuals do not face the same kind of diminished “everyday life activities” such as “work options, economic independence, educational advancement, and cultural enrichment” as others typically considered under Olmstead, those in the MCS could regain a level of functional communication and benefit from a more integrated, community-based treatment center.422 In the same vein, rehabilitation services and communication aids, while potentially essential to those in the MCS, might provide no benefit to a patient correctly diagnosed as vegetative. If an individual’s validated diagnosis leaves no potential for future recovery, then they would not benefit from community orientated treatment and would be unsuccessful in an Olmstead action.

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417. Id. at 473.
418. See Brefel-Courbon et al., supra note 104.
419. See Fins & Bernat, supra note 10.
420. See Taylor, supra note 408, at 1473-75.
C. *A Hypothetical Olmstead Action: Revisited*

The key questions in a hypothetical *Olmstead* action are: (1) who would bring suit, (2) the identity of the entity being sued, (3) the nature of the *Olmstead* injury, and (4) whether the requested relief requires a "fundamental alteration" of the challenged public program or service.\(^{423}\) Here, we will apply this framework to a potential lawsuit brought on behalf of an individual classified as C&LC to serve as a roadmap for practitioners moving forward.\(^{424}\)

In the past, we have pointed out that perhaps the most effective action would be to institute class action lawsuits on behalf of persons with severe brain injury alleging ADA and *Olmstead* violations,\(^{425}\) similar to the lawsuit that resulted in a settlement in Massachusetts.\(^{426}\) However, as became evident in Massachusetts, settlements require ongoing enforcement and may promise more than they can deliver.\(^{427}\) Instead, it would be highly beneficial to the field for future litigation to result in a judicial opinion that has significant precedential value. Such an opinion could become an *Olmstead* equivalent for the C&LC.\(^{428}\) Even if 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.

1. **The Plaintiffs**

In general, the plaintiff could be any combination of the C&LC patients, described previously in Part II:

- (1) *individuals who have suffered institutionalization or are at risk of institutionalization*, but by their very nature, patients with disorders of consciousness often lack the resources or ability to participate as named plaintiffs in a suit;

\(^{423}\) See generally id. (holding that the State can be required to provide home care and community living options for persons with disabilities).
\(^{424}\) Specifically an individual in the MCS.
\(^{425}\) See sources cited supra note 321.
\(^{426}\) Hutchinson *ex rel.* Julien v. Patrick, 636 F.3d 1, 6 (1st Cir. 2011).
\(^{427}\) Id. (considering various issues arising out of a settlement agreement between persons with disabilities and the State).
\(^{428}\) This could be difficult for plaintiffs, however, who initiate lawsuits for immediate remedies rather than symbolic victories.
(2) their guardians, who can sue as a substituted real party in interest, although guardians often lack the resources needed to mount a legal challenge against the state;

(3) public-interest organizations, which are often better-equipped to bring lawsuits; or

(4) the Department of Health and Human Services and Department of Justice, an extremely effective source of Olmstead enforcement, but one that is subject to limited agency resources and political pressure.

While the choice of plaintiff will have little impact on the legal questions presented by the case, it will have significant impact on the logistics. Ideally, our plaintiff would be a member of the class of covertly or liminally conscious individuals, as these patients will be able to benefit from increased rehabilitation and communication devices, without these interventions being deemed medically unnecessary.

Due to the nature of C&LC, it will likely be logistically difficult for currently institutionalized patients to actively participate in the proceedings, even through guardians. On the other hand, a public interest organization or the DOJ, suing on behalf of a class of such patients, would increase the scope and impact of such a case.

2. The Defendants

A hypothetical action would most likely target the State’s Medicaid program, as well as any programs that relate to brain injury. Depending on the scope of the litigation, an Olmstead action would name the heads of one or multiple state health departments as the defendants of the action. For example, in Haddad v. Dudek, the plaintiff sought declaratory and injunctive relief against the Interim Secretary of the Florida Agency for Health Care Administration and the Secretary of the Florida Department of Health for violations of the ADA and Rehabilitation Act. The defendants argued that the plaintiff’s claim would “‘allow’ the ADA to ‘ trump’ the Medicaid Act resulting in a ‘fundamental alteration’ of the state’s Medicaid Program.” The United States District Court for the Middle District of Florida rejected this argument, noting that:

430. Id. at 1329.
As confirmed by the Supreme Court in *Olmstead*... Plaintiff’s claims do not seek to alter any Medicaid program; instead Plaintiff seeks relief alleging that the [particular Medicaid Program] offered by the state violates the ADA and the Rehab Act because it would result in her involuntary isolation and segregation in a nursing home, which the Supreme Court has said may be contrary to the ADA’s proscription against discrimination.\(^{431}\)

The district court went on to deny the defendants’ motion to dismiss based on the fundamental alteration defense.\(^{432}\) A case would also name the administrator or head of the particular hospital or care facility that denied the plaintiff’s request for services.

### 3. The Claim

It is imperative to remember the elements of a successful claim: (1) “the affected persons do not oppose such treatment”; (2) “the State’s treatment professionals determine that such placement is appropriate,” which would require evidence (e.g., expert affidavits) regarding recent shifts in treatment standards; and (3) “the placement can be reasonably accommodated.”\(^{433}\) A C&LC patient would already satisfy the requirement that discrimination is based on disability.\(^{434}\)

The central claim would be a request for specific provisions. In terms of specific technological requests, we would expect requests to be for low-cost communication devices and modalities, such as word boards, physical and speech therapy, and, potentially, neuromodulation technologies. A further request would be access to pharmaceutical interventions that can aid communication, coupled with rehabilitation and therapy, with the goal of regaining the ability to functionally communicate. Of course, the specific request will evolve depending on the nature of the facility, what is already being provided to the patient, and what is appropriate given the standard of care. The plaintiff must make a formal request to the long-term care facility or State’s Medicaid program for these accommodations before any lawsuit can proceed.\(^{435}\) Without a formal request and a denial of

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431. *Id.*
432. *Id.* at 1331.
434. *See 42 U.S.C. § 12102(1)(A); Wright & Fins, supra note 66, at 266-67.*
said request, the plaintiffs would lack standing since no injury would have yet occurred.\textsuperscript{436}

We must remember that assistive technology is merely a means for an integrative end. Without some restoration of functional communication, C&LC patients remain segregated from society, unable to integrate to the maximum extent possible, which represents a violation of \textit{Olmstead}.\textsuperscript{437}

In constructing a given claim, it is thus essential to frame the current care for the C&LC as segregation with no end in sight and argue that failure to care for patients along a spectrum of disorders threatens further and perhaps permanent institutionalization. Throughout, proper care must be framed as requiring access to assistive communication devices and other efforts that can help restore functional communication, which is the only way for these individuals to regain community. The suit must argue that failure to provide communication devices keeps C&LC patients isolated and prevents community reintegration, even if physical integration remains limited.

Throughout, we must be careful to avoid a fundamental-alteration defense. This should be done by framing the requested relief as services already offered by the defendants (e.g., integrative care or rehabilitation services). The suit must also argue that any requested relief would not force defendants to significantly reduce services to others or disrupt an implemented "effectively working plan." \textsuperscript{438} This argument is bolstered by requesting lower cost communication devices or pharmaceutical interventions, which facilities should be able to provide and the State should be able to pay for with little burden. Requests for greater rehabilitation and therapy may face a more difficult test, but both should be available to plaintiffs, to the extent that they "can be reasonably accommodated" and would not constitute a fundamental alteration of the services provided.\textsuperscript{439}

It should be noted that certain accommodation requests could fall under the scope of "medically necessary" in some states, which

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\textsuperscript{436} See \textit{id}.
\textsuperscript{437} \textit{Olmstead}, 587 U.S. at 600-01.
\textsuperscript{438} See \textit{id} at 605-06 (plurality opinion).
\textsuperscript{439} See \textit{id} at 587 (majority opinion).
\end{flushright}
might provide more leverage. For example, Washington’s Department of Social and Health Services may cover costs for “medically necessary” interventions, defined as “those that are ‘reasonably calculated to prevent, diagnose, correct, cure, alleviate or prevent worsening of conditions in the client that endanger life, or cause suffering or pain, or result in an illness or infirmity, or threaten to cause or aggravate a handicap, or cause physical deformity or malfunction.’” Couching requests for treatments and diagnoses in the State’s chosen statutory language could help further the push for accommodations. It is important to stress that what is being requested for this population is, at its heart, the new standard of care.

D. Challenges

One foreseeable challenge to a successful Olmstead lawsuit for C&LC individuals is the ability to get professional consensus that the current level of care is unjustifiable and that changing care would be in a patient’s “best interests.” This determination is particularly important, as the Olmstead court “concluded that the state should be able to rely upon the assessments of its professionals.” Fortunately, given the recent publication of the new AAN/ACRM/NIDILRR Guideline, discussed previously, professional consensus has occurred, and access to communication modalities, newer diagnostic tools, and rehabilitation interventions now sits squarely within the accepted standard of care.

Regardless, the lack of a State’s determination that community-based treatment or additional services are appropriate is not fatal to a claim—nor is the presence of a finding that community-based treatment is inappropriate sufficient for dismissal. Accordingly, there is room to challenge the level of services and placement provided to a patient regardless of what professional evaluation there has been.

441. Id. (quoting WASH. ADMIN. CODE § 182-500-0070 (2012)).
442. See Fins & Bernat, supra note 10, at 473-76.
444. See supra text accompanying notes 80-85.
445. See Giacino et al., supra note 9, at 450; see also Fins & Bernat, supra note 10 (describing how advances in care are central to the treatment of MCS patients).
A greater frustration is the difficulty in determining (1) who has covert or liminal consciousness and (2) the likelihood of recovery for each patient. This challenge in distinguishing between patients can frustrate the ability to determine what is unjustifiable on an individual basis. "Absent such qualification[s]" as are required to be eligible for certain programs, "it would be inappropriate to remove a patient from the more restrictive setting." In an instructive case, later dismissed for lack of standing, a magistrate judge’s report and recommendation suggested that a class certification for a proposed class of "fragile children" was "over inclusive because it includes children who are unharmed by the policies alleged to be causing institutionalization" and would lack standing without "proof of an Olmstead violation as to each child" to show any presumed harm. We must learn from these lessons and recognize that any lawsuit must be cautious of being over-inclusive where a given harm or remedy would not likely be common to the entire class.

1. Affected Persons Do Not Oppose Treatment

Unfortunately, most patients’ preferences relating to treatment or placement are only considered relevant when they decline services. "[A] state must do more than wait until the residents of its facilities have affirmatively asked to be placed in the state’s integrated residential settings" and instead should seek to determine what would be in the patient’s objective “best interests.”

Even so, courts consider whether a patient has affirmatively expressed a desire to be moved to a community placement setting. For example, Connecticut violated the ADA when it not only "failed adequately to provide for the evaluation of all class members
for community placement” but also “failed to place in the community class members for whom such placement was found to be appropriate . . . and who had consented to or requested such placement.”

This becomes a Catch-22, as the goal of intervention is to foster communication in those presently unable to voice a preference. In the absence of patient expression, the court should turn to a legally authorized representative. Without this remedy, the patient is particularly at risk of not receiving proper services.

2. Who Can Ascertain a Patient’s Will

C&LC patients may be capable of asserting their own wills with technological aids. As noted in In re M.R., “that a person is generally incompetent does not mean that person is incompetent for all purposes. A person who is generally incompetent can still make choices about specific matters.” While someone in a MCS or those with CMD may not be broadly able to communicate, they may be able to express that they are in pain, find a certain environmental stimulus bothersome, or would like more social interaction. Furthermore, there is the opportunity to better ascertain and express some level of patient preferences through use of methods such as supported decision making or mosaic decision making.

As the Messier v. Southbury Training School opinion suggests, consent or request may be relevant where it arises “either through [a patient’s] guardians or, where appropriate, [from] themselves.” The court in In re Easly noted that “a close family member of a once competent adult who is now in a permanent vegetative state may

452. Messier, 562 F. Supp. 2d at 345 (emphasis added).
453. See generally id. (noting that C&LC patients can obtain and exercise independence after receiving adequate care and resources).
454. In re M.R., 638 A.2d 1274, 1281 (N.J. 1994) (citation omitted) (remanding a case for determination as to whether a developmentally disabled adult daughter was competent to express a reliable preference for where she wanted to live).
456. See Fins, supra note 421, at 164-73.
effectuate substituted judgment on the patient’s behalf . . . where there is enough data for the decision-maker to ascertain what the patient would have desired.” Importantly, the requirements for proper “substitute[d] judgment” are at the discretion of the state.

3. Reasonable Modifications and Accommodations

As stated in 28 C.F.R. § 35.130(b)(7)(i), “[a] public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.” What is being requested for a patient with brain injury is therefore central to whether or not the ADA mandates its provision. Two limitations are embedded in the “reasonable modifications” provision: cost and whether that benefit is provided to other disabled patients who do not share the particular disability of the person requesting it.

a. Implementation Cost and Fundamental Alterations

Many accommodations will require additional costs. Recognizing this, the ADA does not require “an individual [to] allege that the cost of the sought-after accommodation will be less than maintaining the status quo” to state a proper claim. Although “a state’s budgetary constraints alone will not excuse failure to comply with [t]itle II,” there is a narrow exception based on the extent of the financial burden a proposed change could impose on the state: when “[t]he immediate shift of resources sought” to provide the

459. See Cruzan ex rel. Cruzan v. Dir., Mo. Dep’t of Health, 497 U.S. 261, 286-87 (1990); see also 28 C.F.R. pt. 35 app. B (2019) (“[N]othing in the regulation authorizes the representative or guardian of an individual with a disability to decline food, water, medical treatment, or medical services for that individual.”).
461. Id. § 35.130(b)(7)(i)-(ii).
accommodations would result in a “fundamental alteration” of services in light of “the needs of others with mental disabilities.”

If the State asserts that the requested relief would cause a “fundamental alteration” of its services and programs as an affirmative defense, the State must show that “in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities.” As the court in Williams v. Wasserman explained:

While the State may not confine patients to mental institutions who do not belong there simply because it is financially or politically expedient to do so, it is sufficient if a state acts reasonably to implement community placement, without arbitrary or undue delay in light of legitimate budget constraints and the competing demands of other disabled citizens.

Accordingly, it is vital that any requests for additional modifications and accommodations for patients are balanced by what would be financially plausible.

The scope of patients to whom the modifications or accommodations would apply must be carefully considered. For example, the court in Cruz v. Dudek determined that providing community-based care for two quadriplegic plaintiffs would “cost the State less ... than [providing them] institutional care in a nursing home, and this relief w[ould] not fundamentally alter any of the State’s programs.” This narrow balancing test did not consider the potential burden of a broader application of the decision—namely to the roughly “605 other persons with spinal cord injuries on a wait list for community-based Medicaid services under the Traumatic Brain Injury/Spinal Cord Injury waiver program” as of the year before the

466. Id. at 604 (majority opinion).
467. 164 F. Supp. 2d at 627 (citations omitted). The plurality in Olmstead acknowledged that “[i]f ... the State were to demonstrate that it had a comprehensive, effectively working plan ... the reasonable-modifications standard would be met.” 527 U.S. at 605-06 (plurality opinion).
case, since “[d]efendants limit community-based Medicaid services to 375 persons with spinal cord injuries.” 469 And the court in Radaszewski ex rel. Radaszewski v. Maram rejected a fundamental alteration defense based on broader application of the plaintiff’s case as well, noting:

The State may be able to show that in view of the obligations it has not just to [Plaintiff] but to all individuals with similar disabilities, it cannot fund a home placement for [Plaintiff] without fundamentally altering the care it provides to others with similar needs. But the evidence might also show something different to be true.470

Identifying scope presents a difficulty for our population, as there remains profound lack of knowledge concerning the true prevalence of DoC in the United States.471 But these examples highlight that it may be advantageous to approach any litigation that asks for services with potentially significant financial implications on a case-by-case basis for the purpose of best establishing the associated costs and the benefits to patients that would weigh against any burden to the State.

Having noted this, it is also important to point out that restoration of functional communication could decrease overall costs because patients could express distress and discomfort earlier, before more costly complications set in. In a hypothetical cost-benefit analysis of neuromodulation, one of us illustrates the potential cost offsets, a point that should factor into Olmstead enforcements.472

b. Benefits Must Be Provided to Others

It is also important to note that Olmstead does not “hold that the ADA imposes on the States a ‘standard of care’ for whatever medical services they render, or that the ADA requires States to ‘provide a certain level of benefits to individuals with disabilities.’”473 The discrimination that the ADA prohibits is instead “discrimination

469. Id at *1.
470. 383 F.3d 599, 614 (7th Cir. 2004).
471. See Fins et al., supra note 27.
against the disabled within the services that are provided. Services offered in one setting and requested for another, as well as services requested for longer periods of time than typically provided, may constitute benefits as long as they do not require fundamental alteration. When those programs and services are not currently provided to any other group, a state has no obligation to provide them under the ADA.

It is thus essential that requests made on behalf of patients are framed as falling within the scope of benefits already provided to other disabled persons. This would, at minimum, include pain abatement measures. However, it should encompass some level of intellectual stimulation and community integration. For instance, many states already provide services to individuals with autism or Down syndrome to support their ability to communicate with others and to rejoin their communities, which could be the basis to argue that the State should also provide these services to patients with brain injuries. In particular, efforts to enable effective communication should be requested and framed as already being provided to other patients who are not prevented from functional communication by their diagnosis.

4. What Do We Mean by Community Integration?

Above, we have proposed recommendations that rely on and advocate for the concept of “community reintegration” for patients, like Don Herbert, who could benefit from more integrated treatment and recovery. Ultimately, community reintegration is an essential element in reconstituting the civil rights of C&LC patients who have been misdiagnosed, placed in long-term care facilities, and denied the opportunity to regain the ability to communicate. As long as conscious patients recovering from brain injury remain ignored by

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474. Buchanan v. Maine, 469 F.3d 158, 173-74 (1st Cir. 2006); see also M.R. v. Dreyfus, 697 F.3d 706, 713 (9th Cir. 2012) (noting that the State of Washington covers personal care for persons with disabilities).
475. Radaszewski, 383 F.3d at 611-12.
477. See Fins, supra note 8.
healthcare providers and isolated from society in unnecessary institutional care, their rights continue to be violated.\textsuperscript{479}

However, what exactly do we mean by "community reintegration," and what would this look like for individuals like Don Herbert? Furthermore, who gets to define community integration, and how would this concept work in practice for patients and their families?

These are complex questions that must be considered. However, our quest for answers must be balanced by an appreciation of the necessity of involving individuals with disabilities and their families in the discussion. Without stakeholder input concerning what "community" means and what those who seek to be integrated actually want, efforts to support individuals with disabilities, even when well-intentioned, could fail or entrench paternalism.

Fundamentally, we must remember the rallying cry "Nothing About Us Without Us" as we develop a definition of community that responds to the needs and capabilities of those recovering from brain injury.\textsuperscript{480} The only way to build a responsive definition of community integration is through seeking out and incorporating the voices of those with DoC or those who have recovered from DoC.

However, efforts to include the voices of individuals with brain injury and their families are rare.\textsuperscript{481} Without this input, any definition of community will risk excluding those we are trying to help. Seeking these narratives is not easy, as it requires patience and understanding to respond to the unique communication difficulties that many of these individuals present. But such work is essential, as it would be hypocritical to restore functional communication to the C&LC, only to disregard their ability to communicate.

Difficult is not the same as impossible. Narratives can be obtained through interviews and careful communication that understands the unique difficulties in reliably communicating with individuals with DoC.\textsuperscript{482} These narratives will not only teach us how to understand community for those with brain injuries but also help

\textsuperscript{479} Id. at 131-45.
\textsuperscript{480} See generally CHARLTON, supra note 18 (titling the book after the adopted slogan of the disability rights movement).
\textsuperscript{481} See generally id. (noting people with disabilities are their own best advocates).
\textsuperscript{482} Id.
guide future research. Qualitative data from subjects will help inform subsequent legal theory and disability law.

Hopefully, such narratives can help us begin to understand how society can work to better support and involve individuals with brain injury. By incorporating their voices into the process of understanding and defining community and community integration, we can respect the notion of “Nothing About Us Without Us” while ensuring that we do not further disempower this already vulnerable population.483

VII. CONCLUSION

Individuals with moderate-to-severe brain injury, especially those with DoCs and covert and liminal consciousness, deserve respect and support. These individuals are among the most vulnerable patients, unable to advocate for themselves and left at the mercy of their caregivers and loved ones upon whom they rely for support. Despite the potential for recovery, too many individuals are written off as hopeless, segregated into long-term care centers, and isolated from their communities. In these facilities, patients are often unable to access the assistive technologies and rehabilitative therapies that could help restore some level of functional communication. Tragically, many receive inadequate pain relief therapy due to a mistaken belief that their DoC obviates the need for regular pain management.484

Without communication, diagnosis, and the provision of rehabilitation and treatment, DoC patients find themselves doubly segregated. They are physically segregated by their position in long-term care centers, kept apart from healthy individuals and normal interaction. But, perhaps more importantly, they are socially segregated from the community by their inability to reliably and effectively communicate. Indeed, without communication, there is no genuine potential for these individuals to gain the benefit of societal interaction or community, as they are effectively trapped alone in their heads. This segregation represents a violation of the ADA in exactly the way that Olmstead was meant to remedy.

483. See id.
484. See Fins & Bernat, supra note 10, at 473.
While *Olmstead* has been applied to individuals with brain injuries in the past,\(^485\) we have argued here for an expanded reconceptualization of *Olmstead*. We aim to apply *Olmstead* to demand integration through restoration of functional communication as a means to overcome segregation that has both biological and social determinants. While classical *Olmstead* remedies involved physical deinstitutionalization, a more theoretical conception, appropriate for patients with brain injury, would be to view the *Olmstead* mandate as requiring that society work toward reintegrating patients trapped in their own heads. The only way to do this effectively is by providing patients the tools to allow them to communicate. Such communication could allow the C&LC to escape their mental segregation and regain some form of community, even if they physically remain in care facilities designed to support their physical condition. Indeed, it would be a definitional trap to view the integration mandate *solely as a physical one*.

Although some will call this new legal theory, the purpose of the ADA and subsequent applications and interpretations of *Olmstead* have convinced us that such a claim is not only entirely consistent with *Olmstead* but also required, as it represents the true work of deinstitutionalization for this population. Indeed, individuals with DoC will always face challenges physically integrating into community-based placements. However, if these patients were able to regain the ability to functionally communicate, they would no longer be segregated from the community around them, as they would be able to interact with their healthcare providers and loved ones. This reintegration is exactly what was envisioned by the ADA and promised by *Olmstead*, even if it does not fit into the concept of community integration as traditionally conceived of for other populations.

*Olmstead* enforcements alone will not remedy the holistic needs of this population. There are other supportive efforts that would improve the situations of those with moderate-to-severe brain injury. As we have highlighted, this population remains marginalized and underserviced. There should be a significant and concerted effort to increase access to rehabilitation therapies and assistive communication devices for these individuals, even without resorting

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to coercive lawsuits. This makes public advocacy and awareness more important than ever, as increased funding and support can only come with increased political will and visibility.

Furthermore, there needs to be more funding for work to advance the rights of this marginalized population. Undertaking study at the intersection of law, medicine, and bioethics has convinced us of the value of approaching solutions for this population from a multidisciplinary perspective and in an organized manner. This can allow medical and scientific expertise to be translated directly into supportive efforts.

A major next step would be the establishment of a legal defense fund for brain injury, inspired by the NAACP Legal Defense Fund, which helped catalyze the modern civil rights movement. An interdisciplinary defense fund would blend the expertise of both lawyers and doctors and would help focus on issues related to brain injury and the law. The work of such a center could be augmented by linking it to new clinical courses and centers at law schools across the nation.

Indeed, a brain injury law clinic—where law students, clinical instructors, lawyers, and doctors could work together to develop legal strategy and eventually bring actual lawsuits on behalf of improperly institutionalized patients—would help bring needed attention and legal resources to bear on behalf of this marginalized population. Such work would go a long way toward advancing disability law, while increasing recognition and awareness of the vulnerability and indignity that many patients are forced to endure. We call upon law schools to explore the establishment of brain injury clinics, an idea upon which we will elaborate.

Efforts like this will hopefully begin to turn the tide of doubt into one of optimism, as more individuals with brain injury and their families learn about avenues for advocacy that can allow them to petition for needed services. It is our hope that *Olmstead* enforcements will result in an influential and precedential opinion and

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advance the rights and accommodations for this population. Such an opinion would help shift the standard practice of states, causing them to include patients with moderate-to-severe brain injuries in their Olmstead plans. Beyond clinics and advocacy, we renew our call for increased study and focus on individuals with brain injuries.488

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We have laid out the preceding arguments precisely so that advocates can promote and effectuate a paradigm shift in disability law and civil rights by utilizing Olmstead enforcements. We hope our work will provide a scaffold for a cause of action alleging Olmstead violations for patients with moderate-to-severe brain injury. We call upon the broader legal community to recognize the needs of this vulnerable population, given the remarkable possibilities afforded by advances in neuroscience. Only then can legal advocacy bend the arc of justice toward the reintegration of these patients into civil society.

488. See Fins et al., supra note 14, at 304-06.