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Designing an Americans with Abilities Act: Consciousness, Capabilities, and Civil Rights

Zachary E. Shapiro

Weill Cornell Medical College, zas4001@med.cornell.edu

Allison Rabkin Golden

Yale Law School

Gregory E. Antill

Yale Law School

Katherine Fang

Yale Law School

Chaarushena Deb

Latham & Watkins, LLP

See next page for additional authors

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Authors

Zachary E. Shapiro, Allison Rabkin Golden, Gregory E. Antill, Katherine Fang, Chaarushena Deb, Elizabeth Clarke, Alexis Kallen, Hanya M. Qureshi, Kai Shulman, Caroline V. Lawrence, Laura C. Hoffman, Megan S. Wright, and Joseph J. Fins

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ZACHARY E. SHAPIRO,
ALLISON RABKIN GOLDEN, GREGORY E. ANTILL, KATHERINE FANG,
CHAARUSHENA DEB, ELIZABETH CLARKE, ALEXIS KALLEN,
HANYA M. QURESHI, KAI SHULMAN, CAROLINE V. LAWRENCE,
LAURA C. HOFFMAN, MEGAN S. WRIGHT, AND JOSEPH J. FINS

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ZACHARY E. SHAPIRO* ET AL.**

Abstract: The Americans with Disabilities Act (ADA) is a seminal piece of legislation aimed at protecting those with disabilities from discrimination. The ADA, however, has not been consistently able to integrate people with disabilities successfully into society. With a specific focus on individuals with serious brain injuries, this Article aims to provide insight into the shortcomings of the ADA, specifically focusing on lackluster enforcement of the legislation and its failure to incorporate promising new technologies. These limitations of the ADA are made even more clear in light of the evolution occurring in the understanding of rights and capabilities. As such, the time has come for a new piece of legislation that fully incorporates the advanced technology available to individuals, while promoting a more positive understanding of advancing rights and capabilities. The proposed Americans with Abilities Act (AWAA) will correct the deficiencies in the ADA, ultimately allowing individuals with disabilities to integrate more fully into society.

INTRODUCTION

When Congress passed the Americans with Disabilities Act of 1990 (ADA), it represented a landmark piece of civil rights legislation.¹ Yet, it mainly focused on eliminating discrimination because of disability and it was sporadically enforced. More than thirty years later, much has changed in the disa-

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* Zachary E. Shapiro, JD, MSc, is an Adjunct Assistant Professor of Medical Ethics Research in Medicine in the Division of Medical Ethics at Weill Cornell Medical College; the Co-Chair of the Hospital Ethics Committee at The Rockefeller University Hospital in New York City; and a Senior Research Fellow and Senior Advisor at Yale Law School in New Haven, Connecticut, where he works with the Consortium for the Advanced Study of Brain Injury (CASBI) at the Solomon Center for Health Law & Policy. Zas4001@med.cornell.edu.

** Allison Rabkin Golden; Gregory E. Antill; Chaarushena Deb; Katherine Fang; Elizabeth Clarke; Alexis Kallen; Hanya M. Qureshi; Kai Shulman; Caroline V. Lawrence; Dr. Laura C. Hoffman; Professor Megan S. Wright; and Dr. Joseph J. Fins. The co-authors' biographies are set forth at the end of the Article. The authors want to thank the Solomon Center for Health Law and Policy at Yale Law School, Professor Abbe Gluck, and Katherine Kraschel for their support.

¹ Americans with Disabilities Act (ADA) of 1990, Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101–12213).

bility rights landscape, making the present an ideal time to envision the next step in disability rights legislation, an *Americans with Abilities Act* (AWAA).

Forward legislative progress is necessary not just because of the limitations of the ADA, but because of the explosive growth and advancement of technology that can better integrate people with disabilities into society, allowing them to thrive. Novel medical technology can help individuals with disabilities regain functions and realize capabilities that were inaccessible before. These technologies, that can be both in-dwelling and external, vary depending on the use, case, and condition that is affecting the user. Some can be used to aid and enhance diagnosis or rehabilitation. Others can be substituted for lost capabilities, allowing disabled individuals to regain functions they have lost, due to their condition and the societal response, or a lack of adaptation to their functional state. Although many of these technologies have shown promise, we are finally at the point where clinical study and years of use can confirm that these interventions work and have the potential to improve the lives of those with disabilities.

Our work has often focused on those with severe brain injury, and we will use this population as a prism through which to refract our arguments in favor of an AWAA.² These individuals are disabled by damage to their brains, and their conditions generally render them unable to speak or move. Whether these individuals are unconscious in the vegetative state³ or liminal state of minimal consciousness,⁴ society often treats them as lost causes.⁵ Many are segregated from the broader community in nursing homes and long-term care facilities.

There are more technological methods than ever emerging that might help this extraordinarily vulnerable population.⁶ Examples include newer brain computer interfaces, word boards, eye-tracking technology, and other neuro-

² See Joseph J. Fins, Opinion, *Brain Injury and the Civil Right We Don't Think About*, N.Y. TIMES (Aug. 24, 2017), <https://www.nytimes.com/2017/08/24/opinion/minimally-conscious-brain-civil-rights.html> [<https://perma.cc/MHG9-BRRW>] [hereinafter Fins, *Brain Injury*] (arguing for better recognition and protection of autonomy in patients who have suffered brain injuries). See generally JOSEPH J. FINS, RIGHTS COME TO MIND: BRAIN INJURY, ETHICS, AND THE STRUGGLE FOR CONSCIOUSNESS (2015) [hereinafter FINS, RIGHTS COME TO MIND] (examining the existence and treatment of brain injuries from a legal standpoint).

³ Bryan Jennett & Fred Plum, *Persistent Vegetative State After Brain Damage: A Syndrome in Search of a Name*, 299 THE LANCET 734, 734 (1972).

⁴ J.T. Giacino et al., *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 NEUROLOGY 349, 349–50 (2002) (describing the state of the science about disorders of consciousness).

⁵ See FINS, RIGHTS COME TO MIND, *supra* note 2, at 9.

⁶ See Joseph J. Fins & James L. Bernat, *Ethical, Palliative, and Policy Considerations in Disorders of Consciousness*, 91 NEUROLOGY 471, 472 (2018); Megan S. Wright et al., *Severe Brain Injury, Disability, and the Law: Achieving Justice for a Marginalized Population*, 45 FLA. ST. U. L. REV. 313, 331–34 (2018). See generally FINS, RIGHTS COME TO MIND, *supra* note 2 (covering certain technologies such as neuroimaging, deep brain stimulation, and prosthetics).

prosthetics that have enabled some patients with a brain injury to regain the ability to communicate, even if they must do so through a technological interface.⁷ Other interventions, such as functional neuroimaging and pharmaceutical treatments, can help improve our ability to diagnose accurately the cognitive state of those with brain injuries, and thus allow better rehabilitation. Overall, this supports the goal of restoring function, augmenting consciousness, and enabling communication.

We have written about how the inability to communicate is a major factor in the continuing segregation of those with a moderate-to-severe brain injury.⁸ Yet, despite the potential of various technologies to aid in communication and spur community reintegration, many with brain injuries who would benefit from such interventions remain unable to access them.⁹ This is also true for diagnostic technology such as functional neuroimaging, rehabilitative technology such as brain-computer interfaces, and assistive technology such as eye-trackers.¹⁰ Such technologies highlight that we have obligations to individuals who may appear behaviorally inert, but are actually covertly conscious.¹¹ Nor is this problem limited to individuals with brain injuries, as many others with different disabilities (in particular, communication disabilities) could benefit from access to such technologies. The current state of disability rights legislation, however, is ill-equipped to implement and incentivize the uptake of disruptive technology, and significant barriers in our current legislative framework prevent individuals with disabilities from easily accessing helpful, novel medical technology. This problem will—paradoxically—become worse in the coming years as the science advances.¹²

⁷ See Zachary E. Shapiro et al., *Olmstead Enforcements for Moderate to Severe Brain Injury: The Pursuit of Civil Rights Through the Application of Law, Neuroscience, and Ethics*, 95 TUL. L. REV. 525, 538 (2021); see also Caroline Lawrence, Zachary E. Shapiro & Joseph J. Fins, *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, 169–70 (2019) (detailing the use of brain-computer interface (BCI) technology to facilitate communication in individuals with brain injuries).

⁸ See Shapiro et al., *supra* note 7, at 544 (“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.”).

⁹ *Id.* at 530.

¹⁰ *Id.* at 539.

¹¹ Martin M. Monti et al., *Willful Modulation of Brain Activity in Disorders of Consciousness*, 362 NEW ENG. J. MED. 579, 588–89 (2010) (describing the potential for technology to aid individuals with brain injuries).

¹² See generally FINS, RIGHTS COME TO MIND, *supra* note 2 (debating the best path forward regarding technology and brain injuries); Shapiro et al., *supra* note 7, at 530 (“While there are more interventions and treatments for these patients, access to desperately needed rehabilitation days has decreased over the past fifteen years” (citing Fins & Bernat, *supra* note 6, at 474)).

We are coming upon an age where technology will be able to help individuals with disabilities rapidly regain function, while providing alternative means of participating in society, and realizing capabilities in new and exciting ways. These pathways will remain closed if those with disabilities are unable to readily access advanced technological modalities. This creates questions about what obligations society has in promoting and providing this technology to those who would benefit from it. Unfortunately, it has been clear for some time that the ADA, and mechanisms such as *Olmstead* enforcements, fall short in creating and incentivizing frameworks to facilitate the widespread distribution and adoption of assistive and rehabilitative technology.¹³ As technology improves, legislation that is now outdated will seem ancient and will continue to struggle to keep pace with the realities of what technology can do. Ultimately, this will leave people with disabilities behind once again, and perhaps even worse than before the passage of the original ADA.

The ADA was drafted in the late 1980s and enacted in the early 1990s, when many of the disruptive technological modalities considered in this Article were not yet fully developed or even envisioned, and thus, were not contemplated by the ADA.¹⁴ Although the passage of the ADA Amendments Act of 2008 rectified significant injustices that arose from limiting interpretations of the ADA, it missed an opportunity to address issues involving technology. This left people with disabilities vulnerable to the *status quo*. Despite this, the ADA's legislative history did reference the inevitability of technological development.¹⁵ Although the ADA's focus on retrospectively curing discrimination through vindicating the rights of those with disabilities is logical when removing barriers to employment, it disregards legislation's ability to play a more forward-looking role in promoting an accessible societal ecosystem to advance and realize capabilities.¹⁶

Indeed, our thinking about fundamental rights in the second half of the twentieth century and the early twenty-first century advanced significantly by moving away from rights in terms of 'negative' freedom from interference and

¹³ See generally Shapiro et al., *supra* note 7, at 598–99 (explaining the need for additional action outside of *Olmstead* enforcements).

¹⁴ *ADA—Findings, Purpose, and History*, ADA 31 YEARS, https://www.adaanniversary.org/findings_purpose [<https://perma.cc/Q6RM-4ZBF>]; see 42 U.S.C. § 12101(b)(3)–(4); see also *Civil Rights in the United States, A Brief History: ADA Amendments Act of 2008*, GEO. L. LIBR., <https://guides.ll.georgetown.edu/c.php?g=592919&p=4230126> [<https://perma.cc/T8KF-7L2B>] (Feb. 28, 2022).

¹⁵ See Blake E. Reid, *Internet Architecture and Disability*, 95 IND. L.J. 591, 596 (2020) (“Of course, the legislative history of the ADA makes clear that it was not intended to exclude future technology, noting that ‘the types of accommodation and services provided to individuals with disabilities, under all of the titles of [the ADA], should keep pace with the rapidly changing technology of the times.’” (alteration in original) (quoting H.R. REP. NO. 101-485, pt. 2, at 381 (1990)), *reprinted in* 1990 U.S.C.C.A.N. 303, 391, 1990 WL 125563).

¹⁶ See Shapiro et al., *supra* note 7, at 598–99.

toward a conception of positive rights.¹⁷ This shift also included a more nuanced understanding of the ‘real’ or ‘substantive’ freedom to develop and exercise fundamental capabilities.¹⁸

An approach aimed at maximizing capabilities represents a change in focus away from the past and present (such as access to present resources, remedying past and ongoing discrimination, or other forms of interference in the presently available means to pursue one’s life plan) in favor of focusing on potential (such as the development of new choices and capabilities, the rethinking of the present-day environment, and the ability to achieve goals in the future). Capabilities-approaches understand freedom as the ability to achieve certain ends and projects by unlocking potential unrealized capabilities and promoting human flourishing, rather than the formal freedom to have access to whatever means might happen to be presently available.¹⁹

Just as the law is essential in the backwards-looking task of rectifying past discrimination to preserve the ‘negative rights’ of Americans with disabilities enshrined in the ADA, legal scaffolding is also necessary in promoting a more forward-looking capabilities-approach for those with disabilities. This is because advancing capabilities must involve many levels of structural change, ranging from fostering technological advances, to promoting access to these innovations, while also integrating medical technology in a person-centered

¹⁷ See, e.g., FINS, RIGHTS COME TO MIND, *supra* note 2, at 296–99; see also Megan S. Wright & Joseph J. Fins, *Rehabilitation, Education, and the Integration of Individuals with Severe Brain Injury into Civil Society: Towards an Expanded Rights Agenda in Response to New Insights from Translational Neuroethics and Neuroscience*, 16 YALE J. HEALTH POL’Y L. & ETHICS 233, 253 (2016).

¹⁸ See FINS, RIGHTS COME TO MIND, *supra* note 2, at 296–99; see, e.g., Amartya Sen, *Human Rights and Capabilities*, 6 J. HUM. DEV. 151, 154–55 (2005); Martha C. Nussbaum, *Capabilities as Fundamental Entitlements: Sen and Social Justice*, 9 FEMINIST ECON., no. 2–3, 2003, at 33, 37. Although the capabilities-approach is often contrasted with a “human rights approach,” as we will do here, it can also be understood not as replacing rights talk entirely, but supplementing a view of human rights which, absent a focus on capacities, is too narrow. As Nussbaum explains, the capabilities-approach is best understood as a substantive view that “fundamental rights . . . [and] what it is to secure them to people is [best thought of] in terms of capabilities.” Nussbaum, *supra*, at 37. Nussbaum posits that:

Capabilities . . . are very closely linked to rights, but the language of capabilities gives important precision and supplementation to the language of rights. The idea of human rights is by no means a crystal-clear idea. Rights have been understood in many different ways, and difficult theoretical questions are frequently obscured by the use of rights language Are human rights primarily rights to be treated in certain ways? Rights to a certain level of achieved well-being? Rights to resources with which one may pursue one’s life plan? Rights to certain opportunities and capacities with which one may make choices about one’s life plan?

The capabilities approach has the advantage of taking clear positions on these disputed issues, while stating clearly what the motivating concerns are and what the goal is.

Id.

¹⁹ FINS, RIGHTS COME TO MIND, *supra* note 2, at 296–99.

manner, with the goal of unlocking future potential. Forward-looking change for those with disabilities, such as individuals with moderate-to-severe brain injuries, must involve the promotion and dissemination of assistive and rehabilitative technology, work that implicates regulation and administrative agencies, as well as the relationship between government and science, and science and society.

New disability legislation must be designed to foster a supportive environment for use and access to technology, so that individuals with disabilities can navigate in society, fulfilling the promise of reintegration, even when it is aided by underlying medical technology. A failure to integrate technological advancement into society, so that end users can be maximally benefited, will undercut even the most promising of innovations.

In this Article, we will begin the conversation about the next movement required in disability rights legislation. As a critical next step, we envision new legislation, called the *Americans with Abilities Act* (AWAA). This statute will serve as a mechanism designed to promote human flourishing by ensuring the provision of medical technology to individuals with disabilities. Although existing legislation has helped to advance and vindicate rights, the next step is for these rights to be realized, not just retrospectively when there has been a violation (such as remediation through litigation or *Olmstead* enforcement), but *prospectively* through the provision of technologies that help individuals achieve their forward-looking potential. To wit, an AWAA is not just a collection of corrective steps, but proactive measures to create societal infrastructure that helps individuals with disabilities to rehabilitate and more fully integrate into the nexus of their families and communities.

We argue that now is the time for Congress to consider an AWAA, to help support those with disabilities, such as a brain injury, through their recovery, rehabilitation, and eventual reintegration into society. New legislation will focus not just on protecting rights, but advancing capabilities, and making sure that society is able to support and respond to these new capabilities through reintegration. In this way, the AWAA will be designed to be forward-looking, to promote human flourishing most effectively now and in the future.

Part I will describe the disruptive technology that our existing disability law framework fails to implement adequately.²⁰ This Part will introduce some of the new diagnostic and assistive technology that motivates our call for new legislation. Our goal here is not to explore and elucidate the full suite of current and potential future technologies that could one day help all individuals with disabilities. Rather, we will focus on the subset of diagnostic and assistive technology aimed at disabled individuals with a moderate-to-severe brain inju-

²⁰ See *infra* notes 25–100 and accompanying text.

ry. This marginalized population will be used as an exemplar class of individuals with disabilities, who are, and will continue to be, particularly reliant on assistive technology to exercise their capabilities. We focus on this population so that the lessons can be generalized to other populations with disabilities.

Part II will explore current disability rights legislation, specifically the ADA, highlighting not only where it has fallen short in promoting access to cutting edge assistive technology, but also exposing other problems that hamper its potential effectiveness.²¹ We aim to interrogate critically current legislative schema to consider whether a new approach could provide more value.

Part III will explore the concept of rights versus capabilities, highlighting the philosophical motivation that undergirds our call for new legislation.²² This discussion will explain why it is important to begin the transition from a focus on vindicating rights through punishing enforcements to a perspective of promoting human flourishing, by allowing individuals with disabilities to access technology that can enable them to realize and maximize their capabilities.

Part IV will highlight our guiding vision for the AWAA.²³ The goal of this Article is not to elucidate every aspect of this new legislation or provide an exact blueprint for what should be included in an AWAA. Indeed, it is essential that any new disability legislation be crafted with significant stakeholder input, considering the wide range of individuals affected, while drawing on the feedback and expertise of those in, and adjacent to, the disability community. In this Part, we again limit ourselves to the example of a moderate-to-severe brain injury to contemplate a few discrete ideas that could help catalyze a focus on capabilities and foster the supportive technological ecosystem that is necessary for the dissemination and uptake of medical technology.

Lastly, Part V illuminates the restraints of legislation and the need for forward progress outside of the AWAA.²⁴ We conclude by discussing radical inclusion, and the true goals of any new disability rights legislation.

I. TECHNOLOGY AND RECOVERY

Technology is constantly evolving, and disability rights legislation is not keeping up. As more technological options for diagnosis, treatment, and rehabilitation are proven efficacious, individuals with disabilities will rapidly find themselves with more methods than ever to regain functions that were once lost or to participate in society more fully. Novel technologies will allow them to rejoin their communities and become more active in society than they were

²¹ See *infra* notes 101–180 and accompanying text.

²² See *infra* notes 181–206 and accompanying text.

²³ See *infra* notes 207–309 and accompanying text.

²⁴ See *infra* notes 310–322 and accompanying text.

previously, but individuals with disabilities will remain exiled from full inclusion if they cannot access the benefits of these technological innovations.

It is futile to attempt to envision every new technology that could be utilized by those with disabilities to aid in their recovery, restoration of function, or reintegration to their communities. This is especially difficult because so many promising modalities remain investigational, or in proof-of-principle phase.²⁵ This can complicate the ability to design forward-looking legislation, as the rapid pace of advancement can quickly leave legislation outdated, even before it is enacted.

To combat this dilemma, rather than explore the vast theoretical possibilities that future technology can provide, we instead focus on one population of disabled individuals whose reintegration and care is closely tied to the promise of technology. In this Article, as in our past efforts, we will rely on our expertise in the field of moderate-to-severe brain injury, using brain injury as a lens to examine some of the most promising emergent medical technologies. Brain injury serves as an excellent exemplar of the intersection of disability and technology, as those with brain injuries find themselves disabled by their condition, often rendering them unable to speak, move, or interact.

There are numerous technologies that can unlock the potential of those with a moderate-to-severe brain injury. Technological modalities include diagnostic methods, such as neuroimaging and pharmaceutical interventions, as well as assistive and rehabilitative neuroprosthetics, such as communication boards, eye trackers, or more complex devices such as deep brain stimulation (DBS). Such technologies offer the potential for those with a brain injury to interact with the world around them, or communicate in a limited, but reproducible, fashion. Although many of these interventions remain investigational, more are being proven efficacious every day, and we have argued in the past that modalities that can augment consciousness and restore communication should be available to patients through clinical trials.²⁶ In fact, expanded access would have the dual benefit of promoting access to technology, while also growing translational research, resulting in more robust data.

In the sphere of brain injury, we loosely divide these technologies into two baskets: diagnostic technology that can help recognize and diagnose brain injury and consciousness, and assistive technology that can be used for rehabilitation, with the aim of restoring, augmenting, or in some cases, replacing capabilities and functions that disease or disability has hampered. Although this division is a useful heuristic, it is important to note that both types of these technologies can

²⁵ Pete Sherer, *What Is Proof-of-Principle*, OPTIMIZATION BLOG (Apr. 20 2016), <https://blog.optimization.us/what-is-proof-of-principle> [<https://perma.cc/S3DB-C9ZL>].

²⁶ See FINS, RIGHTS COME TO MIND, *supra* note 2, at 295.

aid in restoring communication and community integration, while also enabling more accurate diagnosis and assessment of individuals with brain injuries. This Part discusses existing diagnostic technology in Section A.²⁷ It then introduces the currently available assistive technology in Section B.²⁸ It concludes with an evaluation of current access to technology in Section C.²⁹

A. Diagnostic Technology

For those with a brain injury, accurate diagnosis remains challenging and elusive. One study found that 41% of patients with severe traumatic brain injury (TBI) in long-term care, who were diagnosed as vegetative, were actually minimally conscious.³⁰ Others have found similar diagnostic error rates between 20–45%.³¹ Diagnoses are difficult because of the underlying presentation of severe brain injury and accompanying disorders of consciousness (DoC).

As we have noted previously,³² most injuries leading to a DoC are characterized by an initial loss of consciousness.³³ If this loss of consciousness is prolonged, it can evolve into a coma, an eyes-closed state of unconsciousness³⁴ and unresponsiveness.³⁵ Comas are self-limited, lasting for up to two weeks unless they are prolonged by medication or by an intercurrent illness.³⁶ Patients in comas may eventually recover completely (such as after anesthesia),

²⁷ See *infra* notes 30–71 and accompanying text.

²⁸ See *infra* notes 72–87 and accompanying text.

²⁹ See *infra* notes 88–100 and accompanying text.

³⁰ Caroline Schnakers et al., *Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment*, BMC NEUROLOGY, July 2009, at 35, 35 (highlighting that up to 40% of MCS patients are incorrectly determined vegetative).

³¹ Keith Andrews et al., *Misdiagnosis of the Vegetative State: Retrospective Study in a Rehabilitation Unit*, BRIT. MED. J., 6 July 1996, at 13, 14; F.C. Wilson, J. Harpur, T. Watson & J.I. Morrow, *Vegetative State and Minimally Responsive Patients—Regional Survey, Long-Term Case Outcomes and Service Recommendations*, 17 NEUROREHABILITATION 231, 231 (2002).

³² We present much of our discussion here on the characteristics of several different types of disorders of consciousness, including coma, vegetative state, minimally conscious state, and, later, cognitive motor dissociation, as well as some discussion on both misdiagnosis and interventions, from our previous work published in 2021 by the *Tulane Law Review*. See generally Shapiro et al., *supra* note 7.

³³ See Giacino et al., *supra* note 4, at 349 (noting that the inability to perceive or engage with one’s surroundings is consistent with disorders of consciousness). See generally *id.* (detailing the status of scientific investigation of DoC).

³⁴ See *id.* at 349.

³⁵ See *id.*

³⁶ Cf. *id.* at 350 tbl. (illustrating the characteristics that distinguish coma from other DoC).

progress to brain death, or transition into the vegetative state (VS) or the minimally conscious state (MCS).”³⁷

The VS is the isolated recovery of the autonomic functions of the brain stem without higher integrative cortical function.³⁸ 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.³⁹ Vegetative patients have sleep-wake cycles and random eye movement and are able to breathe spontaneously without ventilator support because they have an intact brain stem.⁴⁰ Patients may improve from the VS into the MCS, a higher functional state.⁴¹ The MCS formally entered the medical literature in 2002, after the Aspen Neurobehavioral Conference Workgroup published a consensus statement in *Neurology*.⁴²

In contrast to vegetative patients, those in the MCS are conscious, although this is often not recognized.⁴³ MCS individuals show fluctuating but reproducible signs of awareness.⁴⁴ Although these patients are capable of manifesting emotional and behavioral responses, these behaviors occur sporadically, complicating detection of awareness.⁴⁵ Minimally conscious patients may demonstrate irregular or unpredictable verbal output, object use, verbal command response, or purposeful communicative gestures (such as eye movements).⁴⁶ MCS patients may demonstrate memory, attention, and focus.⁴⁷ Their eyes may track a family member, and sometimes these individuals are able to say people’s name, or grasp for objects.⁴⁸ Recovery from MCS is defined by the emergence of either some sort of reliable “[f]unctional interactive communication” or “[f]unctional use of . . . objects.”⁴⁹

³⁷ JEROME B. POSNER, CLIFFORD B. SAPER, NICHOLAS D. SCHIFF & JAN CLAASSEN, PLUM AND POSNER’S DIAGNOSIS AND TREATMENT OF STUPOR AND COMA 6–9 (5th ed. 2019)).

³⁸ See Jennett & Plum, *supra* note 3, at 734–35 (noting that VS patients can be awake, but lack the ability to engage with their surroundings beyond “primitive postural and reflex movements”).

³⁹ *Id.* at 734.

⁴⁰ *Id.* at 735.

⁴¹ It is also possible for patients to recover from a diagnosis of VS to progress into MCS. See Joseph T. Giacino, Joseph J. Fins, Steven Laureys & Nicholas D. Schiff, *Disorders of Consciousness After Acquired Brain Injury: The State of the Science*, 10 NATURE REV. NEUROLOGY 99, 99–101 (2014).

⁴² See Giacino et al., *supra* note 4, at 349–51 (introducing the MCS and discussing how it differs from other DoC).

⁴³ See *id.* at 350 tbl. (noting the distinctions between MCS and VS). See generally FINS, RIGHTS COME TO MIND, *supra* note 2 (emphasizing the commonality of misdiagnosis with brain injuries).

⁴⁴ See Giacino et al., *supra* note 4, at 349–50.

⁴⁵ See *id.* (suggesting a link between the frequency of misdiagnosis of VS in MCS patients to the inconsistency of MCS patients’ behaviors).

⁴⁶ *Id.* at 350–52.

⁴⁷ *Id.*

⁴⁸ *Id.*

⁴⁹ *Id.* at 351.

In the MCS, behaviors are not dependably reproduced and are episodically demonstrated. For instance, when a patient is asked to repeat a behavior seen by family members, MCS patients are typically unable to comply with the request. This results in practitioners believing that the family's observations are unreliable, prompted by wishful thinking or denial, when really this failure derives from the underlying nature of the condition that allows individuals to express their consciousness only intermittently.⁵⁰ Furthermore, recovery from MCS, and other severe brain injuries, is open-ended and unpredictable, with no reliable time course.⁵¹

New diagnostic technology has the potential to help reduce the misdiagnosis rate for this population. Until recently, evaluation of consciousness was conducted exclusively through behavioral findings made at bedsides.⁵² Practitioners employed a mechanistic diagnostic approach known as the JFK Coma Recovery Scale-Revised (CRS-R), a neuropsychological examination that is best undertaken multiple times.⁵³

Increased use of diagnostic technology, however, such as validating examinations with neuroimaging, has the potential to reveal cerebral blood flow indicative of brain activity, improve our ability to determine what state of consciousness an individual is in, and ultimately help reduce the significant misdiagnosis rate.⁵⁴

Reducing misdiagnosis would be a major step forward for this population, as accurate diagnosis is the first step to providing proper clinical and rehabilitative interventions. "Clinical management of patients with [brain injuries]" often focuses on "prevention of secondary medical complications and restoration of cognitive-behavioural functions."⁵⁵ Although natural recovery is an option for some, it is typically reserved for people on the very mild end of the disorders of consciousness spectrum, and even then, is still usually combined with focused rehabilitative approaches. Indeed, the most common cognitive impairments resulting from head injuries, including "attention deficits, prob-

⁵⁰ FINS, RIGHTS COME TO MIND, *supra* note 2, at 80 (noting that loved ones may witness patient activities that practitioners do not to emphasize that "inconsistency is part of the definition of MCS and intrinsic to its biology").

⁵¹ Michele H. Lammi, Vanessa H. Smith, Robyn L. Tate & Christine M. Taylor, *The Minimally Conscious State and Recovery Potential: A Follow-Up Study 2 to 5 Years After Traumatic Brain Injury*, 86 ARCHIVES PHYSICAL MED. & REHABIL. 746, 746 (2005).

⁵² See Shapiro et al., *supra* note 7, at 536 (citing Lammi et al., *supra* note 51, at 749).

⁵³ Joseph T. Giacino, Kathleen Kalmar & John Whyte, *The JFK Coma Recovery Scale-Revised: Measurement Characteristics and Diagnostic Utility*, 85 ARCHIVES PHYSICAL MED. & REHAB. 2020, 2020–29 (2004).

⁵⁴ See Zachary E. Shapiro, *Truth, Deceit, and Neuroimaging: Can Functional Magnetic Resonance Imaging Serve as a Technology-Based Method of Lie Detection?*, 29 HARV. J.L. & TECH. 527, 532 (2016) (discussing how blood flow can be indicative of how a brain is functioning).

⁵⁵ See Giacino et al., *supra* note 41, at 107.

lems with concentration, memory, perception, information processing speed, and problem solving,” can occur over an extended two-year timeframe, and often require specialist follow-up and meticulous evaluation.⁵⁶ Ultimately, the gravity of an individual’s brain injury is but one element in a myriad of factors impacting the scope and trajectory of their long-term recovery.⁵⁷

In recent years, research has focused on therapeutics. One landmark study found that amantadine hydrochloride substantially decreased recovery time among vegetative patients over a four-week administration interval.⁵⁸ The speed of progress slowed, however, in the two weeks following the end of the drug therapy, eventually becoming appreciably longer than recovery of those in the placebo group.⁵⁹ Although the “overall improvement in [Disability Rating Scale] scores . . . was similar [between] the two groups, the gains in the amantadine hydrochloride intervention group were maintained even after treatment ended.⁶⁰ Furthermore, a greater proportion of the amantadine hydrochloride group recovered the ability to follow commands dependably, answer yes-no questions accurately, use objects in a functional manner, and communicate functionally.⁶¹ Such therapeutic trials therefore also implicate prognosis.

Another pharmacologic intervention that gained prominence in the field following clinical trials is zolpidem, a selective omega-1 γ -aminobutyric acid (GABA) agonist.⁶² Although it is more commonly used to induce sleep, zolpidem has actually led to marked improvements in the consistency and complexity of behavioral responses in some patients on the disorder of consciousness spectrum.⁶³

Such interventions blur the line between diagnostic, rehabilitative, and assistive therapeutics, yet it is important to recognize that many individuals with a brain injury are unable to be accurately diagnosed without comprehensive assessment and sometimes the empiric administration of one of these interven-

⁵⁶ See Michael P. Barnes, *Rehabilitation After Traumatic Brain Injury*, 55 BRIT. MED. BULL. 927, 937–38 (1999); Giacino et al., *supra* note 41, at 99 (detailing the variety of disorders of consciousness that can result from brain injuries).

⁵⁷ Sallie Baxendale, Dominic Heaney, Fergus Rugg-Gunn & Daniel Friedland, *Neuropsychological Outcomes Following Traumatic Brain Injury*, 19 PRAC. NEUROLOGY 476, 476 (2019) (“Neuropsychological outcomes do not depend solely on brain injury severity but result from a complex interplay between premorbid factors, the extent and nature of the underlying structural damage, the person’s neuropsychological reserve and the impact of non-neurological factors in the recovery process.”).

⁵⁸ See Joseph T. Giacino et al., *Placebo-Controlled Trial of Amantadine for Severe Traumatic Brain Injury*, 366 NEW. ENG. J. MED. 819, 819 (2012).

⁵⁹ *Id.*

⁶⁰ *Id.*

⁶¹ See *id.* at 824.

⁶² 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).

⁶³ *Id.* (introducing a study on the effects on zolpidem on patients with disorders of consciousness).

tions. For instance, there are covertly conscious patients who experience an overt “state change from appearing behaviorally vegetative to being minimally conscious once they have received certain pharmaceuticals (such as amantadine or zolpidem),”⁶⁴ “or neurostimulation” through a DBS.⁶⁵ These patients are best recognized as being MCS patients with under-activated, but intact, neural networks.⁶⁶ These individuals appear behaviorally vegetative before treatment, but are actually minimally conscious, existing in a state of potentiality.⁶⁷ Further, as we have noted in previous work, “[a]n overlapping subset of patients are covertly conscious individuals with CMD,” or cognitive-motor dissociation.⁶⁸ For these patients, “behavioral examination [is] unable to reveal an accurate diagnosis, as these individuals can have largely intact [and active] neural networks but remain unable to manifest signs of consciousness on a behavioral examination.”⁶⁹ For the purposes of measuring patient awareness, “these neural networks cannot be detected with behavioral examination, [but] evidence of consciousness can be found” by employing diagnostic neuroimaging and measuring cerebral blood flow “when patients try to follow volitional commands.”⁷⁰

For these individuals, and others with a moderate-to-severe brain injury, diagnosing consciousness may only be possible if they are provided with the correct technological interventions. If accurate diagnosis is only possible after employing pharmaceutical interventions, or other diagnostic technology, such as neuroimaging, then this makes such technology medically essential, rather than just discretionary for this population. Indeed, if technology is the only method that can allow care teams to recognize their obligations to conscious but unresponsive individuals with brain injuries, then failing to provide this technology directly contributes to their risk of continued segregation and separation from the broader community. We have argued in the past that individuals

⁶⁴ Shapiro et al., *supra* note 7, at 542 (citing Brefel-Courbon et al., *supra* note 61, at 102–05).

⁶⁵ *Id.* (citing Giacino et al., *supra* note 41, at 101–04); *see also* Giacino et al., *supra* note 41, at 108 (detailing studies on such individuals).

⁶⁶ *See generally* POSNER ET AL., *supra* note 37, at 7 (defining MCS to include those patients with “pockets of cognitive function”).

⁶⁷ Even with intervention, these individuals may continue to appear vegetative, and would thus fall in the final category discussed above.

⁶⁸ Shapiro et al., *supra* note 7, at 543 (citing Nicholas D. Schiff, *Cognitive Motor Dissociation Following Severe Brain Injuries*, 72 JAMA NEUROLOGY 1413, 1414–15 (2015)). *See generally* Joseph J. Fins & Nicholas D. Schiff, *Shades of Gray: New Insights into the Vegetative State*, HASTINGS CTR. REP., Nov.-Dec. 2006, at 8 (examining the variety of states of consciousness within the MCS).

⁶⁹ Shapiro et al., *supra* note 7, at 543 (citing Schiff, *supra* note 68, at 1414–15); Fins & Schiff, *supra* note 68, at 8 (describing a scenario where a patient “recovered to at least the level of MCS, even though behavioral evidence was lacking”).

⁷⁰ Shapiro et al., *supra* note 7, at 543 (citing Monti et al., *supra* note 11, at 580–86); *see* Monti et al., *supra* note 11, at 580–86; Fins & Schiff, *supra* note 68, at 8 (calling for use of additional evaluative methods, not just behavioral tests, when determining patient consciousness).

have a right to have their covert consciousness identified, and without the provision of advanced diagnostic technology, we are arguably ignoring these individuals if we are not actively searching for signs of conscious awareness.⁷¹

B. Assistive Technology

Accurate diagnosis is also essential in determining what assistive interventions may be beneficial. The goal of assistive technology is multi-faceted, as many serve a rehabilitative function, while others help expand or even substitute for capabilities.⁷²

Rehabilitation-oriented interventions can aid individuals with DoC in recovering consciousness.⁷³ The goal of rehabilitation for this population is some level of restoration of the ability to communicate. For those with higher levels of function, rehabilitation assists with the challenges of daily life. In the example of DoC, it is possible for patients to recover spontaneously from a coma or transition from a VS to a MCS. There is, however, consensus that a patient's prognosis is improved by rehabilitation-oriented treatments. 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, better allowing these individuals to participate in their own care. Perhaps most importantly, rehabilitation can help DoC patients finally be able to communicate with their families.⁷⁴

For this population, a diagnostic error can be devastating.⁷⁵ Although those in the MCS may be amenable to rehabilitation and progressive improvement, patients who are diagnosed as chronically vegetative are less likely to

⁷¹ Shapiro et al., *supra* note 7, at 544.

⁷² Although assistive technology has a wide-ranging definition, we understand assistive technology to refer to "any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities." See *What Is AT?*, ASSISTIVE TECH. INDUS. ASS'N, <https://www.atia.org/home/at-resources/what-is-at/> [<https://perma.cc/8RA3-QK4D>].

⁷³ See generally Barnes, *supra* note 56 (evaluating the effect of rehabilitation on patients with traumatic brain injuries).

⁷⁴ See Shapiro et al., *supra* note 7, at 544.

⁷⁵ See Anbesaw W. Selassie et al., *Incidence of Long-Term Disability Following Traumatic Brain Injury Hospitalization, United States, 2003*, 23 J. HEAD TRAUMA REHAB. 123, 125–29 (2008) (highlighting the problematic lack of data on the prevalence of individuals with disabilities resulting from traumatic brain injuries in the United States); Eduard Zaloshnja, Ted Miller, Jean A. Langlois & Anbesaw W. Selassie, *Prevalence of Long-Term Disability from Traumatic Brain Injury in the Civilian Population of the United States, 2005*, 23 J. HEAD TRAUMA REHAB. 394, 399 (2008) (detailing the hardships individuals with long term disabilities resulting from brain injuries face); Risa Nakase-Richardson et al., *Longitudinal Outcome of Patients with Disordered Consciousness in the NIDRR TBI Model Systems Programs*, 29 J. NEUROTRAUMA 59, 64 (2012) (indicating the need for increased research, diagnosis, and rehabilitation of patients with brain injuries).

receive subsequent rehabilitation. This makes any diagnostic error dangerous, as it may prevent a care team from recommending treatments that could help in the restoration of function, or the regaining of consciousness.⁷⁶ Withholding rehabilitation is especially problematic, as nearly 70% of patients with TBI who receive inpatient rehabilitation are able to recover consciousness, and just over 20% will regain functional independence.⁷⁷ Rehabilitation, however, will not be provided if a bleak diagnosis seems to obviate any potential for recovery.

Perhaps the most exciting frontier in induced recovery interventions is neuroprosthetics, whose goal is to enable individuals to rejoin the cognate community through restoration of the communication feedback loop.⁷⁸ Such neuroprosthetics thus exist as both assistive and rehabilitative technologies.⁷⁹ In their simplest forms, neuroprosthetics are non-invasive, consisting of elements like “word boards Morse code-like systems,” whereby patients can signify different alphabetical or numerical values by blinking or moving their eyes.⁸⁰ Slightly more involved forms of neuroprosthetic communication devices also incorporate EEG (electroencephalogram) recordings and electrode placement to enhance and refine an individual’s neural activity pathways before converting them into letters or words.⁸¹

The most advanced forms of neuroprosthetics, however, are in-dwelling, meaning they require invasive surgical procedures to implant.⁸² For example, a cochlear implant “is an electronic device that partially restores hearing” among some patients with “severe hearing loss from inner-ear damage.”⁸³ The device is implanted surgically and utilizes a sound processor to target the auditory nerve directly via a receiver and series of electrodes.⁸⁴ Although more studies with larger sample sizes are needed, preliminary data suggests that similarly invasive neuroprosthetics, such as central thalamic deep brain stimulation (CT-DBS), could be applied to patients with a moderate-to-severe brain injury.⁸⁵

⁷⁶ See Selassie et al., *supra* note 75, at 128 (finding that “an estimated 43.3% of hospitalized TBI survivors in 2003 experienced TBI-related long-term disability”); Zaloshnja et al., *supra* note 75, at 399 (finding that approximately 3.17 million people in the United States were “living with [a] long-term or lifelong TBI-related disability” in 2005).

⁷⁷ Nakase-Richardson et al., *supra* note 75, at 62.

⁷⁸ See Lawrence et al., *supra* note 7, at 169 (describing devices which may restore patient speech).

⁷⁹ See *id.* at 171–72.

⁸⁰ *Id.* at 172 (citing Jane E. Huggins & Debra Zeitlin, *BCI Applications*, in *BRAIN-COMPUTER INTERFACES: PRINCIPLES AND PRACTICE* 197, 197 (Jonathan R. Wolpaw & Elizabeth Winter Wolpaw eds., 2012)).

⁸¹ See *id.* at 172–77.

⁸² See *id.* at 178.

⁸³ *Cochlear Implants*, MAYO CLINIC (Aug. 11, 2020), <https://www.mayoclinic.org/tests-procedures/cochlear-implants/about/pac-20385021> [<https://perma.cc/QY7A-Z57C>].

⁸⁴ *Id.*

⁸⁵ See Giacino et al., *supra* note 41, at 108. See generally Joseph J. Fins & Zachary E. Shapiro, *Deep Brain Stimulation, Brain Maps and Personalized Medicine: Lessons from the Human Genome*

CT-DBS as a neural circuit modulator could be used as a form of induced recovery to affect “arousal, attention, and drive”; it has already been shown to improve “arousal level[s], functional movements of the upper extremities, and oral feeding” among some patients in the MCS.⁸⁶

Finally, we anticipate that brain-computer interfaces, combined with rehabilitation and some of the aforementioned treatment modalities, will one day revolutionize the way that physicians, families, and patients alike construe brain injuries. In operating independently of “the brain’s normal [nerve and muscle] output channels,” brain-computer interfaces, much like the cochlear implant, focus primarily on granting users communication autonomy.⁸⁷

C. The Catch-22 of Access to Technology

Those with brain injuries frequently do not have access to promising technologies that might accurately diagnose them or help them “recover[] consciousness and functional abilities.”⁸⁸ Many reasons contribute to this outcome.⁸⁹

One reason is that individuals in the MCS are misdiagnosed at an extraordinarily high rate of 30–45%.⁹⁰ Between the misdiagnosis rate and the lack of any predictable time course for these patients, individuals with DoC are often neglected, contributing to “nihilism concerning [their] prospects for recovery,” which in turn leads to medical mismanagement.⁹¹ Another closely-related issue concerns “inpatient rehabilitation admission criteria and health care insurance funding constraints.”⁹² For example, certain rehabilitation facilities sometimes demand, prior to admission, that a patient be minimally conscious upon release, or employ the unlawful “improvement standard.”⁹³ Many with severe brain injuries cannot satisfy these conditions, even though some of them could

Project, 27 BRAIN TOPOGRAPHY 55 (2014) (postulating on the potential of “DBS as [a type of] [p]ersonalized [m]edicine”).

⁸⁶ Giacino et al., *supra* note 41, at 108 (first citing Nicholas D. Schiff, *Recovery of Consciousness After Brain Injury: A Mesocircuit Hypothesis*, 33 TRENDS NEUROSCIENCE 1, 1–9 (2010); and then citing Joseph Giacino, Joseph J. Fins, A. Machado & Nicholas D. Schiff, *Central Thalamic Deep Brain Stimulation to Promote Recovery from Chronic Posttraumatic Minimally Conscious State: Challenges and Opportunities*, 15 NEUROMODULATION 339, 339–49 (2012)).

⁸⁷ Jonathan R. Wolpaw et al., *Brain-Computer Interface Technology: A Review of the First International Meeting*, 8 IEEE TRANSACTIONS ON REHAB. ENG’G 164, 164 (2000).

⁸⁸ Wright & Fins, *supra* note 17, at 245.

⁸⁹ *Id.* at 245–47.

⁹⁰ See Schnakers et al., *supra* note 30, at 35; Wright & Fins, *supra* note 17, at 246 (citing Schnakers et al., *supra* note 30, at 35).

⁹¹ Shapiro et al., *supra* note 7, at 543 (citing Giacino et al., *supra* note 41, at 108–10); see Wright & Fins, *supra* note 17, at 246–47.

⁹² *See id.*

⁹³ *Id.* at 247 (citing Giacino et al., *supra* note 41, at 109).

regain consciousness if provided with rehabilitation.⁹⁴ Another problem is that many technological methods remain investigational, which can complicate the provision of such technology, even if it shows promise in early research.

Without access to diagnostic and assistive technology, those with brain injuries who are institutionalized in chronic care centers will find themselves unable to progress functionally to a point where they can leave these facilities and rejoin the cognate community. These centers are not well suited to recovery, as they are often under-resourced and under-staffed.⁹⁵ They often lack the state-of-the-art tools that can assist in diagnosing fleeting signs of conscious awareness or trained staff that can provide the skilled physical therapy that can lead to the recovery of functional independence in up to twenty-one percent of DoC patients.⁹⁶ Many are unable to provide access to assistive communication devices, or even to lower cost modalities, such as eye trackers and word boards that could help some patients regain functional communication. This leaves disabled individuals trapped in “custodial care,” unable to access the technological interventions that could enable them to benefit from a more community-focused placement.

These factors contribute to the isolation and segregation of those with brain injuries. Their lack of access to technology that could help them regain functions means that many DoC individuals are likely to remain segregated in long-term care facilities. Further, while at these facilities, they are generally unable to access the latest and most promising forms of medical technology that can help them regain their functions and improve to the point where they could reasonably leave such facilities in favor of a more community focused placement.

This creates a catch-22 scenario, as the means that could allow individuals to escape institutionalization are harder to access because of that very institutionalization.⁹⁷ The status quo ends up perpetuating a negative feedback loop that keeps certain disabled individuals, such as those with DoC, segregated in long-term care facilities, even when promising rehabilitative and assistive technologies could be available.

Both diagnostic and assistive technologies have the potential to reveal and advance capabilities in individuals with disabilities, such as brain injury. Crucially, both the diagnostic and assistive technology show that society might

⁹⁴ *Id.*

⁹⁵ See generally FINS, RIGHTS COME TO MIND, *supra* note 2 (describing the insufficient resources of care facilities where individuals with brain injuries are sent to recover).

⁹⁶ Nakase-Richardson et al., *supra* note 75, at 59–64 (reporting that 21% of DoC patients “improve[] to become capable of living without in-house supervision”).

⁹⁷ See generally JOSEPH HELLER, CATCH-22 (1961) (providing the origin of the phrase “Catch-22,” which means a problem with no satisfactory solution because two or more of the problem’s fundamental elements conflict).

have obligations to help these disabled individuals in ways that would not be possible without access to this fundamental technology. This creates significant questions, not just about how society is obliged to provide this technology to those with disabilities, but also about how to support their utilization and functionality with that technology.

This makes providing technology to disabled individuals, such as those with a brain injury, a necessary and perhaps fundamental step in recognizing the civil rights, and aiding the desegregation, of this population. New legislation could serve as an essential tool to help individuals with brain injuries access some of the most promising technology that could improve and eventually help them regain functions they are currently unable to access. New legislation must take a forward-looking view, recognizing that there are promising modalities that may be in early stages of development. This way, technology can be promoted in the present and in the future when it emerges from the research and development pipeline.

We have argued before that we are on the cusp of a Kuhnian paradigm shift in our conception of brain injury, covert and liminal consciousness, and civil and disability rights.⁹⁸ Paradigm shifts “are triggered by explosive new theories which radically alter the previous conception of the scientific world, causing a new [disruptive way] of thinking to replace the old one.”⁹⁹ Standing at this moment in history, we can understand how scientific advances bring new legal and normative obligations towards the vulnerable population of individuals with moderate-to-severe brain injury.

This complicated, holistic task requires new legislation, because current disability rights law falls particularly short in creating schemes that incentivize the creation, dissemination, and adoption of advanced technological modalities. This presents a major problem in the disability rights space, as this population remains particularly reliant on legislation to vindicate their rights.¹⁰⁰

The next Part briefly explores the current state of disability rights legislation, focusing on the Americans with Disabilities Act of 1990, to understand why current legislation falls short in incentivizing the distribution and uptake of cutting-edge technological modalities among the community of individuals who could benefit from such interventions.

⁹⁸ See Shapiro et al., *supra* note 7, at 542–45; THOMAS S. KUHN, *THE STRUCTURE OF SCIENTIFIC REVOLUTIONS* 66–76 (4th ed. 2012)).

⁹⁹ Shapiro et al., *supra* note 7, at 545. See generally KUHN, *supra* note 98, at 66–76 (discussing “Crisis and the Emergence of Scientific Theories” as a part of paradigm shifts).

¹⁰⁰ In the future we will explore this unique reliance on legislation and discuss whether constitutional arguments may offer more success going forward.

II. THE AMERICANS WITH DISABILITIES ACT OF 1990

Although there are many legitimate critiques of the Americans with Disabilities Act of 1990 (ADA), it is important to remember that this legislation represented a sweeping victory for people with disabilities, their families, and disability rights advocates.¹⁰¹ Passed in 1990 after significant advocacy, the bill represented a bipartisan consensus that those with disabilities deserved protection largely based on human dignity and offered a mechanism to help vindicate rights denied by public facilities and others.¹⁰² The ADA focused particularly on employment, but covered a variety of other areas including transportation, public accommodations, communications, and access to state and local government programs and services.¹⁰³

The ADA and the subsequent Americans with Disabilities Act Amendments Act of 2008 (ADAAA) defined disability in an intentionally broad manner.¹⁰⁴ Under the ADAAA, an individual is considered disabled if there exists “a physical or mental impairment that substantially limits one or more major life activities of such individual; . . . a record of such an impairment; or . . . [if the individual is] regarded as having such an impairment.”¹⁰⁵ The broad definition is a major positive element of the legislation, as it allows the ADA to protect a wide range of individuals, in a broad range of circumstances.

The ADA is organized into five titles that touch on employment, public services, public accommodations, telecommunications, and miscellaneous enforcement provisions.¹⁰⁶ It follows a split enforcement structure for its five titles, with the Equal Employment Opportunity Commission (EEOC), Department of Justice (DOJ), Federal Communications Commission (FCC), Department of Labor (DOL), and Department of Transportation (DOT) each responsible for enforcing different aspects, often preempting state authority to intervene.¹⁰⁷ The statutory scheme leaves a significant amount of discretion to administrative agencies, resulting in broad leeway. Because the ADA primarily

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

¹⁰² See Shapiro et al., *supra* note 7, at 552–53.

¹⁰³ ADA—Findings, Purpose, and History, ADA 30 YEARS, https://www.adaanniversary.org/findings_purpose [<https://perma.cc/7M7V-5MW8>].

¹⁰⁴ Americans with Disabilities Act Amendments Act (ADAAA), 42 U.S.C. § 12101 note (Findings and Purposes of Pub. L. 110-325).

¹⁰⁵ § 12102(1); see Meg E. Ziegler, Note, *Disabling Language: Why Legal Terminology Should Comport with a Social Model of Disability*, 61 B.C. L. REV. 1183, 1184 (2020) (noting the “person-first language” of the ADA as a positive aspect of the Act (citing 42 U.S.C. § 12112)).

¹⁰⁶ Mid-Atlantic ADA Center, *An Overview of the Americans with Disabilities Act*, ADA NAT’L NETWORK (2017), <https://adata.org/factsheet/ADA-overview> [<https://perma.cc/9SL5-2N9Z>]; Shapiro et al., *supra* note 7, at 553–55.

¹⁰⁷ See Mid-Atlantic ADA Center, *supra* note 106.

provides overarching goals, many of the interlocking agency actions constitute the primary social safety net for individuals with disabilities. Such legislative schemes catch larger populations, but easily allow vulnerable members of society, like individuals with a moderate-to-severe brain injury, to fall through the gaps.¹⁰⁸

Although the ADA broadened the rights of millions of individuals with disabilities, aspects of its current model fall short of achieving the statute's stated purpose of societal integration for people with disabilities. The ADA was designed to be forward-looking and proactive. The legislation went beyond holding parties accountable for discriminatory actions; it aimed to eliminate such discrimination from American society.¹⁰⁹ When enacting the ADA in 1990, Congress found that the nation should strive "to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for" persons with disabilities.¹¹⁰

Similarly, the ADA was grounded in collaborative ideals.¹¹¹ At the first anniversary of the legislation, President George H.W. Bush applauded the bipartisan legislation as "show[ing] what can happen when we work together, drawing upon the fundamental decency of the American people."¹¹² In practice, however, the ADA has not fully lived up to its lofty objectives of collaboration and societal transformation.¹¹³ Shortly after the ADA was passed, data indicated the possibility that the cost of wrongful termination lawsuits stemming from the ADA was less expensive than the cost of actually accommodating disabled workers, resulting in sharp declines in employment rates for disabled men and women likely due to the ADA.¹¹⁴ The declines were largely due

¹⁰⁸ Wharton Bus. Daily, *The ADA at 25: Important Gains, but Gaps Remain*, KNOWLEDGE@WHARTON (Aug. 7, 2015), <https://knowledge.wharton.upenn.edu/article/the-gaps-that-remain-as-the-ada-turns-25/> [<https://perma.cc/E2UD-7W53>] (describing some of the gaps remaining in the ADA).

¹⁰⁹ See § 12101(b)(1) (stating that one purpose of the ADA is "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities").

¹¹⁰ § 12101(a)(7).

¹¹¹ 29 C.F.R. § 1630.2(o)(3) (2021) (urging "covered entit[ies]" and disabled persons to work together to devise effective accommodations). See generally Jessica Leigh Rosenthal, Comment, *The Interactive Process Disabled: Improving the ADA and Strengthening the EEOC Through the Adoption of the Interactive Process*, 57 EMORY L.J. 247 (2007) (detailing the collaborative process embedded within the regulations).

¹¹² George H.W. Bush, Remarks Commemorating the First Anniversary of the Signing of the Americans with Disabilities Act of 1990 (July 26, 1991), <https://bush41library.tamu.edu/archives/public-papers/3245> [<https://perma.cc/ENV9-WHDM>].

¹¹³ See generally Arlene S. Kanter, *The Americans with Disabilities Act at 25 Years: Lessons to Learn from the Convention on the Rights of People with Disabilities*, 63 DRAKE L. REV. 819 (2015).

¹¹⁴ Daron Acemoglu & Joshua Angrist, *Consequences of Employment Protection? The Case of the Americans with Disabilities Act 2* (Nat'l Bureau of Econ. Rsch., Working Paper No. 6670, 1998) (detailing the impact of the ADA on employment numbers for the disabled); Les Picker, *Consequences of the Americans with Disabilities Act*, NAT'L BUREAU ECON. RSCH. DIG., Dec. 1998, <https://>

to reduced hiring rather than job loss and were more pronounced in medium-size businesses.¹¹⁵

More recent data suggests that just eighteen percent of work-eligible individuals with disabilities have jobs and “the employment rate for people with disabilities [remains] 40 percent lower than [that of] people without disabilities.”¹¹⁶ Working individuals with disabilities are compensated around 33% less than people without disabilities and often work in less prestigious roles, do not log as many hours, and continue to face challenges and social stigma.¹¹⁷

Indeed, scholars have long critiqued the ADA for succumbing to political pressure to focus too narrowly on employment, rather than adopting a universalist approach.¹¹⁸ In some ways, the ADA has depended too heavily on the “goodwill of employers and providers of services” balanced primarily by the risk of litigation.¹¹⁹ Universalist critics of the ADA cast the law as “tax base” enlarging,¹²⁰ but it fails to do that.¹²¹ Section A of this Part will introduce the technological advances made for people with serious brain injuries.¹²² Section B will then connect those advances in technology to the enforcement of the ADA.¹²³ Lastly, Section C will address continued short-fallings of the ADA and the need for more forward-looking legislation.¹²⁴

A. Technology

Although the ADA’s retrospective focus on vindicating rights may be defensible in contexts such as employment and public access, the legislation falls short in *prospectively* supporting those with disabilities through the provision of technologies that can help maximize potential. The ADA does a particularly poor job when dealing with technologies that were not specifically conceived of when the legislation was drafted in the late 1980s and early 1990s. This is

www.nber.org/digest/dec98/consequences-americans-disabilities-act [https://perma.cc/L8XL-459C] (reporting on Working Paper No. 6670).

¹¹⁵ Acemoglu & Angrist, *supra* note 114, at 2.

¹¹⁶ Kanter, *supra* note 113, at 831 (citing Michelle Maroto & David Pettinicchio, *The Limitations of Disability Antidiscrimination Legislation: Policymaking and the Economic Well-Being of People with Disabilities*, 36 LAW & POL’Y 370, 394 (2014)).

¹¹⁷ *Id.*

¹¹⁸ See generally Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 28, 71–73 (2004) (criticizing the ADA for not taking on other aspects of social welfare including healthcare and insurance).

¹¹⁹ Kanter, *supra* note 113, at 823.

¹²⁰ *Id.* at 835.

¹²¹ *Id.* at 831 (describing the limited impact the ADA has had on the employment of people with disabilities).

¹²² See *infra* notes 125–136 and accompanying text.

¹²³ See *infra* notes 137–180 and accompanying text.

¹²⁴ See *infra* p. 1759.

problematic, especially for individuals with certain types of disabilities, such as brain injuries. These people are unlikely to be able to reenter the workforce but could reintegrate into their communities through the provision of more recent rehabilitative and assistive technologies. Although science has moved forward, the ADA is stuck in a time before these advances existed.

Technology that allows people with disabilities greater functionality in this world is often quite expensive. Unfortunately, unless these individuals can find a workplace that pays for accommodations beyond what their healthcare, a government entity, or a non-governmental organization (NGO) provides, they are often unable to pay for this technology.¹²⁵ The ADA does little to help ensure access or defray costs. As a result, people with disabilities routinely go into significant debt trying to pay for the technology or decline to take advantage of promising interventions that could greatly decrease their barriers to interacting with the world.

The case of Lee Huffman, a man with Stargardt disease, a genetic eye disease that results in severe vision loss over time, illustrates the significant costs associated with emerging technology.¹²⁶ Huffman works as an editor of a magazine, but due to his disability, needs expensive assistive technology to complete his job tasks. Such technology, including particular laptops or tablets that individuals with similar vision impairments need to participate in society and compete for employment can set them back thousands of dollars.¹²⁷ Indeed, “a tablet with a braille keyboard and braille display . . . [costs] about \$5,500.”¹²⁸ Unfortunately, most healthcare plans refuse to pay for such technologies.

The high cost of these kinds of technologies is especially concerning given the limited financial resources of many of those with disabilities. A study conducted in October 2020 “estimate[d] that a household containing an adult with a disability . . . requires, on average, 28 percent more income (or an additional \$17,690 a year) to obtain the same standard of living as a similar household without a member with a disability.”¹²⁹ This is due in part to the exorbi-

¹²⁵ Certain NGO’s serve people living with a specific disability, such as United Cerebral Palsy or the American Foundation for the Blind. See, e.g., UNITED CEREBRAL PALSY, <https://ucp.org/> [<https://perma.cc/7EHE-QFWF>] (serving those with cerebral palsy); AM. FOUND. FOR THE BLIND, <https://www.afb.org/> [<https://perma.cc/9KGB-NHP4>] (serving the blind or visually impaired).

¹²⁶ Sintia Radu, *Who’s Paying for Assistive Technology?*, U.S. NEWS (Dec. 1, 2017), <https://www.usnews.com/news/best-countries/articles/2017-12-01/assistive-technology-keeps-growing-but-paying-for-it-is-next-challenge> [<https://perma.cc/H95Y-35GF>].

¹²⁷ *Id.*

¹²⁸ *Id.* (quoting Eric Duffy, Director of the Assistive Technology Team, National Federation of the Blind).

¹²⁹ NANETTE GOODMAN, MICHAEL MORRIS, ZACHARY MORRIS & STEPHEN MCGARITY, NAT’L DISABILITY INST., THE EXTRA COSTS OF LIVING WITH A DISABILITY IN THE U.S.—RESETTING THE POLICY TABLE 1 (2020) (emphasis omitted), <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-living-with-disability-brief.pdf> [<https://perma.cc/SVP6-DLGG>].

tant expenses associated with the technology that people with disabilities need to navigate the world at least somewhat equally to their non-disabled peers. This cost is exacerbated by the fact that people with disabilities experience lower employment rates, are paid less, and are “twice as likely . . . to have incomes under the poverty threshold,” compared to individuals without disabilities.¹³⁰ Due to the high cost, people with disabilities often either go into significant debt trying to pay for novel technology or do not access it, which can lead to impoverishment and can continue to segregate them from vital components of daily living and integration. We need new legislation that accounts for these costs and allows people with disabilities to access life-changing technology. These costs could also be alleviated by new legislation that requires the opening of markets for these technologies, which is discussed later in this Article.¹³¹

Nor is cost the only example of the ADA’s failures to consider future technological challenges. For instance, people with disabilities are less likely to vote than the general population, and scholars have highlighted that technology plays a direct role in this.¹³² The ADA does not specifically address requirements for accessible voter registration technology, but Title II of the Act requires state and local governments to ensure that people with disabilities have an equal opportunity to vote.¹³³ The ADA’s recognition of accessibility should thus extend to new voting technology. The ADA has not adapted, however, to continue to uphold these rights during a time when most voter registration is done online.

Indeed, increasing the accessibility of voter registration technology was consistently deprioritized under the Trump Administration. The DOJ’s rulemakings under Title II of the ADA “for websites . . . and state and local governments” were repeatedly categorized as inactive under the Trump Administration’s Unified Regulatory Agenda.¹³⁴ As a result, over the last few years, minimal progress has been made to increase the accessibility of state voter reg-

¹³⁰ *Id.* at 2.

¹³¹ *Id.* at 4.

¹³² Andrew Ward, Paul M.A. Baker & Nathan W. Moon, *Ensuring the Enfranchisement of People with Disabilities*, 20 J. DISABILITY POL’Y STUD. 79, 79–80 (2009); LISA SCHUR & DOUGLAS KRUSE, PROJECTING THE NUMBER OF ELIGIBLE VOTERS WITH DISABILITIES IN THE NOVEMBER 2016 ELECTIONS 1–3 (2016), https://smr.rutgers.edu/sites/default/files/Documents/Centers/Program_Disability_Research/Disability%20Electorate%20Projections%202016%20Elections.pdf [<https://perma.cc/99CN-JD6G>] (stating that developments in medical technology have helped increase the “number of eligible voters with disabilities,” but “reported voter turnout [is] 5.7 percentage points lower” for individuals with disabilities than for those without).

¹³³ See 42 U.S.C. §§ 12131–12134.

¹³⁴ Minh N. Vu, *DOJ Places Website Rulemaking on the ‘Inactive’ List*, SEYFARTH (July 21, 2017), www.adatitleiii.com/2017/07/doj-places-website-rulemaking-on-the-inactive-list/ [<https://perma.cc/Y92J-C5RN>].

istration websites; instead, persons with disabilities have lodged an increasing number of lawsuits over the inaccessibility of public websites.¹³⁵ Despite this, voter registration websites remain inaccessible to many voters with disabilities due to overly complex wording and graphics, and being unreadable by a screen reader. This is especially concerning given that now, more than ever before, people are using the internet to register to vote and to obtain information associated with how to exercise their franchise.¹³⁶

Due to its nonspecific nature and the way that the DOJ enforces it, the ADA has shown that it cannot adequately address the inaccessibility of voter registration websites. This highlights the problems with disability legislation that fails to keep up with the current technological landscape.

B. Enforcement and Technology

Scholars have long highlighted significant downsides to the ADA's model of litigation-focused enforcement, a *reactive* model that is particularly ill suited to promote *prospective* access and development of the necessary technology to assist those with disabilities in regaining capabilities. As an example, we turn to the Supreme Court's 1999 decision in *Olmstead v. L.C. ex rel. Zimring* and its implications for those with a severe brain injury.¹³⁷

We have argued in the past that failure to provide assistive communication devices directly increases the risk of institutionalization (and hence societal segregation) for those with brain injuries, and thus constitutes unlawful discrimination in violation of the ADA and *Olmstead*.¹³⁸ *Olmstead* and the ADA, however, have been exceedingly slow in providing access to the necessary technologies for this population. For example, Title II of the ADA prohibits disability discrimination in programs, activities, and services offered by public entities. In the case of a Title II violation, TBI/DoC patients should be able to rely on *Olmstead*, an enforcement mechanism, to vindicate their Title II rights to community integration.

In *Olmstead*, the Court considered whether the ADA's nondiscrimination mandate required community-based housing rather than institutionalization.¹³⁹ In the case, respondents Lois Curtis and Elaine Wilson, who were institutional-

¹³⁵ *Id.*

¹³⁶ Gus Alexiou, *Covid Reminds Us That Web Accessibility Helps All Users, Not Just the Disabled*, FORBES (Aug. 23, 2020), www.forbes.com/sites/gusalexiou/2020/08/23/covid-reminds-us-that-web-accessibility-helps-all-users-not-just-the-disabled/?sh=24a845216df1 [https://perma.cc/PH9K-A7BD].

¹³⁷ See 527 U.S. 581, 607 (1999). See generally Shapiro et al., *supra* note 7, at 544 (noting the potential violation of *Olmstead v. L.C. ex rel. Zimring*).

¹³⁸ Shapiro et al., *supra* note 7, at 542–45.

¹³⁹ 527 U.S. at 587.

ized with mental disabilities in a state-funded facility, argued they were entitled to “community-based treatments and supports” under the ADA.¹⁴⁰ The Supreme Court held that, unless the service being requested “would fundamentally alter the nature of the service, program, or activity,” and in some cases if the cost would be prohibitive, states had a duty under Title II of the ADA to furnish the requested integrated services.¹⁴¹ The plurality acknowledged that segregation and isolation of individuals with disabilities was discriminatory.¹⁴²

As we have discussed in previous work, those “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.”¹⁴³ Further, although “neuroprosthetics were not mentioned specifically in the text of the ADA, such communication aids should be classified . . . under the catchall provisions concerning necessary services and aids,” entitled “[o]ther similar services and actions.”¹⁴⁴ To be sure, “scholars writing about the ADA have highlighted that ‘the specific requirements [of the ADA’s reasonable accommodation requirements] may vary as technological advances occur.’”¹⁴⁵ To think otherwise undermines the legislative intent.

“Services and auxiliary aids are legally required in order ‘to ensure effective communication with individuals with disabilities.’”¹⁴⁶ Furthermore, stemming from this duty is the responsibility of others to communicate functionally with people with disabilities.¹⁴⁷ “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.”¹⁴⁸ We continue to assert that “[w]ithout these interventions, communication will remain impossible,” in violation of the above regulation.¹⁴⁹

Olmstead permits suits against institutions subject to the ADA for denying individuals, because of their qualified disability, “the benefits of the services, programs, or activities of a public entity,” or for any discrimination committed

¹⁴⁰ See Shapiro et al., *supra* note 7, at 544 (summarizing the *Olmstead* respondent’s position).

¹⁴¹ *Olmstead*, 527 U.S. at 592, 607 (quoting 28 C.F.R. § 35.130(b)(7) (1998)).

¹⁴² *Id.* at 600; see Shapiro et al., *supra* note 7, at 561–62 (summarizing the *Olmstead* Court’s recognition of Congress’s intent in passing the ADA).

¹⁴³ Shapiro et al., *supra* note 7, at 582.

¹⁴⁴ *Id.* Compare 42 U.S.C. § 12103(1)(D) (citing to “other similar services and actions”), with 28 C.F.R. § 36.303(b)(4) (2021) (same).

¹⁴⁵ Shapiro et al., *supra* note 7, at 582 (quoting Nancy Lee Jones, *Overview and Essential Requirements of the Americans with Disabilities Act*, 64 TEMP. L. REV. 471, 495 (1991)).

¹⁴⁶ *Id.* at 582–83 (quoting 28 C.F.R. § 36.303(c)(1)).

¹⁴⁷ *Id.* at 583 (quoting 28 C.F.R. § 36.303); see 28 C.F.R. pt. 36, app. B.

¹⁴⁸ *Id.*

¹⁴⁹ *Id.*

by the institution.¹⁵⁰ To demonstrate a violation of the integration mandate, plaintiffs must prove 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.”¹⁵¹ This three-factor test is satisfied when considering the provision of assistive communication and rehabilitative devices to those with severe brain injury.¹⁵² Despite the clear applicability of *Olmstead* to the situations of those with moderate-to-severe brain injury, however,¹⁵³ little progress has been made in using *Olmstead* to obtain access to the rehabilitative technologies and communicative devices that this particular population so badly needs.

Indeed, *Olmstead* enforcements continue to be systemically underutilized. During the George W. Bush administration, hardly any plaintiffs pursued *Olmstead* actions.¹⁵⁴ Instead, the Department of Health and Human Services (HHS) emphasized shorter-term goals, while the DOJ engaged in what independent reports have found to be subpar enforcement activity.¹⁵⁵ The Obama administration enforced the ADA more assertively than the Bush administration, starting with the announcement of the Year of Community Living on the tenth anniversary of *Olmstead*.¹⁵⁶ During this time, the DOJ brought fifty *Olmstead* cases, and both HHS and DOJ collaborated on a “Dear Colleague” guidance letter to the Department of Labor (DOL) on labor protections for home-care workers.¹⁵⁷

Even with this push, *Olmstead* enforcements are subject to political change and are not always reliable. The Trump administration failed to maintain the DOJ’s running list of completed *Olmstead* investigations, and only one action was filed between 2016 and 2020.¹⁵⁸ They also rescinded guidance on *Olmstead* enforcements.¹⁵⁹ In the twenty years following the *Olmstead* decision, fifty-nine *Olmstead* actions have been initiated by the DOJ in Democratic

¹⁵⁰ *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 590 (1999) (quoting 42 U.S.C. § 12132); Shapiro et al., *supra* note 7, at 568. An individual, class, or one individual on behalf of another may bring an *Olmstead* action. Shapiro et al., *supra* note 7, at 569–70.

¹⁵¹ Shapiro et al., *supra* note 7, at 571 (quoting *Olmstead*, 527 U.S. at 607 (plurality opinion)).

¹⁵² *See id.* at 544 (describing the ethical imperative and potential legal obligation to provide communication aides and other rehabilitation devices to individuals with brain injuries).

¹⁵³ *Id.*

¹⁵⁴ *See id.* at 565 (noting the lack of progress despite the Administration’s backing of *Olmstead*).

¹⁵⁵ *Id.*

¹⁵⁶ *Id.* at 566; *see* Press Release, Off. of the Press Sec’y, President Obama Commemorates Anniversary of *Olmstead* and Announces New Initiatives to Assist Americans with Disabilities (June 22, 2009), <https://obamawhitehouse.archives.gov/the-press-office/president-obama-commemorates-anniversary-olmstead-and-announces-new-initiatives-ass> [<https://perma.cc/P97B-688E>].

¹⁵⁷ Shapiro et al., *supra* note 7, at 566.

¹⁵⁸ *Id.* at 575.

¹⁵⁹ *Id.* at 576.

administrations (eight years) compared with only five during Republican administrations (twelve years).¹⁶⁰

Still, even with perfect enforcement, hurdles keep many from using the ADA to enforce their rights. For a recovering TBI patient struggling to maintain a job, pay medical bills, and adapt to society with a new ability level, bringing a lawsuit is harder and more expensive than applying for more jobs. There remains an uncertain prospect of recovery, and significant downsides to bringing litigation-focused enforcement.¹⁶¹

Often, the adversarial enforcement model perpetuates a backwards-looking regime that does not consistently enforce ADA compliance or address harmful norms and stigma.¹⁶² The current ADA enforcement model falls well short of achieving its goal of eliminating discrimination against people with disabilities because it does not adequately address the harmful norms and stigma that perpetuate such discrimination.¹⁶³ For example, in Title I actions, courts are often unwilling to require employers to modify “structural norms” of the workplace, such as working hours and schedules, because they view the norms as “essential functions of the job.”¹⁶⁴ Because a reasonable accommodation under Title I should allow an employee “to perform the essential functions of [the employment] position,”¹⁶⁵ a defendant can argue that an accommodation is not reasonable if it changes or dispenses with the essential functions that need to be performed.¹⁶⁶ Some scholars refer to the tendency for courts to view structural workplace norms as essential functions as “counter-intuitive.”¹⁶⁷ Ac-

¹⁶⁰ U.S. Dep’t of Just. Civ. Rts. Div., Olmstead: *Community Integration for Everyone*, ADA.GOV, https://www.ada.gov/olmstead/olmstead_cases_list2.htm [<https://perma.cc/3TXY-94H5>].

¹⁶¹ See generally Shapiro et al., *supra* note 7, at 568–75 (detailing the required elements of a litigation enforcement claim).

¹⁶² See Kelly Kagan, Note, *To Trigger or Not to Trigger: The Catch-22 of the Americans with Disabilities Act’s Interactive Process*, 57 SAN DIEGO L. REV. 501, 531 (2020) (“[C]urrent proposed solutions focus on legal recourse instead of ensuring ADA protections at the outset.”).

¹⁶³ See 42 U.S.C. § 12101(b)(1) (stating that one purpose of the ADA is “to provide a clear and comprehensive national mandate for the elimination of the discrimination against individuals with disabilities”).

¹⁶⁴ Nicole Buonocore Porter, *The New ADA Backlash*, 82 TENN. L. REV. 1, 70–74 (2014) (citing the following cases as examples of the application of this standard: *Tucker v. Mo. Dep’t of Soc. Servs.*, No. 11-CV-04134, 2012 WL 6115604, at *6 (W.D. Mo. Dec. 10, 2012) (finding that the ability to staff all shifts was necessary to employment); *Kallail v. Alliant Energy Corp. Servs., Inc.*, 691 F.3d 925, 933 (8th Cir. 2012) (holding that the ability to staff rotating shifts was necessary to employment); *Thomas v. Bala Nursing & Ret. Ctr.*, No. 11-5771, 2012 WL 2581057, at *1 (E.D. Pa. July 3, 2012) (finding “genuine issues of material fact” as to whether plaintiff’s consistent lateness inflicted a hardship on the employer)).

¹⁶⁵ 42 U.S.C. § 12111(9) (defining “reasonable accommodation” under the ADA); 29 C.F.R. § 1630.2 (2021) (same).

¹⁶⁶ Michelle A. Travis, *Recapturing the Transformative Potential of Employment Discrimination Law*, 62 WASH. & LEE L. REV. 3, 62 (2005) (citing 29 C.F.R. § 1630.2(o) (2004)).

¹⁶⁷ Porter, *supra* note 164, at 78.

commodating a change in hours or work schedule is generally less costly than changing the physical requirements of employment, and the ADAAA specifically includes modifications to work hours and schedules as examples of reasonable accommodations.¹⁶⁸ An employer's hesitancy to change structural norms in the workplace may arise from concerns about the anticipated encumbrance the accommodation will put on other employees, "special treatment stigma," or slippery-slope beliefs about the ways that accommodating one request will catalyze a string of requests from other employees.¹⁶⁹ The inclination of courts to acquiesce to these concerns reveals shortcomings in the current enforcement model. Although the "expanded definition of disability" under the ADAAA has allowed more employees to bring Title I claims, litigation is not necessarily effective at addressing harmful normative barriers that prevent employees with disabilities from achieving full participation and opportunity in the workplace.¹⁷⁰

Addressing harmful stigma is a key component of ending discrimination against people with disabilities. Although the ADA provides a comprehensive legal framework for individuals to remedy discriminatory events, situations exist where the adversarial enforcement model may actually exacerbate stigma. In the employment context, it is especially important to address the role of stigma as a barrier to fair treatment and equal opportunity for people with disabilities.¹⁷¹ "Special-treatment stigma" encompasses the resentment that coworkers may feel toward employees who receive reasonable accommodations, and the negative beliefs that employers may harbor about the cost and burden of employing people who require accommodations.¹⁷² In some cases, employers and coworkers may be more willing to provide accommodations before the aggrieved employee files a lawsuit. Once litigation commences, it is possible that the enforcement process inadvertently worsens existing resentment or ill feelings by forging adversarial relationships and legal obligations.¹⁷³ In addition, scholars argue that by requiring employees to divulge disabilities to their employers, the ADA subjects employees with hidden disabilities to stigmatiza-

¹⁶⁸ *Id.*; 42 U.S.C. § 12111(9)(B); 29 C.F.R. § 1630.2(o)(2)(ii).

¹⁶⁹ Porter, *supra* note 164, at 79–81.

¹⁷⁰ *See id.* at 78 (noting the lowered standard plaintiffs will have to meet to prove their disability status).

¹⁷¹ *See* Stacy A. Hickox & Keenan Case, *Risking Stigmatization to Gain Accommodation*, 22 U. PA. J. BUS. L. 533, 551 (2020) ("The potential barrier to requesting accommodations created by this potential 'backlash' makes it important to understand the influence of stigma and stereotypes on employees and applicants with disabilities.").

¹⁷² *See* Nicole Buonocore Porter, *Mutual Marginalization: Individuals with Disabilities and Workers with Caregiving Responsibilities*, 66 FLA. L. REV. 1099, 1108–10 (2014).

¹⁷³ *Id.* at 1110–11.

tion,¹⁷⁴ potentially leading to discrimination.¹⁷⁵ To combat these effects, employers have a duty to limit the amount of information they gather related to the disability as part of the accommodation process.¹⁷⁶

The adversarial nature of litigation may also create incentives or opportunities for potential defendants to reinforce harmful stigmas. For example, following the passage of the ADA, the Equal Employment Opportunity Commission (EEOC) drafted new regulations that expanded the definition of impairment discrimination.¹⁷⁷ In response to the agency's call for public comment, members of the business community submitted statements arguing against the proposed change.¹⁷⁸ Many submissions invoked images of people with disabilities as lazy, violent, disruptive, and undependable.¹⁷⁹ These comments demonstrate the ongoing existence of stigma against people with disabilities, but they also probe a larger question as to whether the adversarial enforcement process itself creates opportunities for potential defendants to invoke harmful stigma to protect themselves from liability.¹⁸⁰

¹⁷⁴ Hickox & Case, *supra* note 171, at 534.

¹⁷⁵ *Id.* at 555 (“Multiple studies have found that more than half of employees who disclosed their psychiatric disabilities experienced at least one unfavorable circumstance following disclosure” (first citing Marsha Langer Ellison, Zlatka Russinova, Kim L. MacDonald-Wilson & Asya Lyass, *Patterns and Correlates of Workplace Disclosure Among Professionals and Managers with Psychiatric Conditions*, 18 J. VOCATIONAL REHAB. 3, 8–9 (2003); then citing Otto F. Wahl, *Mental Health Consumers' Experience of Stigma*, 25 SCHIZOPHRENIA BULL. 467, 473, 476 (1999); then citing SARAH VON SCHRADER, VALERIE MALZER, WILLIAM ERICKSON & SUSANNE BRUYÈRE, ILR SCH. EMP. & DISABILITY INST., CORNELL UNIV., EMERGING EMPLOYMENT ISSUES FOR PEOPLE WITH DISABILITIES 19–20 (2011), <https://files.eric.ed.gov/fulltext/ED537099.pdf> [<https://perma.cc/Q4K6-ZNRB>]; and then citing Marjorie L. Baldwin & Steven C. Marcus, *Perceived and Measured Stigma Among Workers with Serious Mental Illness*, 57 PSYCHIATRIC SERVS. 388, 389–90 (2006))).

¹⁷⁶ *Id.* at 588 (introducing the ADA guidance suggesting employers only request information “directly relevant to [an employee’s] request for a reasonable accommodation” (citing Izabela Z. Schultz, Terry Krupa & E. Sally Rogers, *Best Practices in Accommodating and Retaining Persons with Mental Health Disabilities at Work: Answered and Unanswered Questions*, in WORK ACCOMMODATION AND RETENTION IN MENTAL HEALTH 445, 458 (Izabela Z. Schultz & E. Sally Rogers eds., 2011))).

¹⁷⁷ See Regulations to Implement the Equal Employment Provisions of the Americans with Disabilities Act, as Amended, 74 Fed. Reg. 48,431, 48,439 (Sept. 23, 2009) (to be codified at 29 C.F.R. pt.1630); Shapiro et al., *supra* note 7, at 556.

¹⁷⁸ Michelle A. Travis, *Lashing Back at the ADA Backlash: How the Americans with Disabilities Act Benefits Americans Without Disabilities*, 76 TENN. L. REV. 311, 315 (2009). The EEOC proposed regulations including mitigation-based and symptom-based decisions as a part of impairment discrimination. Regulations to Implement the Equal Employment Provisions of the Americans with Disabilities Act, as Amended, 74 Fed. Reg. at 48,443.

¹⁷⁹ Travis, *supra* note 178, at 315–17.

¹⁸⁰ See *id.* at 315–18.

C. *The Need for Modernized Legislation*

Although the ADA made major advancements for people with disabilities, the drafters did not effectively anticipate how the ADA would address accessing cutting-edge technological developments that can improve the lives of people with disabilities. The failure to secure access to emerging technology for disabled individuals, coupled with a focus on remedial enforcement under the ADA, has prevented Americans with disabilities from fully realizing their rights, and accessing the world around them.

In short, the ADA is failing to adapt to the modern era and scientific advances. As technology emerges to allow access to different facets of society and rights for people with disabilities, the ADA has not been able to secure reasonable access to that technology for many. Moreover, because many of the most important technologies for opening new options and activities in the lives of people with disabilities are either recently emergent or still on the horizon, it is important for new disability legislation to adopt a forward-looking framework. This should center on advancing capabilities and should include the resources to adopt a generative approach in envisioning state obligations of the creation, dissemination, and use of such technologies. We need modernized legislation that will ensure access to cutting-edge technology for people with disabilities through both direct subsidies and changes in the market for these technologies. Because focusing on capabilities does not limit our freedom to the technology we have today, but countenances assistive technology that may only exist in the future, adopting a capabilities-approach creates an obligation to help make those technologies a reality, while providing societal support for individuals to access, and then use, these technologies to their full potential.

Central to this evolution is the place of disability rights in our understanding of the moral status of this population, and the need for law to focus on expanding the capabilities of individuals with disabilities, as opposed to simply being a retrospective tool to vindicate denied rights.

The next section will explore the theoretical framework of rights and capabilities, to highlight how an *Americans with Abilities Act* can not only buttress the technological scaffoldings for those with disabilities, but also help to shift the conversation and perception around the marginalized population of individuals with disabilities in a meaningful way.

III. MOVING FROM RIGHTS TO CAPABILITIES

The technology discussed in Part I, coupled with continued advancements, can allow individuals with a brain injury to regain functions once lost to them, thereby enabling access to a broader range of activities, life experiences, and possibilities. In this way, providing supportive technology for those with disabilities is a mechanism that can move us from a traditional view of using

law to vindicate rights toward a model of legal support that advances and restores capabilities. This Part will explore this important concept, as new legislation gives us the opportunity to do more than simply promote and incentivize uptake of important medical technologies. First, Section A introduces a novel approach to understanding freedom.¹⁸¹ Then, Section B applies this new approach to disability law.¹⁸² Lastly, Section C incorporates technology into the approach to provide insight into the future of disability law.¹⁸³

A. An Introduction and Primer on the Capabilities-Approach

Although early precursors of the capabilities-approach reach as far back as Aristotle and Karl Marx, the contemporary capability-approach has its roots in the work of Isaiah Berlin, Amartya Sen, and Martha Nussbaum.¹⁸⁴ Despite differences in their views, what is common to this approach is a change in focus away from the present and toward potential. Capabilities-approaches understand freedom as the liberty to achieve certain ends and projects by unlocking potential unrealized capabilities, rather than merely exercising the freedom to access whatever means happen to be presently available.

This trend is sometimes understood in terms of the contrast between positive and negative freedoms.¹⁸⁵ Negative freedom involves freedom from interference.¹⁸⁶ An agent is free when no other agent is restricting them from exercising their agency as they see fit. On this view, for example, one's freedom of movement is restricted when someone else has imprisoned them. A positive conception of freedom, in contrast, focuses on the freedom to achieve one's goals.¹⁸⁷ Although interference can be one limit on achieving goals, it is not the

¹⁸¹ See *infra* notes 184–193 and accompanying text.

¹⁸² See *infra* notes 194–199 and accompanying text.

¹⁸³ See *infra* notes 200–206 and accompanying text.

¹⁸⁴ See ISAIAH BERLIN, TWO CONCEPTS OF LIBERTY (1958) (postulating on the different meanings of liberty); Amartya Sen, *Equality of What?*, in THE TANNER LECTURE ON HUMAN VALUES, May 1979, at 197, https://www.ophi.org.uk/wp-content/uploads/Sen-1979_Equality-of-What.pdf [<https://perma.cc/8YDQ-QA2J>] (evaluating different approaches to and understandings of equality); Martha Nussbaum, *Nature, Function, and Capability: Aristotle on Political Distribution*, in OXFORD STUDIES IN ANCIENT PHILOSOPHY 145, 145 (Julia Annas & Robert H. Grimm eds., Supp.1988) (introducing the theory of political distribution and the role that capabilities play in this theory).

¹⁸⁵ BERLIN, *supra* note 184, at 7–24.

¹⁸⁶ *Id.* at 7.

¹⁸⁷ See, e.g., Ingrid Robeyns, *The Capability Approach*, STAN. ENCYCLOPEDIA PHILOSOPHY, <https://plato.stanford.edu/entries/capability-approach/> [<https://perma.cc/8K3J-ACTD>] (“Real freedom in this sense means that one has all the required means necessary to achieve that doing or being if one wishes to. That is, it is not merely the formal freedom to do or be something, but the substantial opportunity to achieve it. Someone might, for example, have the formal freedom to vote in elections in the sense that she has the right to do so and that no one will stop her from doing so, but she might lack the substantial possibility to vote because the closest voting station is 200 kilometers away and she does not own a car and does not have access to other means of transportation.”).

only limit. Robinson Crusoe, for example, alone on his desert island, is not constrained by anyone, and is in that sense free from any negative infringement on his freedom.¹⁸⁸ No one is preventing him from leaving the island, nor restricting his access to the island's resources. Because of his lack of resources, however, the limits of his educational background, of technology, and his natural limitations as an individual human with no innate capacity for flight, he is in another sense every bit as unfree as if he had been jailed. He and the prisoner, despite the different sources of their limitations, are no more able to roam where they wish.

These differing conceptions can have dramatically different consequences for how we understand the proper role and obligations of government with respect to human freedom and agency. Considering the negative view of freedom, government typically restricts freedom. Social structures relate to freedom merely as new potential sources of interference or oppression. The more power any group amasses, the more they can stop individual agents from doing as they wish. The proper role of government, in this view, is at most ameliorative. It can intervene when someone's agency has been interfered with, but cannot take proactive steps toward expanding human agency in other ways as a driver of new technologies and capacities.

On the positive front, government and other social structures are potential sources of new substantive freedoms. The more power a social group acquires by working together, the more ends they are capable of pursuing with that power. If we are capable of inventing and constructing airplanes together as a collective project, which none of us could do by ourselves, we achieve the freedom to fly that we would have otherwise lacked.

The capabilities-approach to freedom encourages us to move past what currently exists when thinking about the extent of our freedom and to imagine what might be. As the Crusoe example shows, a focus on a substantive freedom involves not just the formal freedom to pick between the existing available choices, but also the creation of new choices to pursue and goals to realize. Before the advent of planes, we lacked the freedom to choose to fly. Before a child is taught to play an instrument, or to speak a new language, they lack the freedom to choose among and engage in the activities that those capabilities make possible.

Thus, resources and freedom from interference are still *part of* positive freedom, as they are necessary means to exercise the capacities that an agent has developed. Yet, the availability of ends to pursue—which is the heart of positive freedom—remains a function of the capabilities one is able to exercise.

¹⁸⁸ BERLIN, *supra* note 184, at 25–29.

Capabilities can be more finely- or coarsely-grained. Many theorists follow Nussbaum in identifying several broad categories of capabilities, including life-sustaining abilities. These include bodily health; bodily integrity; mobility; the ability to use one's senses, imagination, and thought; the ability to live one's life according to personal preferences; the ability to form relationships and love; an ability to live in contact with the natural world; play; and an ability to exert control over one's environment.¹⁸⁹

Rights are often thought to involve corresponding obligations.¹⁹⁰ In the case of negative liberty rights, those obligations are primarily obligations of non-interference. Others are obligated not to hamper an individual while they pursue their goals as best as they are able. In contrast, if we take a positive conception of rights, the conceptual space for corresponding obligations of the community becomes much wider, encompassing obligations to help and care for one another and to help one another achieve one's own ends.¹⁹¹

If people with disabilities have a positive right to exercise the same capabilities that people without disabilities enjoy, it does not matter whether the current absence of those capacities is due to our interference or not. Society can violate the rights of persons with disabilities not just through acts of discrimination, but through inaction. This re-imagining of rights opens entire new spaces for government action.

Policymakers, politicians, and activists concerned with disability rights can no longer limit themselves to policing discriminatory interference. The creation of prophylactic measures to prevent future interference, or remedial measures to make up for past interference is also needed, indeed required. Instead of focusing on spelling out the discriminatory actions from which society is obligated to refrain, adopting a positive conception of rights centered around the right to develop capacities suggests a corresponding generative obligation by society to act affirmatively in ways that help develop those capacities.

A society concerned with promoting positive freedom, then, is one concerned primarily with people's rights to develop and exercise capacities, constitutive of such freedom. It is concerned not just with refraining from acting in ways that are harmful to freedom, but with imagining new ways to act that promote freedom. This perspective creates a forward-looking obligation, through technology, education, and the construction of our shared environment, to ensure

¹⁸⁹ MARTHA C. NUSSBAUM, WOMEN AND HUMAN DEVELOPMENT: THE CAPABILITIES APPROACH 78–80 (2000).

¹⁹⁰ See, e.g., Wesley Newcomb Hohfeld, *Some Fundamental Legal Conceptions as Applied in Judicial Reasoning*, 23 YALE L.J. 16, 30–32 (1913). For a more thorough discussion of rights, see RONALD DWORKIN, TAKING RIGHTS SERIOUSLY (1977).

¹⁹¹ See, e.g., STEPHEN HOLMES & CASS R. SUNSTEIN, THE COST OF RIGHTS: WHY LIBERTY DEPENDS ON TAXES 44 (1999) (“All rights are claims to an affirmative governmental response.”).

that everyone can realize their own capabilities, in their own ways, to flourish and engage in the activities they choose as autonomous agents.

Although past measures, such as the Americans with Disabilities Act, may not have restricted themselves entirely to a ‘negative freedom’ conception of rights, the limiting conception of ‘negative freedom’ still casts its shadow over the landscape of disability law today.¹⁹² With the *Americans with Abilities Act*, we hope to put a capabilities-approach to disability front and center, and see what light such an approach can shed on much of the overlooked terrain of past disability rights law.¹⁹³

B. The Capabilities-Approach and Disability Rights

Disability rights theorists were among the first to take up the capabilities-approach. Some ethicists worried that a focus on objective capabilities threatens to overstate the negative relationship between disability and well-being, and so appears hostile toward disability compared to more traditional rights-based accounts. Yet, critical disability theorists have helped develop the capabilities-approach into a more nuanced picture of the capabilities constitutive of real freedom. As Adrienne Asch and David Wasserman note:

“Those who maintain that disability forecloses opportunity, and that any foreclosed opportunity diminishes life, focus too narrowly on the activity and do not see it as a means to an end, e.g., . . . walking instead of mobilizing or exploring; talking instead of communicating. . . .” [M]uch of what we value in seeing, talking, and walking is instrumental. We value them as ways of achieving communication with other people, reading, and moving from place to place, are themselves be bearers of intrinsic value.¹⁹⁴

¹⁹² See generally FINS, RIGHTS COME TO MIND, *supra* note 2 (discussing the common conception of disability as a lack of freedom).

¹⁹³ In making this call to re-imagine the legal rights of Americans with disabilities, we echo a similar movement in medical ethics to conceive of health not just in terms of a negative ‘absence from disease’ and toward a more holistic picture centered on promoting all the capacities required for a full and flourishing life. See FINS, RIGHTS COME TO MIND, *supra* note 2, at 309.

¹⁹⁴ David Wasserman, Adrienne Asch, Jeffrey Blustein & Daniel Putnam, *Disability: Health, Well-Being, and Personal Relationships*, STAN. ENCYCLOPEDIA PHILOSOPHY, <https://plato.stanford.edu/entries/disability-health/> [<https://perma.cc/5HYC-BUY7>] (quoting Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315, 327 (2003)).

General capabilities, like communication or mobility, involve a wide variety of more specific underlying capacities.¹⁹⁵ One might communicate to friends through means of email, speech, or writing. Others might decide to travel downtown by foot, by train, or by car. Because a fundamental capability like communication or mobility can be realized in multiple ways, a focus on *typical* agents, and the ways that they typically choose to communicate or travel, can mask the ways that Americans with disabilities exercise the relevant fundamental capability.¹⁹⁶ Even immutable disabilities do not translate into an immutable loss of capabilities. Walking is not the same as mobility—and just because paraplegia may preclude someone from walking does not mean it excludes the potential to engage in mobility through other means. Similarly, speech is not the same thing as communication, and an inability to speak does not exclude the possibility of communication through other means. These disabilities constitute ‘impairments’ only when we focus on the typical mechanism for realizing the more fundamental capability.¹⁹⁷

An *Americans with Abilities Act* would focus on the rights of Americans with disabilities to develop and exercise these fundamental capabilities through a broad variety of novel and atypical mechanisms. It would recognize that the current set of capabilities Americans with disabilities are free to exercise is not inevitable, but rather a product of the choices society makes regarding education, technology, and the environment. They are artifacts of how we choose to build the environment to privilege members of societies who possess certain typical abilities rather than others.¹⁹⁸

Before considering how society can move forward to promote capabilities for Americans with disabilities through new technologies, it is worth looking back at the history of technological development. This history shows that the perceived lack of capabilities for Americans with disabilities is often the result of a society that focuses its resources on expanding the capabilities of Americans without disabilities at the expense of those with disabilities. Our society

¹⁹⁵ Wasserman et al., *supra* note 194 (“[E].g., [visual instead of aesthetic pleasure;] walking instead of mobilizing or exploring; talking instead of communicating.” (quoting Asch, *supra* note 194, at 327)).

¹⁹⁶ For more, see Hilary Putnam, *Psychological Predicates*, in *ART, MIND, AND RELIGION* 37, 37 (W.H. Capitan & D.D. Merrill eds., 1967) (introducing the rules of analytical philosophers).

¹⁹⁷ See, e.g., ELIZABETH BARNES, *THE MINORITY BODY: A THEORY OF DISABILITY* (2016) (evaluating different models of disability); Rosemarie Garland-Thomson, *Integrating Disability, Transforming Feminist Theory*, *NWSA J.*, Autumn 2002, at 1, 1 (introducing feminist disability theory).

¹⁹⁸ See, e.g., Ron Amundson, *Disability, Handicap, and the Environment*, 23 *J. SOC. PHIL.* 105, 109 (1992) (“The opportunities which are lost to a disabled person are to be attributed not only to the species-atypicality of the person’s biology, but also to the architectural design of the buildings in which some of those opportunities reside.”); see also Gregory Antill, *Agency, Akrasia, and the Normative Environment*, 5 *J. AM. PHIL. ASS’N* 321 (2019) (introducing the connection between the normative environment and agency).

thinks to provide ramps or auditory crosswalk signals for the visually impaired as an example of its beneficence. This attitude fails to recognize that, in designing the built environments as it did, it was the society itself that, through its choices (such as installing light-based crosswalks), forced persons with disabilities to bear the mobility costs to begin with. This choice benefitted those with typically-realized mobility capabilities. As Amartya Sen observed with regret in 2009, despite his first formulating the capabilities-approach in the 1970s, this societal lack of self-awareness still persists today.¹⁹⁹ What capabilities are required for equality of access is in large part a product of the built environment and prior choices society has made.

In light of this ‘unshared burden’ it is clear that, even within the space of a ‘negative liberty’ conception of rights, much work remains. Job discrimination against an individual because of disability involves a lack of freedom for the employee to engage in meaningful work. In a country of built environments, the lack of freedom for those with mobility impairments to enter a public space because that space was constructed with stairs and not ramps involves a rights violation that would be cognizable even on a ‘negative liberty’ conception of freedom. Misdiagnosed individuals with locked-in-syndrome and disorders of consciousness, who may be subjected to surgery without analgesics, are suffering because of interference from others, even if that interference is well-meaning. Therefore, they have claims even under a limited conception of negative rights.

The time has come to expand our focus, moving outward from an attempt to prevent the violation of the negative rights of Americans with disabilities, and toward an effort to vindicate the positive rights of Americans with disabilities. To do so, we should ensure that society lives up to its obligation to help all Americans develop and exercise their full capabilities. This will allow them effectively to realize the American promise of life, liberty, and the pursuit of happiness, an aspirational vision of potentiality.

In particular, as the preceding discussion suggests, a focus on a capabilities-approach to the rights of Americans with disabilities leads naturally to a focus on several areas of emphasis. These include technological development, correlative infrastructure development, and accompanying enforcement that helps promote and ensure the technology’s dissemination.

¹⁹⁹ AMARTYA SEN, *THE IDEA OF JUSTICE* 259–60, 296 (2009) (“Given what can be achieved through intelligent and humane intervention, it is amazing how inactive and smug most societies are about the prevalence of the unshared burden of disability.”).

C. The Right to Technological Innovation

Under a capabilities-approach, society has an obligation to take positive steps to promote the fundamental capabilities—like mobility or communication—that all citizens need to flourish. We recognize that the number of fundamental capabilities each citizen can exercise is not an immutable feature of the world, but rather, a function of how many alternative paths exist to the same fundamental capability. Society can fulfill its obligation by promoting alternative paths where they exist and creating more paths in the future where they do not. Although some routes are natural, many are the result of technological innovation. The invention of wheels, motors, and flight all dramatically expanded the possible paths to mobility, just as the invention of the telephone, the computer, and fMRIs²⁰⁰ all dramatically expand the possible paths to communication, and eventually, community reintegration. Importantly, many of the most promising technological paths are neither natural capacities nor external assistive technology. Rather, they represent paths within the emerging field of embedded technology, such as DBS, neuroprosthetics, and other brain-computer interfaces that either promote brain plasticity to create alternative neurological pathways to realize capacities²⁰¹ or provide novel paths to reacquire capabilities like motor control.²⁰² To see this point more concretely, we will consider some of the technologies canvassed in the previous sections, and highlight their role in realizing the right to communicative capacities for individuals with moderate-to-severe brain injuries.

One fundamental capability underlying the ability to assert rights is the capability for communication.²⁰³ Communication is required to assert one's preferences and to form relationships with one's friends and family. Communication through voting is required to assert one's rightful place in collective decision-making, and the ability to communicate one's basic needs may very well be required to assert one's right to life itself.²⁰⁴ Communication is essen-

²⁰⁰ See Shapiro, *supra* note 54, at 530–34.

²⁰¹ Ronald P. Endicott, *Species-Specific Properties and More Narrow Reductive Strategies*, 38 ERKENNTNIS 303, 312 (1993).

²⁰² For an overview, see Sara Goering & Eran Klein, *Embedding Ethics in Neural Engineering: An Integrated Transdisciplinary Collaboration*, in A GUIDE TO FIELD PHILOSOPHY: CASE STUDIES AND PRACTICAL STRATEGIES 17, 17 (Evelyn Brister & Robert Frodeman eds., 2020) (exploring the “ethical implications of innovative neural engineering research and development”).

²⁰³ See Shapiro et al., *supra* note 7, at 544; see also FINS, RIGHTS COME TO MIND, *supra* note 2, at 292.

²⁰⁴ See FINS, RIGHTS COME TO MIND, *supra* note 2, at 272–73 (“To ensure that the fate of the next generation of minimally conscious patients is better . . . neuroscience will need to enable [individuals with brain injuries] to communicate and show that they are here, and deserve a hearing. Science needs to enable them to more fully demonstrate, through their interactions, that they remain part of a human community, a community that is bound together through communication . . .”).

tial in discussing and managing medical care, as it allows individuals to participate in their care and help direct their treatment.²⁰⁵ In a world of digital spaces, communication can constitute a form of mobility. Even if one cannot physically move, communication, in conjunction with video messaging technology, allows one to join the outside community and stay connected to those in other places. The capability of communication is thus key to being active in communal life, and communication can be considered the heart of community.

For Americans with disabilities, exercising this capability is not always straightforward. For those with cognitive disabilities, communication may require specialized education or speech therapy. For those who are sight- or hearing-impaired, it can necessitate access to alternative communicative media. For many of those with disabilities, communication requires technological innovations. For instance, non-invasive neuroprosthetics like eye-trackers and wordboards allow individuals with reduced motor function, such as some in the MCS, to spell out words to communicate with their caretakers and loved ones. More invasive modalities, such as in-dwelling BCIs, can allow interfacing with other technologies, such as word processing or vocalization software. All of these modalities enable some form of limited communication, mediated through a technological interface.

This focus on capacities helps center the importance of the technological innovations we have discussed thus far. Under a capabilities-approach, society has an obligation to ensure that every American has the capability to communicate, both as a fundamental right, and as a pre-requisite to asserting other rights to exercise further capabilities. The AWAA specifically requires accessibility to and implementation of the necessary technology for ensuring that every American can exercise their varied communicative capabilities as part of a right, rather than a benefit. This is a departure from the ADA, bringing the AWAA more in line with international efforts.²⁰⁶

If we are positively obligated to help people realize their capabilities, rather than negatively obligated to avoid restricting an agent's exercise of their capabilities, then we have to ensure that as many paths to those capabilities exist as possible. This requires creating a system that encourages the imagining of new technologies and new pathways, the development of those new technologies, their dissemination, and the creation of an environment where those technologies will enable people with disabilities to use them to pursue their goals and flourish.

²⁰⁵ See Lawrence et al., *supra* note 7, at 172.

²⁰⁶ See generally FINS, RIGHTS COME TO MIND, *supra* note 2 (noting the limitations of the ADA surrounding technology requirements).

Taken seriously, this means a commitment to disability rights involving a substantial commitment to promoting a variety of new technologies for health, communication, mobility, and more. Further, this requires the recognition that a choice to pursue only those technologies that further the freedoms of the non-disabled is every bit as discriminatory against Americans with disabilities as is the refusal to grant Americans with disabilities access to the technologies and resources we have today. Both equally prevent individuals with disabilities from achieving the ends that their fellow Americans are allowed to pursue.

IV. WHAT IS THE AWAA?

The ADA was a seminal step forward for disability rights advocates, but the historical marginalization of and discrimination against disabled Americans meant that it mainly contemplated remedial measures. These were quickly dated by the available technologies. The ADA provided scarce resources to accomplish the lofty goals of disability rights advocates and failed to account for the fast pace of future technological advances.

New legislation offers the opportunity to fill existing gaps, while starting a shift for the disability community from the vindication of rights to the advancement of capabilities. Vital to goals of rehabilitation, reintegration, and nurturing capabilities, are promoting new medical advances in diagnostic and assistive technology, making sure that these advances are safe and effective, and that such technologies not only make it to market, but into the hands (and minds) of those with disabilities. This will involve both the creation and dissemination of advanced technologies, such as those discussed in Part I. An AWAA should also help foster a supportive ecosystem for use of the necessary technology, so that individuals with disabilities can begin to reintegrate into their communities and flourish.

We remain focused on those with moderate-to-severe brain injuries, and the technologies that can one day help this population. Brain injuries continue to serve as an example of how new legislation, like the AWAA, can holistically promote human flourishing. We by no means intend, however, to limit the AWAA just to those with brain injuries. Indeed, the lessons and examples of those with brain injury should be generalized to other populations of disabled individuals who can benefit from advanced diagnostic and assistive technology. Section A of this Part lays out the potential framework of the AWAA.²⁰⁷ Section B then discusses the role that technology will play in the AWAA.²⁰⁸ Lastly, Section C explains the impact the AWAA will have on various stakeholders.²⁰⁹

²⁰⁷ See *infra* notes 210–224 and accompanying text.

²⁰⁸ See *infra* notes 225–296 and accompanying text.

²⁰⁹ See *infra* notes 297–309 and accompanying text.

A. Pillars of an AWAA

The AWAA should strive to facilitate both the advancement of persons with a moderate-to-severe brain injury and the innovations that may serve them. Although our goal is not to provide an exact blueprint for every facet of new legislation, there are certain elements that are essential to the envisioning of an AWAA, and serve as pillars when considering novel legislation.

Perhaps the most important element of the AWAA is the promotion of assistive technology that will enable individuals with disabilities to advance their own capabilities and reintegrate into their communities. Because technologies will increasingly become integral to the ability of those with disabilities to recognize their capabilities, it is essential that an AWAA maintain a forward focus, so that it can support the promotion and distribution of necessary technology, not just when it is enacted, but well into the future.

To create an enduring ecosystem for new assistive technology, the AWAA should focus on the three stages of medical technological development: creation, dissemination, and evolution. To develop a robust network, the AWAA should direct its support to individual patients, their communities, and institutions, as well as government agencies.

Due to the political realities of its era, the design of the ADA was employment focused.²¹⁰ Economic empirics, however, demonstrate that the ADA has not been successful along many employment metrics.²¹¹ This failure indicates that a universalist approach that provides comprehensive in-home care, for example, may more fully serve the educational and social needs of disabled people. Further, promoting new assistive technology development and adoption may be a better societal investment. Indeed, the universalist approach should both enlarge the tax base and empower the stated beneficiaries of the law. Such a holistic approach can better shift focus on prospectively promoting capabilities, rather than retrospectively vindicating rights.

On the agency side, the ADA has prompted disjointed initiatives that fail to catch all people with disabilities adequately in the promised safety net.²¹² An AWAA offers the chance to take a holistic view of supporting the government agencies that help protect and serve those with disabilities. Part of this is the recognition that different agencies are far too often siloed from each other. Therefore, a coordinating group might help bridge the different enforcement

²¹⁰ Bagenstos, *supra* note 118, at 6.

²¹¹ Kanter, *supra* note 113, at 831; Acemoglu & Angrist, *supra* note 114, at abstract; Picker, *supra* note 114.

²¹² See Shapiro et al., *supra* note 7, at 553–57 (detailing the structure of the ADA and roles of different agencies).

and managerial streams to design and implement a more effective system of disability rights monitoring and enforcement.

The AWAA should promote an enforcement model that is collaborative and most critically proactive. One such model is collaborative governance.²¹³ Collaborative governance argues for a model “that views the administrative process as a problem-solving exercise in which parties share responsibility for all stages of the rule-making process, in which solutions are provisional, and in which the state plays an active, if varied, role.”²¹⁴ Scholars have described a collaborative governance framework for the ADA as a model that retains adjudication options but relies on self-evaluations, accommodations plans grounded in individual communities’ needs,²¹⁵ flexible solutions with agency and court facilitation,²¹⁶ and a broadening of the EEOC’s process-based regulatory approach for reasonable accommodations claims.²¹⁷

Collaborative governance is not widespread in civil rights frameworks because civil rights enforcement is traditionally reliant on bureaucracy, prohibitions, and litigation.²¹⁸ In the disability rights space, however, collaborative governance is particularly well-suited for legislation. A litigation-centric civil rights enforcement model will often result in an “enforcement gap” due to a lack of capacity and inherent lag time.²¹⁹ On the other hand, a proactive, collaborative model does not rely on the backwards-looking, adversarial system to guarantee civil rights for individuals with disabilities. Similarly, scholars have argued that disability rights legislation “incorporate[es] a vision of distributive justice” in which costs are borne by actors (public entities, owners of small

²¹³ The collaborative governance model challenges “‘traditional’ regulation, whereby certain enumerated practices are directly prohibited and a centralized enforcement agency implements and enforces the law, usually through adversarial litigation by that entity or by private actors.” Michael Waterstone, *A New Vision of Public Enforcement*, 92 MINN. L. REV. 434, 481–82 (2007).

²¹⁴ Jody Freeman, *Collaborative Governance in the Administrative State*, 45 UCLA L. REV. 1, 6, 22 (1997) (outlining the collaborative governance model as: “1. A problem-solving orientation”; “2. Participation by interested and affected parties in all stages of the decision-making process”; “3. Provisional solutions. Rules are viewed as temporary and subject to revision”; “4. Accountability that transcends traditional public and private roles in governance”; and “5. A flexible, engaged agency” (emphases omitted)).

²¹⁵ Waterstone, *supra* note 213, at 492–93.

²¹⁶ *Id.* at 493.

²¹⁷ *Id.* at 495; see 29 C.F.R. § 1630.2(o)(3) (2007).

²¹⁸ See Olatunde C.A. Johnson, *Overreach and Innovation in Equality Regulation*, 66 DUKE L.J. 1771, 1776–77 (2017) (“Though it may be familiar in other regulatory contexts, this mode of regulation is less familiar in the civil rights context, which has depended on prohibitions and traditional bureaucratic use of federal power.”); Waterstone, *supra* note 213, at 481–82 (“[T]his body of work challenges the predominance of ‘traditional’ regulation, whereby certain enumerated practices are directly prohibited and a centralized enforcement agency implements and enforces the law, usually through adversarial litigation by that entity or by private actors.”).

²¹⁹ Waterstone, *supra* note 213, at 479 (“[E]nforcement agents—whether public or private—will never be able to bring every even potentially meritorious case.”).

businesses, employers) who may not intend to discriminate against people with disabilities.²²⁰ A focus on building collaborative solutions—rather than assigning blame—may better serve the goals of legislation by allowing people to work together to serve common ends and help individuals move forward with life goals.²²¹

In addition, although remedying past harms is important, a collaborative governance model will help the AWAA work toward correcting harmful norms and stigmas, with the goal of preventing discrimination before it occurs. A collaborative model will offer individuals with disabilities a greater voice in the governance process.²²² Enhanced community involvement will help stakeholders develop solutions that are responsive to individual needs and local contexts.²²³ In addition, the reliance on information sharing within a collaborative governance model allows for successful processes and solutions to spread from entity to entity.²²⁴

Dovetailing into the ADA's enforcement regime, the main incentives provided by the AWAA should be in the form of carrots, not sticks. New legislation should aim both to reduce barriers for technologies to enter the market while also creating incentives for developers to invest in the technology space, such as regulatory and patent advantages and specific funding allocations. To ensure the promise of the technologies is realized, the AWAA should strive to support rehabilitation and reintegration of those with disabilities by promoting technology-integrated housing and accessible education.

The AWAA's overarching goals of promoting rehabilitation and reintegration would be better served by taking these holistic views of a disabled individual's life, as well as the technologies and institutions that support them.

²²⁰ *Id.* at 487 (citing Julie Chi-hye Suk, *Antidiscrimination Law in the Administrative State*, 2006 U. ILL. L. REV. 405, 420–23).

²²¹ *Id.*; see Mary Crossley, *Infected Judgment: Legal Responses to Physician Bias*, 48 VILL. L. REV. 195, 302 (2003) (acknowledging that in the medical discrimination context, a civil-rights enforcement model such as the ADA focuses on “backwards-looking . . . ‘sanctioning’” (quoting Sidney D. Watson, *Race, Ethnicity and Quality of Care: Inequalities and Incentives*, 27 AM. J.L. & MED. 203, 219 (2001))).

²²² See Jaime Alison Lee, “*Can You Hear Me Now?*”: *Making Participatory Governance Work for the Poor*, 7 HARV. L. & POL’Y REV. 405, 412 (2013) (noting that in its ideal form, “New Governance” grants marginalized groups “greater access to decision-making” and allows individuals to engage in social justice reform without the “procedural and substantive hurdles of litigation” (citing Waterstone, *supra* note 213, at 438–39, 479)).

²²³ *Id.* (noting that the benefits of “New Governance,” in its ideal form, includes making social programs more responsive to individual groups’ needs). *But see* Lisa T. Alexander, *Stakeholder Participation in New Governance: Lessons from Chicago’s Public Housing Reform Experiment*, 16 GEO. J. ON POVERTY L. & POL’Y 117, 121 (2009) (arguing that in the context of Chicago public housing reform, it was “difficult for traditionally marginalized stakeholders” to achieve rights and benefits from collaboration without “rights-based legal protections” and processes).

²²⁴ Waterstone, *supra* note 213, at 482.

Across fields, many government agencies have implemented programs that aim to promote innovation in particular areas and help establish widespread access to certain services and technology.

The AWAA will build off these existing policy structures to create a comprehensive regulatory picture that harmonizes innovation and adoption of reintegration technology to serve disabled individuals, such as individuals with a moderate-to-severe brain injury. Complementing the enforcement regime created by the ADA, an AWAA should aim proactively to incentivize investment in assistive technology and support individuals, institutions, and agencies in promoting widespread implementation for such technologies.

B. The AWAA: A Regulatory Tapestry to Promote Technology

Thirty-one years after the ADA was passed, we envision a comprehensive regulatory schema that provides a productive framework for facilitating rehabilitation and reintegration for those with moderate-to-severe brain injuries. Although there is a variety of relevant medical technology we could discuss, we will only consider regulation and technology aimed at those with moderate-to-severe brain injuries. An AWAA should help forge a robust patient assistance network and a healthy technology ecosystem.

Although enforcement is an important element of legislation, it is essential to remember that enforcement is a form of remediation. Ideally, the AWAA is designed to create a supportive environment that holistically supports those with disabilities. In an ideal world, enforcement would be a secondary concern, and the AWAA is designed to ensure compliance prospectively.

Subsection 1 of this section will discuss how the AWAA can support the creation of new technologies and champion widespread adoption by eradicating barriers to access.²²⁵ New legislation should take a universal view toward creating an enduring technological ecosystem by providing support throughout the product life cycle. This involves considering the development of new technology, the dissemination of that technology, and efforts to remain on the cutting edge of evolving possibilities.

Subsection 2 of this section will focus on the stakeholders and individuals impacted by our new legislation.²²⁶ In both subsections, we will discuss existing measures taken by regulatory agencies and support networks to promote growth in specific technology areas. We draw on these examples to explore how an AWAA could build from them and promote innovation and access to brain injury technologies, and to consider lessons that can apply to other technologies for different populations in the future.

²²⁵ See *infra* notes 227–266 and accompanying text.

²²⁶ See *infra* notes 267–296 and accompanying text.

1. Technology Ecosystem

This Subsection will first discuss the funding for research and ethics that should be implemented into the AWAA.²²⁷ Next, we will explore potential initiatives to de-risk innovation in the area.²²⁸ Then, this Subsection will highlight the necessary dissemination of new technology under the AWAA.²²⁹ Lastly, we will consider how the AWAA must be flexible enough to account for future technological inventions.²³⁰

a. Research Funding and Ethics

The National Institutes of Health (NIH), the National Science Foundation (NSF), and other agencies, including the Department of Defense (DOD), provide research grants for science. Although they prioritize and deprioritize areas of research through their distribution of allocated funds, Congress has historically also taken action to promote research in certain areas of interest.²³¹ For example, almost all of NIH's funding is provided in the annual Departments of Labor, Health and Human Services, and Education and Related Agencies Appropriation Act, over which it has large discretion.²³² Despite this, it has a mandatory budget authority for Type 1 diabetes research through Section 33B of the Public Health Service Act.²³³ This program has been very successful, directing more than \$2.76 billion toward Type 1 diabetes research, resulting in a plethora of medical innovations for this patient group as a result.²³⁴ Because clinical studies require long time frames, the special diabetes fund has been vital in diabetes research over the last two decades.²³⁵

²²⁷ See *infra* notes 231–235 and accompanying text.

²²⁸ See *infra* notes 236–248 and accompanying text.

²²⁹ See *infra* notes 249–261 and accompanying text.

²³⁰ See *infra* notes 262–266 and accompanying text.

²³¹ See, e.g., Kellie Moss & Jennifer Kates, *The U.S. Congress and Global Health: A Primer*, KFF (Nov. 11, 2021), <https://www.kff.org/global-health-policy/report/the-u-s-congress-and-global-health-a-primer/> [<https://perma.cc/C5C4-UPK2>] (explaining Congress's role in health policy); *A Brief Guide to the Federal Budget and Appropriations Process*, AM. COUNCIL ON EDUC., <https://www.acenet.edu/Policy-Advocacy/Pages/Budget-Appropriations/Brief-Guide-to-Budget-Appropriations.aspx> [<https://perma.cc/AQ44-KPF2>] (providing insight into the federal budget process).

²³² H.R. 7614, 116th Cong. (2020).

²³³ KAVYA SEKAR, CONG. RSCH. SERV., R43341, NATIONAL INSTITUTES OF HEALTH (NIH) FUNDING: FY1996-FY2022, at 3 (2021), <https://crsreports.congress.gov/product/pdf/R/R43341> [<https://perma.cc/7SXY-JB5M>].

²³⁴ Nat'l Inst. of Diabetes & Digestive & Kidney Diseases, *About the Special Diabetes Program*, NAT'L INST. OF HEALTH, <https://www.niddk.nih.gov/about-niddk/research-areas/diabetes/type-1-diabetes-special-statutory-funding-program/about-special-diabetes-program> [<https://perma.cc/L37V-DQXV>].

²³⁵ *Id.*

Through the AWAA, Congress could create a mandatory budget authority for research into moderate-to-severe brain injuries that could promote similar advances at the early stages of basic research. These funds could prove foundational in creating the long-term infrastructure to support development of new technologies for rehabilitation and reintegration akin to the advances made in addressing diabetes. Additionally, creating an annual mandatory budget authority could help curb political pressures. We believe this could receive bipartisan support.

b. Financially and Scientifically De-Risking a Biomedical Venture

After preclinical data proves promising in clinical trials, rehabilitation and reintegration technology will need to be developed in a commercial setting. This requires significant capital investments to develop the safety and efficacy profile of the given technology. One area for potential assistance would be taking steps to de-risk the scientific or financial investment to incentivize new innovations and help those with moderate-to-severe brain injuries.

Assistive technologies that qualify as medical devices need to undergo FDA approval before entering the market. The FDA has previously created incentive programs for different underserved patient populations, such as the orphan drug designation for therapies that address small patient populations and priority review vouchers for neglected “tropical diseases, rare pediatric diseases, [and] medical countermeasures.”²³⁶ Orphan Drug designation gives market exclusivity, faster review, more feedback from regulators on study design, and a more lenient cost-benefit analysis.²³⁷ This was specifically designed to promote investment in an area that would otherwise not be served by market forces, because therapies would likely not be economically viable to develop. The Orphan Drug Act (ODA) drove significant investment to otherwise underfunded research areas.²³⁸ Drug companies, however, have been able to charge

²³⁶ U.S. GOV'T ACCOUNTABILITY OFF., DRUG DEVELOPMENT: FDA'S PRIORITY REVIEW VOUCHER PROGRAMS 2 (2020), <https://www.gao.gov/assets/gao-20-251.pdf> [<https://perma.cc/SF2U-W2MP>].

²³⁷ MIKE LANTHIER, OFF. OF THE COMM'R, U.S. FOOD & DRUG ADMIN., INSIGHTS INTO RARE DISEASE DRUG APPROVAL: TRENDS AND RECENT DEVELOPMENTS 3 (2017), <https://www.fda.gov/files/about%20fda/published/Insights-into-Rare-Disease-Drug-Approval--Trends-and-Recent-Developments-%28October-17--2017%29.pdf> [<https://perma.cc/9JNR-RZTR>].

²³⁸ Sarah Jane Tribble & Sydney Lupkin, *Drugs for Rare Diseases Have Become Uncommonly Rich Monopolies*, NPR (Jan. 17, 2017), <https://www.npr.org/sections/health-shots/2017/01/17/509506836/drugs-for-rare-diseases-have-become-uncommonly-rich-monopolies> [<https://perma.cc/7H95-DTXU>] (describing the financial impact of the Act on research and development of drugs); Zachary Brennan, *FDA: 2019 Continues Uptick in Orphan Drug Approvals*, REGUL. AFFS. PROS. SOC'Y (Jan. 6, 2020), <https://www.raps.org/news-and-articles/news-articles/2020/1/fda-2019-continues-uptick-in-orphan-drug-approval> [<https://perma.cc/6NH7-UKK3>] (explaining the Act's potential for helping to develop drugs for rare diseases).

exorbitant prices for rare disease medication and have often expanded their market by getting secondary approvals, resulting in an overuse of the system.²³⁹

Another set of FDA incentive initiatives, the Priority Review Voucher (PRV) programs, enable Congress to direct private funding to under-resourced research areas.²⁴⁰ They do so by issuing a voucher to expedite FDA review of a future drug for companies that successfully develop a therapy. Notably, these vouchers can be sold to other companies desiring expedited FDA review. The result is private capital doing the monetary legwork of this incentive program. The vast majority of PRVs originate from rare pediatric disease therapies and can sell for as much as \$350 million.²⁴¹

Similar policy structures could be adopted to promote innovation and spur investment in technologies aimed at those with moderate-to-severe brain injuries. Though the Orphan Drug Act has certainly driven investment, the perverse market incentives it creates could limit access to assistive technologies if blindly adopted by the AWAA. As such, any incentive program that shadows the ODA's provisions should also incorporate protections, such as price gouging limitations.

A PRV program would be well-suited to incentivize development of brain injury therapies. One of the main benefits of PRVs is that the incentive kicks in only after the therapy has entered the market, ensuring the technology reaches patients. This delayed incentive structure, however, may not adequately incentivize smaller biotech firms that need earlier capital investments to complete their clinical trials. Additionally, as outstanding evergreen PRVs begin to collect in the market, the value sharply declines.²⁴² Creating another avenue to earn PRVs for brain injury therapies could harm the value for all PRVs, making the incentive system less attractive. Nonetheless, a combination of a voucher program and an ODA with protections would likely drive significant investment towards brain injury research.

To secure investment, most new assistive technology will require intellectual property protection in the form of patents granted by the United States Pa-

²³⁹ Tribble & Lupkin, *supra* note 238 (noting that seven of the top ten best-selling drugs in 2015 were orphan drugs). In fiscal year 2019, over 40% of the drugs approved by the FDA were orphan drugs. Brennan, *supra* note 238.

²⁴⁰ See U.S. GOV'T ACCOUNTABILITY OFF., *supra* note 236, at 2.

²⁴¹ Alexander J. Varond, *Priority Review Voucher Updates: Valuation, Eligibility, Reauthorization*, HYMAN, PHELPS & MCNAMARA FDA L. BLOG (Aug. 30, 2015), <https://www.fdalawblog.net/2015/08/priority-review-voucher-updates-valuation-eligibility-reauthorization/> [<https://perma.cc/D6T8-2P2H>] (tracking the recent developments in the PRV program).

²⁴² Michael McCully, *What Happened to the Value of Priority Review Vouchers (PRV)?*, LOCUST WALK (Mar. 2, 2017), <https://www.locustwalk.com/what-happened-to-the-value-of-priority-review-vouchers-prv/> [<https://perma.cc/5MWS-ADSX>] (“As much as [sellers] may have desired to maximize the value of their PRV based on the buyers NPV, that is virtually impossible to do if the buyer can find an alternate seller to negotiate with.”).

tent and Trademark Office (USPTO). There is a fast-track review process for “green” technologies and patent terms are generally restored for pharmaceutical innovations.²⁴³ The Patent Term Restoration Act already covers medical devices, which most rehabilitation technologies would be classified as, but additional de-risking policy incentives can be provided.²⁴⁴ Patents covering technologies that assist with moderate-to-severe brain injuries can be promoted by the USPTO through fast tracking the review process and waiving the additional costs usually required by the “Track I” priority review.²⁴⁵ The USPTO could also implement a priority review voucher program, such as the one described above in the context of the FDA, thereby shifting the financial burden onto the private sector. Empirical evidence suggests that the ADA’s requirements in certain fields resulted in an uptick in assistive technology patents and it is likely that an AWAA would have a similar effect by promising a viable economic landscape for assistive technologies.²⁴⁶

One of the largest financial de-risking steps for biomedical innovations is the Centers for Medicare and Medicaid Services (CMS) reimbursement rate. This rate setting helps companies gauge how much baseline return on their investment they can hope to see from Medicare and Medicaid, which many disabled individuals rely upon.

Although the ADA did not specifically contemplate this at the outset, following the Supreme Court’s *Olmstead* decision in 1999, Medicaid pivoted from only reimbursing long-term care rendered in medical facilities to supporting care provided in personal and community contexts.²⁴⁷ Because of the shift in reimbursement policy, long-term care became accessible to many more people

²⁴³ Cathie Kirik, *Accelerated Review of Green Technology Patent Applications*, INVENTORSEYE (U.S. Pat. & Trademark Off., Alexandria, Va.), June 2011, <https://web.archive.org/web/20210812004500/https://www.uspto.gov/learning-and-resources/newsletter/inventors-eye/accelerated-review-green-technology-patent> [<https://perma.cc/NHD9-3Q5H>].

²⁴⁴ CDER Small Bus. & Indus. Assistance, *Small Business Assistance: Frequently Asked Questions on the Patent Term Restoration Program*, U.S. FOOD & DRUG ADMIN. (Feb. 4, 2020), <https://www.fda.gov/drugs/cder-small-business-industry-assistance-sbia/small-business-assistance-frequently-asked-questions-patent-term-restoration-program> [<https://perma.cc/45B8-Z2V4>].

²⁴⁵ *USPTO’s Prioritized Patent Examination Program*, U.S. PAT. & TRADEMARK OFF., <https://www.uspto.gov/patent/initiatives/usptos-prioritized-patent-examination-program> [<https://perma.cc/5LWQ-9NQZ>] (“Track One gives your application special status with fewer requirements than the current accelerated examination program and without having to perform a pre-examination search.”).

²⁴⁶ Heidi M. Berven & Peter David Blanck, *The Economics of the Americans with Disabilities Act Part II—Patents and Innovations in Assistive Technology*, 12 NOTRE DAME J.L. ETHICS & PUB. POL’Y 9, 18–19 (1998) (“These core findings suggest that ADA implementation is affecting the AT consumer market in economically positive ways and is creating profit-making opportunities for inventors and manufacturers in the sector.”).

²⁴⁷ COMM. ON HEALTH CARE UTILIZATION & ADULTS WITH DISABILITIES, THE NAT’L ACADS. OF SCIS. ENG’G MED., *HEALTH-CARE UTILIZATION AS A PROXY IN DISABILITY DETERMINATION* 40 (2018), https://www.ncbi.nlm.nih.gov/books/NBK500102/pdf/Bookshelf_NBK500102.pdf [<https://perma.cc/3LSC-Y5VA>].

and promoted the advent of more innovation in at-home technologies. An AWAA should similarly restructure CMS reimbursement such that rehabilitation and reintegration technologies are significantly reimbursable, thus ensuring financial stability for innovators and access to technologies once developed.

Throughout the technology development process and beyond, innovator companies must grapple with tax burdens. By shifting the tax burden of researchers, developers, and implementers, the AWAA can promote entry into the rehabilitation space and help companies redistribute resource allocation into further discovery and development. The Orphan Drug Act is an example of a successful tax reimbursement policy that has drawn innovators into the research space.²⁴⁸ Much of the research cost associated with developing an orphan drug can be applied as a tax credit for companies, thus allowing biomedical innovators to enter the space with reduced financial risk. The main downside is that this incentive structure skews toward prioritizing larger firms that already have the capital needed to develop new assistive technology and thus may cut out start-ups hoping to develop such technology. To circumvent this issue, the AWAA could task the Securities and Exchange Commission (SEC) with easing the process of an initial public offering or subsequent securities requirements for small biotechnology firms making brain injury technology. This would allow them to rely on public markets for the necessary capital to develop their technology fully.

c. Disseminating New Technology

Devising a regulatory framework that helps promote the development of new technologies is only a first step. Without creating pathways for access, such legislation would reserve these publicly-subsidized innovations for only the wealthiest individuals, instead of serving the most vulnerable in our society. Some suggestions for expanding access in an AWAA are provided below to foster dissemination of relevant technologies once they are developed, so they can achieve widespread adoption.

After new technologies are developed, generic versions of medical devices will be critical in ensuring every person can afford them. In the context of drugs, generic entry can reduce the price of brand name medication by 39% with a single competitor, 79% with four generic competitors, and in excess of 95% with six or more competitors.²⁴⁹ It has previously been noted that generic

²⁴⁸ Tribble & Lupkin, *supra* note 238 (noting the Act's success in facilitating the production of drugs targeting rare diseases); Brennan, *supra* note 238 (detailing the continuing increase in approvals of orphan drugs).

²⁴⁹ RYAN CONRAD & RANDALL LUTTER, U.S. FOOD & DRUG ADMIN., GENERIC COMPETITION AND DRUG PRICES: NEW EVIDENCE LINKING GREATER GENERIC COMPETITION AND LOWER GENER-

medical devices face many barriers to market entry, such as a lack of a coherent abbreviated premarket approval pathway akin to the Abbreviated New Drug Application used for generic drugs.²⁵⁰ Because the current regulatory regime incentivizes small recursive changes to devices rather than encouraging equivalency, we suggest adopting an equivalency framework similar to the one created for biosimilars under the Biologics Price and Competition and Innovation Act.²⁵¹ This could be coupled with a 510(k) preemption regime to protect generic manufacturers against tort liability to further entice manufacturers into the space.²⁵²

To promote accessibility, other policy suggestions could be supplemented with price gouging provisions and accessibility plans. The danger of high drug prices resulting from the Orphan Drug regime warrants a companion price gouging limitation, perhaps enforced by the Federal Trade Commission (FTC).²⁵³ Although this would likely fall under the gambit of the existing FTC Act, qualifying as an unfair and deceptive practice, an explicit grant of authority from Congress would bolster any attacks on the FTC's jurisdiction.

In the same vein of facilitating generic entry, the USPTO could build off the generic entry "patent dance" that biosimilars must go through to create an analogous patent dance for generic medical devices.²⁵⁴ Streamlining the process of patent litigation prior to generic entry could provide huge monetary incentives to generic manufacturers creating technology, thus lowering the cost of rehabilitation and reintegration technology.

IC DRUG PRICES 2–3 (2019), <https://www.fda.gov/media/133509/download> [<https://perma.cc/MW5R-ALQX>].

²⁵⁰ Zachary E. Shapiro et al., *Nothing Generic About It: Promoting Therapeutic Access by Overcoming Regulatory and Legal Barriers to a Robust Generic Medical Device Market*, 98 N.C. L. REV. 595, 607 (2020) ("[G]eneric drugs are afforded a range of regulatory and legal protections that are not available to generic medical devices.").

²⁵¹ *Id.* at 613–14, 623–24.

²⁵² *Id.* at 625 (requiring that any "major modification" be presented by the manufacturer to the FDA, and that a potential plaintiff to a liability action demonstrate that the device could have been conceptualized and developed differently).

²⁵³ The FTC has used its powers to stop unfair and deceptive acts to target firms engaging in pandemic price gouging. See Alex Brackett, Kevin Lally, Elizabeth Tyler & Sarah Zielinski, *Price Gouging Enforcement in the Wake of COVID-19: Where Is the FTC?*, JDSUPRA (May 28, 2020), <https://www.jdsupra.com/legalnews/price-gouging-enforcement-in-the-wake-69217/#:~:text=In%20late%20March%2C%20Democratic%20members,down%20COVID%2D19%20price%20gouging> [<https://perma.cc/SBB3-G6YT>].

²⁵⁴ Shapiro et al., *supra* note 250, at 617, 620–27; Kayleigh McGlynn, Grant Rice, Jenny Shmuel & Cheryl Wang, *A Biosimilar's Guide to the BPCIA Patent Dance: Five Key Questions for Every Biosimilar Applicant to Consider*, JDSUPRA (Apr. 20, 2020), <https://www.jdsupra.com/legalnews/a-biosimilar-s-guide-to-the-bpcia-80004/> [<https://perma.cc/YEJ4-9RP2>] (detailing the specifics of the "patent dispute resolution process known as the 'patent dance'").

CMS reimbursement policies can have profound effects on what types of care and technology are available for the general population.²⁵⁵ By making in-home care reimbursable, more people will be able to access the much-needed service.²⁵⁶ CMS could similarly set market priorities for what kinds of assistive technologies should be widely adopted, prompting the dissemination of new technologies. Additionally, CMS can ensure that assistive technology and services are not saddled with unfavorable coverage limits, as it does under the Mental Health Parity and Addiction Equity Act.²⁵⁷ This parity requirement also applies to private insurers regulated by the DOL, who could similarly apply a parity requirement on private insurers for disability services and technology.²⁵⁸

The Federal Communications Commission (FCC) was integral in passing legislation that created closed captioning technology through grants. Then, after noting low market penetrance, it helped pass legislation mandating closed captioning be integrated into all televisions, thus ensuring access.²⁵⁹ By expanding their definitions of utility and relying on the FCC's existing role in integrating assistive technologies into communications media, the FCC could once again be a crucial partner in ensuring that reintegration technologies developed under the auspices of the AWAA become accessible to the populations that need them the most.

The Department of Education (ED) will also be a necessary partner in facilitating the widespread adoption of new technologies. Annually in the United States, nearly half a million children under the age of fourteen endure a traumatic brain injury, and of those, roughly thirty thousand suffer from long-term disabilities.²⁶⁰ Laws like the Individuals with Disabilities Education Act (IDEA) already supplement the gaps in educational protections left by the ADA, but the ED can also participate in the technology and services programs provided by the AWAA. The ED already offers grants to states and educational institutions through the IDEA for intervention services, technology develop-

²⁵⁵ Joseph J. Fins et al., *Whither the "Improvement Standard"?: Coverage for Severe Brain Injury After Jimmo v. Sebelius*, 44 J.L. MED. & ETHICS 182, 182 (2016).

²⁵⁶ COMM. ON HEALTH CARE UTILIZATION & ADULTS WITH DISABILITIES, THE NAT'L ACADS. OF SCIENCES, *supra* note 247, at 40 (noting that CMS is a substantial provider of insurance coverage for long-term care and that long-term care is especially critical for people with disabilities).

²⁵⁷ Ctrs. for Medicare & Medicaid Servs., *The Mental Health Parity and Addiction Equity Act (MHPAEA)*, CMS.GOV, https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/mhpaea_factsheet [<https://perma.cc/4RNM-SYSG>].

²⁵⁸ *Id.*

²⁵⁹ *A Brief History of Captioned Television*, NAT'L CAPTIONING INST., <https://web.archive.org/web/20110719060406/http://www.ncicap.org/caphist.asp> [<https://perma.cc/ZHT4-EZGV>] (detailing that the plan for integration included a transition period and implementation schedule).

²⁶⁰ Mary R. Prasad, Paul R. Swank & Linda Ewing-Cobbs, *Long-Term School Outcomes of Children and Adolescents with Traumatic Brain Injury*, 32 J. HEAD TRAUMA REHAB. E24, E24 (2017).

ment, and assistive technology dissemination.²⁶¹ These grants can be updated to incorporate accommodations standards and provide funds for implementation of technology developed through the AWAA.

d. Evolving with Advances in Technology

One of the major shortcomings of the ADA was the failure of the law to anticipate changes in technology. A holistic view of the technology life cycle should build in structures that recognize and respond to the evolution of technology in general, and assistive technology in particular.

The Department of Education is not only an existing enforcement agency for the ADA, but has also filled in gaps in the ADA safety net. It awards grants to create new technologies and enable assistive technologies to serve a larger population. In 2006, the ED “awarded a grant to [the National Public Radio] . . . to develop accessible radio technology” because radio was one of the few technologies that had yet to be closed-captioned.²⁶² By recognizing a gap in existing technology, the ED was able to extend radio access to people who are deaf and hard of hearing. An AWAA could similarly appoint agencies to keep up with technology developments and ensure that no population or technology area gets left behind.

It is crucial, however, that an AWAA mandates frequent updates to create a regime that is preemptive rather than reactionary. Congress passed the ADA in 1990, prior to the widespread use of the internet. As such, the internet was not treated as a “place of public accommodation” until a 2011 lawsuit against Netflix for its lack of captions on its streaming service.²⁶³ Around the same time, Congress passed the Twenty-First Century Communications and Video Accessibility Act (CVAA) to modernize some elements of the ADA’s tele-

²⁶¹ *About IDEA*, U.S. DEP’T OF EDUC., <https://sites.ed.gov/idea/about-idea/> [<https://perma.cc/PM6N-KA4K>] (detailing the formula and discretionary grants authorized by IDEA).

²⁶² Emily Lenzer & Mary Watkins, *NPR and WGBH’s National Center for Accessible Media Partner to Research and Create Services for Accessible Radio Technology*, NAT’L CTR. FOR ACCESSIBLE MEDIA (Oct. 11, 2006), http://ncamftp.wgbh.org/ncam-old-site/about/news/pr_10112006.html [<https://perma.cc/Y8DM-JE3V>] (“The Accessible Digital Radio Broadcast Services grant, in the amount of \$150,000 for the first year, will help fund an anticipated three-year research and development project to prototype, field test and assess the cutting-edge radio technologies to serve the needs of people with sensory disabilities.”).

²⁶³ Even then, *Cullen v. Netflix*, 880 F. Supp. 2d. 1017 (N.D. Cal. 2012), a concurrent case in a different jurisdiction, came out the other way. Emily Griffin & Jaclyn Leduc, *NAD v. Netflix ADA Lawsuit Requires Captioning for Streaming Video*, 3PLAYMEDIA, <https://www.3playmedia.com/blog/nad-v-netflix-ada-lawsuit-requires-closed-captioning-on-streaming-video/> [<https://perma.cc/EGY6-MN9W>] (Oct. 6, 2021) (providing context to the 2011 lawsuit *National Ass’n of the Deaf v. Netflix, Inc.*, No. 11-cv-30168, 2011 WL 5519883 (D. Mass. Nov. 10, 2011)).

communications provisions.²⁶⁴ Some provisions created interstate funds to supply assistive technology to low-income disabled individuals, while others required captioning on television-broadcasted videos that were also streamed on the internet.²⁶⁵ The Act did not, however, mandate captioning for “programs shown only on the internet.”²⁶⁶ The CVAA, passed five years after the creation of YouTube, did little to bring accessibility law into the modern era. The AWAA should avoid this mistake, by incorporating and funding frequent technology reevaluation intervals and provide appropriations both for evaluating the current state of assistive technology and for partnering with developers to help bridge significant gaps.

2. Support Networks

Turning now to the actors impacted by our proposed Act, it is critical that the AWAA provide support for core stakeholders. This subsection will consider how the AWAA can establish a robust assistance network by supporting: (a) individuals with moderate-to-severe brain injuries;²⁶⁷ (b) their communities and institutions;²⁶⁸ and (c) the government agencies tasked with protecting and serving them.²⁶⁹

a. Individuals

The AWAA should strive to make sure people with moderate-to-severe brain injuries not only have sufficient job opportunities, but have stable shelter, meals, transportation, and access to education and health care.

Housing stability is particularly important for those recovering from moderate-to-severe brain injuries. Under the Obama Administration, the Department of Housing and Urban Development (HUD) started a reentry program for “incarcerated individuals [to assist] with a successful transition to their community after they are released.”²⁷⁰ This program helped with job

²⁶⁴ *21st Century Communications and Video Accessibility Act (CVAA)*, FED. COMM’NS COMM’N, <https://www.fcc.gov/consumers/guides/21st-century-communications-and-video-accessibility-act-cvaa> [<https://perma.cc/TZ5V-GPKM>] (Jan. 27, 2021).

²⁶⁵ *Id.* (describing that certain components of Title I of the Act focused on telecommunications access, and that Title II focused on video programming).

²⁶⁶ *Id.* (“Requires video programming that is closed captioned on TV to be closed captioned when distributed on the Internet . . .”).

²⁶⁷ *See infra* notes 270–278 and accompanying text.

²⁶⁸ *See infra* notes 279–283 and accompanying text.

²⁶⁹ *See infra* notes 284–288 and accompanying text.

²⁷⁰ Cynthia Caporizzo, *Prisoner Reentry Programs: Ensuring a Safe and Successful Return to the Community*, WHITE HOUSE: BLOG (Nov. 30, 2011), <https://obamawhitehouse.archives.gov/blog/2011/11/30/prisoner-reentry-programs-ensuring-safe-and-successful-return-community> [<https://perma.cc/2CUG-598P>].

placement and supportive services in housing placement.²⁷¹ Because many individuals with a brain injury may have been out of the workforce for a long period of time or may need additional support in their search for safe housing, HUD could provide similar reentry services through an AWAA. Additionally, studies note that 25 to 87% of inmates report a history of traumatic brain injury, compared with 10 to 38% in the general population.²⁷² At a cost of over \$30,000 per year to keep an inmate incarcerated, a state government could efficiently reallocate its funds to support at-risk individuals preemptively.²⁷³ It could do so by providing them with supportive housing communities and reintegration through education and work opportunities, all as part of their brain injury rehabilitation.

Similarly, the ED could provide alternative education pathways for individuals with brain injuries to reintegrate into society more fully. Following the switch to large-scale remote schooling during the COVID-19 pandemic, the ED could expand accessibility requirements for learning institutions and their respective broadcast and assignment tools, like Zoom and Canvas, so that people with moderate-to-severe brain injuries can access a wider variety of learning opportunities.

Children with moderate-to-severe brain injuries commonly require classroom accommodations and often need to receive additional tutoring or to repeat a grade.²⁷⁴ Insufficient supervision of academic development following an injury, however, can prevent the identification of brain injury-associated academic issues.²⁷⁵ Lack of oversight prevents students from accessing the full panoply of services they have a right to under federal law.²⁷⁶ Under the AWAA, educational outreach programs to teach parents about the dangers of brain injury and about federal disability rights could help improve utilization of existing resources.

In the era of remote everything—school, work, doctor’s appointments, religious and family gatherings—the AWAA should strive to ensure that people with moderate-to-severe brain injuries are not further segregated from their community. For instance, the ED issued guidelines early in the pandemic informing

²⁷¹ *Id.* (“Specifically, the Strategy calls for supporting post-incarceration reentry efforts by assisting in job placement, facilitating access to drug-free housing, and providing other supportive services.”).

²⁷² Marlana M. Wald, Sharyl R. Helgeson & Jean A. Langlois, *Traumatic Brain Injury Among Prisoners*, BRAIN INJ. PRO., 2008, at 22, 22.

²⁷³ See Annual Determination of Average Cost of Incarceration, 83 Fed. Reg. 18,863 (Apr. 30, 2018) (“The average annual cost to confine an inmate in a Residential Re-entry Center was \$29,166.54 (\$79.69 per day) for FY 2016 and \$32,309.80 (\$88.52 per day) for FY 2017.”).

²⁷⁴ Prasad et al., *supra* note 260, at E30.

²⁷⁵ *Id.*

²⁷⁶ *Id.* (noting the lack of monitoring as “a barrier to accessing appropriate supports”).

schools that the accessibility provisions of the ADA and IDEA were very lenient with regards to remote learning during the pandemic, instead of providing proactive ways to serve impacted students.²⁷⁷ Suffering under these “emergency” guidelines, students already at risk of academically falling behind their peers may have their academic career further stunted. To support such individuals preemptively, the AWAA can integrate an emergency conditions clause that is triggered during a declared emergency, like a pandemic, that elevates certain necessary technologies and services to the standard of “public accommodation.”²⁷⁸

b. Communities and Institutions

The AWAA must create support structures for the communities and institutions where individuals with disabilities are trying to reintegrate. By keeping the different facets of individuals’ lives in mind, beyond workplace accommodations, the AWAA can holistically serve individuals with moderate-to-severe brain injuries in their journey to rehabilitate and reintegrate.

More than three decades after the ADA’s passage, less than eighteen percent of individuals with a disability are employed.²⁷⁹ The Job Accommodation Network (JAN), contractually subsidized from the DOL’s Office of Disability Employment Policy (ODEP), is one resource that tries to help employers learn about their ADA obligations and ways to accommodate employees with brain injuries.²⁸⁰ Because reduced job hiring occurs disproportionately in smaller companies lacking robust accommodations departments, the JAN model can be expanded to provide subsidized consulting. This could include either actual accommodations experts or artificial intelligence-powered chatbots to facilitate business owners in navigating accommodations.²⁸¹ Similarly, small business

²⁷⁷ Press Release, U.S. Dep’t of Educ., Urging States to Continue Educating Students with Disabilities, Secretary DeVos Publishes New Resource on Accessibility and Distance Learning Options (Mar. 21, 2020), <https://portal.ct.gov/-/media/SDE/Digest/2019-20/2020323-USED-Communication.pdf> [<https://perma.cc/E8FV-XV9X>].

²⁷⁸ See *ADA—Findings, Purpose, and History*, *supra* note 103.

²⁷⁹ News Release, Bureau of Lab. Stat., U.S. Dep’t of Lab., Persons with a Disability: Labor Force Characteristics—2020 (Feb. 24, 2021), https://www.bls.gov/news.release/archives/disabl_02242021.pdf [<https://perma.cc/R6GU-72UB>].

²⁸⁰ See *About JAN*, JOB ACCOMMODATION NETWORK, <https://askjan.org/about-us/index.cfm> [<https://perma.cc/RGN7-QRYJ>] (explaining the purpose of the resource in helping with disability employment); *Brain Injury*, JOB ACCOMMODATION NETWORK, <https://askjan.org/disabilities/Brain-Injury.cfm> [<https://perma.cc/AGK7-XJGK>] (covering common questions and accommodations for employers to consider).

²⁸¹ See Acemoglu & Angrist, *supra* note 114, at 2 (noting the reduction in employment of disabled individuals occurred more in medium-sized employers than large or small employers); Picker, *supra* note 114 (“[M]id-sized companies show the most pronounced decrease in hiring the disabled.

grants through the Small Business Innovation Research program can provide subsidies for accommodations consulting to eliminate barriers to hiring people with disabilities.

Making communications technology accessible benefits communities and institutions as well. For example, shifting the financial burden of closed captioning on televisions to all buyers rather than just disabled buyers makes the technology accessible even to people with low incomes, allowing hearing impaired individuals to engage fully with that part of society,²⁸² and even benefiting people outside the target audience.²⁸³ In the context of the pandemic, elevating communications technologies, like video conferencing, to the level of being a “public accommodation” could benefit all communities and institutions, allowing fuller engagement in settings like school, work, religious ceremonies, and family gatherings. Outside of a pandemic, such accommodations would help enrich these communities by allowing those with moderate-to-severe brain injuries to participate fully.

c. Government Agencies

One of the pitfalls of the ADA is the disjointed enforcement regime it has created. An AWAA should aim to support and coordinate all of the governmental agencies protecting and serving people with moderate-to-severe brain injuries. This can be accomplished in several ways. One option is an intra-agency coordinating committee, such as the one created for diabetes research.²⁸⁴ The AWAA could also create an entirely new disability rights agency that could centralize ADA enforcement actions and guidelines, working in concert with other agencies to ensure they have the resources necessary to accomplish their stated goals under the ADA and AWAA. To avoid political capture of such an agen-

Large companies probably have sufficient resources to absorb compliance costs . . .” (citing Acemoglu & Angrist, *supra* note 114)).

²⁸² Luchina Fisher, *How Marlee Matlin Helped Force Streaming Video Closed Captions into Digital Age*, ABC NEWS (Apr. 29, 2014), <https://abcnews.go.com/Entertainment/marlee-matlin-helped-force-streaming-video-closed-captions/story?id=23503281> [<https://perma.cc/QCU8-7LXM>].

²⁸³ Morton Ann Gernsbacher, *Video Captions Benefit Everyone*, 2 POL’Y INSIGHTS FROM BEHAV. & BRAIN SCIS. 195, 195 (2015) (“Captions are particularly beneficial for persons watching videos in their non-native language, children and adults learning to read, and for persons who are D/deaf or hard of hearing.”).

²⁸⁴ Nat’l Inst. of Diabetes & Digestive & Kidney Diseases, *Diabetes Mellitus Interagency Coordinating Committee (DMICC)*, NAT’L INST. OF HEALTH, <https://www.niddk.nih.gov/about-niddk/advisory-coordinating-committees/diabetes-mellitus-interagency-coordinating-committee-dmicc> [<https://perma.cc/36U4-9WMX>] (“The DMICC facilitates cooperation, communication, and collaboration on diabetes among . . . government entities.”).

cy,²⁸⁵ the leadership could consist of a non-partisan director or a cadre of bipartisan commissioners like the FCC²⁸⁶ or the Federal Election Commission.²⁸⁷

Today, much of disability policy originates from the National Council on Disability, which advises the executive branch and Congress.²⁸⁸ Rather than create an entirely new agency from scratch, a politically feasible option could be to expand the powers of the NCD. Congress could empower it with enforcement capabilities and the ability to coordinate funding between agencies to accomplish the goals of the AWAA.

d. Offering Incentives Versus Sanctions

As we work toward a new AWAA, we have an opportunity to consider critically the enforcement of disability legislation. This will allow us not only to fix some of the problems with past enforcement, but also to help design a system that supports the change and technological advancement we hope to incentivize with an AWAA. Although this is a multifaceted undertaking, there are certain concrete efforts to keep in mind when considering how a new AWAA would work from an enforcement standpoint. In particular, it is critical to be careful about explicitly balancing enforcement with incentives, and make a concerted effort to offer more carrots, rather than sticks, particularly in regard to creating a supportive environment for use and dissemination of assistive technology.

The AWAA can begin the transition from rights vindication under the ADA to a new regime of incentivizing capability development. To ensure the promise of technology is realized, the AWAA should strive to support rehabilitation and reintegration of individuals by promoting technology-integrated housing and accessible education.

A major shortcoming of the ADA is that it operates primarily through goodwill and enforcement actions. Because there is no affirmative action provision in the ADA, employers may opt not to hire disabled individuals and bear the cost of wrongful termination suits and ADA enforcement litigation if

²⁸⁵ See Shapiro et al., *supra* note 7, at 565–66 (discussing the political disparities in *Olmstead* enforcements).

²⁸⁶ See PATRICIA MOLONEY FIGLIOLA, CONG. RSCH. SERV., RL32589, *The Federal Communications Commission: Current Structure and Its Role in the Changing Telecommunications Landscape* 1 (2018), <https://crsreports.congress.gov/product/pdf/RL/RL32589> [<https://perma.cc/MBH2-2CJP>] (defining the FCC as “an independent federal agency”).

²⁸⁷ See *Leadership and Structure*, FED. ELECTION COMM’N, <https://www.fec.gov/about/leadership-and-structure/> [<https://perma.cc/ERU3-4S5Y>] (defining the FEC as “an independent, regulatory agency” that is “led by six Commissioners”).

²⁸⁸ *About Us*, NAT’L COUNCIL ON DISABILITY, <https://ncd.gov/about> [<https://perma.cc/WJ6G-46QG>] (explaining the role of the NCD as “advis[or to] the President, Congress, and other federal agencies”).

it is financially cheaper.²⁸⁹ Similarly, the “valley of death” in assistive technology development may deter many investors preventing the adoption of better, and possibly more affordable, technologies.²⁹⁰ Complementing the enforcement regime created by the ADA, an AWAA should proactively aim to incentivize investment in assistive technology and support their widespread implementation.

The AWAA’s overarching goals of rehabilitation and reintegration would be better served by taking a holistic view of a person’s life as well as the technologies and institutions that support them. The transition from rights enforcement to capability development, or from sticks to carrots follows a larger trend in modern legal systems.²⁹¹ Some commentators have argued that incentive-based policy levers can be superior in two main instances: (1) when lawmakers encounter “specification problems” (for example, where impacted individuals are highly unique and the distribution is unknown to lawmakers); and (2) when implementation on or for some citizens necessitates a much more laborious endeavor than for others.²⁹² In both cases, uniform application of sticks results in inefficient transaction costs, inability to comply, and inadvertent distributional alterations.²⁹³ Commentators argue that particularly in highly complex regimes, carrots are superior to sticks.²⁹⁴ The superiority arises because citizens typically know more about their distinctive skills or “situational characteristics” than lawmakers.²⁹⁵

This is precisely the case for those disabled by a brain injury. Every person with a brain injury has highly-individualized needs. The distribution of those needs is wholly unknown to lawmakers and norm shifting in different societal spaces may require significantly different levels of regulatory effort. In fact, the knowledge of an individual’s recovery may be so imperfect that their

²⁸⁹ Acemoglu & Angrist, *supra* note 114, at 2 (“[L]arge firms can more easily absorb the costs imposed by the ADA.”); Picker, *supra* note 114 (“Large companies probably have sufficient resources to absorb compliance costs . . .” (citing Acemoglu & Angrist, *supra* note 114)).

²⁹⁰ RICHARD GREENWALD & JONATHAN LURIE, CTR. FOR TRANSLATION OF REHAB. ENG’G ADVANCES & TECH., *EVADING THE VALLEY OF DEATH: DE-RISKING PRODUCT DEVELOPMENT OF MEDICAL DEVICES AND ASSISTIVE TECHNOLOGY FOR REHABILITATION* (2017), https://www.asnr.com/files/2017%20Annual%20Meeting/Rick_Greenwald_14_45.pdf [<https://perma.cc/L2JC-KYJV>] (demonstrating the impact of the “Valley of Death” on the development of assistive technologies).

²⁹¹ Gerrit De Geest & Giuseppe Dari-Mattiacci, *The Rise of Carrots and the Decline of Sticks*, 80 U. CHI. L. REV. 341, 343 (2013) (analogizing positive enforcements to carrots and negative enforcements to sticks and following the decline of the use in sticks as compared to carrots in the legal system).

²⁹² *Id.* at 341.

²⁹³ *Id.* (including “undesirable wealth changes” and “artificially impoverishing those from whom much is required”).

²⁹⁴ *Id.* at 345–46 (“[I]n societies with more specialization and division of labor, carrots will be used more often. But . . . also . . . carrots will be used more often in situations that involve a higher degree of complexity.”).

²⁹⁵ *Id.*

own physicians misdiagnose them up to forty percent of the time.²⁹⁶ Adding onto this is the complexity that brain injury patients' capabilities may be evolving throughout their rehabilitation journey, especially with the introduction of accessibility technologies, and it becomes impossible for lawmakers to predict the perfect balance of incentives upfront.

The last thirty years of ADA enforcement, or lack thereof, has proven the shortcomings of a "stick-based" policy regime in the context of disability rights. The incentive-based enforcement structures at the core of the AWAA demonstrate a recognition of this highly complex population and responds with appropriate policy levers that avoid unintended distributional effects, protect against enforcement discretion, and shift the burden off individuals and toward building healthy societal support structures that benefit everyone. Promoting capabilities, such as neuro-technologies, is foundational, but the real work lies in creating the legal scaffolding that allows those with disabilities to realize the full potential of those capabilities. To do one without the other would be akin to giving someone a car, but not having any public roads for them to travel on. This new legislation will help people with a moderate-to-severe brain injury navigate the long and complicated road to recovery.

C. The Tapestry Weavers: AWAA Advocates

Transitioning from punishing enforcement to an incentive-based approach also allows us to consider how to include other stakeholders in promoting disability rights and reintegration. Although we discussed some core stakeholders earlier, one of the most enduring lessons from working in the disability rights space is how those with disabilities are often reliant on a broader community of individuals and supports to lead more fulfilling and productive lives. Given the broad range of stakeholders who are truly involved in the care and promotion of those with disabilities, an AWAA should strive to consider stakeholders who are impacted by disability legislation, but who may not be the traditional targets of legislative consideration. This Section will discuss specifically how the AWAA might affect patient advocacy groups,²⁹⁷ innovators,²⁹⁸ and service providers.²⁹⁹

1. Advocacy Groups

Patient advocacy groups, typically made up of patients and their families, played a crucial role in the passage of the ADA and the Orphan Drug Act. The

²⁹⁶ FINS, RIGHTS COME TO MIND, *supra* note 2, at 81 (citing Schnakers et al., *supra* note 30).

²⁹⁷ See *infra* notes 300–302 and accompanying text.

²⁹⁸ See *infra* notes 303–305 and accompanying text.

²⁹⁹ See *infra* notes 306–309 and accompanying text.

ADA would not have been passed in its current form without significant support from patient groups, who even took to public demonstration on the steps of the United States Capitol to overcome opposition to the bill.³⁰⁰ Similarly, the National Organization for Rare Disorders actively lobbied Congress to pass the Orphan Drug Act after the safety and efficacy requirements of the 1962 Kefauver-Harris Amendments to the Food, Drug, and Cosmetic Act made therapies for orphan drugs economically disfavored.³⁰¹

Patient advocacy groups for those with a moderate-to-severe brain injury could play a substantial role in bringing a public voice to the concerns and narratives of patients. This is important work that can help inform framework shifts in how the government can better support these patients by promoting healthy innovation and supporting medical access. It is also one of the only ways to honor the “Nothing About Us, Without Us” mission.³⁰²

2. Innovators

Historically, innovators have been at the forefront of ensuring that their technologies are picked up for larger distribution. For example, the Japanese electronics company, Sanyo, developed and sold set-top companions for television sets to provide closed captioning and testified before Congress in support of integrating such closed captioning chips into all televisions.³⁰³ Ultimately, this shifted the price burden off hearing-impaired individuals.³⁰⁴

³⁰⁰ Becky Little, *When the ‘Capitol Crawl’ Dramatized the Need for Americans with Disabilities Act*, HISTORY (July 24, 2020), <https://www.history.com/news/americans-with-disabilities-act-1990-capitol-crawl#:~:text=On%20March%2013%2C%201990%2C%20over,crawled%20up%20the%20Capitol%20steps> [https://perma.cc/N649-SB3T] (detailing how “about 60 of [patient activists] cast aside their wheelchairs and other mobility aids and crawled up the Capitol steps”).

³⁰¹ Koichi Mikami, *Orphans in the Market: The History of Orphan Drug Policy*, 32 SOC. HIST. MED. 609, 613 (2017) (noting the Amendments led to the “abandonment of unprofitable drugs by pharmaceutical companies”).

³⁰² See Eli A. Wolff & Mary Hums, “*Nothing About Us Without Us*”—*Mantra for a Movement*, HUFFINGTON POST, [huffpost.com/entry/nothing-about-us-without-us-mantra-for-a-movement_b_59aea450e4b0c50640cd61cf](https://www.huffpost.com/entry/nothing-about-us-without-us-mantra-for-a-movement_b_59aea450e4b0c50640cd61cf) [https://perma.cc/F2Q9-8Y3D] (Sept. 6, 2017) (detailing the origins of the movement to include people with disabilities in the conversation about disability law).

³⁰³ Television Decoder Circuitry Act, Pub. L. No. 101-431, § 2(8), 104 Stat. 960, 960 (1990) (codified as amended at 47 U.S.C. § 303 note (Congressional Findings Regarding Access by Hearing-Impaired People to Television Medium)) (“[T]echnology is now available to enable closed-caption decoding capability to be built into new television sets during manufacture at a nominal cost . . .”).

³⁰⁴ See Kimberly Adams, *How the FCC Regulates Accessibility for New Technologies*, MARKETPLACE TECH (Aug. 12, 2020), <https://www.marketplace.org/shows/marketplace-tech/fcc-accessibility-regulation-new-technology-streaming-video-mobile-browsers-teleconferencing-closed-captioning-audio-descriptions/> [https://perma.cc/YR4T-WXFK] (noting “tech has definitely outpaced the law” when it comes to the Communications and Video Accessibility Act (quoting Brian Scarpelli, co-chair of the FCC’s Disability Advisory Committee)); *A Brief History of Captioned Television*, *supra* note 259 (“Now, millions of people have access to captions with the push of a button on their remote controls.”).

Innovators that develop technology for individuals with a moderate-to-severe brain injury are in a unique position to highlight issues faced by researchers focused on new technologies for rehabilitation and reintegration. Some argue that the FDA's current formulation of risk-benefit analysis fails to consider that investigational devices may present poor risk benefit-analyses in the context of therapeutics, but may be imperative for developing a sufficient understanding of disorders of consciousness.³⁰⁵ An AWAA must help reorient these incentives, providing additional support to de-risk these endeavors financially and scientifically. Offering additional market-based incentives could also increase the willingness of innovators to address the needs of those with disabilities, by offering support for the assistive technology market.

3. Service Providers

Service providers will be impacted by any sort of disability rights mandates. Historically, many have lobbied against efforts like the ADA, resulting in fractured legislation.³⁰⁶ Hopefully because the AWAA provides incentives in the form of carrots, rather than enforcement sticks, there will be interest convergence between patient groups and service providers.

Educational institutions are critical service providers as well. In contemplating the ADA and other disability rights litigation, educational institutions, like Gallaudet University, have played a large role in organizing legislative advocacy and providing Congressional testimony. Unfortunately, institutions of education have also often been on the receiving end of ADA enforcement actions. In one such instance, MIT and Harvard were sued for failing to adhere to closed captioning accuracy standards.³⁰⁷ Such institutions, however, are also a hotbed for medical innovation and are frequently the recipients of federal research grants. Technologies, like deep brain stimulation,³⁰⁸ are developed at

³⁰⁵ Joseph J. Fins, Commentary, *Neuroethics and Disorders of Consciousness: Discerning Brain States in Clinical Practice and Research*, 18 *AMA J. ETHICS* 1182, 1187–88 (2016).

³⁰⁶ The Television Decoder Circuitry Act was a separate piece of legislation because of the worry that major broadcasting companies would stop the ADA from passing. Sy DuBow, *The Television Decoder Circuitry Act—TV for All*, 64 *TEMP L. REV.* 609, 615–16 (1991).

³⁰⁷ Emily Griffin & Jaclyn Leduc, *Overview of NAD v. Harvard and NAD v. MIT Lawsuits*, 3PLAYMEDIA, <https://www.3playmedia.com/blog/harvard-mit-sued-captioning-violation-ada-rehabilitation-act/> [<https://perma.cc/NNX7-SUVS>] (Feb. 18, 2022); see Emily Griffin & Rebecca Klein, *How Much Do Closed Captioning Services Cost? (And Why Price Isn't Everything)*, 3PLAYMEDIA, <https://www.3playmedia.com/blog/how-much-does-closed-captioning-service-cost/> [<https://perma.cc/GRB5-VUZZ>] (Feb. 3, 2022) (noting “the number one barrier to captioning was cost and budget”).

³⁰⁸ *Deep Brain Stimulation*, WEILL CORNELL BRAIN & SPINE CTR., <https://weillcornellbrainandspine.org/procedure/deep-brain-stimulation> [<https://perma.cc/4J39-59QZ>] (demonstrating the involvement of institutions in the development of assistive technology).

such institutions and some even have Assistive Technology hackathons.³⁰⁹ By offering their expertise on the front-end and helping to design regulatory structures that provide access to these technologies, educational institutions can fulfill the societal imperatives of their research and prevent against costly litigation on the back end.

V. MOVING CHANGE BEYOND LEGISLATION

The previous parts described how new legislation, like the AWAA, could help disabled individuals, such as those with a brain injury, to reintegrate into society and realize their capability of leading fulfilling lives. Envisioning the next steps of disability rights legislation, however, highlights the shortcomings of existing legal frameworks.

Scholars have argued that the fundamental logic of disability law, the belief that society can reduce disability discrimination by fostering encounters between disabled and non-disabled individuals, fails to account for the “stickiness” of aesthetic or emotional preferences, making attitudes on disability more resistant to change.³¹⁰ They are also norm-resistant; sincerely held convictions on the equality and dignity of disabled people may not alter intuitive repulsion felt upon encountering somebody with facial deformity.³¹¹

Moreover, judgments of contempt or moral disgust often turn upon a demonstration of incompetence. Although the fact of a functional basis for moral judgment can be redeeming for TBI/DoC patients who are recovering—one study showed middle school students were more eager to interact with their disabled classmates when they exhibited their competence in traditional fashions—the same fact can challenge individuals whose disabilities prevent them from conforming in the way they perform their competence. This is especially poignant for nonverbal individuals.³¹² Competence can be manifested when individuals have access to the technologies they require to demonstrate their capabilities.

The aesthetics of disability also fracture experiences trying to secure accommodations. Those who visibly present as disabled may be rejected under

³⁰⁹ ASSISTIVE/TECH @ MIT, <http://assistivetechnology.mit.edu/> [<https://perma.cc/2BKA-CM6S>] (describing the assistive technology hackathon put on by MIT each year).

³¹⁰ See Dan M. Kahan, *Gentle Nudges vs. Hard Shoves: Solving the Sticky Norms Problem*, 67 U. CHI. L. REV. 607, 608 (2000) (“[N]orms stick when lawmakers try to change them with ‘hard shoves’ but yield when lawmakers apply ‘gentle nudges.’”).

³¹¹ See Jasmine E. Harris, *The Aesthetics of Disability*, 119 COLUM. L. REV. 895, 904 (2019) (“These physical and sensory markers of difference . . . produce emotional responses . . . that are often viewed as noncognitive, visceral, and thus involuntary reactions.”).

³¹² *Id.* at 939 (citing Cendri A. Hutcherson & James J. Gross, *The Moral Emotions: A Social-Functionalist Account of Anger, Disgust, and Contempt*, 100 J. PERSONALITY & SOC. PSYCH. 719, 721 (2011)).

the guise of upsetting customers, while those who do not visibly present as disabled may be denied accommodations because they do not seem to need them.³¹³ Even when individuals bring their claims to court, judges have at times denied individuals with disabilities the chance to describe their conditions, claiming they were “pander[ing] for sympathy.”³¹⁴

Furthermore, current disability laws are shrouded in shame and secrecy.³¹⁵ Other laws cementing rights for protected classes reject the notion that individuals in these classes should need to hide their identity or conform.³¹⁶ This re-frames “privacy norms as problematic, anti-agentic, and, at times, counter to structural reform goals.”³¹⁷ Disability laws, on the other hand, are structured to maintain privacy. For instance, it is illegal under the ADA for a potential employer to ask about the “nature or severity of [a] disability” during an interview.³¹⁸

What can be done to remedy these subtler instances of disability discrimination? Some scholars prescribe institutional redesign that does not take for granted the contact theory, or the idea that familiarity will breed acceptance rather than contempt.³¹⁹ Scholars also propose empirical research.³²⁰ Such research must disaggregate disability among various aesthetic dimensions and think through its impact in the classroom and the workplace, especially for statutory terms such as what makes a special education program “appropriate” and what goals a workplace antidiscrimination effort is furthering.³²¹

However, even with legal protections, attitudes toward inclusivity will not shift on their own. This implies that disability rights activists should think critically about how to buttress legal protections while advocating for and creating a more inclusive society.

One possibility is focusing on changing attitudes in decision-makers who can expedite social change in the halls of power. Scholars have highlighted court cases where judges prevented individuals with disabilities from prevail-

³¹³ *Id.* at 941–42 (providing examples of employers and others’ reactions to visible and non-visible presentations of disability).

³¹⁴ *Id.* at 944 (quoting Brief for the Appellant at 19, *Johnson v. Jennings*, 772 F. App’x 822 (11th Cir. 2018) (No. 18-10537-C), 2018 WL 3998136, at *19).

³¹⁵ Jasmine E. Harris, *Taking Disability Public*, 169 U. PA. L. REV. 1681, 1682 (2021) (“[D]isability rights law values privacy norms to preempt discrimination; in other words, if you never reveal the information, no one can discriminate against you because of that information.” (emphasis omitted)).

³¹⁶ *Id.* at 1681–82 (emphasis omitted).

³¹⁷ *Id.* at 1682 (emphasis omitted).

³¹⁸ *Id.* at 1710 (quoting 42 U.S.C. § 12112(d)(4)(A)).

³¹⁹ *Id.* at 1742 (“The operative prescription or set of prescriptions must ask how we make disability more visible . . .”).

³²⁰ *Id.* at 1743 (“On the front end, data collection and institutional subsidies can help advance visibility.”).

³²¹ *Id.* at 1744.

ing in their discrimination claims.³²² Given the “stickiness” of aesthetic preference, we add to existing suggestions by saying it would be fruitful to focus on changing the preferences of those with power to create situations that would, by increased contact or vindication of individual rights, set into motion societal change. More use should also be made of continuing legal education programs for judges, especially in rapidly developing areas such as technology and health care. Better judicial comprehension of disabilities will not only lead to more suitable outcomes for these patients and their families, but also more efficient allocation of medical resources. Ideally, it will lead to changes that will improve the lives of patients with these conditions in ways that better reflect our societal values.

CONCLUSION: MODERNIZING DISABILITY RIGHTS AND THE AWAA

Throughout this Article, those with a moderate-to-severe brain injury have provided a lens within the broader category of individuals with disabilities. This population is illustrative of the current challenges that exist when accessing diagnostic and assistive technologies under the prevailing disability rights landscape, particularly the ADA. Although we have used this population as an exemplar, we anticipate that more and more individuals with disabilities will turn to technological modalities to restore and enhance their capabilities, meaning that the problems faced by those with a moderate-to-severe brain injury will hinder other populations in the future. As technology becomes more ubiquitous in everyday life, there has to be an accompanying call for legislative means to encourage and sustain these rapid changes.

Fundamentally, for those with brain injuries and the larger population of people with disabilities, substantial change requires the modernization of legislation. We believe the best method to do this is not by changing the ADA, but by moving to the next step in disability rights legislation. We have designed the AWAA to ensure that technological development and access is embedded into legal frameworks in forward-looking ways, to enable Americans with different abilities to access and benefit from the technological advances that help their capabilities to flourish.

In the preceding pages, we have endeavored to begin this important discussion, so that others can join the conversation. Although this Article was not designed to explore every nuance of a new legislative approach, we hope that having laid the groundwork for the AWAA as presented, the door will be opened for others to move the field and discussion forward. Designing collaborative legislation is especially important for this population that has long been

³²² See, e.g., *supra* note 314 and accompanying text.

marked by paternalism.³²³ Indeed, experience has shown that true forward change necessitates listening to and involving a multitude of stakeholders, ranging from individuals with disabilities, to their families and loved ones, to researchers and policymakers.³²⁴

We have started the conversation with a focus on technology, so that it can be at the center of thinking as society crafts future disability rights legislation. A focus on technology would represent a major step forward and would break from past frameworks that had to play catch up to technology for years. The status quo has left people with disabilities substantially behind—the very vision the original ADA hoped to abandon. Furthermore, by embracing a new perspective in disability rights law that focuses on capabilities as opposed to negative freedoms, our AWAA seeks to revolutionize society’s still present stigma.

But the need to promote technological progress is not the sole reason to advocate for an AWAA. Coupled with the problems posed by advancing technology, there has been a growing dissatisfaction with the ADA, and critique of the legislative and regulatory framework supporting the reintegration of those with disabilities into their communities.³²⁵ Although mechanisms currently exist for individuals with brain injuries to utilize the ADA to demand access to technology through *Olmstead v. L.C. ex rel. Zimring*³²⁶ in order to argue for a variety of new technologies to aid in community reintegration, progress has been slow to non-existent.³²⁷ Furthermore, enforcement of the ADA is often fickle, remedial, and subject to numerous political and societal pressures. Unfortunately, with the ADA’s focus on employment, and the adversarial nature of enforcement, individuals undertaking piecemeal recoveries, such as those with a moderate-to-severe brain injury, often fall through the cracks of the current legislative scheme.

As new technology helps move us from a rights-based approach to a capabilities-focused view, the conceptual work will be in articulating the legal framework that allows individuals with disabilities to access said technology and realize their capabilities. This involves promoting research, improving access to novel technologies, and considering and removing barriers in regulation, while exploring new incentives for technological development. This must be done in tandem with building out and creating the societal infrastructure to

³²³ See Shapiro et al., *supra* note 7, at 596 (“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.”).

³²⁴ *Id.*

³²⁵ See *generally id.* (highlighting some of the failures of the ADA).

³²⁶ See 527 U.S. 581, 596 (1999) (holding that segregation of disabled individuals from society constitutes discrimination under the ADA).

³²⁷ See Shapiro et al., *supra* note 7, at 565.

allow these technologies to flourish. This multifaceted effort will begin to finally enable individuals with disabilities to access and utilize technology to realize their capabilities and more fully reintegrate into society. Proposing new legislation also represents an opportunity to interrogate existing mechanisms of enforcement and regulation, allowing us to consider whether a better enforcement model might be more effective in promoting disability rights and reintegration. A new AWAA is the first step in this complicated work.

Fortunately, we do not have to start this endeavor from the very beginning. Indeed, other areas of disability legislation have long utilized alternative enforcement mechanisms that can enable a more complete and holistic system that supports individuals with disabilities.

For instance, we have long drawn parallels to education when considering the rehabilitation and recovery of those with a severe brain injury.³²⁸ We have analogized the recovery of individuals with a moderate-to-severe brain injury to the neurodevelopment that takes place in adolescent learning and brain development. Indeed, recovery from a severe brain injury often involves new axonal sprouting and brain development that is, in many ways, similar to the new neural pathways that young brains create as they learn new skills and information. In both situations, there is novel axonal growth, as new connections spring up between neurons.³²⁹ Both the young brain and the injured brain share a common mechanism of axonal sprouting: the first as a developmental process, and the second as a regenerative one.³³⁰ Just as education assists in the developmental process, rehabilitation aids in healing. In fact, many of those with a brain injury speak of their recovery in terms of “re-learning,” further highlighting the link between rehabilitation of the injured brain and education.

We believe that the Individuals with Disabilities Education Act (IDEA), a groundbreaking piece of disability legislation, can serve as a useful enforcement model when designing a system to support holistically the capabilities of those recovering from disabilities through supportive technology. Expanding our conception of rehabilitation to include re-education can allow efforts to go beyond a mere medical care entitlement and into the sphere of legally-created expectations.

The AWAA can be the catalyst for change, both as far as the next chapter in disability rights, but also in transforming society’s conception of disability from a place of burden or difference to one of commonality and acceptance. In

³²⁸ See Wright & Fins, *supra* note 17 (analogizing the right to rehabilitation with the right to education).

³²⁹ Randolph J. Nudo, *Recovery After Brain Injury: Mechanisms and Principles*, FRONTIERS HUM. NEUROSCIENCE, Dec. 2013, at 1, 1–2.

³³⁰ See FINS, RIGHTS COME TO MIND, *supra* note 2, at 306–07 (“The first time around, this process is developmental. After an injury, the process is regenerative . . .”).

this way, the AWAA is designed to help people proudly “claim” their disability, helping individuals muster their diagnosis into a powerful part of their positive identity.³³¹ This pride and acceptance is an integral component to promoting true human flourishing so that individuals can thrive, whether disabled or not.

We have endeavored to highlight the AWAA, as a mechanism to lay out a philosophical framework, accompanied by several concrete suggestions, that can help move the conversation toward the next step in disability rights legislation. Although the ADA has been a landmark step in disability rights, the next part is prospectively expanding and supporting the capabilities of those with disabilities, through the provision of novel technology. This is the real work of any new disability rights legislation, and we believe that an *Americans with Abilities Act* is the next step in respecting dignity, and moving disability rights forward. In doing so, we can promote human flourishing, aided by technology. It is our hope that the AWAA will engender the capabilities needed for a national reassessment of disability law.

³³¹ See Katie Eyer, *Claiming Disability*, 101 B.U. L. REV. 547, 548 (2021) (“Claiming disability identity thus holds the potential to offer a liberatory alternative to the current experience of impairment, even as it paves the way for broader transformations in disability rights.” (emphasis omitted)).

CO-AUTHOR BIOGRAPHIES

Allison Rabkin Golden (YLS '21) is a recent graduate of Yale Law School. *Gregory E. Antill*, PhD (YLS '23) is a second-year student at YLS. *Chaarushena Deb* (YLS '21) is a first-year associate at Latham & Watkins, LLP. *Katherine Fang* (YLS '22) is a third-year student at YLS. *Elizabeth Clarke* (YLS '23) is a second-year student at YLS. *Alexis Kallen* (YLS '23) is a second-year student at YLS. *Hanya M. Qureshi* (Yale Medical School '23) is a student at Harvard Medical School. *Kai Shulman* is an undergraduate at Yale. *Caroline V. Lawrence* (YLS '21) is a recent graduate of Yale Law School.

Dr. Laura C. Hoffman is a Visiting Professor of Law and the Acting Director for the Center for Health Law and Policy at Cleveland-Marshall College of Law.

Professor Megan S. Wright, J.D., Ph.D., is Assistant Professor of Law, Medicine, and Sociology at Penn State Law and the Departments of Humanities and Public Health Science at Penn State College of Medicine, as well as an affiliate faculty member with the Department of Sociology and Criminology and the Rock Ethics Institute in the College of the Liberal Arts at the Pennsylvania State University. She is also an Adjunct Assistant Professor of Medical Ethics in Medicine at Weill Cornell Medical College. Concurrently, she served as a Research Fellow and Senior Adviser to the Consortium for the Advanced Study of Brain Injury Project at the Solomon Center for Health Law and Policy at Yale Law School (CASBI@YLS). Professor Wright earned a Ph.D. in Sociology from the University of Arizona.

Joseph J. Fins, M.D., M.A.C.P., F.R.C.P. is the E. William Davis, Jr. M.D. Professor of Medical Ethics and Chief of the Division of Medical Ethics at Weill Cornell Medical College where he is a Tenured Professor of Medicine, Professor of Medical Ethics in Neurology, Professor of Medical Ethics in Rehabilitation Medicine, Professor of Health Care Policy and Research, and Professor of Medicine in Psychiatry. He is the founding Chair of the Ethics Committee of New York-Presbyterian Weill Cornell Medical Center where he is an Attending Physician and Director of Medical Ethics. A member of the Adjunct Faculty of Rockefeller University and Senior Attending Physician at The Rockefeller University Hospital, Professor Fins co-directs, the Consortium for the Advanced Study of Brain Injury (CASBI) at Weill Cornell Medicine and Rockefeller. He is a Visiting Professor of Law and the *Solomon Center Distinguished Scholar in Medicine, Bioethics and the Law* at Yale Law School where he leads CASBI@YLS. Professor Fins is a Master of the American College of Physicians and Fellow of The Royal College of Physicians (London). He is an elected Member of the National Academy of Medicine (formerly the Institute of Medicine) of the National Academy of Sciences, a Fellow of the American Academy of Arts and Sciences, the Dana Alliance for Brain Initiatives, and by Royal Appointment an *Academico de Honor* (Honored Academic) of the *Real Academia Nacional de Medicina de España* (the Royal National Academy of Medicine of Spain). Professor Fins gratefully acknowledges the support of a grant from the NIH BRAIN Initiative for "Cognitive Restoration: Neuroethics and Disability Rights" [1 RFA MH12378-011].