Realizing *The Americans with Abilities Act*: Promoting Civil Rights & Capabilities in the Service of Individuals with Brain Injury

ZACHARY E. SHAPIRO,† TIFFANY LI,† KAIULANI S. SHULMAN,† MELISA OLGUN,† CHANTELLE VAN WILTENBURG,† MOLLY TEAGUE,† EMMA KROMM,† BRANDY ALLEN,† ELLIOT E. C. PING,† JOHN D. BOWERS,† REBECCA HARRIS,† NAYLA BASMA,† APURV HIRSH SHEKHAR,† GREGORY E. ANTILL,† MEGAN S. WRIGHT,† AND JOSEPH J. FINS†

---

† 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; 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. In 2017, he clerked for the Honorable Judge Timothy B. Dyk on the U.S. Court of Appeals for the Federal Circuit in Washington, D.C. Shapiro received his B.A. from Brown University, MSc. from the London School of Economics and Political Science and graduated from Harvard Law School cum laude in 2016. Zas4001@med.cornell.edu.; Zachary.E.Shapiro@yale.edu.

† Tiffany Li (YLS '24) is a recent graduate of Yale Law School.

† Kaiulani S. Shulman (YC '22) is a recent graduate of Yale College and was a Research Assistant in the Division of Medical Ethics at Weill Cornell Medicine.

† Melisa Olgun (YLS '24) is a recent graduate of Yale Law School.

† Chantelle van Wiltenburg (YLS LLM '22) received her LLM from Yale Law School in 2022.

† Molly Teague (YLS' 23) is a recent graduate of Yale Law School.

† Emma Kromm (YLS '24) is a recent graduate of Yale Law School.

† Brandy Allen (YLS' 23) is a recent graduate of Yale Law School.

† Elliot E. C. Ping is a recent graduate of Yale Law School.

† John D. Bowers (YLS' 23) is a recent graduate of Yale Law School.

† Rebecca Harris (YLS '24) is a recent graduate of Yale Law School.

† Nayla Basma (YLS '22) is a recent graduate of Yale Law School.

† Apurv Hirsh Shekhar (Yale Medical School '23) is a recent graduate of Yale Medical School.

† Gregory E. Antill, PhD (YLS '23) is a Lecturer-In-Law and an Academic Fellow at Columbia Law School and a recent graduate of Yale Law School (YLS '22).

† Professor Megan S. Wright, J.D., Ph.D., is a 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 a Visiting Lecturer in Law at Yale Law School, where she works for the Advanced Study of Brain Injury Project at the Solomon Center for Health Law and Policy at Yale Law School (CASBI@YLS). She is also an Adjunct Assistant Professor of Medical Ethics in Medicine at Weill Cornell Medical College.

† Joseph J. Fins, M.D., D. Hum. Litt. (hc), 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

Brain injuries often result in varying degrees of impairment to communication and cognitive processes, impeding an individual's ability to engage in daily activities, participate in social interactions, and achieve independence. This paper builds upon our legislative proposal from Designing An Americans With Abilities Act: Consciousness, Capabilities, and Civil Rights, published in the Boston College Law Review in 2022. That paper proposed new legislation called "The Americans with Abilities Act" ("AWAA"), a comprehensive framework for the effective development, uptake, and utilization of advanced assistive technology ("AT"). These technologies aid individuals with brain injuries in realizing their capabilities and reintegrating into broader society.

Addressing the crucial need for person-centered disability legislation, the AWAA would establish a comprehensive and coordinated governmental effort to assist the recovery journey of brain injury survivors and their families. It does this through establishing tailored support networks and new mechanisms for improved research, development, and uptake of accessible AT. When offered to those with brain injuries, AT can foster communication and improve reintegration.

This paper builds on our 2022 paper, focusing on administrative law and civil rights to introduce a central component of the AWAA: an innovative interagency committee called "The Interagency Committee for Brain Injury Recovery" ("ICBIR"). The ICBIR will synergize efforts among healthcare providers, technology experts, rehabilitation specialists, those with brain injuries and their family members, to create cohesive individualized care plans. These plans will more effectively address the multifaceted needs of brain injury survivors throughout their long recovery, while supporting their civil liberties and fostering reintegration.

Our legislation includes a structured framework that ensures equitable access to rehabilitation, medical support, and state-of-the-art AT tailored to the needs of brain injury survivors. These benefits improve independence, quality of life, and communication. By facilitating effective communication, cognitive rehabilitation, and community reintegration, the AWAA aims to address the unique challenges that brain injury survivors encounter during their recovery process. The AWAA will also nurture the independence and well-being of brain injury survivors

---

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, Association of American Physicians, 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]. The authors want to thank the Solomon Center for Health Law and Policy at Yale Law School and Professor Abbe Gluck for her support and for making this collaboration possible.

by broadening their capabilities, thus enhancing their prospects for community reintegration and independent living.

Through a person-centered administrative law approach, the AWAA and its constitutive ICBIR catalyze governmental support systems for brain injury survivors by bolstering their capabilities and safeguarding their civil rights. Ultimately, this legislative endeavor exemplifies a transformative step toward fostering inclusivity, maximizing potential, and creating a society that embraces diverse abilities.

TABLE OF CONTENTS

INTRODUCTION: GREGOR AND GREG

Any thoughtful and effective policy response that aims to promote disability rights must be informed by the perspectives of individuals with disabilities. This Article is Part Two of a series[1] where we offer a new vision for disability legislation in the United States, focusing on brain injury as an example. To foreground the perspectives of those impacted by brain injury, we begin with a true story about a man named Greg.

Greg was a sharp dresser and hard worker, who "never got into trouble and did not like to fight."[2] He was also the father of a young daughter.[3] At the age of thirty-eight, Greg was assaulted and had his brain "smashed . . . in,"[4] causing a brain injury so severe that he was not expected to live. Doctors placed Greg on a respirator and informed his family that "he's going to be a vegetable the rest of his life."[5] Although Greg's family decided against withdrawing life-sustaining therapy, they agreed to a "Do Not Resuscitate" order. As Greg's mother put it, "[w]hy try to keep him alive and he's still suffering, he's not the complete person that he was before?"[6]

Although Greg did not fight back against his attackers, he continued to fight for his life. He initially remained in a vegetative state, a state of wakeful unresponsiveness,[7] before progressing toward a low-level minimally conscious state called liminal consciousness.[8] Greg remained in this state for years, mute and largely unresponsive, with inconsistent responses to verbal stimuli via eye movements.[9] With few options for treatment or improvement, Greg languished in his state of altered consciousness.

According to standard behavioral criteria, Greg displayed few external indicators of consciousness, but neuroimaging studies hinted at a richer inner life.[10] One imaging study revealed that Greg's brain had normal activation

---

[1] Part One was published in 2022 in the Boston College Law Review. Zachary E. Shapiro et al., *Designing An Americans with Abilities Act: Consciousness, Capabilities, and Civil Rights*, 63 BOS. COLL. L. REV. 1729 (2022) [hereinafter *AWAA*].

[2] JOSEPH J. FINS, RIGHTS COME TO MIND: BRAIN INJURY, ETHICS, AND THE STRUGGLE FOR CONSCIOUSNESS 204 (2015) [hereinafter RCTM]. Dr. Fins secured permission from the family to discuss this case with a HIPPA waiver and IRB approval for the writing of his book, "Rights Come to Mind."

[3] *Id.*

[4] *Id.*

[5] *Id.* at 205.

[6] *Id.*

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

[8] *See generally* Joseph T. Giacino, Stephen Ashwal, Nancy Childs, Ronald Cranford, Bryan Jennett, Douglas I. Katz, James P. Kelly, Jay H. Rosenberg, John Whyte, Ross D. Zafonte & Nathan D. Zasler, *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 NEUROLOGY 349 (2002) (describing MCS as a transitional state characterized by inconsistent but discernible signs of awareness).

[9] RCTM, *supra* note 2, at 205–06.

[10] *Id.*

patterns for forward-language comprehension.[11] Trapped in an inconsistently less responsive body, Greg continued to experience a world that—save for a few loved ones—had largely forgotten about him.

***

Although Greg's story is true, it is not told in Greg's own voice. Greg's narrative is gleaned from his care providers' perspectives and conveys only that which is objectively observable.[12] To delve deeper, we must imaginatively and empathetically engage with the perspectives of individuals like Greg. Any person capable of picking up and reading this Article occupies a privileged sphere of dialogue, deliberation, and power. Many of these privileges remain largely inaccessible to individuals with serious brain injuries. Through the Consortium for the Advanced Study of Brain Injury at Yale Law School ("CASBI@YLS"),[13] we strive to give a voice to individuals like Greg.

Our work promotes inclusion by examining legal theories and technological innovations that restore the promise of community, communication, and dignity for individuals with brain injury. While our focus is primarily on brain injury, the lessons learned directly apply to disability law more generally.[14] We aim to amplify the patient's voice and develop a legal framework for disability that heeds the admonition: "Nothing About Us Without Us."[15]

Those with brain injuries face barriers in communication. Silence may first result from a person's physical limitations, but it is exacerbated by social structures that deny individual holistic recovery and community integration. Building on the previous work of CASBI@YLS, this Article expands our vision for the Americans with Abilities Act ("AWAA"), novel disability legislation that promotes the capabilities of individuals with disabilities like brain injuries. This paper is Part Two of a series, following our introduction of the AWAA in the Boston College Law Review in 2022.[16]

The AWAA complements the Americans with Disabilities Act of 1990 ("ADA") and seeks to foster social change that accommodates advances in

---

[11] Nicholas D. Schiff, Diana Rodriguez-Moreno, Ayeesha Kamal, Kwang H.S. Kim, Joseph T. Giacino, Fred Plum & Joy Hirsch, *fMRI Reveals Large-Scale Network Activation in Minimally Conscious Patients*, 64 NEUROLOGY 514, 519 (2005).

[12] RCTM, *supra* note 2.

[13] Zachary E. Shapiro, Chaarushena Deb, Caroline Lawrence, Allison Rabkin Golden, Megan S. Wright, Katherine L. Kraschel & Joseph J. Fins, *The Scholarly and Pedagogical Benefits of the Legal Labratory: Lessons from the Consortium for the Advanced Study of Brain Injury at Yale Law School*, 51 J.L., MED. & ETHICS 672, 673 (2023).

[14] *AWAA*, *supra* note 1; Zachary E. Shapiro, Chaarushena Deb, Caroline Lawrence, Allison Rabkin Golden, Jaclyn Wilner, Allison Durkin, Zoe M. Adams, Wenqing Zhao, Keturah James, Adam Pan, Megan S. Wright, & Joseph J. Fins, 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, 531–32, 538 (2021).

[15] *See, e.g.*, JAMES I. CHARLTON, NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT 3–4 (Univ. of Cal. Press ed. 1998).

[16] *AWAA*, *supra* note 1.

neurotechnology.[17] The AWAA aims to promote human flourishing in a long-marginalized population by envisioning and helping build a supportive environment that uses assistive technology ("AT") and scientific advancements.[18]

Previously, we argued that novel disability legislation must promote capabilities by philosophically placing increased value on the abilities of individuals with disabilities, rather than remediating discriminatory practices. This call was motivated by advancements in medical care, rehabilitation, and AT. Emerging devices such as brain computer interfaces, deep brain stimulation, and eye trackers—all AT methods—have the potential to restore communicative and expressive abilities.[19] They enable individuals with brain injuries to communicate with others and participate more fully in their communities.[20] Despite these advances, even individuals benefitting from these emerging technologies have difficulty accessing care and navigating social structures. This is further complicated because, while American law has focused on disability, it remains rather silent on how to accommodate people who become more able—and less disabled—through the advent of neuroscience and medical technology.

To address these lacunae in the law, we have focused on capabilities to complement the traditional emphasis on rights. We have shifted to a "capabilities approach" because it empowers people with disabilities and augments opportunities for community integration.[21]

By recognizing the unique strengths of people with disabilities and fostering these capabilities through providing AT and focused rehabilitation, the law can design a more inclusive and supportive environment. Moving beyond the negative frame of freeing people with disabilities *from* discrimination, the AWAA advances policies that recognize, foster, and embrace emergent abilities, especially those facilitated by advances in medical technology and rehabilitation. This approach is intended to better catalyze the reintegration and participation of individuals with brain injuries into the multifaceted spheres of social and political life.

While our introduction of the AWAA in 2022 focused on developing robust technological scaffolding for AT research and use, this Article considers the consequences of this progress for people with brain injuries and their families. Specifically, we trace how the AWAA might assist individuals with

---

[17] *Id.* at 1768.

[18] *Id.* at 1795.

[19] *See generally* RCTM, *supra* note 2 (describing the promise of assistive neurotechnologies, including brain-computer interfaces and deep brain stimulation, to restore expressive capacity in patients with disorders of consciousness).

[20] *See generally id.* (arguing that restored communication through assistive technologies can reestablish social connection, enable reintegration, and affirm the civil rights of individuals with covert consciousness).

[21] *See* Amartya Sen, *Equality of What?*, *in* THE TANNER LECTURES ON HUMAN VALUES 197, 218–19 (McMurrin ed. 1988); Martha Nussbaum, *Nature, Function, and Capability: Aristotle on Political Distribution*, *in* OXFORD STUDIES IN ANCIENT PHILOSOPHY: SUPPLEMENTARY VOLUME 145, at 1, 6 (Oxford Univ. Press 1988).

brain injuries as they progress from acute care in the hospital to recovery in a chronic care or rehabilitation facility and, ultimately to their communities, schools, family and work.

Our endeavor to better support the recovery and reintegration of individuals with brain injuries calls for a holistic approach, combining both conceptual and organizational changes within a new legal framework. This conceptual change challenges us to rethink our legal approach by maximizing individual capabilities and promoting human flourishing. Concurrently, the organizational change proposes the creation of a novel interagency coordinating committee to streamline and synchronize care across various governmental sectors throughout the recovery journey for individuals with brain injuries. The Interagency Committee for Brain Injury Recovery ("ICBIR"), created by the AWAA, would help mobilize resources needed to support those with brain injuries and their families as they navigate the challenging recovery process. This dual-pronged transformation not only elevates the quality of care received by brain injury survivors but also reaffirms society's commitment to their well-being and full participation in the community.

***

This Article begins where Greg's story left off—with an attempt to better understand Greg's subjective experience. We start with a metaphoric reading of Franz Kafka's *The Metamorphosis,* in which a sudden trauma transforms the life of Gregor Samsa and his family. After discussing Kafka's *The Metamorphosis*, Part II will review the biology and nosology of brain injuries and outline the timeline of recovery, familiarizing readers with key touch points along the route to recovery and reintegration.

In Part III, we will discuss the capabilities approach, highlighting our continued desire to move from vindicating rights toward legislation intended to maximize the potential of people with brain injuries.

In Parts IV and V, we will operationalize the capabilities approach through the ICBIR, demonstrating how an interagency committee can improve recovery processes by mobilizing resources and services to support a tailored recovery and rehabilitation plan. We also defend the interagency approach as the most feasible means to this end.

In Part VI, we will then briefly discuss some caveats about policy initiatives related to marginalized communities, such as those with disabilities, and the need to be inclusive and humble when centering the perspective of those whose voices too often remain unheard. Finally, we end with a discussion of deliberative democracy, legislation, and the Constitution, situating the proposed AWAA and ICBIR as just one step forward in the essential work of advancing the civil rights of individuals with disabilities such as brain injuries.

I. THE METAMORPHOSIS

To begin, we will trade fact for fiction. Instead of returning to the real-life Greg, let us consider a fictive protagonist who goes by a similar name. Kafka's famous novel, *The Metamorphosis*, tells the story of Gregor Samsa who wakes up one morning to find himself inexplicably transformed into an "enormous bug."[22] What begins as an uneasy dream, descends into nightmare as Gregor's society and social network responds with disgust to his new body.[23] Kafka illustrates the social project of dehumanization, as Gregor transforms from a beloved son and brother into a forgotten artifact, left to languish, decay, and ultimately perish in his room.[24]

For over a century, *The Metamorphosis* has been mined for its metaphoric potential. Gregor's transformation has been read as an allegory for women, unemployment, mental illness, old age—the list goes on.[25] Here, we examine *The Metamorphosis* through the lens of disability and brain injury. To be clear, this analogy is not intended to suggest that individuals with disabilities are insectile or the objects of shame. Instead, Kafka's story provides an inroad into themes of empowerment, voice, and, most importantly, the social construct of disability.

The opening pages of *The Metamorphosis* are grounded in the physical.[26] Gregor awakens to the disturbing revelation that he is trapped in the body of a large insect.[27] Lying in bed, Gregor looks down to find a brown, domelike belly and numerous "pitifully thin" legs that "flickered helplessly before his eyes."[28] In excruciating detail, Kafka outlines Gregor's difficult attempts at coordination.[29] Gregor struggles to flip himself over to no avail: "[n]o matter how energetically he threw himself onto his right side, each time he rocked back into the supine position. He must have tried a hundred times, closing his eyes to avoid seeing his squirming legs[.]"[30] Through a meticulous account of Gregor's attempts at coordination, Kafka captures Gregor's sense of physical ineffectuality.

The story's opening underscores some of the challenges posed by brain injuries. Many individuals regain consciousness only to discover that their body behaves unfamiliarly. Small tasks, such as scratching an itch or getting out of bed, can present overwhelming difficulties. But beneath these physical

---

[22] FRANZ KAFKA, *The Metamorphosis*, *in* THE METAMORPHOSIS AND OTHER STORIES 11, 11 (Stanley Appelbaum trans., 1996).

[23] *Id.* at 19.

[24] *See generally* KAFKA, *supra* note 22 (presenting a surreal allegory of exclusion and decline following the loss of physical normalcy).

[25] *Id.*

[26] KAFKA, *supra* note 22.

[27] *Id.*

[28] *Id.*

[29] *Id.* at 11–14.

[30] *Id.* at 11.

impediments, there often remains a rich world of consciousness, feeling, and humanity.

Taking his physical predicament in stride, Gregor at first seeks to adhere to his daily routine and get ready for the workday: "[f]irst [Gregor] wanted to get up in peace and unmolested, get dressed and, especially, have breakfast, and only afterwards give the matter [of his transformation] further thought."[31] Beyond these mundane continuities, Gregor maintains the same innermost desires—for example, he reflects on his secret plan to send his musically gifted sister to the conservatory.[32] Though he faces new challenges in communicating this inner world to others, Gregor is still Gregor.

While Gregor distinguishes his identity from his physical predicament, this distinction begins to break down through his interactions with society and his family. Others exhibit immediate negative reactions toward Gregor's new corporeal form: his mother collapses; his father shields his eyes and begins to weep; and his employer, hand pressed against his mouth, "step[s] slowly backward as if driven by some invisible force operating with uniform pressure."[33] Gregor's subsequent attempts to approach his friends antagonize them further: his mother shrieks and runs away; his father, hissing, drives Gregor back into his room with a cane; and his employer disappears down the stairs.[34] When others discover Gregor's physical predicament, their fear and despair eclipse any imperative to communicate with Gregor, the man trapped within.

Kafka shows how the experience of alienation can be far more deadly than physical impediments. Over time, Gregor learns to maneuver his new body, manage its shortcomings and explore its new capabilities. However, Gregor is incapable of overcoming the devastating estrangement from society. Through the perceptions of others, Gregor's underlying personhood becomes obscured by his physical state. His family does not inquire about Gregor's needs or desires, instead supplanting their own assessments that reaffirm his otherness and undermine his identity. In the words of Gregor's mother, the family is waiting for "when Gregor comes back to us again."[35] Devoid of human connection, Gregor endures days of "featureless solitude" bereft of "all direct human communication."[36] Gregor remains motionless in the dark for weeks on end, in a process evocative of the "warehousing" of individuals with brain injuries in long-term care facilities.[37] We come to appreciate that society's

---

[31] *Id.* at 13.

[32] *Id.* at 29.

[33] *Id.* at 21.

[34] *Id.* at 22–23.

[35] *Id.* at 24.

[36] *Id.* at 31.

[37] *See generally* Shapiro et al., *supra* note 14 (advocating for legal and technological reforms that promote communication, inclusion, and dignity for individuals with brain injuries, and emphasizing how social neglect and isolation—not just physical impairments—undermine personhood). *See* DORA ANDERSON, DENISE ANDERSON & CLENORA HUDSON-WEEMS, THE ROSA PARKS OF THE DISABLED MOVEMENT: PLANTATION

response to Gregor's condition is far more deadly and isolating than his insectile form.

Far too often, a similar process of alienation occurs when an individual suffers a brain injury. Society is quick to define a person by their injury, which can eclipse their autonomy and identity. In the hopes of waiting for someone to "come back," society leaves individuals in stasis, undermining their personhood. Difficulties in accessing care and resources for treatment relegates individuals to lives of solitude, without meaningful opportunities for identify-affirming participation in the public sphere.[38]

In addition to capturing the devastation of estrangement, Kafka reveals the social construction of disability. At the outset of the story, Gregor is described as an "enormous bug"—a neutral term, devoid of any value judgment.[39] Although Gregor initially struggles with mobility, Gregor gains command over his new body.[40] When Gregor emerges from his room, however, his physical form is branded as something deficient and shameful.[41] Society is unwilling to give Gregor the space to maneuver or the chance to speak for himself. This hostility, rather than personal incapacity, is what condemns Gregor to stasis, silence, and, ultimately, death.

Kafka hints that the unrealized solution to Gregor's predicament is empowerment. The story's only mention of a cure occurs when Gregor first learns how to walk in his new body.[42] When Gregor finally propels himself onto the floor, he realizes that "his little legs . . . obeyed perfectly . . . they were eager to carry him wherever he wanted to go; and he now believed that a *definitive cure* for all his sorrow was immediately due."[43] Crucially, Kafka underscores society's ability to assist Gregor. At the outset of the story, Gregor struggles to flip from his back and get out of bed.[44] The narrator laments "it occurred to [Gregor] how simple everything would be if someone came to help him."[45]

The tragedy of *The Metamorphosis*, read with this perspective, sheds new light on current approaches to disability rights. If disability is understood as a social construct, structural changes can facilitate the exercise of autonomy and help individuals thrive. Fortunately, this same empowerment touched the world of real-life Greg.

After years of languishing in a minimally conscious state with little prospect of improvement, Greg underwent investigational deep brain

---

POLITICS AND A BLACK WOMAN'S STRUGGLE AGAINST GM, UAW AND GOVERNMENT BUREAUCRATS 171–72 (2008).

[38] *See* RCTM, *supra* note 2.

[39] KAFKA, *supra* note 22, at 11.

[40] *Id.* at 49.

[41] *Id.* at 50.

[42] *Id.* at 23.

[43] *Id.*

[44] *Id.* at 11.

[45] *Id.* at 15.

stimulation ("DBS").[46] Shortly after the surgery, Greg appeared more responsive and alert, and began to speak.[47] Over time, Greg regained the ability to respond to questions and voice his preferences.[48] His mother discovered that Greg enjoyed shopping and had strong clothing preferences, so they began to take outings to Old Navy.[49] Access to innovative treatment engaged Greg's inner life, allowing him to express himself and connect with his family.

As the intersecting stories of Gregor and Greg show, communication, identity, and belonging represent relational components of the human experience. To move beyond the failings demonstrated in Kafka's story, we must reject passive paradigms that curtail rehabilitative efforts. We must instead help the person before us fully actualize their autonomy, to turn over a new leaf, as it were. This is a collaborative exercise that necessitates communication, resources, care, and respect. As Gregor's story reminds us: "how simple everything would be if someone came to help him."[50] By supporting individuals with disabilities to expand their capabilities, they can more fully design their lives, realize their goals, and become empowered to advocate for themselves.

Gregor needed just a little bit of help to regain mobility. The AWAA is designed to offer help and support individuals with disabilities and their families throughout their recovery and rehabilitation.[51] This legislation focuses on protecting and promoting the interests of individuals with disabilities.[52] In particular, the AWAA addresses those whose recovery can be aided by advanced medical technology, such as those with moderate-to-severe brain injuries.[53]

In our 2022 article in the Boston College Law Review, we argued that a new law is needed to address the evolving landscape of disability rights and to provide greater protections for people with mutable disabilities, especially those who depend on AT to improve their rehabilitation and reintegration efforts.[54] These individuals and their families require focused support to enable community reintegration as their conditions improve through rehabilitation and the provision of medical technology. The proposed AWAA offers a framework for achieving these goals, while building upon the successes of the ADA. Despite its successes, the ADA is limited in addressing new and emerging issues—most importantly, the provision of cutting-edge medical technology. The AWAA would move disability and civil rights forward by providing additional protection and support for people with brain injuries.

---

[46] Joseph J. Fins, Maria G. Master, Linda M. Gerber & Joseph T. Giacino, *The Minimally Conscious State: A Diagnosis in Search of an Epidemiology*, 64 ARCHIVES NEUROLOGY 1400, 1400–01 (2007).

[47] *See* RCTM, *supra* note 2, at 238.

[48] *Id.*

[49] *Id.*

[50] KAFKA, *supra* note 22, at 15

[51] *See AWAA*, *supra* note 1, at 1735.

[52] *Id.* at 1730.

[53] *Id.* at 1794.

[54] *Id.* at 1792.

Our previous paper focused on justifying new legislation, and developing a scaffolding to promote the development, uptake, and successful use of AT for individuals with disabilities such as brain injuries.[55] Individuals with brain injuries often have difficulty communicating due to impairments in their ability to speak, write, or understand language. New medical technologies, such as brain-computer interfaces ("BCIs") and assistive communication devices, provide alternative means of communication.[56] For instance, BCIs allow those with motor function injuries to control a computer using their brain signals, bypassing their physical limitations.[57] Similarly, assistive communication devices like word boards help individuals communicate using text, symbols, and synthetic speech.[58]

In this paper, we continue this work by focusing on how the AWAA can improve the lives of individuals with disabilities and their families, further promoting recovery and reintegration. While there are many promising programs and technologies supporting individuals with brain injuries, accessing appropriate care while navigating the longitudinal challenges of recovery can be difficult and burdensome. Navigating these programs, which vary across state and federal agencies, requires extensive research and advocacy on behalf of the individual. These programs are siloed and often strictly focus on one particular service, rather than taking a longitudinal view of the individual's recovery. These fragmented offerings limit opportunities for holistic care and lead to a heightened risk of brain injury survivors not receiving appropriate services when needed. Without a roadmap for recovery, individuals with brain injuries regularly face barriers to care, miscommunications, and many lack advocacy and education about rehabilitation that can help improve their function.

When considering how to improve this situation for Americans with brain injuries, we suggest that the best way to provide legal support is through the creation of a dedicated interagency committee that we call the ICBIR. The ICBIR would bring expertise in navigating the complicated bureaucracy of governmental and healthcare programs, including dynamics between insurance companies, hospitals, and nursing homes. To tailor the help to the individual with a brain injury, the ICBIR will help support a new group of employees that we call "care navigators." Qualifying individuals with brain injuries will work not just with the ICBIR, but also with an individual care navigator throughout their recovery journey. Through resources provided by the ICBIR, care

---

[55] *Id.* at 1787.

[56] *See* 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).

[57] *See generally id.* (discussing how advances in neuroscience and medical technology—such as brain-computer interfaces—raise novel ethical and legal challenges and urging anticipatory legal frameworks to protect patient dignity and autonomy).

[58] *See generally id.* (noting that new medical technologies can restore communication for individuals with brain injuries, including tools that allow patients to convey preferences using symbols, speech synthesis, or other non-traditional interfaces).

navigators will help guide the individual and their family through the recovery process: from injury to recovery, rehabilitation, and on to societal reintegration.

Care navigators can plan for the different stages of brain injury recovery and the multiple handoffs that patients experience throughout their trajectory of improvement. Early on, for instance, patients are helped by programs at the hospital, which might fall under the purview of Health and Human Services ("HHS"). Later, they may require the assistance of a state-based agency to coordinate care and rehabilitation. As they progress and improve to the point where they can leave a care facility, these individuals will need help navigating programs offered by Housing and Urban Development ("HUD") or vocational programs offered by other agencies. We have specifically designed the ICBIR and its infrastructure to improve the coordination of care and hand-offs. Having a dedicated federal interagency, as well as a care navigator who is able follow the individual throughout their recovery journey, is a major advantage of the ICBIR compared to the status quo.

In order to more fully appreciate the need for the coordinated care enabled by the interagency committee, we will briefly depict the experience of those with brain injuries and the longitudinal care challenges they face.

II. BRAIN INJURY: BIOLOGY, TECHNOLOGY, AND COMMUNITY

A successful legal framework to support recovery from brain injuries requires a deep understanding of the underlying biology, nosology, and medical response. In the following Part, we outline this interaction, highlighting longitudinal challenges for patients, families, and health-care providers. Additionally, we demonstrate how novel technological advances make appropriate therapy and rehabilitation ever more important.

A. BIOLOGY OF BRAIN INJURY

We will focus on three disorders of consciousness ("DoC") that result from injury, illness, or other medical conditions: Coma, Vegetative State ("VS"), and Minimally Conscious State ("MCS").[59] As we discussed previously,[60] all injuries leading to a DoC are characterized by an initial loss of consciousness.[61] If loss of consciousness is sustained, it can evolve into a coma, an eyes-closed

---

[59] Joseph J. Fins, *Disorders of Consciousness in Clinical Practice: Ethical, Legal, and Policy Considerations*, *in* PLUM AND POSNER'S DIAGNOSIS AND TREATMENT OF STUPOR AND COMA 449, 452 (5th ed. 2019).

[60] We present 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. *See* Shapiro et al., *supra* note 14.

[61] *See* Giacino et al., *supra* note 8, at 349–50; *see generally* Shapiro et al., *supra* note 14 (reviewing diagnostic criteria for disorders of consciousness and noting that coma, vegetative state, and minimally conscious state typically follow an initial loss of consciousness due to injury or illness).

state of unconsciousness[62] and unresponsiveness.[63] Coma is a transitory state lasting up to several weeks.[64] A person in a coma is not aware of their surroundings and does not respond to stimuli such as sound, touch, or pain.[65] Patients in comas may eventually recover completely (as with induced comas during anesthesia), progress to brain death, or transition into longer-term disorders of consciousness, such as the VS or the MCS.[66]

The VS is a state of unconsciousness in which a person appears to be awake but is not aware of their surroundings.[67] The VS is generally regarded as the isolated recovery of the autonomic functions of the brain stem without higher integrative cortical function.[68] People in a VS may open their eyes, move their limbs, and even make sounds, but they do not respond to stimuli or show other signs of awareness or consciousness.[69]

Patients may improve from the VS into the MCS, a higher functional state.[70] The MCS formally entered the medical literature in 2002, after the Aspen Neurobehavioral Conference Workgroup published a consensus statement in *Neurology*.[71] The MCS is an altered level of consciousness in which a person has limited level of awareness and responsiveness.[72] People in a MCS may intermittently and unreliably be able to follow simple commands, such as opening their eyes or moving their limbs.[73] They may also show some signs of awareness of their surroundings, such as recognizing familiar people or responding emotionally to stimuli.[74] However, their awareness has significant limitations, and they may not be able to communicate or interact with others consistently. While those in the MCS demonstrate memory, attention, and focus, in addition to emotional and behavioral responses, these behaviors occur sporadically, complicating detection of awareness.

---

[62] *See* Giacino et al., *supra* note 8, at 349; Shapiro et al., *supra* note 14, at 534 (describing coma as a state of complete unconsciousness marked by closed eyes, lack of arousal, and unresponsiveness to sensory stimulation).

[63] *See* Giacino et al., *supra* note 8, at 349; Shapiro et al., *supra* note 14, at 534.

[64] 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 REVS. NEUROLOGY 99, 100 (2014).

[65] *Id.*

[66] JEROME B. POSNER, CLIFFORD B. SAPER, NICHOLAS D. SCHIFF & JAN CLAASSEN, PLUM AND POSNER'S DIAGNOSIS AND TREATMENT OF STUPOR AND COMA 7 (5th ed. 2019).

[67] *See* Bryan Jennett & Fred Plum, *Persistent Vegetative State After Brain Damage: A Syndrome in Search of a Name*, 299 LANCET 734, 734 (1972) (defining the vegetative state as a condition of wakefulness without awareness and distinguishing it from other disorders of consciousness).

[68] *See id.* (explaining that patients in a vegetative state can be awake but lack the ability to engage with their surroundings).

[69] *Id.*

[70] It is also possible for patients to recover from a coma directly to the MCS. *See* Giacino et al., *supra* note 64.

[71] *See* Giacino et al., *supra* note 8, at 350 (introducing the MCS and discussing how it differs from other DoC).

[72] *See id.* at 349–50.

[73] *See id.* (suggesting a link between the frequency of misdiagnosis of VS in MCS patients to the inconsistency of MCS patients' behaviors).

[74] *Id.* at 350–52.

Some patients who progress to the MCS may recover full consciousness.[75] Others may only regain partial functioning relative to their pre-injury levels.[76] With time and rehabilitation, individuals can become more responsive, and can better communicate with others, re-establishing communal ties.[77] Recovery is not static, and improvements can happen over years and decades.

This progression of recovery for moderate-to-severe brain injuries can be piecemeal and lengthy, with trajectories varying widely across individuals. Recent studies suggest that around seventy percent of individuals with brain injuries who receive inpatient rehabilitation will improve their level of cognitive state, and many of those will emerge with some degree of conscious functioning.[78] These outcomes can be improved with the proper technological interventions and rehabilitation support.

B. BRAIN INJURY AND EVOLVING CARE NEEDS

1. *Brain Injury Trajectories*

Various challenges arise throughout the often long and arduous recovery process that follows a brain injury. In part because brain injuries present uncertain temporal parameters for recovery, medical science is limited in its ability to predict the degree of functional recovery expected for an individual with a DoC.[79]

Brain injury is not static, but rather evolves through time; thus, care must evolve with it.[80] The healthcare system must provide support and guidance to patients and their families, from the initial acute care episode throughout the long-term recovery process. Unfortunately, existing resources are not well integrated—they exist across a variety of networks that are not in communication with one another. For instance, while placement in rehabilitation centers is often inappropriate after acute hospitalization, these centers may become useful later in the patient's trajectory.[81] But a patient's evolving needs

---

[75] Shapiro et al., *supra* note 14, at 533–536.

[76] *Id.*

[77] *See generally* RCTM, *supra* note 2 (describing how patients with disorders of consciousness can regain responsiveness and functional communication over time, particularly with rehabilitative support and emerging neurotechnologies).

[78] *See* 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).

[79] *See* 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. & REHAB. 746, 747 (2005).

[80] Joseph J. Fins & Nicholas D. Schiff, *Differences that make a Difference in Disorders of Consciousness*, 8 AM. J. BIOETHICS-NEUROETHICS 131, 131 (2017).

[81] *Other Interagency Activities*, INTERAGENCY COMM. ON DISABILITY RSCH., https://icdr.acl.gov/otherinteragencies#gsc.tab=0 (last visited Jan. 19, 2024).

present logistical difficulties to the extent rehabilitation programs do not interface with housing programs or vocational training.[82]

While patients do not necessarily need all these programs simultaneously, a proper longitudinal view requires consideration of the individual's present and future so that services can be tailored to their ongoing needs. Without a holistic perspective, patients may miss out on necessary care or remain unable to receive appropriate support as their status and function improves.

The uncertain and dynamic nature of brain injury recovery, coupled with a desire to expand and advance capabilities which are unique to the individual, motivates us to propose a new administrative body to help track, support, advocate for, and coordinate care for this population.

Navigating the recovery process while considering and planning for changing needs is particularly complicated. Many care inadequacies result from a failure to contextualize the patient's situation at a particular time within a broader recovery process. This myopic view of patients hampers the application of therapeutic and rehabilitative interventions that might help the patient progress to a higher level of consciousness. In response, we have identified three stages of a brain injury, each having their own needs and complexities: Stage One is acute care and hospitalization; Stage Two is rehabilitation or chronic care; and Stage Three is reintegration into the community. To understand how our proposed law and the interagency coordinating committee could improve this trajectory, we will review challenges faced during each stage and during care transitions.

a. Stage One: Hospitalization and Intensive Care

Stage One generally begins in a hospital emergency room, where patients are taken after they suffer an acute brain injury. After this, the patient moves to an Intensive Care Unit ("ICU") room before transitioning into a hospital room.[83] During this stage, the patient and their family grapple with uncertainty and an evolving prognosis.

In the acute setting, the patient is unable to communicate with the medical care team.[84] Surrogates must consider not only what is in the patient's best interest, but also, to the extent possible, what would be consistent with the patient's prior wishes.[85] This makes it important to support surrogates and family members as they navigate difficult choices, such as pre-existing Do Not Resuscitate ("DNR") orders or advance directives.

---

[82] *Id.*

[83] *See* Fins et al., *supra* note 46.

[84] *See* Joseph J. Fins & James L. Bernat, *Ethical, Palliative, and Policy Considerations in Disorders of Consciousness*, 91 NEUROLOGY 471, 474 (2018).

[85] Joseph J. Fins & Jennifer Hersh, *Solitary Advocates: The Severely Brain Injured and Their Surrogates*, *in* PATIENTS AS POLICY ACTORS 21, 21 (Beatrix Hoffman, Nancy Tomes, Rachel Grob, Mark Schlesinger eds., 2011).

Discharge planning is a particular challenge during Stage One. Once a patient survives their initial injury, post-hospital placement becomes an important consideration. Data from family narratives indicates discharges are often precipitous and sudden, with little prospective planning, making this crucial transition potentially counterproductive to ongoing recovery.[86] For instance, a patient who is sent to a nursing home versus rehabilitation facility is less likely to regain function or undergo proper longitudinal evaluation as his or her brain states progress.[87] Thus, it is important that clinicians view discharge placement as a critical juncture in the patient's care trajectory that can determine long-term outcomes.

b. Stage Two: Rehabilitation and Long-Term Care

Stage Two begins as the patient moves from the hospital setting into a rehabilitation center or chronic care facility. This discharge is a critical juncture in the patient's care trajectory, as rehabilitation (or lack thereof) impacts long-term outcomes.[88] Many facilities are ill-suited for patients with on-going medical needs and may not provide appropriate rehabilitation. For example, a patient in the MCS who has been misdiagnosed as being vegetative and sent to a chronic care facility, rather than a rehabilitation facility, is less likely to regain function.[89] This makes the choice of discharge facility integral in determining outcome trajectory.[90] While their brain heals, many patients are denied access to proper longitudinal evaluation and, consequently, adequate rehabilitation.[91]

Misdiagnosis remains a significant problem for this patient population. Research suggests that as many as forty-one percent of patients with traumatic brain injury ("TBI") in chronic care—thought to be in the VS—are actually in the MCS, when evaluated properly with the Coma Recovery Scale, a behavioral neuropsychological test.[92] Another diagnostic challenge is cognitive motor dissociation, in which patients appear behaviorally to be in the VS but have covert consciousness on volitional neuroimaging.[93] Avoiding these diagnostic errors requires access to neuropsychological testing, brain imaging, and/or other diagnostic tools such as electroencephalogram. This is important because treatments and prognoses vary considerably depending on diagnosed brain

---

[86] RCTM, *supra* note 2, at 2.

[87] *See* Fins & Bernat, *supra* note 84.

[88] Shapiro et al., *supra* note 14, at 536–39.

[89] *See*, *e.g.*, RCTM, *supra* note 2.

[90] *See*, *e.g.*, *id.*

[91] Shapiro et al., *supra* note 14, at 536–39.

[92] *See* Caroline Schnakers, Audrey Vanhaudenhuyse, Joseph Giacino, Manfredi Ventura, Melanie Boly, Steve Majerus, Gustave Moonen & Steven Laureys, *Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment*, 9 BMC NEUROLOGY 35, 35 (2009) (highlighting that up to 40% of MCS patients are incorrectly determined vegetative).

[93] Nicholas D. Schiff, *Cognitive Motor Dissociation Following Severe Brain Injuries*, 72 J. AM. MED. ASSOC. NEUROLOGY 1413, 1415 (2015).

state.[94] A socially constructed cause of misdiagnosis can result from pervasive nihilism regarding the possibility of recovery for individuals with DoC.[95] This can lead to errors of omission, neglect, and uniformed decisions to withhold or withdraw treatment.

One egregious consequence of misdiagnosis is untreated pain. Patients with covert consciousness—thought to be in the VS—can endure suffering due to inadequate pain management and neglect.[96] This oversight is inhumane and has been urged by scholars to be considered a tort, exposing the hospital or care facility to liability in addition to violating the dignity of the patient.[97]

Beyond diagnostics, access to drugs and devices is important therapeutically. Modalities range from pharmaceutical interventions to assistive and rehabilitative neuroprosthetics, such as communication boards, eye trackers, and more investigational devices including deep brain stimulators. Such interventions offer the potential for those with brain injuries to interact with the world around them. Although many of these interventions remain investigational, more are proven efficacious every day.[98] We have argued previously that these modalities should be available to patients more broadly.[99] Assessment and access to AT are essential and require significant planning, research, and advocacy so that resources adhere to the patient's ongoing biological needs.

At Stage Two, support services and rehabilitation often falter due to a lack of coordination, advocacy, access, and planning. When this happens, individuals with brain injuries are at high risk of languishing rather than improving.[100] Furthermore, many providers fail to envision the individual's potential for robust recovery. This stage also presents challenges to families, arising from questions of insurance coverage and potential financial strain. Navigating reimbursement from Medicare and Medicaid can be difficult and unfamiliar.[101] These burdens compound the family's adjustment as they grapple with their family member's condition.

---

[94] *See generally* RCTM, *supra* note 2 (detailing the variability of treatments). *See* Jan Claassen et al., *Detection of Brain Activation in Unresponsive Patients with Acute Brain Injury*, 380 NEW ENG. J. MED. 2497, 2498 (2019).

[95] *Accord* Joseph J. Fins, *Constructing an Ethical Stereotaxy for Severe Brain Injury: Balancing Risks, Benefits and Access*, 4 NATURE REVS. NEUROSCI. 323, 323–26 (2003).

[96] *See* Zachary E. Shapiro & Joseph J. Fins, *Pain Management, Disorders of Consciousness, and Tort Law: An Emergent Tort to Fix a Longstanding Injustice*, 98 IND. L.J. 693, 695 (2023).

[97] *See generally id.* (proposing a strict-liability "emergent tort" to hold facilities civilly accountable for the systemic undertreatment of pain in patients with disorders of consciousness, characterizing such neglect as an inhumane rights violation).

[98] *See, e.g.*, *AWAA*, *supra* note 1, at 1737.

[99] *Id.*; *see also* Shapiro et al., *supra* note 14, at 538; RCTM, *supra* note 2, at 301.

[100] *See generally* Shapiro et al., *supra* note 14, at 539 (arguing that inadequate rehabilitation and persistent institutionalization violate civil rights obligations under *Olmstead*, and that failure to coordinate care can lead patients with brain injuries to remain segregated, misdiagnosed, and deprived of recovery opportunities).

[101] *See* RCTM, *supra* note 2, at 5.

Even if the patient improves, however, challenges remain as the individual, family, and medical team navigate discharge and community reintegration. The scope of this responsibility includes finding appropriate housing, vocational and educational opportunities, and ongoing rehabilitation. A good discharge plan considers these needs as well as proximity to family or chosen family.

c. Stage Three: Community Integration

At Stage Three, the individual and the family must identify resources for housing, education, employment, and healthcare. Navigating and researching the various programs and support systems can be complicated and burdensome, as programs generally exist across a multitude of agencies and do not interface with each other. This burden is especially onerous since individuals with brain injuries require a variety of supports housed across different, and often siloed, governmental agencies and programs, the specifics of which we will discuss later. Because of the complexity, family members and support networks play an essential role at this stage. The family is often left with the difficult task of research and advocacy for their loved one whose condition prevents them from undertaking these complex tasks on their own.

During Stage Three, care should continue to include access to good medical services, including neurological, medical, and psychiatric support. It is important that individual and family therapy continue to support the well-being of the individual and their family as they navigate the recovery process. For people with disabilities, especially those living at home, their family members' mental health is an important environmental element impacting their cognitive, behavioral, and physical injuries.[102]

C. BROADER CONSEQUENCES

As previewed in Part II(B), disabilities such as brain injuries impact not only the individual, but also the entire family unit. Though Kafka narrates *The Metamorphosis* from Gregor's perspective, one could easily imagine the same story recounted by his parents. They are suddenly faced with a son they no longer recognize and are unable to communicate with him or understand his needs. Weathering the financial consequences of their son's newfound unemployment and the social consequences of his new body, Gregor's parents find themselves unprepared to navigate his new condition and the accompanying challenges.

Researchers place a growing emphasis on the importance of promoting family-centered medical care and social services in medicine and the law.[103] As one parent put it, "[i]f you've got a disabled child, you've got a disabled family

---

[102] *See AWAA*, *supra* note 1, at 1766.

[103] Ian James Dempsey & Deb Keen, *A Review of Processes and Outcomes in Family-Centered Services for Children with a Disability*, 28 TOPICS EARLY CHILDHOOD SPECIAL EDUC. 42, 42–52 (2008).

. . . and that is very, very true."[104] A family-centered approach is especially crucial in the context of a brain injury,[105] where family members serve not only as caregivers, but also as advocates and surrogate decision-makers, navigating a society ill-equipped for their loved one's needs.[106] Any system aimed at facilitating the social integration of individuals with brain injuries must, therefore, be created with the family in mind. [107]

1. *Families*

In the United States, the family unit is often forced to privatize the welfare function of the state.[108] In the absence of more robust social welfare programs, like those typically found in other countries, family members in the United States (generally women) often take on under- or uncompensated duties of social caregiving.[109] In the context of brain injuries, caregiving is a sweeping role that includes many responsibilities. Caregivers may perform patient advocacy, research and education, surrogate decision-making, coordination of insurance coverage, and occasionally personally provide rehabilitation.[110] As a result, brain injuries can have a significant—but highly variable—impact on caregivers and on the family unit as a whole, across financial, emotional, and relational dimensions.

a. Financial and Professional Consequences

Individuals with brain injuries are frequently unable to work,[111] which alters their functional role within their family and the capitalist social system.[112] Oftentimes family members must negotiate with insurance companies to ensure their loved one has access to rehabilitation and other services. To afford out-of-pocket care, they often must sell assets or take on additional work.[113] Furthermore, caregivers and family members face professional consequences of

---

[104] *See* Mark Whiting, *Children with Disability and Complex Health Needs: The Impact on Family Life,* 26 NURSING CHILD. & YOUNG PEOPLE 26, 30 (2014).

[105] Philip W. Henry, John Knippa & Charles J. Golden, *A Systems Model for Therapy with Brain-Injured Adults and Their Families*, 3 FAM. SYS. MED. 427, 428 (1985) ("[B]rain impairment to the individual is a catastrophe which affects the family as well as other social systems. Thus, therapy for the brain-injured adult must actively integrate the familial, social, and work spheres of life along with the appropriate medical and rehabilitative procedures.").

[106] *See* RCTM, *supra* note 2, at 26.

[107] Note that our use of the word "family" also contemplates one's chosen family.

[108] *See* Maxine Eichner, *The Privatized American Family*, 93 NOTRE DAME L. REV. 213, 214 (2017).

[109] *See* Barbara Laslett & Johanna Brenner, *Gender and Social Reproduction: Historical Perspectives*, 15 ANN. REV. SOCIO. 381, 383 (1989).

[110] *See, e.g.*, Caron Gan, Kent A. Campbell, Monica Gemeinhardt & Gerald T. McFadden, *Predictors of Family System Functioning after Brain Injury*, 20 BRAIN INJ. 587, 587 (2006) ("Family members are typically the major source of support for individuals after a brain injury and, therefore, play a pivotal role in promoting healthy adjustment throughout the rehabilitation process. It is also the family who often shoulders the responsibility of caring for the individual, long after formal rehabilitation has ended."); Fins, *supra* note 59.

[111] *See* Henry et al., *supra* note 105, at 433.

[112] *Id.*

[113] *See* Fins, *supra* note 59, at 469.

their own as they balance their new, time-intensive role as a patient advocate with their pre-existing obligations.[114]

b. Emotional and Mental Health Domains

Individuals with brain injuries and their family members often face mental health challenges.[115] Caregivers of individuals with disabilities may experience depression,[116] anger, helplessness,[117] anxiety,[118] and isolation[119] while simultaneously navigating changes in care settings, obstacles to care services, and skepticism or ignorance from friends and healthcare providers.[120] Notably, caregiver depression is more closely correlated with their loved one's cognitive disabilities and behavior problems than with physical disability or the severity of the injury.[121] It is important to note, however, that not all families and family members experience psychological distress or dysfunction.[122]

Furthermore, the caregiving experience is highly variable across individuals: different categories of caregivers, like spouses and parents, experience this role differently. Researchers posit that such differences stem from the degree of departure from the pre-injury relationship—while parents may see caregiving as an extension of their previous relationship with their children, spouses may see caregiving as a greater change from before the

---

[114] *Id.* at 472; *see also* Whiting, *supra* note 104, at 27.

[115] *See* Amaryll Perlesz, Glynda Kinsella & Simon Crowe, *Psychological Distress and Family Satisfaction Following Traumatic Brain Injury: Injured Individuals and Their Primary, Secondary, and Tertiary Carers*, 15 J. HEAD TRAUMA REHAB. 909, 917–18 (2000); FINS, *supra* note 59, at 472; Laurence Miller, *Family Therapy of Brain Injury: Syndromes, Strategies, and Solutions*, 21 AM. J. FAMILY THERAPY 111, 113 (1993) ("Probably the commonest response to brain injury is depression.").

[116] *See* Robert Gillen, Howard Tennen, Glenn Affleck, & Rhea Steinpreis, *Distress, Depressive Symptoms, and Depressive Disorder Among Caregivers of Patients with Brain Injury*, 13 J. HEAD TRAUMA REHAB. 31 (1998). Notably, however, in this study, the greatest predictor of depression was a pre-injury depressive episode.

[117] Diane Duff, *Family Impact and Influence Following Severe Traumatic Brain Injury*, 27 AXON/L'AXONE 9, 11 (2005).

[118] Martin G. Livingston & D. Neil Brooks, *The Burden on Families of the Brain Injured: A Review*, 3 J. HEAD TRAUMA REHAB. 6, 10 (1988).

[119] Muriel D. Lezak, *Living with the Characterologically Altered Brain Injured Patient*, 39 J. CLINICAL PSYCHIATRY 592, 593 (1978); Nancy E. Reichman, Hope Corman & Kelly Noonan, *Impact of Child Disability on the Family*, 12 MATERNAL & CHILD HEALTH J 600, 679–83 (2008).

[120] *See* Fins, *supra* note 59, at 468.

[121] *See generally* Karen Allen, Richard T. Linn, Horacio Gutierrez & Barry S. Willer, *Family Burden Following Traumatic Brain Injury*, 39 REHAB. PSYCH. 29 (1994) (examining the various types and levels of burdens placed on family members who step into caregiver roles).

[122] *See* Duff, *supra* note 117, at 11.

injury.[123] Women frequently take on additional caregiving responsibilities alongside their existing roles.[124]

The emotional and psychological impacts of a brain injury change over time, reflecting, in part, the patient's treatment trajectory. In the immediate aftermath of the injury, family members often face shock, denial, and anger as they reckon with their new reality and adjust expectations for their loved one.[125] After the "acute care heroics of emergency rooms, neurosurgery, and high-tech interventions," family members are faced with agonizing decisions over DNRs and withdrawing or extending treatment.[126] In reflection years later, family members describe a range of emotions, from personal growth and a deeper sense of meaning to psychological distress and guilt for not being more involved in their loved one's care, particularly among non-primary caregivers.[127] These recollections highlight the deeply personal and individualized experience for families affected by a family member's brain injury. Just as the biological progression of disability is dynamic, so is its impact on family.

c. Family Dynamics

While individuals with brain injuries and their family members may individually experience psychosocial issues, brain injuries can also strain interpersonal family dynamics as family members negotiate new financial, caregiving, and domestic responsibilities.[128]

> Within the family system, each member plays a special role, with implicit and explicit tasks, upon which the balanced functioning of the family units are predicated. Brain injury alters the ability of one individual within the family to fulfill the "contractual" role; the resulting disequilibrium may strain the family's ability to reorganize.[129]

---

[123] *See* Allen et al., *supra* note 121 ("Relative to spouses, parents reported significantly greater burden related to lifespan care. Spouses reported significantly less personal reward than did parents."); Gan et al., *supra* note 110; Henry et al., *supra* note 105, at 428. *But see* Gillen et al., *supra* note 116, at 31, 38 (finding that spouses were no more likely to be depressed than mothers).

[124] Gan et al., *supra* note 110, at 596 ("This indicates that the biggest problem for caregivers may [center] on role changes in the family. The increased dependence of the person with ABI often leads to additional responsibilities for the caregiver who is closest to that person, often the spouse or the mother.").

[125] *See* Henry et al., *supra* note 105, at 433; Miller, *supra* note 115, at 114 ("At least in the beginning stages, denial is common. . . . Denial may be adaptive when it preserves family stability, keeps the family members from being overwhelmed, and maintains appropriate role functioning within the family.").

[126] RCTM, *supra* note 2, at 42.

[127] Charles Edmund Degeneffe & Marjorie F. Olney, '*We Are the Forgotten Victims': Perspectives of Adult Siblings of Persons with Traumatic Brain Injury*, 24 BRAIN INJ. 1416, 1422 (2010).

[128] *See* Duff, *supra* note 117, at 9.

[129] Henry et al., *supra* note 105, at 432–33.

Family restructuring is common after a brain injury[130] and may range from separation and divorce to increased closeness.[131] Caregivers who are parents must balance continuing to care for their children while tackling the sudden, radically different needs of their injured family member or spouse.[132] Some family members—often siblings—resent or envy the attention their injured loved one receives, while also wrestling with guilt about their envy.[133]

While the experiences of siblings are shaped, in part, by their stage of life at the time of the injury, having a sibling with a brain injury can impact individuals no matter their age.[134] As they get older, many siblings anticipate taking over caregiving responsibilities from aging parents, which informs the decisions they make in their own families and lives.[135] Each family member uniquely grapples with a shift in responsibilities as they recalibrate their expectations for the future. These adjustments undoubtedly impact the way individual members relate to each other and how the family unit functions as a whole.

III. CONCEPTUAL FRAMEWORK FOR THE AWAA: FROM RIGHTS TO CAPABILITIES

When designing new legislation to support individuals with disabilities, we must learn from past efforts, taking into account both successes and failures, in order to design the best legislation possible. With this in mind, there are many lessons from past efforts to support disability rights that can help guide us when designing the AWAA.

The ADA was passed in 1990 and is generally considered the most important piece of disability-focused legislation in the United States. Modeled after the Civil Rights Act of 1964, the ADA follows an "equal opportunity" framework to create a protected class of disabled individuals.[136] Eligibility for the protected class is established by the statute.[137] By not prescriptively enumerating all disabilities, Congress left to the courts the task of determining the conditions under which an individual may qualify for the protected class.

---

[130] *Id.* at 435–36.

[131] ACTON.SHAPIRO, NO TIME FOR US: RELATIONSHIPS BETWEEN PARENTS WHO HAVE A DISABLED CHILD 6 (2003); Degeneffe & Olney, *supra* note 127, at 1421 ("Participants wrote about how the injury of their sibling either made the family closer or pulled the family apart. These reactions were predictably strong and extreme.").

[132] FINS, *supra* note 59 at 20, 96; *see* Degeneffe & Olney, *supra* note 127, at 1421 ("Parents became much less available to non-injured siblings after the accident and a number of siblings indicated that they were forced to grow up fast and be relatively independent.").

[133] *See* Miller *supra* note 115; Degeneffe & Olney *supra* note 127.

[134] *See also* Gan et al., *supra* note 110, at 587–600 (describing how siblings, mothers, and spouses, but not offspring or fathers, were impacted by ABI).

[135] *See* Degeneffe & Olney *supra* note 127, at 1421; *see also id.* at 1422 (describing choosing job locations and adjusting life goals to accommodate future caregiving responsibilities).

[136] Shapiro et al., *supra* note 14, at 551–57.

[137] Americans with Disabilities Act, 42 U.S.C. § 12102; *id.* § 12102(2)(A).

Before long, courts were asked to define the parameters of the ADA. In its first test, *Bragdon v. Abbott*, the Court broadened the ADA to encompass conditions that impose effects on major life activities outside of public activities.[138] The *Bragdon* decision resulted in the optimistic belief that subsequent tests would broaden the definition of disability, increasing the population of eligible individuals protected under the Act.[139]

However, employers and financial actors soon responded to *Bragdon* by asking courts to narrow the definition of disability.[140] Following *Bragdon*—in a series of cases referred to as the "mitigation trilogy"—the Supreme Court introduced a test requiring courts to consider "mitigating factors" in disability claims.[141] These cases narrowed the definition of "disability," and thus the reach of the ADA, by assessing disability not according to its so-called "untreated" state, but according to corrective measures that may result in an appearance of "normal functioning."[142] The Court further narrowed eligibility requirements in *Toyota Motor Manufacturing v. Williams*, heightening the extent to which a condition must impact an individual's life to qualify as a disability.[143]

These measures narrowed the scope of disability, but failed to clarify or secure the definition of disability; instead, they "provoked a series of new questions with respect to the technological morphing of normalcy."[144] Several theories propose explanations as to why courts have construed the definition of disability so narrowly: (1) the statute was poorly drafted; (2) there was confusion over the new statute; and (3) the ADA claims were weak.[145] However, the "backlash" theory, which posits that courts deliberately narrowed the protected class because they were hostile to the ADA, seems to best explain the high failure rate of claims under the ADA.[146] For instance, poverty law and social welfare researcher Matthew Diller states, "[t]he term *backlash* suggests a [] hostility to the statute and toward those who seek the enforce it. The backlash thesis suggests that judges are not simply confused by the ADA: rather, they are resisting it."[147]

---

[138] Bragdon v. Abbott, 524 U.S. 624, 624–25 (1998).

[139] Fiona Kumari Campbell, *Legislating Disability: Negative Ontologies and the Government of Legal Identities*, *in* FOUCAULT AND THE GOVERNMENT OF DISABILITY 108, 122 (Shelley Tremain ed., 2015).

[140] Eugenia Liu, Bragdon v. Abbott*: Extending the Americans with Disabilities Act to Asymptomatic Individuals*, 3 J. HEALTH CARE L. & POL'Y 382, 386 (2000).

[141] Nicole Buonocore Porter, *Explaining "Not Disabled" Cases Ten Years After the ADAAA: A Story of Ignorance, Incompetence, and Possibly Animus*, 26 GEO. J. ON POVERTY L. & POL'Y 383, 384 (2019); Sutton v. United Air Lines, Inc., 527 U.S. 471, 482 (1999); Murphy v. United Parcel Serv., Inc., 527 U.S. 516, 516 (1999); Albertson's, Inc. v. Kirkingburg, 527 U.S. 555, 556 (1999).

[142] *See* Campbell, *supra* note 139.

[143] Toyota Motor Mfg. v. Williams, 534 U.S. 184, 197 (2002).

[144] Campbell, *supra* note 139, at 123.

[145] *See AWAA*, *supra* note 1.

[146] *See* Porter, *supra* note 141, at 388; Matthew Diller, *Judicial Backlash, the ADA, and the Civil Rights Model of Disability*, *in* BACKLASH AGAINST THE ADA 62, 64–65 (Linda H. Krieger ed., 2003).

[147] Nicole Buonocore Porter, *Disclaiming Disability*, 55 U.C. DAVIS L. REV. 1829, 1837 (2022) (quoting Diller, *supra* note 146, at 63–65).

In response to backlash against the ADA, Congress amended the Act through the ADA Amendments Act of 2008 ("ADAAA" or "Amendments"). Instead of changing the statutory definition of disability, the Amendments clarified the definition by overruling the mitigation trilogy and *Toyota* standard.[148] Referencing *Toyota*, the Amendments mandated that courts should not follow the *Toyota* standard but should instead follow the standards promulgated by the U.S. Equal Employment Opportunity Commission ("EEOC").[149] Referring to the mitigation trilogy, the Amendments prohibited the consideration of many mitigating measures.[150] The Amendments further expanded the scope of the ADA by untethering the definition of disability to functional limitation, thus expanding the protected class to cover individuals with, for example, endocrine, immune, neurological, and circulatory impairments.[151] The Amendments challenged the association of disability with functional incapacity and inability to work, thus decoupling disability "from negative conceptions of functional impairment."[152] We need to move beyond the ADA and ADAAA to offer the AWAA to account for the difficulties surrounding the support, recovery, and reintegration of individuals with brain injuries. These complex challenges require a more holistic and capacious approach—one we have previously described as a paradigm shift from a rights-based approach to one that embraces capabilities. Not to be misconstrued, the AWAA draws upon a capabilities approach *in addition to* the traditional reliance of disability law on civil rights. These dual efforts lay the groundwork for a more compassionate, effective, and sustained system of legal support for those with brain injuries and their families.

An important conceptual change is at the heart of this paradigm shift, which involves redefining the scope of our responsibilities toward individuals with brain injuries. The conceptual shift moves beyond a rights-based approach. It involves embracing a new philosophical framework centered on optimizing individual capacities and fostering human well-being. This means viewing brain injury survivors not as passive recipients of aid, but as dynamic individuals with

---

[148] The Amendments revised the definition of disability by: (1) deeming the "demanding standards" in *Toyota* incorrect and clarifying "substantially limits"; (2) expanding "major life activities"; and (3) changing the "regarded as" prong in the mitigation trilogy. Alex B. Long, *Introducing the New and Improved Americans with Disabilities Act: Assessing the ADA Amendments Act of 2008*, 103 NW. U. L. REV. COLLOQUY 217, 218 (2008).

[149] 29 C.F.R. § 1630.2.

[150] The prohibition included: (1) medication, medical supplies, equipment, low-vision devices, prosthetics, hearing aids, and cochlear implants; (2) assistive technology; (3) reasonable accommodations or auxiliary aids and services; and (4) learned behavioral or adaptive neurological modifications. *ADA Amendments Overrule Supreme Court Decisions on what Constitutes a Disability*, FAEGRE DRINKER (Jan. 15, 2009), https://www.faegredrinker.com/en/insights/publications/2009/1/ada-amendments-overrule-supreme-court-decisions-on-what-constitutes-a-disability.

[151] *See* Porter, *supra* note 141, at 390; Katie Eyer, *Claiming Disability*, 101 B.U. L. REV. 547, 554 (2021). Furthermore, the Amendments expanded the protected class by: (1) clarifying that it is sufficient for an impairment to limit one major life activity and (2) providing a non-exhaustive list of major life activities qualified under the statute that is more exhaustive than the EEOC's regulations. *See* 42 U.S.C. §§ 12102(2)(A)–(B).

[152] *See* Eyer, *supra* note 151, at 554–55.

potential for growth, adaptation, and contribution to society. By emphasizing their agency and fostering an environment conducive to their personal development, we empower individuals with brain injuries to strive for their fullest potential, despite the challenges they face.

In previous work, we advocated for understanding disability law through the lens of a *capabilities approach*, rather than a more traditional rights-based approach focused on rectifying past discrimination.[153] We have designed the AWAA to reflect the goal and philosophy of the capabilities approach. By adopting a capabilities approach to legislating, we can design supports and systems that expands the possibilities of individuals with brain injuries, opening new avenues for self-expression, community reintegration, and enjoyment of life. This perspective can help redefine the trajectory of recovery and transcend the traditional notion of passive care, emphasizing active efforts to enable affected individuals to achieve their fullest potential and lead fulfilling lives.

In Part One of this series, we argued that a capabilities approach to disability law highlights the importance of techno-logical solutions, which are central to a forward-looking AWAA that guarantees all Americans have equally meaningful and substantive opportunities. This perspective also motivates our new interagency committee, the ICBIR, designed to help support and nurture the capabilities of recovering individuals with brain injuries. Through providing easier access to the existing network of supports, the ICBIR will help individuals with a brain injury expand their horizons and achieve their full range of possibilities. From a legal perspective, a focus on capabilities involves imagining what the individual will be capable of in the *future* and supporting them as they realize this potential.

We previously focused on how a capabilities approach might further the integration of technological solutions into disability law. Now, we emphasize a more holistic approach to rehabilitation and community reintegration. The interagency committee is designed to support individuals with brain injuries from recovery through reintegration—helping provide access to available programs and supports that help individuals flourish, not languish. A capabilities approach is particularly well-suited to the dynamic nature of brain injury recovery because viewing the individual's capabilities as static hinders meaningful progression. In this capabilities approach, we focus on a triumvirate of (i) technology, (ii) infrastructure, and (iii) focused support, rehabilitation, and personal development. Each triumvir is necessary for a full vindication of the rights of persons with disabilities.

A. REINTRODUCING THE CAPABILITIES ACCOUNT

As a continuation of our previous work, we call for conceptualizing disability law through the lens of a capabilities approach, that transitions from

---

[153] *See AWAA*, *supra* note 1, at 1747.

the 'negative' right to freedom from interference to a more holistic picture of 'positive' rights. This allows for the development and exercise of fundamental capacities constitutive of human flourishing and necessary for a robust human autonomy.[154]

The negative conception of rights traditionally focuses on the freedom from interference from others.[155] The right to freedom of movement is constrained, for example, when one is imprisoned and forcibly prevented from going where they wish. The positive conception of rights, on the other hand, highlights the freedom to achieve one's ends or goals. In the case of freedom of movement, this involves the freedom to go where one wishes.[156] This view is broader than the negative conception of freedom because ends may be frustrated in multiple ways. For instance, an end can be frustrated even if no one else has interfered or prevented the end from being achieved. As we observed in Part One of this series, Robinson Crusoe trapped on his island is no more free to move than a prisoner in a jail cell, even though no one prevents him from leaving.[157] Robinson Crusoe is *not* free because he cannot leave the island, regardless of whether the constraints are due to outside influence.

Similarly, we can take a more imaginative view of the government's duties toward the disability community in employment or housing. An employer that discriminates against a person with disabilities violates the employee's rights, restricting the employee's freedom to exercise their ability to engage in meaningful work. But such discrimination is just one way that a person with disabilities may be unable to exercise their capabilities. They may be equally prevented by the absence of government funding for the necessary AT, such as speech-to-text technology for someone with dyslexia[158] or brain computer interfaces for individuals with physical mobility or speech limitations.[159] The existence of AT may allow these individuals to re-engage with their communities in new ways.[160] While the absence of research into or dissemination of such technology does not involve an interference of the same nature as intentional discrimination, it still prevents people with disabilities from pursuing their chosen ends. By restricting these individuals' opportunities, their liberties are constrained and their positive rights are violated, even if this does

---

[154] *Id.* at 1759–72. The contemporary capability-approach traces back to the work of Isiah Berlin, Amartya Sen, and Martha Nussbaum. *See* ISAIAH BERLIN, TWO CONCEPTS OF LIBERTY 11 (1966); Sen, *supra* note 21, at 219; Nussbaum, *supra* note 21.

[155] *See, e.g.*, BERLIN, *supra* note 154, at 7.

[156] *Id.*

[157] *AWAA*, *supra* note 1, at 1761.

[158] Kelly D. Roberts & Robert A. Stodden, *The Use of Voice Recognition Software as a Compensatory Strategy for Postsecondary Education Students Receiving Services Under the Category of Learning Disabled*, 22 J. VOCATIONAL REHAB. 49, 60 (2005).

[159] *See infra* page 107.

[160] *AWAA*, *supra* note 1, at 1784.

not involve a legally cognizable violation of a more traditional, negative conception of rights.[161]

Someone who is provided AT in an accessible environment may still struggle to realize their potential absent additional factors, such as housing, rehabilitative, educational and vocational services, and support networks. From a capabilities approach, these factors must be considered as they also affect whether the agent can successfully exercise their rights. Our approach will promote capabilities through assisting these individuals as they realize and attain their personal goals and desires.

In Part One of this series, we argued that a negative rights approach strictly focusing on freedom from interference may lead to an over-emphasis on reactive remedies in legislation like the ADA.[162] On the capabilities account, this "backward-looking" approach of rectifying past discrimination is insufficient to guarantee the rights of the disability community. While an individual's rights can be violated through the interference of others—such as through acts of discrimination—freedom can also be frustrated when individuals lack equitable access to the requisite resources necessary to achieve substantive ends.[163]

A more nuanced conception of rights as capabilities can help us expand our legislative imagination and develop policies that provides individuals with disabilities the tools they need to flourish as autonomous human beings. The AWAA is focused on expanding the possibilities and opportunities available to individuals with brain injuries, supporting this population as they realize their goals.

B. CAPABILITIES AND TECHNOLOGY

Previously, in Part One, we tied this "forward-looking" capabilities account of disability rights to the need for development and dissemination of new technologies.[164] If individuals are free to the extent that they can meaningfully pursue their desired ends, the government can expand this freedom by providing technologies that allow individuals new ways of realizing their capabilities. Unlike the concept of negative freedom, which is maximized by the absence of outside interference, the upper bounds of freedom are positively expanded with new technologies through the capabilities approach.

Similarly, technology increases the capabilities of persons with disabilities to pursue their chosen ends. This process involves envisioning novel technological means to allow persons with disability to pursue general ends. Prominent proponents of the capabilities approach, such as Martha Nussbaum

---

[161] *Id.* at 1762.

[162] *Id.* at 1753.

[163] The capabilities approach thus shares some features in common with an *anti-subordinative,* rather than *anti-classificatory*, conception of the equal protection clause. *See* Owen M. Fiss, *Groups and the Equal Protection Clause*, 5 PHIL. & PUB. AFFS. 107, 136 (1976).

[164] *Id.* at 162.

and Amartya Sen, have distinguished the general capabilities necessary to achieve most human ends, and more specific capacities through which those general capabilities are realized. For Nussbaum, these general capabilities include mobility, bodily integrity, autonomy, love, and communication,[165] which can be realized in multiple ways. For example, suppose an individual wishes to communicate with a friend. They may do so through speech or writing. If one wishes to move to a new location, they might go by foot or by car. Technological advances allow new and better means to realize these general capabilities.

According to the capabilities framework, the perception of Americans with disabilities as incapable of pursuing certain ends is similarly myopic. This perspective focuses only on currently available capacities, without considering incremental capabilities that *might* yet be realized through technological innovation. Even if a person's disability prevents them from exercising their general capabilities like communication or mobility through the typical biological means—for example, through vocalized speech or by walking—technology can provide new ways for them to achieve the same ends.

Consider the freedom of movement. On the capability front, to enjoy this freedom, an agent must have some locomotive capacity, either through the biological motor system or technological augmentation. Such technology includes *embedded technologies* such as artificial prosthetics as well as *external technologies* such as a wheelchair.

Consider also communication, a capacity intimately intertwined with a holistic path toward rehabilitation. As noted, communication is the most fundamental capability.[166] Communication allows one to assert their preferences—a pre-requisite to leading one's life as desired. Furthermore, communication fosters relationships with one's friends and family by allowing them to express their perspective and take part in collective decision-making. The ability to communicate one's basic needs is often required to assert one's right to life itself, whether through attaining education, medical treatment, or some other means.[167]

Exercising this capability is not necessarily straightforward for individuals with disabilities. For individuals with cognitive disabilities, communication may hinge on a right to specialized education or speech therapy.[168] For individuals with vision or hearing impairments, communication necessitates access to AT and rehabilitation.[169] For individuals with brain injuries, communication may

---

[165] MARTHA C. NUSSBAUM, WOMEN AND HUMAN DEVELOPMENT: THE CAPABILITIES APPROACH 70–80 (2000).

[166] *See generally* RCTM, *supra* note 2 (discussing the role of communication in the recovery and ethical recognition of patients with disorders of consciousness).

[167] *Id.* at 272–73.

[168] *See* Shapiro et al., *supra* note 14, at 587.

[169] Joseph J. Fins et al., *A Descriptive Analysis of Access to Assistive Technology in Children with Acquired Brain Injury: The Right to Assistive Devices*, 39 J. HEAD TRAUMA REHAB. 1, 2 (2023).

require a mix of the above, along with further technological innovations such as the use of brain imaging, brain-computer interfaces, or speech-assistive technologies, depending on their abilities.[170]

Under a capabilities approach, society has an obligation to ensure that every individual has the means to communicate as a fundamental method to assert further preferences. This is consistent with the broader, holistic mandate of the United Nations Convention on the Rights of Persons with Disabilities.[171] Society has affirmative duties to vindicate the rights of individuals with disabilities, ensuring that these individuals can pursue their chosen ends. Therefore, society has an affirmative obligation not just to eradicate discrimination, but also to promote new technologies that provide individuals with disabilities with equal opportunities.

Achieving this requires the ability to exercise one's capabilities. Thus, an individual must have the requisite technology and a supportive ecosystem in which they may employ these means. As stated by philosopher Ingrid Robeyns:

> Real freedom in this sense [the sense of capabilities] means that one has all the required means necessary to achieve that doing and 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.[172]

Previously, we argued that the obligation to create "substantive opportunities" requires an ecosystem in which new ATs can be developed, utilized, and made accessible.[173]

But substantive opportunity requires more than just a technological ecosystem. In our view, it necessitates legal frameworks that remove roadblocks

---

[170] *Id.* at 6; *AWAA*, *supra* note 1, at 1732.

[171] U.N. Convention on the Rights of Persons with Disabilities, *opened for signature* Mar. 30, 2007, 2515 U.N.T.S (entered into force May 3, 2008).

[172] Ingrid Robeyns & Morten Fibieger Byskov, *The Capability Approach,* STANFORD ENCYCLOPEDIA OF PHIL. (Apr. 17, 2025), https://plato.stanford.edu/entries/capability-approach/.

[173] *See* RCTM, *supra* note 2, at 293; *AWAA*, *supra* note 1, at 1745; Gregory E. Antill, *Agency, Akrasia, and the Normative Environment*, 5 J. AM. PHIL. ASS'N 321, 327 (2019). This is not to deny that such obligations would also exist even on a more traditional account of rights. *See AWAA*, *supra* note 1, at 1765 ("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 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.").

and provide supports to maximize the potential of individuals with brain injuries. These technological ecosystems are insufficient unless the individual has the appropriate support, training, rehabilitation, and education required to use the technology properly. Absent such support, the technology will go unutilized just as it would absent an appropriate ecosystem. Thus, the AWAA provides a technological ecosystem and a holistic support network through an interagency committee, helping individuals with brain injuries access, integrate, and utilize AT.

Social, educational, and medical support networks encourage the development of all sorts of capacities—technological or otherwise—which are necessary for individuals to achieve their goals under the capabilities approach. Rehabilitation is particularly central to restoring communicative capacities since its interactive nature presupposes and helps individuals develop such capacities. Beyond this, individuals need training and support to learn how to maximize the benefits of technology. Thus, on a capabilities approach, supportive rehabilitation networks must be centralized to foster communication and supplement technology-based intervention.

C. CAPABILITIES AND FAMILIES

The current piecemeal approach is ill-suited to longitudinal patient recovery without a capabilities framework. Consider communication—one of the end goals of Stage Two, nursing home rehabilitation. As noted previously, the transition from Stage One to Stage Two is often mediated by technological and medical interventions to improve the functioning of an individual with a brain injury. But these interventions, while necessary, are not sufficient. The transition from Stage One to Stage Two requires not just medical treatment but also family support to motivate and communicate with the patient. During this transition, families face questions of insurance coverage, discharge planning, rehabilitation, vocational training, and housing, to name just a few.[174] These concerns implicate a variety of crosscutting services spanning multiple agencies and exceeding the purview of any one institution.

Consider also the goal community integration, a major component of the transition from Stage Two to Stage Three. Again, emerging technological and medical interventions, such as deep brain stimulation and/or brain-computer interfaces, are necessary but insufficient for the transition on their own. Fully realizing the individual's capabilities—that is, returning to meaningful engagements and social connections—requires a variety of supports.

Realizing these capabilities requires access to technological interventions coordinated with continued medical rehabilitative, vocational, and educational training. Later in recovery, these social, technical, and medical interventions

---

[174] *See* RCTM, *supra* note 2, at 156–57 (noting that rehabilitation was initially excluded from the ACA and only added after advocacy, highlighting coverage uncertainties for families).

require employment training with appropriate accommodations and long-term housing.

If we think of capacities as a puzzle, requiring different pieces that fit together—technology, social networks, as well as medical, vocational, educational, and housing support—it becomes clear that no one agency or service provider has the holistic viewpoint or expertise necessary to *fully* support individuals with brain injuries. Addressing these intersectional challenges in isolation is insufficient for the individual and their family as they embark on recovery and longitudinal societal re-integration.

D. BEYOND THE ADA: ACHIEVING REGULATORY OHERENCE

A capabilities approach makes clear the shortcomings of the current statutory system. Presently, each stage in the brain injury recovery process is siloed, as medical and legal professionals focus on meeting the patient where they are, rather than envisioning their future progress. This approach is inappropriate when considering the dynamic nature of a brain injury. This issue extends to the currently available legal frameworks, such as the ADA, and motivates our desire to propose new legal mechanisms to support this vulnerable population.

The ADA is split into separate titles, each covering an area of public life, with distinct enforcement structures stemming from different agencies.[175] The EEOC issues, enforces, and provides technical assistance on Title I employment regulations, which require employers to provide reasonable accommodations and prohibit discrimination based on disability.[176] Title II, which prevents public entities from denying services to people with disabilities, is regulated by several agencies, including the Department of Labor ("DOL"), Department of Housing and Urban Development, and Department of Transportation.[177] Several other agencies enforce Title III—the title addressing public accommodations—and Title IV—the title on telecommunications.[178]

These wide-ranging agencies tasked with enforcement power have not made structural litigation a priority, following the patterns of prior federal statutes that also left enforcement up to agencies, such as the Civil Rights Act and Fair Housing Act.[179] As a result, the ADA has made limited strides for people with disabilities across many aspects of life. For instance, the employment rate for people with work-limiting disabilities declined after the passage of the ADA, from fifty percent in 1988 to twenty-two percent in 2014.[180]

---

[175] Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101–12213 (2018).

[176] *Id.* at §§ 12111–12117; *see also Federal Agencies and Resources*, ADA NAT'L NETWORK, http://adata.org/federal-agencies (May 2025).

[177] 42 U.S.C. §§ 12131–12165.

[178] *Id.* at §§ 12181–12189; Communications Act of 1934, 47 U.S.C. § 225.

[179] *Michael E. Waterstone*, *Disability Constitutional Law*, 63 EMORY L. J. 527, 547 (2014).

[180] Michelle Maroto & David Pettinicchio, *Twenty-Five Years after the ADA: Situating Disability in America's System of Stratification*, 35 DISABILITY STUD. Q 1, 6 (2015).

Average earnings for people with disabilities have been stagnant compared to the rising earning of people without disabilities.[181] Occupational segregation is also widespread, with many people with disabilities confined to specific employment sectors.[182]

Even if fully enforced, the ADA lacks the forward-looking approach necessary for maximal reintegration outcomes and realization of capabilities for individuals with disabilities. As discussed in Part III, individuals with brain injuries undergo a long recovery and rehabilitation process, with each stage involving different agencies. The development of and access to technology has emerged as a critical part of reintegration, implicating agencies far beyond the scope of the ADA. The National Institutes of Health ("NIH") and National Science Foundation ("NSF") provide grants for disability research, while the Food and Drug Administration ("FDA") and Center for Medicare and Medicaid Services ("CMS") are involved in the development of, and reimbursement for, medical technology.[183] Improved coordination between agencies is critical to bridge gaps between different enforcement schemes and more effectively monitor disability rights, especially for individuals requiring focused support while recovery from a brain injury.

While the ADA advanced the rights of people with disabilities, it arguably did not seek to organize a cohesive *government-wide response* to address the needs of this population. This is a pressing need. Currently, multiple agencies and entities focus on disability. For instance, the Interagency Committee on Disability Research ("ICDR"), created by the Rehabilitation Act of 1973, promotes coordination of over ten agencies on disability, independent living, and rehabilitation research programs.[184] The ICDR was originally established as the Interagency Committee on Handicapped Research under the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, which amended the Rehabilitation Act of 1973 and promoted the coordination of disability-related research.[185] The National Institute on Disability, Independent Living, and Rehabilitation Research ("NIDILRR") aims to support individuals with disabilities.[186] NIDILRR's stated mission is "to generate new knowledge and to promote its effective use to improve the abilities of individuals

---

[181] *Id.* at 5–6.

[182] *See* 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, 374 (2014).

[183] *See AWAA*, *supra* note 1, at 1773.

[184] *Interagency Committee on Disability Research*, ADMIN. FOR CMTY. LIVING, https://icdr.acl.gov/about#gsc.tab=0 (last visited Aug. 1, 2025).

[185] *Interagency Committee on Disability Research: History and Significance*, INTERAGENCY COMM. ON DISABILITY RSCH. 3 (Sept. 2020) [hereinafter *ICDR*], https://pfs2.acl.gov/strapib/assets/ICDR_History_Paper_2020_1006_508_ecb67065f3.pdf.

[186] *About the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)*, ADMIN. FOR CMTY. LIVING, https://acl.gov/about-acl/about-national-institute-disability-independent-living-and-rehabilitation-research (last visited Aug. 1, 2025).

with disabilities to perform activities of their choice in the community, and to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities."[187] To this end, NIDILRR funds research and the development of new rehabilitation technologies, among other efforts. While other federal agencies implement disability technology, NIDILRR is unique in that it focuses on helping persons of all age groups, with an eye toward longer-term outcomes.[188]

NIDILRR also operates the Traumatic Brain Injury Model System, which was created in 1987 and supports research to meet the needs of people with TBI.[189] Today, NIDILRR is a subordinate of the Administration for Community Living ("ACL"), within HHS. But for many years, NIDILRR—then known as the National Institute on Disability & Rehabilitation Research ("NIDRR")—was nested within the Department of Education ("DOE"). With the passage of the Workforce Innovation and Opportunity Act ("WIOA") in 2014 amending Title II of the Rehabilitation Act, Congress renamed NIDRR to NIDILRR and transferred it to ACL.[190]

The National Council on Disability ("NCD") is an advisory agency on disability policy, advising the President, Congress, and other agencies focused on emerging disability issues.[191] There are many other agencies and offices across the federal ecosystem. One key agency is the Office of Behavioral Health, Disability, and Aging Policy ("BHDAP"). The BHDAP, formerly known as the Office of Disability, Aging, and Long-Term Care Policy ("DALTCP"), is situated within HHS, under the Assistant Secretary for Planning and Evaluation.[192] It "focuses on policies and programs that support the independence, productivity, health and well-being, and long-term care needs of people with disabilities, older adults, and people with mental and substance use disorders."[193] Other entities with a role in this arena include: the EEOC; the Office of Special Education Programs ("OSEP"); the Office of Disability Employment Policy ("ODEP"), which is situated within the DOL and is a "non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with

---

[187] *Id.*

[188] *Id.*

[189] *Traumatic Brain Injury (TBI) Model System*, MODEL SYS.' KNOWLEDGE TRANSLATION CTR., https://msktc.org/about-model-systems/tbi (last visited May 31, 2025).

[190] Workforce Innovation and Opportunity Act, Pub. L. No. 113-128, 128 Stat. 1425 (2014) (codified at 29 U.S.C. § 3101).

[191] NATIONAL COUNCIL ON DISABILITY, https://ncd.gov (last visited Aug. 1, 2025).

[192] *See generally* CHRISTOPHER GIESE, ANNIE GUNNLAUGSSON & KEVIN BROWN, MILLIMAN, ACTUARIAL ANALYSIS OF LONG-TERM SERVICES AND SUPPORTS REFORM PROPOSALS (2025), https://aspe.hhs.gov/sites/default/files/documents/6df6e767d3412ca25ce315d5d4a95fa7/actuarial-analysis-ltss-reform-proposals.pdf (discussing the role of BHDAP).

[193] *Office of Behavioral Health, Disability, and Aging Policy (BHDAP)*, OFF. ASSISTANT SEC'Y. FOR PLAN. & EVALUATION, https://aspe.hhs.gov/about/offices/bhdap (last visited Aug. 1, 2025).

disabilities";[194] and the U.S. Access Board, "an independent federal agency that promotes equality for people with disabilities through leadership in accessible design and the development of accessibility guidelines and standards."[195] In addition, the Office of Special Education Programs ("OSEP")—which sits within the Office of Special Education and Rehabilitative Services ("OSERS") in the DOE—administers the Individuals with Disabilities Education Act ("IDEA").[196]

This brief recounting is a through line between these entities: agencies are not coordinated, may lack enforcement ability,[197] and are generally confined to one defined area of need, such as education or research. The lack of coordination amongst these useful, but varied, programs highlights a major shortcoming in the existing structure.

Beyond the question of exactly how to define disability, interagency collaboration is often considered one of the critical challenges of modern governance.[198] When passing laws, Congress often fails to consider how they are implemented in practice, creating "overlapping, fragmented, and duplicative delegations that ultimately require agencies to share regulatory space[.]"[199] This failure presents serious management challenges for agencies and the President,[200] but removes policies from political influence and fosters

---

[194] *About ODEP*, U.S. DEP'T OF LABOR: OFF. OF DISABILITY EMP. POL'Y, https://www.dol.gov/agencies/odep/about (last visited Aug. 1, 2025).

[195] *About the U.S. Access Board*, U.S. ACCESS BD., https://www.access-board.gov/about/ (last visited Aug. 1, 2025).

[196] *Office of Special Education Programs (OSEP)*, U.S. DEP'T OF EDUC., https://www.ed.gov/about/ed-offices/osers/osep (last visited Aug. 1, 2025).

[197] The IDEA provides federal funding to states and local educational agencies (LEAs) "for the education of children with disabilities and imposes certain conditions for the receipt of federal funds." CONG. RSCH. SERV., R41833, THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA), PART B: KEY STATUTORY AND REGULATORY PROVISIONS 20 (2024). The Secretary of Education "monitors the implementation of IDEA through the oversight of states' required general supervision of the implementation of IDEA requirements, and through the states' required state performance plans (SPP). These plans evaluate a state's efforts to implement the requirements and purposes of IDEA and describe how the state will improve implementation. . . . The Secretary must enforce IDEA and must also require states to monitor and enforce the implementation of IDEA by LEAs." *Id.* at 24. States must establish measurable targets in their SPPs, and report performance in an Annual Performance Report. *Id.* at 25. "If the Secretary determines that a state does not meet requirements, IDEA specifies a number of enforcement actions depending on the Secretary's specific determination. These actions range from advising the state of available sources of technical assistance, to requiring the state to prepare a corrective action plan, to withholding, in whole or in part, further IDEA funds to the state." *Id.* at 26; s*ee* Jon Romberg, *The Means Justify the Ends: Structural Due Process in Special Education Law*, 48 HARV. J. LEGIS. 415, 416 (2011) (citing Bd. of Educ. of Hendrick Hudson Cent. Sch. Dist. v. Rowley, 458 U.S. 176, 205–06 (1982)); *see also* Megan S. Wright, Nina Varsava, Joel Ramirez, Kyle Edwards, Nathan Gueveremont, Tamar Ezer & Joseph J. Fins, *Severe Brain Injury, Disability, and the Law: Achieving Justice for a Marginalized Population*, 45 FLA. ST. U. L. REV. 313, 345 (2018).

[198] *See* Jody Freeman & Jim Rossi, *Agency Coordination in Shared Regulatory Space*, 125 HARV. L. REV. 1131, 1133 (2012); EUGENE BARDACH, GETTING AGENCIES TO WORK TOGETHER: THE PRACTICE AND THEORY OF MANAGERIAL CRAFTSMANSHIP 17 (1998); Jody Freeman, *Collaborative Governance in the Administrative State*, 45 UCLA L. REV. 1, 2 (1997).

[199] Freeman & Rossi, *supra* note 198, at 1209.

[200] *Id.* at 1201.

compromise among lawmakers.[201] Beyond rulemaking,[202] poor interagency coordination impacts adjudications, causing human rights violations around immigration and other areas of public law.[203] Recent failures in responses to COVID-19 demonstrate the importance of agency coordination. For example, the failure of the CDC, FDA, and CMS to work together to expand COVID-19 test access resulted in significant delays and shortages.[204]

The challenge of coordination is complex. Existing federal programs are siloed and typically provide benefits based on the individual's level of impairment or inability to work, rather than acknowledging their strengths and potential to offer unique contributions to society. Furthermore, these programs were rarely designed to provide sufficient support for AT or vocational training tailored to the needs of disabled individuals with brain injuries. Without access to these resources, individuals cannot achieve their full potential. Additionally, these programs are difficult to research and burdensome to access, requiring family support and advocacy on behalf of the individual with a brain injury. These challenges may intimidate stakeholders, limiting opportunities for access, personal growth, and independence.

When recovering individuals are not provided with ample services that can foster additional improvement, they lose the potential to be self-actualizing. This perpetuates the status quo and demands a remedy. With this in mind, we elaborate on the ICBIR, a core component of the AWAA, by proposing a novel interagency committee to support individuals with brain injuries and their families as they navigate injury, recovery, rehabilitation, and reintegration.

E. COORDINATING LONGITUDINAL CARE

The current fragmented nature of care often leads to inefficiencies, gaps in service delivery, and overlapping efforts. Fixing this requires mechanisms to coordinate seamless care throughout the dynamic trajectory of recovery in an efficient and non-redundant manner.

At the heart of this paradigm shift is a conceptual change, which involves redefining the scope of our responsibilities toward individuals with brain injuries. The shift involves embracing a new philosophical framework centered on optimizing individual capabilities and fostering human well-being. This means viewing brain injury survivors not as passive recipients of aid, but as

---

[201] *Id.* at 1138–45.

[202] *See* Hiba Hafiz, *Interagency Coordination on Labor Regulation*, 6 ADMIN. L. REV. ACCORD 199, 199 (2021) (discussing challenges of interagency coordination for labor regulations).

[203] Bijal Shah, *Uncovering Coordinated Interagency Adjudication*, 128 HARV. L. REV. 805, 806 (2015).

[204] *See* Rachel E. Sachs, *Encouraging Interagency Collaboration: Learning from COVID-19*, 4 PA. J.L. & INNOVATION 71, 75–78 (2022) (citing examples of lack of coordination including the CDC blocking an FDA official from entering the building at one point); I. Glenn Cohen, *Introduction to Part IV: Innovation During COVID-19*, *in* COVID-19 AND THE LAW: DISTRIBUTION, IMPACT AND LEGACY 221, 221 (I. Glenn Cohen, Abbe R. Gluck, Katherine Kraschel & Carmel Sachar eds., 2023).

dynamic individuals with potential for growth, adaptation, and contribution to society. By emphasizing their agency and fostering an environment conducive to their personal development, we empower individuals with brain injuries to strive for their fullest potential, despite their ongoing challenges. By adopting a capabilities approach to public policy, we can design supports and systems that work toward expanding the possibilities of these individuals, opening new opportunities for self-expression, community reintegration, and improved life satisfaction. This perspective redefines the trajectory of recovery and transcends the traditional notion of passive care.

This re-conceptualization of care requires a workable strategy for implementation. We believe that the ICBIR is an ideal means to coordinate care across the continuum of brain injuries. An interagency approach has the potential to overcome the fragmented care environment encountered by brain injury survivors and their families. Because brain injury recovery is a prolonged and evolving process, patients and families must traverse multiple domains during their journey. These domains include healthcare, rehabilitation, education, housing, and social services. As discussed above, no single agency has jurisdiction or oversight over these various sectors, leading to gaps in service delivery along with significant inefficiency. An interagency committee could facilitate the seamless coordination and efficient allocation of governmental care and services throughout the dynamic trajectory of recovery.

To this end, the ICBIR would serve as a collaborative platform where representatives from each relevant sector can streamline care and exchange knowledge to ensure a synchronized and harmonious approach. By fostering collaboration among various sectors, both within the government and externally, an interagency committee could help promote consistent and holistic care tailored to the individual's evolving needs.

Furthermore, the interagency committee could facilitate long-term planning adapted to the changing needs of brain injury survivors. Given the dynamic nature of brain injury recovery, where progress can be non-linear and unpredictable, a centralized coordinating body can promptly adjust strategies, allocate resources effectively, and bridge emerging gaps in care. This adaptability ensures that individuals receive the necessary interventions at the right time, preventing setbacks and optimizing their potential for recovery and reintegration into society. Coordination could improve the utilization and efficacy of these resources, as it can de-silo isolated programs and transform them into a cohesive web of support networks.

The synergistic implementation of these conceptual and organizational changes is the core of the AWAA. This new legislative model would create a legal framework that not only addresses immediate needs but also promotes sustained well-being and successful reintegration for those impacted by brain injuries. From a philosophical standpoint, interagency collaboration will help ensure that patients' capabilities are maximized. Rather than focusing on negative rights, a new interagency committee will ensure that government actors can truly be responsive to and accommodating toward the evolving nature and needs of patients and their families.

Ultimately, by adopting these changes, we can pave the way for a more inclusive, empathetic, and effective system that upholds the dignity and potential of every individual affected by a brain injury.

IV. IMPLEMENTATION OPTIONS

A. STRUCTURING INTERAGENCY COORDINATION

The decision to create a proposal for a novel interagency committee was not taken lightly. This endeavor will require designing, staffing, and implementing a new working administrative body with the agency and medical expertise to advocate for and support individuals with brain injuries and their families. While this task requires considerable resources, the benefits, including long-term cost savings, far outweigh the costs.

We considered three administrative models for the AWAA. Given the challenges of interagency coordination and the unique regulatory space that disability requires, a new executive-level agency dedicated to enforcing disability law could be a centralized and direct solution given its access to the President. Alternately, an independent agency with the full range of agency powers could adopt a more balanced and traditional approach to enforcing new legislation. Recently created agencies serve as precedent, showing that establishing a new disability-focused agency is neither farfetched nor unrealistic. Finally, we conclude with the recommendation that an interagency coordinating committee—empowered to promote and advance capabilities—is the best option at this juncture.[205]

1. *Option One: Cabinet-Level Agency*

The United States Cabinet consists of fifteen department heads of executive-level agencies, all appointed by the President with Senate confirmation.[206] This offers close proximity to the President.[207] Only two executive-level agencies have been established in the past forty years, highlighting the difficulty of establishing new executive-level agencies.[208] Still, the two most recent agencies, the U.S. Department of Veterans Affairs ("VA")

---

[205] While another possibility would be a new agency housed under a current executive department (e.g., the FDA in HHS), this would be less practical because any agency on disability would inevitably intersect with other agencies, thus maintaining the problems of interagency coordination.

[206] *See The Cabinet*, WHITE HOUSE, https://www.whitehouse.gov/administration/cabinet/ (last visited Aug. 1, 2025).

[207] *See* JENNIFER L. SELIN & DAVID E. LEWIS, ADMIN. CONF. OF THE U.S., SOURCEBOOK OF UNITED STATES EXECUTIVE AGENCIES 34 (2d ed. 2018) ("The primary difference between an executive department and a free-standing administration is symbolic. Department status is conferred to confirm the importance of certain constituencies (farmers, business, labor, veterans) or to publicly recognize the priority of dealing with certain key policy problems (cities, transportation, energy, homeland security).").

[208] *See id.* at 29–32.

and the U.S. Department of Homeland Security ("DHS"), provide two distinct but representative frameworks for creating a new cabinet departments.

The VA was first developed to provide medical care and pensions for veterans during the American Revolution[209] and the American Civil War.[210] During World War I, Congress established a new system for veteran benefits to be administered by three federal agencies, which combined into one Veterans Bureau in 1921. [211] In 1930, President Hoover signed Executive Order 5398 to "consolidate and coordinate governmental activities affecting war veterans" by elevating the Veterans Bureau to a federal Veterans Administration.[212] After World War II, the number of veterans increased rapidly and Congress enacted more benefits, such as the GI Bill, which provided loans for homes, unemployment benefits, and free education.[213] The resulting increase in cases and administrative costs finally led Congress to pass the Department of Veterans Affairs Act in 1988, which elevated the Veterans Administration to a cabinet-level executive department.[214] This cabinet seat stemmed from 200 years of history, a practical need for centralization, and a political desire to give veterans a seat next to the President.

The DHS offers a different example of an agency created quickly in the aftermath of a national crisis. After the September 11th attacks, Congress passed the Homeland Security Act of 2002, consolidating twenty-two agencies scattered throughout the government into one agency aimed at preventing terrorist attacks.[215] The 9/11 Commission Report, the official report of the events leading up to the attacks, emphasized that the "terrorists exploited deep institutional failings within our government."[216] The American government had been receiving frequent reports of threats from the start of 2001, with a high probability of near-term attacks by the summer, leading the Director of Central Intelligence, George Tenet, to describe the system as "blinking red."[217] Despite all these alarms, few steps were taken domestically to avert the threat due to disconnect between U.S. officials. President George W. Bush reiterated the

---

[209] *VA History Summary*, U.S. DEPT. OF VETERANS AFFS., https://department.va.gov/history/history-overview/ (last visited Aug. 1, 2025).

[210] Michael R. Ulrich, Megan S. Wright, Kyle Edwards, Nathan Guevremont, Joel Ramirez, Nina Varsava & Joseph J. Fins, *Lincoln's Promise: Congress, Veterans, and Traumatic Brain Injury*, THE HASTINGS CTR. FOR BIOETHICS (June 21, 2016), http://www.thehastingscenter.org/lincolns-promise-congress-veterans-and-traumatic-brain-injury/.

[211] *See generally* ROSEMARY STEVENS, A TIME OF SCANDAL (2017) (examining the creation and operation of the Veterans Bureau).

[212] Exec. Order No. 5,398, 38 C.F.R § 201.1 (1930).

[213] *See About GI Bill Benefits*, U.S. DEPT. OF VETERANS AFFS. (Nov. 29, 2024), https://www.va.gov/education/about-gi-bill-benefits/.

[214] Department of Veterans Affairs Act of 1998, Pub. L. No. 100-527, 102 Stat. 2635 (1988).

[215] Homeland Security Act of 2002, Pub. L. No. 107–296, 116 Stat. 2135 (2002).

[216] 9/11 COMM'N, THE 9/11 COMMISSION REPORT: FINAL REPORT OF THE NATIONAL COMMISSION ON TERRORIST ATTACKS UPON THE UNITED STATES 265 (2004).

[217] *Id.* at 259.

importance of creating "one department" in his proposal for the DHS.[218] He noted a primary mission of protecting the American homeland through securing borders and coordinating communications, among other measures that would improve security.[219] Bush also cited President Truman's prior consolidating acts as "crucial to overcoming the enormous threat… [of] the Cold War," including passing the National Security Act of 1947 to consolidate separate military departments into a single U.S. Department of Defense and create the Central Intelligence Agency ("CIA") and National Security Council.[220] Undoubtedly, substantial national security risks was the primary factor driving the consolidation of many agencies into one cabinet department.

Executive agencies have many advantages, as Cabinet-status is a "symbolic national affirmation" that recognizes a group's interests and importance.[221] However, few agencies have a Cabinet seat, and history shows that it often takes a long period of time or an emergency to catalyze the development of a new Cabinet position.[222] While this may seem to preclude an executive-level disability agency, the United States arguably faces an unprecedented growing population of individuals with disabilities. One in four Americans live with a disability, and two in five adults aged sixty-five and older have a disability.[223] This means almost half of Americans will be disabled by sixty-five, especially as life expectancy increases. Further, the full temporal dimensions of the COVID-19 pandemic continue to evolve.[224] Already, there are many cases of Long COVID, defined as ongoing health symptoms more than a month after COVID infection that impact a person's quality of life. In fact, more than one in five adult COVID survivors under the age of sixty-five in the United States have experienced at least one symptom of Long COVID.[225] Intubation or prolonged unconsciousness, which can occur in severe COVID cases, is also associated with hypoxemia or low blood oxygen levels that contribute to symptoms such as brain fog.[226] The prevalence of Long COVID, along with the many parallels

---

[218] *See* GEORGE W. BUSH, THE DEPARTMENT OF HOMELAND SECURITY 1 (2002); *see also President Bush's Proposal to Create a Department of Homeland Security: Hearing Before the S. Comm. on Gov't Affairs*, 107th Cong. (2002) (statement of Senator Carl Levin), https://www.govinfo.gov/content/pkg/CHRG-107shrg80607/html/CHRG-107shrg80607.htm.

[219] *See* BUSH, *supra* note 218; *see also President Bush's Proposal to Create a Department of Homeland Security: Hearing Before the S. Comm. on Gov't Affairs*, *supra* note 218.

[220] BUSH, *supra* note 218, at 7.

[221] SELIN & LEWIS, *supra* note 207, at 34.

[222] Jesse Greenspan, *The Origins of the Presidential Cabinet*, HISTORY (May 27, 2025), https://www.history.com/articles/history-of-the-presidential-cabinet.

[223] Press Release, Ctrs. for Disease Control & Prevention, CDC: 1 in 4 US Adults Live with a Disability (Aug. 16, 2018), https://archive.cdc.gov/www_cdc_gov/media/releases/2018/p0816-disability.html.

[224] Joseph Fins, *COVID-19 Through Time*, ISSUES SCI. & TECH., Spring 2021, at 73, 78.

[225] Pam Belluck, *More Than 1 in 5 Adult COVID Survivors in U.S. May Develop Long Covid, a C.D.C. Study Suggests*, N.Y. TIMES (May 26, 2022), https://www.nytimes.com/2022/05/24/health/long-covid-infections.html; *Long COVID Basics*, CDC (July 24, 2025), https://www.cdc.gov/covid/long-term-effects/?CDC_AAref_Val=https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html.

[226] Greer Waldrop et al., *Prolonged Unconsciousness is Common in COVID-19 and Associated with Hypoxemia*, 91 ANNALS NEUROLOGY 740, 751 (2022).

with other diseases like Myalgic encephalomyelitis and Lyme Disease, indicates disability may soon become increasingly prevalent and significant to the national economy and healthcare system.

We believe agencies should not only be created after a crisis becomes apparent, and suggest an anticipatory governance approach to act before problems become massive and inflict substantial damage.[227]

2. *Option Two: Independent Agency*

A more politically feasible alternative might be a novel independent agency, or an agency that is not part of the Executive Office of the President.[228] Unlike a Cabinet-level agency, an independent agency is insulated from the President, with agency leadership often protected from presidential at-will removal.[229] A recent example is the Consumer Financial Protection Bureau ("CFPB"), created by the Dodd-Frank Wall Street Reform and Consumer Protection Act in 2010 following the 2007–08 financial crisis.[230] The CFPB was made responsible for consumer protection in the financial sector, with the powers to "administer, enforce, and otherwise implement federal consumer financial laws, which includes the power to make rules, issue orders, and issue guidance."[231] These expansive powers, and the fact that the agency's leadership consisted of a single director, recently led the Supreme Court to strike down for-cause removal protections in *Seila Law LLC v. Consumer Financial Protection Bureau*.[232] Nonetheless, the agency has continued to operate with fewer protections on director removal.[233]

Most independent agencies have existed longer than the CFPB and typically have unique structural features to ensure independence. These features include multi-member boards, with members having fixed terms and for-cause removal protections, as well as explicit term staggering, party balancing, and quorum rules.[234] For instance, the Federal Communications Committee ("FCC"), created under the Communications Act of 1934, is led by a multi-member commission with five Presidentially-appointed and Senate-confirmed Commissioners serving for five-year terms.[235] No more than three of the commissioners can be members of the same party, which helps maintain

---

[227] *See* David H. Guston, *Understanding 'Anticipatory Governance'*, 44 SOC. STUD. SCIENCE 218, 224 (2014).

[228] *See* Jacob E. Gersen, *Designing Agencies*, *in* RESEARCH HANDBOOK ON PUBLIC CHOICE & PUBLIC LAW 333, 347 (Daniel A. Farber & Anne Joseph O'Connell eds., 2010).

[229] *See* SELIN & LEWIS, *supra* note 207, at 96.

[230] Dodd-Frank Wall Street Reform and Consumer Protection Act, Pub. L. No. 111-203, 124 Stat. 1376 (2010).

[231] *Id.*

[232] *See* Seila Law LLC v. Consumer Fin. Prot. Bureau, 591 U.S. 197, 197 (2020).

[233] *See id.* at 205.

[234] SELIN & LEWIS, *supra* note 207, at 96.

[235] PATRICIA MOLONEY FIGLIOLA, CONG. RSCH. SERV., R45699, THE FEDERAL COMMUNICATIONS COMMISSION: CURRENT STRUCTURE, OPERATIONS, AND BUDGET 2 (2025).

bipartisanship and supports the mission of the FCC to ensure a "rapid, efficient, Nationwide, and worldwide wire and radio communication service with adequate facilities at reasonable charges."[236] Many other independent agencies such as the Federal Election Commission, Federal Energy Regulatory Commission, National Labor Relations Board, and United States Postal Service mirror these features. Notably, academics disagree about the ideal leadership structure of an independent agency—some argue a single–director agency ensures agency efficacy and accountability, while others believe multi-member commissions defend against liberty-infringing actions.[237] Either way, independent agencies provide distinct advantages over cabinet agencies. For example, independent agencies offer more bipartisanship and reduced fluctuation with changing presidential administrations, while still being able to exercise the typical functions of an executive agency.[238] Indeed, some positions such as the U.S. Permanent Representative to the United Nations have only intermittently been accorded cabinet rank since 1946.[239]

As another example of an independent agency is Secretary Xavier Becerra's Advanced Research Projects Agency for Health ("ARPA-H"), established in 2022 as a new agency within the NIH.[240] Unlike the NIH, which focuses on fundamental knowledge, ARPA-H funds applied research with short-term teams to provide a "novel pathway to catalyzing transformative health breakthroughs" that cannot be accomplished with traditional research.[241] In these efforts, Congress and the White House have reiterated the importance of new groundbreaking technologies and advancing health equity, which is only further support for a new agency that focuses on disability. These laws may face legislative opposition and constitutional challenges, but it is critical to consider the regulatory framework when passing any new legislation to ensure its full impact.

For issues as far-reaching as brain injuries and disability, an independent agency may be a superior path to ensure an objective, continuous approach uninterrupted by changes in administration. In fact, seven former FDA

---

[236] The Communications Act of 1934 § 1, 47 U.S.C. §151.

[237] *See* Ganesh Sitaraman & Ariel Dobkin, *The Choice Between Single Director Agencies and Multimember* Commissions, 71 ADMIN. L. REV. 719, 723 (2019).

[238] Alice Lesniak, *The Virtues and Necessity of Independent Agencies*, CONST. ACCOUNTABILITY CTR. (Mar. 5, 2025), https://www.theusconstitution.org/blog/the-virtues-and-necessity-of-independent-agencies/.

[239] LUISA BLANCHFIELD, HENRY B. HOGUE & SUSAN G. CHESSER, CONG. RSCH. SERV., IF11618, UNITED NATIONS ISSUES: CABINET RANK OF THE U.S. PERMANENT REPRESENTATIVE 1–2 (2021).

[240] Jeannie Baumann, *Bill to Create Biden's Biomedical Agency Wins House Passage*, BLOOMBERG L., (June 22, 2022, 3:45 PM PDT), http://news.bloomberglaw.com/health-law-and-business/bill-to-create-bidens-biomedical-agency-wins-house-passage; Press Release, Xavier Becerra, Secretary, Health and Human Services, HHS Secretary Becerra Establishes ARPA-H within NIH, Names Adam H. Russell, D.Phil. Acting Deputy Director (May 25, 2022), https://www.hhs.gov/about/news/2022/05/25/hhs-secretary-becerra-establishes-arpa-h-within-nih-names-adam-h-russell-phil-acting-deputy-director.html.

[241] Press Release, Exec. Off. of the President, Off. of Mgmt. & Budget, Statement of Administration Policy: H.R. 5585–ARPA-H Act (June 21, 2022), https://www.whitehouse.gov/wp-content/uploads/2022/06/HR-5585-SAP.pdf.

commissioners recommended in 2019 that the FDA should be moved out of HHS and become an independent federal agency, citing ten overarching reasons, including protecting public health, enhancing transparency, and ensuring predictable decision making.[242] Many of these reasons would also apply to the disability context. However, as of this Article's publication, none of the independent agencies are exclusively focused on disability or public health, despite the clear and long-standing need to do so.

3. *Option Three: Interagency Committee*

Lastly, interagency committees have also made significant policy impacts and united officials across disciplines. Such efforts are generally considered more politically and practically feasible than creating a new Cabinet-level or independent agency. A notable example is the Committee on Foreign Investment in the United States ("CFIUS"), which consists of nine Cabinet members and other officials who assist the President in reviewing the national security risks of foreign investment in the United States.[243] In 1975, President Ford issued an Executive Order creating CFIUS,[244] while Congress passed the Exon-Florio Amendment to the Defense Production Act in 1988 to specify the basic review process after rising concerns over foreign acquisition of certain United States' firms.[245] In 2006, public and congressional concerns about terrorism risks in the Dubai Ports World acquisition led to the Foreign Investment and National Security Act ("FINSA") of 2007,[246] replacing the executive order and fully codifying CFIUS.[247] Similarly, concerns over China's growing investment in the United States led to the Foreign Investment Risk Review Modernization Act of 2018, which further modified CFIUS.[248]

These statutes modified CFIUS to allow the President to block "mergers, acquisitions, or takeovers" by foreign entities upon "credible evidence" that foreign investment could create a national security risk.[249] Notably, the President's actions are not subject to judicial review, which allows for broad unchecked power. For instance, CFIUS raised concerns in 2019 over Beijing Kunlun Company's investment in Grindr and access to private United States'

---

[242] Robert M. Califf, Margaret Hamburg, Jane E. Henney, David A. Kessler, Mark McClellan, Andrew C. von Eschenbach & Frank Young, *Seven Former FDA Commissioners: The FDA Should Be an Independent Federal Agency*, 38 HEALTH AFFS. 84, 85 (2019).

[243] JAMES K. JACKSON, CONG. RSCH. SRV., RL33388, THE COMMITTEE ON FOREIGN INVESTMENT IN THE UNITED STATES (CFIUS) 23–24 (2020).

[244] Exec. Order No. 11,858, 3 C.F.R. § 990 (1971–1975).

[245] JACKSON, *supra* note 243, at 7; Exon-Florio Amendment of 1988, Pub. L. No. 100-418, § 5021, 102 Stat. 1107 (codified at 50 U.S.C. app. § 2170).

[246] Foreign Investment and National Security Act of 2007, Pub. L. No. 110-49, 121 Stat. 246 (codified as amended at 50 U.S.C. app. § 2170).

[247] JACKSON, *supra* note 243, at 10.

[248] Foreign Investment Risk Review Modernization Act of 2018, Pub. L. No. 115-232, 132 Stat. 1636.

[249] JACKSON, *supra* note 243, at 11.

information, resulting in the Chinese firm divesting from Grindr.[250] Of course, a national security focus likely permitted such expansive powers, as reflected by the motivation for codifying the original executive order. However, CFIUS still demonstrates that many agencies can work together to make impactful decisions.[251]

Other interagency committees vary in the scope of their mission under their substantive authorizing statute and enforcement abilities. For instance, the Interagency Steering Committee on Radiation Standards and the Federal Interagency Committee on Indoor Air Quality primarily serve to coordinate radiation and air quality standards, respectively, and facilitate exchanges of information among different agencies.[252] In the health sector, the Diabetes Mellitus Interagency Coordinating Committee ("DMICC") coordinates diabetes activities across the government via meetings, strategic planning, and other means.[253] However, the effectiveness of these committees varies. The DMICC, for instance, has played a key role in strategic planning for diabetes research and ensures consistent information about diabetes is disseminated to the public, but has not always been able to impact policies regarding the price of insulin.[254]

One path forward—epitomized by this description of brain injuries—would be to use the AWAA to create a new interagency committee that operates in the interstitial space between critical agencies, empowered with more expansive capabilities. [255] CFIUS would serve as a model both for the process of creating a new committee—perhaps first an executive order followed by legislation codifying the agency—with expansive powers and successful collaboration. As some agencies today already focus on disability, another potential approach under the AWAA would be to expand the power of the ICDR, NIDILRR, or NCD, by providing enforcement powers to enable more expansive missions and coordinate efforts across programs. Expanding the ICDR may be the most logical because its core mission—to "promote coordination and cooperation among federal departments and agencies conducting disability-related research"[256]—has remained consistent since its establishment in the

---

[250] *Id.*; *see also* Yuan Yang & James Fontanella-Khan, *Grindr Sold by Chinese Owner After US National Security Concerns*, FIN. TIMES (Mar. 7, 2020, 7:33 AM), http://www.ft.com/content/a32a740a-5fb3-11ea-8033-fa40a0d65a98.

[251] *See* Evan J. Zimmerman, *The Foreign Investment Risk Review Modernization Act: How CFIUS Became a Tech Office*, 34 BERKELEY TECH. L.J. 1267, 1268 (2019).

[252] *See Interagency Steering Committee on Radiation Standards*, EPA (July2, 2025), https://www.epa.gov/iscors; *Federal Interagency Committee on Indoor Air Quality,* EPA (Aug. 13, 2025), http://www.epa.gov/indoor-air-quality-iaq/federal-interagency-committee-indoor-air-quality.

[253] *Diabetes Mellitus Interagency Coordinating Committee (DMICC)*, NAT'L INST. DIABETES & DIGESTIVE & KIDNEY DISEASES (May 2025), http://www.niddk.nih.gov/about-niddk/advisory-coordinating-committees/diabetes-mellitus-interagency-coordinating-committee-dmicc.

[254] *Id.*

[255] For instance, HHS, DOT, FCC, HUD, DOL, DoEd, and FTC.

[256] *ICDR*, *supra* note 185, at 4; *see also* Richard R. Leclair, *National Institute of Handicapped Research (NIHR): A Giant Step for Expanded Rehabilitation Research*, BULL. PROSTHETICS RSCH., Fall 1979 at 1, 4

1970s. Subsequent legislation has also added duties to the ICDR, such as the Assistive Technology Act of 1998, which broadened the ICDR's focus to include research incorporating principles of universal design, and the Workforce Investment Act of 1998, which codified requirements to solicit input from the disability community.[257] The AWAA could include a provision further amending the scope of the ICDR, which would be helpful for coordination between agencies. After all, the ICDR today is composed of over fifteen members across many agencies, with various committees and working groups focused on specific topics.[258]

B. THE ICBIR IN PRACTICE

The prior Subpart discussed potential reforms to the current administrative state that could be incorporated into the AWAA. These reforms would create a group within the government designed to foster a patient-centered and capabilities-focused environment for individuals with brain injuries and their families. While we have identified some of the advantages of a new agency, whether at a cabinet or independent level, we ultimately decided on a novel interagency committee, the ICBIR, as our primary proposal.

It is important to note that we do not intend this effort to exhaustively consider every aspect of a novel interagency committee on disability. Nor do we want to dampen enthusiasm for the possibility of a new cabinet level agency or independent agency that focuses on disability, empowerment, and promoting capabilities. Indeed, it is essential that there be genuine stakeholder input into any such decisions, and the path we outline is but one method of achieving our goals.

The ICBIR will help individuals and families affected by brain injuries develop and follow an "individualized recovery plan." These plans are a key component of our conceptual shift, as they allow goals to be set and planned for, while also facilitating a longitudinal focus on maximizing the capabilities of the client making a piecemeal recovery from a brain injury. Throughout the patient's long path of rehabilitation and recovery, the ICBIR will provide a single point of coordination: a care navigator who understands where the individual has come from and helps them and their family envision and plan for future progression. A tailored agency approach is well-suited to provide the necessary holistic perspective and support to chart a positive path forward for individuals with brain injuries and their networks. The ICBIR will consist of individuals from key governmental agencies who foster communication and navigate relevant jurisdictions to provide longitudinal support for societal reintegration.

(discussing the history of the NIHR and ICHR, the precursor to the ICDR, as intended to "provide a mechanism for joint planning, joint funding of research projects, joint peer review within the statutory limitation of participating agencies, and other specific joint activities").

[257] *ICDR*, *supra* note 185, at 4.

[258] *Id.* at 1.

First, at a macro level, the proposed interagency committee would have a standard structure, resembling existing committees such as CFIUS and DMICC. As discussed above, the CFIUS consists of the heads of nine executive departments and offices, with the Secretary of the Treasury serving as the Chair and several White House offices also observing and participating as appropriate.[259] Upon receiving a national security risk notice, the Chair will distribute it to all CFIUS agencies to assess the threat. If the risks are not resolved within thirty days, a lead agency is chosen based on the industrial activity of the investment.[260] Similarly, the DMICC is chaired by the National Institute of Diabetes and Digestive and Kidney Diseases ("NIDDK"), which includes other members of HHS and federal agencies such as the VHA and DOD.[261]

The ICBIR could adopt a similar structure comprised of members from relevant agencies chaired by a lead agency, such as HHS. As with CFIUS's assignment of lead agencies, different agencies could focus on a specific care domain. This way, the specific agency best capable of addressing an individual's needs can be involved at the appropriate time. For instance, HHS agencies like the NIH and CMS would be most involved soon after injury, where proper medical care is critical. Other agencies, such as DOJ and HUD, could become involved later, perhaps after a patient transitions to rehabilitation and needs their disability rights enforced (including through *Olmstead* enforcement) and appropriate housing provided. Later, the Departments of Education and Labor would take point to encourage access to educational opportunities and employment, fostering community reintegration.

Similar to the DMICC, the ICBIR could coordinate activities throughout the government via meetings, strategic planning, coordination of special programs, and evaluation of ongoing efforts, thus ensuring standardization and constant improvement. The ICBIR would take a national approach to help ensure consistent treatment and care across states and communities. Additionally, as discussed earlier, the ICDR currently promotes coordination among over ten agencies on disability, independent living, and rehabilitation research programs.[262] Expanding on this committee, and modeling our ICBIR's work on it, could be a realistic way to begin crafting an interagency committee focused on brain injuries, given substantial overlap in participating agencies and goals.

The ICBIR could be funded similarly to other agencies via existing appropriations and redirecting money, meaning such a system would not require any radical overhaul. For example, CFIUS is funded in part by collecting filing

---

[259] JACKSON, *supra* note 243, at 5; *see also CFIUS Overview*, U.S. DEP'T OF THE TREASURY, http://home.treasury.gov/policy-issues/international/the-committee-on-foreign-investment-in-the-united-states-cfius/cfius-overview (last visited May 31, 2025).

[260] JACKSON, *supra* note 243, at 14.

[261] *See Diabetes Mellitus Interagency Coordinating Committee*, *supra* note 253.

[262] *About ICDR*, INTERAGENCY COMM. ON DISABILITY RSCH. (Nov. 17, 2023), https://icdr.acl.gov/about#gsc.tab=0.

fees for any notice of covered transactions—up to one percent of the value of the transaction or $300,000—which can offset the money that CFIUS obtains in advance from the Treasury Department.[263] From 2019 through 2023, underlying legislation for CFIUS appropriated $20 million each year to the Treasury Department for CFIUS use.[264] Other interagency committees such as the ICDR, however, have faced funding challenges. The ICDR was established to promote collaboration between agencies but has not received dedicated funding, leading to pushes in recent years to establish a dedicated budget.[265] Other agencies focused on disability have received government funding, such as NIDILRR, which received over $100 million in fiscal year 2021.[266] As a result, a new interagency committee can redirect funding from other agencies or perhaps adopt CFIUS's approach and request appropriations via the agency that chairs the committee.

C. CARE NAVIGATORS

The ICBIR would also take a distinct and novel approach from existing committees by supporting a new class of employees called "care navigators." Care navigators will be specifically assigned to patients and their families, rather than to one agency.[267]

At the micro level, the objective would be to develop an individualized recovery plan with a longitudinal focus on maximizing the capabilities of the individual. Throughout the patient's long path of rehabilitation and recovery, the ICBIR would provide a single point of coordination through a care navigator familiar with the individual's clinical history and medical and social needs. Care navigators can follow individuals throughout the recovery process, playing a key

---

[263] DEP'T OF THE TREASURY COMM. ON FOREIGN INV. IN THE U.S. ACTIVITIES, CONGRESSIONAL BUDGET JUSTIFICATION AND ANNUAL PERFORMANCE REPORT AND PLAN FY 2022, at 3–7 (2022).

[264] JACKSON, *supra* note 243, at 33.

[265] Memorandum from Disability & Rehab. Rsch. Coal. to Rosa DeLauro, Chair, House Appropriations Committee and Subcommittee on Labor, Health and Human Services, Education, and Related Agencies & Tom Cole, Ranking Member, House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (May 26, 2021) (on file with the U.S. Department of the Treasury) (requesting a dedicated budget of $2 Million for Fiscal Year 2022).

[266] *Id.*

[267] Reports and reflections on existing agencies, such as the DHS, also provide insights as to why creating a new agency would not be a panacea for patients with disabilities. On the seventh anniversary of September 11, DHS released a report detailing the agency's key challenges. "Key Challenge 1" was that "[h]omeland [s]ecurity [i]s [m]ore than [j]ust [a] [s]ingle [c]abinet [d]epartment." HOMELAND SEC. ADVISORY COUNCIL, TOP TEN CHALLENGES FACING THE NEXT SECRETARY OF HOMELAND SECURITY, *reprinted in* MAINTAINING HOMELAND SECURITY 29, 31–33 (Alan P. Proctor & Jason T. Waleford eds., 2009). Several other challenges also built off of the need to work horizontally with other agencies and vertically with people outside the department, including within the private sector. *Id*. More recently, an October 2022 report also echoed continued difficulties with countering homeland security threats and coordinating border security efforts, noting that DHS needs to further collaborate with law enforcement and other offices. DEP'T OF HOMELAND SECURITY, IMPLEMENTING 9/11 COMMISSION RECOMMENDATIONS 56 (2011). Additionally, agencies have previously moved. NIDILRR was first established as part of the DOE and did not move to HHS until 2016. 45 CFR pt. 1330 (2016).

role in coordination, goal setting, and formulating discharge and individualized recovery plans. They would also help identify services and manage transitions.

Such an approach would improve the patient experience—providing individuals with brain injuries and their families with one contact possessing expertise on government bureaucracy and resources from recovery through reintegration. Care navigators would be available for patients and families as a resource. Furthermore, care navigators will monitor and understand patients longitudinally, helping to ensure better treatment consistent with changing needs and emerging capabilities. Such a system would also provide secondary benefits like representation and increased visibility to the sphere of brain injuries, as there would be individuals and governmental resources focused directly on improving care.

Dedicated care navigators could meet with a patient's family, first while the patient is in the hospital, and later as they move to a rehabilitation facility or nursing home. This longitudinal model would ensure that future needs are anticipated and recognized in the context of the individual's broader life. Additionally, the care navigators would develop a local knowledge of regionally available resources for patients and their families.

There are several models for how care navigators could be employed, ranging from hiring them as federal employees attached to the ICBIR to employment through an AWAA statutory reimbursement plan under Medicare or Medicaid. The latter would allow state healthcare agencies, hospitals, or rehabilitation facilities to hire care navigators themselves. Practically, this would entail training professionals with expertise in brain injury and care navigation. They would communicate with medical teams to ensure proper care, while interfacing directly with the individual with a brain injury and their family, to understand the evolving situation on the ground.

We envision care navigators playing a crucial role in helping individuals with brain injuries access novel technologies essential for recovery and the restoration of functional communication. In this important effort, care navigators will serve as a liaison with clinical staff and vendors, facilitating the timely access of AT.[268] In the next Part, we illustrate how care navigators, supported by the ICBIR, might make a practical difference in the lives of patients and families impacted by a brain injury.

V. INTERAGENCY IMPLEMENTATION

A. INTERAGENCY COMMITTEE'S CARE COORDINATION

Part V traces the role of care navigators, mapping their work onto the temporal stages of brain injuries we introduced in Part II. The ICBIR will support individuals with brain injuries and their families as they navigate acute

---

[268] Fins et al., *supra* note 169, at 1097.

care, rehabilitation and long-term care, and reintegration into society. Working with the ICBIR, the aggregate experience of care navigators could serve as a forum for agency rulemaking and enforcement measures intended to protect the rights and maximize the capabilities of those with a brain injury. At an individual level, the care navigators would provide longitudinal support to individuals and their families. The following Subparts present a chronological overview of how the ICBIR and care navigators might engage with individuals with a brain injury and their families.

1. *Stage One: Acute Care and Hospitalization*

A patient's recovery from a brain injury will generally begin with acute care and hospitalization in the hours or days following the injury. While the acuity of an emergency admission may limit the role of care navigators, their involvement could be critical in ensuring adequate care. At a systems level, it be advantageous to require hospitals to report serious brain injury cases to the ICBIR as part of the intake process for both data-gathering and care navigation purposes. This is important because, while we know where patients with brain injuries go when they are first injured, data on destination after discharge remains inadequate. Without this information, public policy planning is impossible.[269]

The ICBIR's regulatory coordination function would come into play during this early stage of care. While the committee would not—and should not—be in the business of displacing the case-by-case decision-making authority of medical providers, it can nonetheless play a role in setting and monitoring the implementation of best practices for brain injury patient care. Given the uncertainty associated with disorders of consciousness,[270] it is important to conduct several comprehensive assessments of patients to determine the best course of action before nihilism sets in.[271] Providers should consider the patient's prior wishes and the preferences of their family. The American Academy of Neurology ("AAN"), American Congress of Rehabilitation ("ACRM"), and NIDILRR each have guidelines calling for this type of evaluation, which should center on identifying any errors in a Minimally Conscious State diagnosis.[272] Continued assessments provide valuable information, not just about the patient's current state, but also about the patient's prognosis, to inform decisions about patient care.

---

[269] *See generally* RCTM, *supra* note 2; Joseph J. Fins, Nicholas D. Schiff, & Kathleen M. Foley, *Late Recovery from the Minimally Conscious State: Ethical and Policy Implications*, 86 NEUROLOGY 304, 306 (2007).

[270] For comprehensive review of the medical, legal, and ethical issues associated with patient care trajectory, see Fins, *supra* note 59.

[271] Fins & Bernat, supra note 84.

[272] Joseph T. Giacino et al., *Practice Guideline Update Recommendations Summary: Disorders of Consciousness*, 91 NEUROLOGY 450, 451–54 (2018).

In the ICU, it is important for medical professionals to provide an accurate diagnosis and develop a clear understanding of the patient's state. Too often, pessimism can begin to influence care and taint the patient's prognosis. Decisions about end-of-life care should be informed by adequate knowledge of diagnosis, prognosis, available therapies, and the patient's prior wishes.[273] Pain and symptom management must be a priority, especially if a patient requires surgery or there is a misunderstanding of the patient's state of consciousness.[274]

The consent of the patient's legal surrogate would be necessary for the care navigator to provide assistance to the patient's family. Assistance, at minimum, could include facilitating access to the necessary medical, financial, governmental and legal resources. This process would also be the initial step in developing the individualized recovery plan. Furthermore, the care navigator would support the patient's family as they coordinate medical care and set expectations at this early stage. The care navigator would serve as a liaison between the family and medical team, helping the family understand the patient's prognosis, coordinate with insurance companies, and plan discharge. Care navigators will be able to communicate the different services, supporting the family as they pursue the best available care. The care navigator would serve as the family's care hub, connecting them to medical support networks, legal support networks, and other resources as they navigate the complexities of the health care system. The care navigator would also serve as another advocate and sounding board for the patient and their family.

As the patient progresses, care navigators will provide crucial support upon hospital discharge, ensuring that patients obtain rehabilitation services when appropriate. They would oversee and support patients as they transition from the hospital to a rehabilitation facility or nursing home. This is key to securing positive patient outcomes, as individuals denied rehabilitation have greatly increased risk of adverse outcomes.

2. *Stage Two: Care in a Rehabilitation Facility or Nursing Home*

One of the care navigator's key roles would be ensuring that the patient receives active rehabilitation. *Jimmo v. Sebelius*[275] highlights the importance of providing rehabilitation to those in need.[276] Pain management remains a crucial concern, and the care navigators could support the individual and family so as to ensure proper pain and symptom management.

---

[273] Joseph J. Fins, *Cognitive Dissonance and the Care of Patients with Disorders of Consciousness*, *in* GUIDANCE FOR HEALTHCARE ETHICS COMMITTEES, 140, 140–148 (D. Micah Hester & Toby L. Schonfeld eds., 2022).

[274] *See* Shapiro & Fins, *supra* note 96, at 95–97.

[275] *See* Settlement Agreement at 10–12, Jimmo v. Sebelius, No. 5:11-CV-17-CR (D. Vt. Jan. 24, 2013).

[276] Joseph J. Fins, Megan S. Wright, Claudia Kraft, Alix Rogers, Marina B. Romani, Samantha Godwin & Michael R. Ulrich, *Whither the "Improvement Standard"? Coverage for Severe Brain Injury after* Jimmo v. Sebelius, 44 J.L., MED. & ETHICS 182, 183 (2016).

Access to AT is crucial throughout rehabilitation. These technologies enable more effective communication. Assistive communication devices help people with brain injuries rejoin their communities by improving their ability to interact with others. For example, some assistive communication devices use text-to-speech technology to convert written text into audible speech, allowing users with speech difficulties to engage in conversations and participate in social activities more easily. Other devices use picture symbols or gestures to convey meaning, enabling users to express their needs and preferences even if they have difficulty speaking or understanding spoken language. In addition, many assistive communication devices are designed to be portable and easy to use, facilitating independence and participation in community activities such as work, school, or social events. By providing a means of communication tailored to the individual's specific needs and abilities, assistive communication devices help those with brain injuries overcome communication barriers and more fully participate in their communities.

The ICBIR would also play a regulatory role to help ensure that chronic care and rehabilitation facilities meet state and federal standards, involving the relevant agencies like DOJ or HHS when necessary. The care navigators will be critical assets in this process, as their patient-level view of facilities' performance will provide ongoing surveillance and advocacy. For example, if a care navigator identifies an ADA violation, they could report it to the interagency committee; the ICBIR could then refer the violation to the DOJ. Our hope is that increased surveillance will *proactively* stop violations before they occur.

Discharge planning from the rehabilitation facility should also consider the individual's long-term housing and education needs, technological scaffolding and support, as well as family preferences and HHS services. Housing is a major consideration in the transition between Stage Two and Stage Three. One resource might be the Fair Housing Accessibility FIRST program, sponsored by the HUD.[277] More generally, care navigators would also connect individuals and their families with the diversity of state-level programs available to brain injury patients. For example, Florida residents with a brain injury may be eligible for support under the state's Brain and Spinal Cord Injury Program, which funds the "provision of appropriate services and supports" required to help patients "return to a community-based setting, rather than reside in a skilled nursing facility."[278] The care navigator and family should also consider any specialty agencies that may be relevant to their unique situation, such as the VA or agencies operating at the state level. This service surveillance should occur before discharge so that

---

[277] *Fair Housing Accessibility First,* DEP'T OF HOUS. & URB. DEV., http://www.hud.gov/program_offices/fair_housing_equal_opp/accessibility_first_home (last visited Dec. 9, 2023).

[278] *Brain and Spinal Cord Injury Program*, FLA. HEALTH (Apr. 25, 2025, 12:26 PM), http://www.floridahealth.gov/provider-and-partner-resources/brain-and-spinal-cord-injury-program/index.html.

individuals are placed in appropriate settings that maximize community reintegration and well-being, consistent with the Supreme Court's decision in *Olmstead v. L.C.*[279]

3. *Stage Three: Life in the Community*

Unfortunately, outpatient services vary and often exist across an arcane network of agencies and siloed programs. This makes research and identification of relevant programs burdensome. Access to the support networks can also be challenging to navigate due to significant questions about cost and availability, not to mention the logistical challenges of applying for, and utilizing, the various available programs. This work often falls to the injured individual's support networks, meaning outcomes are again highly dependent on variables such as a family's available time, financial resources, or medical understanding.

Importantly, care navigators would make sure that ongoing treatment includes access to good medical services, including neurological, medical, and psychiatric support. This is often a challenge for people with brain injuries once they leave institutional settings. Care navigators can assist with identifying outpatient medical care—connecting individuals with providers sensitive to the needs of people with disabilities and who possess expertise in brain injury medicine.[280] Care navigators can also help arrange for long-term assistive and rehabilitative technology use. Care navigators' approaches to those with brain injuries' long-term care should be predicated on a *prevention* ethic, with the aim of identifying and addressing health problems early. Beyond the medical, the psychological well-being of patients and families is essential. Importantly, individual *and* family therapy should also be available. In addition to injury-specific care, patients should have access to resources like psychiatric counseling and addiction support programs.

Additional resources that might be considered for family respite care include hospice programs.[281] Cross-training hospice workers to provide biopsychosocial services to patients with brain injuries and families might facilitate access to comprehensive care in underserved areas.[282] Previously, we suggested that hospice programs—which provide a broad range of biopsychosocial support to patients and families, and are located in communities throughout the country—could be mobilized to provide assistance with proper cross-training. The AWAA could help coordinate this by modifying eligibility

---

[279] Olmstead v. L.C., 527 U.S. 581, 587 (1999); Joseph J. Fins, Megan S. Wright & Samuel R. Bagenstos, *Disorders of Consciousness and Disability Law*, 95 MAYO CLINIC PROC. 1732, 1736 (2020).

[280] NATHAN D. ZASLER, DOUGLAS I. KATZ, & ROSS D. ZAFONTE, BRAIN INJURY MEDICINE: PRINCIPLES AND PRACTICE 8 (1st ed. 2007).

[281] Joseph J. Fins & Barbara Pohl, *Neuro-Palliative Care and Disorders of Consciousness*, *in* OXFORD TEXTBOOK OF PALLIATIVE MEDICINE 284, 291 (Nathan Cherny Marie Fallon, Stein Kaasa, Russell K. Portenoy & David C. Currow eds., 5th ed. 2015).

[282] *Id.*

for the Medicare Hospice Benefit to include support for patients and families with serious brain injuries.[283]

Individuals will have a variety of housing needs while reintegrating into the community. In some cases, individuals may simply lack a place to live entirely. In others, an individual's home—or their family's home—may require significant renovations or adjustments to meet the needs of the individual.

One particularly noteworthy challenge is the risk of substance abuse in brain injury survivors. Many TBI survivors have been found to engage in an increased use of substances—including alcohol, illicit drugs, and/or prescription medications.[284] For instance, one study found that approximately ten to twenty percent of TBI patients who did not consume alcohol pre-injury became high volume users after.[285] In general, while substance use is generally low or nonexistent in the immediate post-injury period, it tends to begin or increase within one to two years post-injury. Experts thereby recognize that ongoing rehabilitation is necessary to monitor and manage the issue of substance abuse, which can emerge long after a severe TBI.[286]

However, the United States lacks TBI-specific rehabilitative services.[287] To date, Section 1557 of the Affordable Care Act expressly prohibits discrimination based on disability in covered health programs.[288] Nonetheless, post-acute brain injury rehabilitation tends to be terminated prematurely and is often "too short;" in some cases, it is not reimbursed or provided at all.[289] A primary reason underlying this issue is the reality that the United States "does

---

[283] CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE HOSPICE BENEFITS 7 (2025), https://www.medicare.gov/Pubs/pdf/02154-medicare-hospice-benefits.pdf.

[284] James M. Bjork & Steven J. Grant, *Does Traumatic Brain Injury Increase Risk for Substance Abuse?*, 26 J. NEUROTRAUMA 1077, 1078 (2009); John D. Corrigan, Elizabeth Rust & Gary L. Lamb-Hart, *The Nature and Extent of Substance Abuse Problems in Persons with Traumatic Brain Injury*, 10 J. HEAD TRAUMA REHAB. 29, 29 (1995); Zachary M. Weil, John D. Corrigan & Kate Karelina, *Alcohol Use Disorder and Traumatic Brain Injury*, 39 ALCOHOL RSCH.: CURRENT REVS. e1, e3 (2018); Jeffrey S. Kreutzer, Adrienne D. Witol & Jennifer Harris Marwitz, *Alcohol and Drug Use Among Young Persons with Traumatic Brain Injury*, 29 J. LEARNING DISABILITIES, 643, 647 (1996).

[285] Kreutzer et al., *supra* note 284, at 647; Mary R. Hibbard, Suzan Uysal, Karen Kepler, Jennifer Bogdany & Jonathan Silver, *Axis I Psychopathology in Individuals with Traumatic Brain Injury*, 13 J. HEAD TRAUMA REHAB. 24, 32 (1998); Jesse R. Fann, Bart Burington, Alexandra Leonetti, Kenneth Jaffe, Wayne J. Katon & Robert S. Thompson, *Psychiatric Illness Following Traumatic Brain Injury in an Adult Health Maintenance Organization Population*, 61 ARCH. GEN. PSYCHIATRY 53, 53–61 (2004).

[286] Jennie Ponsford, Rochelle Whelan-Goodinson & Alex Bahar-Fuchs, *Alcohol and Drug Use Following Traumatic Brain Injury: A Prospective Study*, 21 BRAIN INJURY 1385, 1390–91 (2007); J. D. Corrigan, G. L. Lamb-Hart & E. Rust, *A Programme of Intervention for Substance Abuse Following Traumatic Brain Injury*, 9 BRAIN INJURY 221, 221 (1995).

[287] *AWAA*, *supra* note 1, at 1730.

[288] Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 260, § 1557 (2010).

[289] Joseph J. Fins, *Why Advances in Treating Those with Brain Injuries Require Advances in Respecting Their Rights*, THE CONVERSATION (Jan. 26, 2017, 9:05 PM), https://theconversation.com/why-advances-in-treating-those-with-brain-injuries-require-advances-in-respecting-their-rights-71679.

not really have a health care system, only a health insurance system."[290] Indeed, "cost containment measures by third party insurance companies and other payors limit or direct care without necessarily being attuned to current scientific evidence substantiating the benefits of sustained treatment."[291] Such findings are troubling given that the long-term clinical trajectory of TBI survivors is difficult to predict.[292] As mentioned, brain injury patients need access to ongoing rehabilitation to carefully monitor and help them avoid issues, such as substance abuse, that may interfere with their recovery.

Care navigators would help individuals and their families identify appropriate long-term living configurations, while connecting them as needed with housing programs offered by HUD and other relevant agencies. For example, low-income individuals with disabilities may be eligible for housing developed under HUD's Section 811 program, which funds the development of low-cost housing for adults with disabilities.[293] Housing should be considered in tandem with other needs, such as family access and proximity to medical care.

Assisting the individual with the return to school or the workplace is another consideration. Here, care navigators could connect individuals with a wide variety of relevant state, federal, and nonprofit programs. For example, the DOL's Employment First program, implemented in cooperation with many states, seeks to expand access to employment opportunities for people with disabilities.[294] The agency also implements the Disability Employment Initiative, which supports education, training, and employment programs for people with disabilities.[295] Other agencies offer further supports: the Social Security Administration's Ticket to Work program supports career development opportunities for people with disabilities who receive Social Security disability benefits.[296] In instances where individuals are not able to pursue gainful employment, care navigators would support them and their families in securing benefits and subsidies that will help bolster their financial security.

---

[290] Mary Gerisch, *Health Care As a Human Right*, AM. BAR ASS'N (Nov. 19, 2018), https://www.americanbar.org/groups/crsj/publications/human_rights_magazine_home/the-state-of-healthcare-in-the-united-states/health-care-as-a-human-right/.

[291] Nathan D. Zasler & Mark J. Ashley, *Post-Acute Rehabilitation: Edifying Efficacy Evidence*, 16 BRAIN INJURY PRO. 8, 10 (2018).

[292] Sandro Rizoli et al., *Early Prediction of Outcome After Severe Traumatic Brain Injury: A Simple and Practical Model*, 16 BMC EMERGENCY MED. 1, 5 (2016).

[293] *Section 811 Supportive Housing for Persons with Disabilities Program*, DEP'T OF HOUS. & URB. DEV., https://www.hud.gov/program_offices/housing/mfh/progdesc/disab811 (last visited Dec. 9, 2023).

[294] *Employment First*, DEP'T OF LABOR, https://www.dol.gov/agencies/odep/initiatives/employment-first (last visited Dec. 9, 2023).

[295] *Disability Employment Initiative,* DEP'T OF LABOR, https://www.dol.gov/agencies/odep/initiatives/disability-employment-initiative (last visited Dec. 9, 2023).

[296] *About Ticket to Work*, SOC. SEC. ADMIN., https://choosework.ssa.gov/about/ (last visited Dec. 9, 2023).

B. THE ICBIR AS A LEARNING SYSTEM

In sum, care navigators can help individuals and their families coordinate the multifaceted community reintegration process holistically, with an awareness of how the various aspects of reintegration bear on one another. Without access to good medical care and safe housing, societal reintegration becomes impossible. This intersectional knowledge has the added value of informing coordinated policy at the ICBIR level. This way, care navigators serve the individual and, in the aggregate, the entire community of individuals with brain injuries and their families. With accumulated real-world knowledge, this information constitutes "a learning healthcare system" as articulated by Ruth Faden and others.[297] This iterative process exemplifies the Deweyan maxim of "learning by doing," through experience.[298] Through this pragmatic effort,[299] the ICBIR is designed to transform legal theory into practice, in the service of broader public policy.

VI. CAVEATS

As we propose the AWAA to better address the needs of people with severe brain injuries—and as a broader model for others with disability that require longitudinal interagency coordination—we are cognizant of reinforcing power structures that have historically sustained bias and fostered discriminatory practices. Our proposed legislation's name, where we write of Americans *with* abilities, is meant to signal the capabilities that are untapped in this population: capabilities that can be unlocked if they receive the proper support needed to realize their potential. Nonetheless, the risk of reifying bias remains in a system that draws heavily upon the medical model and invokes legal definitions drawn from the same font.

The legal definition of disability generally parallels the medical model in that it has historically reduced disability to an individual problem caused by biomedical deficiencies. The resulting disability-as-abnormality in part facilitates state-sponsored regulation of disability through the body.[300] This is accomplished through diagnosis, therapeutic interventions, and "how discourses of care, humanitarianism and benevolence that mobilize certain affective

---

[297] *See e.g.*, Ruth R. Faden, Nancy E. Kass, Steven N. Goodman, Peter Pronovost, Sean Tunis & Tom L. Beauchamp, *An Ethics Framework for a Learning Health Care System: A Departure from Traditional Research Ethics and Clinical Ethics*, 43 HASTINGS CTR. REP. S16, S16 (2013).

[298] JOHN DEWEY, THE MIDDLE WORKS OF JOHN DEWEY, VOLUME 9, 1899-1924, at 192 (Jo Ann Boydston ed., 1980).

[299] Franklin G. Miller, Joseph J. Fins & Matthew D. Bacchetta, *Clinical Pragmatism: John Dewey and Clinical Ethics*, 13 J. CONTEMP. HEALTH L. & POL'Y 27, 27 (1996); Joseph J. Fins, Franklin G. Miller & Matthew D. Bacchetta, *Clinical Pragmatism: Bridging Theory and Practice*, 8 J. KENNEDY INST. ETHICS 39 (1998); Joseph J. Fins, *Clinical Pragmatism and the Care of Brain Damaged Patients: Towards a Palliative Neuroethics for Disorders of Consciousness*, 150 PROGRESS BRAIN RSCH. 565 (2005).

[300] Elizabeth R. Schlitz, *Hauerwas and Disability Law: Exposing the Cracks in the Foundations of Disability Law*, 75 LAW & CONTEMP. PROBS. 23, 24 (2012).

responses to the disabled body are harnessed to mask the regulative, punitive, violent and indeed even lethal effects of these interventions."[301]

Here, Michael Foucault's biopower analysis is a useful lens in exposing the ways in which the experience of life becomes linked to the exercise of state power in pursuit of governing populations.[302] In focusing on the body as a vehicle through which the physical demands of the capitalist system of production are met, biopower analyzes the "relationships through which the life and health of bodies and populations become the objects of scientific discourse and institutional regulation by governments and corporations."[303] In doing so, biopower accounts for the connection between knowledge, power, and change in its consideration of the transformation from the "ancient right to take life or let live" to a "power that foster[s] life or disallow it to the point of death."[304] This transformation is determined through many axes—including the cultural, environmental, economic, and geographical.[305]

The connection between the body politic and the interest of the state is presented through three mechanisms. The first mechanism concerns the use of two axioms of power—called disciplinary and regulatory power—employed by the state to transform the life and health of population into objects of power. Operating on different scales, disciplinary and regulatory power complements each other to "conform bodies and populations to unequal political and economic arrangements."[306] On one hand, disciplinary power operates on the individual scale to produce scientific truths by observing, judging, and examining the body.[307] On the other hand, regulatory power operates on the population level to extract political and economic power to transform the body into "both a ritual of power and procedure for the establishment of truth."[308] As such, regulatory power, in adapting to equilibrium by compensating for

---

[301] Linda Roslyn Steele, *Troubling Law's Indefinite Detention: Disability, the Carceral Body and Institutional Injustice,* 30 SOC. & LEG. STUD. 80, 84 (2021).

[302] ANTHONY RYAN HATCH, BLOOD SUGAR: RACIAL PHARMACOLOGY AND FOOD JUSTICE IN BLACK AMERICA 33 (2016); *see also* SHELLEY LYNN TREMAIN, FOUCAULT AND THE GOVERNMENT OF DISABILITY 13 (2005) ("For Foucault, the question that political philosophy should ask about power is this: *How*, that is, *by what means*, is it exercised? Indeed, one of the most original features of Foucault's analysis is the idea that power functions best when it is exercised through productive constraints, that is, when it *enables* subjects to act *in order* to constrain them.").

[303] Anne Bloom, *Speaking "Truth" to Biopower*, 41 SW. L. REV. 241, 246 (2012); *see* HATCH, *supra* note 302, at 33.

[304] Sujatha Raman & Richard Tutton, *Life, Science, and Biopower*, 35 SCI. TECH., & HUM. VALUES 711, 712–13 (2010).

[305] *Id.* at 714; *see also* TREMAIN, *supra* note 302 ("These processes, together with a whole set of related economic and political problems, become biopower's first objects of knowledge and the targets that it seeks to control.").

[306] *See* HATCH, *supra* note 302, at 34.

[307] *See* TREMAIN, *supra* note 302, at 30.

[308] TODD MAY, BETWEEN GENEALOGY AND EPISTEMOLOGY: PSYCHOLOGY, POLITICS, AND KNOWLEDGE IN THE THOUGHT OF MICHEL FOUCAULT 43 (1993).

population-based variations, constructs norms.[309] Here, epidemiology serves as an example of regulatory power that is deployed on populations who are "a political problem, as a biological problem, and as power's problem."[310] Disciplinary and regulatory power work with the latter two mechanisms of biopower. Economic and political relationships are deployed, in particular, through "racial categorizations" to fulfill the objectification of populations by the state.[311]

In the case of disability, the mechanisms of biopower that concern the acquisition of medical knowledge have arguably "caused the contemporary disabled subject to emerge into discourse and social existence."[312] The so-called "abnormal" body—the disabled body—in the nineteenth century was meant to be managed. Now, too, disabled bodies are "created, classified, managed, and controlled social abnormalities through which some people have been divided from others and *objectivized* as [disabled]."[313] The disabled body as a *subject*, therefore, is twofold in nature: the disabled body is subject to the control and dependence to the state and is tied to an identity by a conscious or self-knowing. This dual-subjectification reveals how people who are disabled are "gradually, progressively, really and materially constituted through a multiplicity of organisms, forces, energies, desires, [and] thoughts."[314] Such an acknowledgement is critical in addressing the ways in which the nexus of medicine and law—in establishing disability law—construct a particular understanding of disability that prompts an examination of not only who is visible in the eyes of the legal definition of disability, but equally as importantly—who is excluded.

In contrast to the medical model and its containment of disability to the biomedical, the social model expands disability by viewing it relation between the individual experience and the surrounding social context.[315] *This* is the model we have endeavored to emulate when designing the AWAA and its proposed ICBIR.

The social model does not reject the premise that disability includes biological impairment; indeed, some of the challenges we hope to address

---

[309] *See* TREMAIN, *supra* note 302, at 14 ("Foucault explained the rationale behind biopower's normalizing strategies: . . . . [T]he law operates more and more as a norm, and . . . the juridical institution is increasingly incorporated into a continuum of apparatuses (medical, administrative, and so on) whose functions are for the most part regulatory. A normalizing society is the historical outcome of a technology of power centered on life.") (internal citations omitted).

[310] MICHAEL FOUCAULT, "SOCIETY MUST BE DEFENDED": LECTURES AT THE COLLÈGE DE FRANCE, 1975–1976, at 245 (Mauro Bertani, Alessandro Fontana, & François Ewald eds., David Macey trans., 2003).

[311] *See* Raman & Tutton, *supra* note 304, at 714; *see* HATCH, *supra* note 302, at 33.

[312] *See* TREMAIN, *supra* note 302, at 14.

[313] *Id.*

[314] *Id.* at 15.

[315] Elizabeth F. Emens, *Framing Disability*, 2012 U. ILL. L. REV. 1383, 1401 (2012); *see also* Bradley A. Areheart, *Disability Trouble*, 29 YALE L. & POL'Y REV. 347, 348 (2011); Joseph J. Fins, Kaiulani S. Shulman, Megan S. Wright & Zachary E. Shapiro, *Brain Injury, Medical Progress, and the Disability Paradox: Towards an Americans with Abilities Act*, 54 NEUROREHABILITATION 141, 145 (2024).

through the AWAA are a direct consequence of medical advances.[316] We welcome this progress. But we also appreciate that we need to understand disability in relation to the surrounding social context. One can hold both views at the same time and they should not be mutually exclusive. This implies that the social model considers social and environmental features to suggest that limitations *are not solely inherent in biology*. As such, the model does not view disability simply as an objective, distinct category, but instead as a conceptualization rooted in broader historical context.[317] It also recognizes the social construction of disability that motivates our shift toward a capabilities account because this allows us to propose more comprehensive and pragmatic solutions and redesigns, rather than being limited by our current conceptions. Indeed, although disability may be rooted in biological mechanisms, we have long recognized that it is also dependent upon adverse social conditions.[318]

The social model has, as such, advanced two prongs of disability through the disablement-impairment binary, in which the "disablement" prong accounts for the socially constructed features of disability and the "impairment" prong accounts for the biomedical features that results in disability.[319] In this sense, disablement shifts the focus away from the medical model of disability by considering the environmental factors that disable—for example, architectural barriers faced by wheelchair users. While the impairment is the inability to walk resulting in a need to use a wheelchair, the disablement is an architect's failure to include ramps that render the wheelchair user unable to enter a building without external assistance.[320] The failure to include ramps results in the exacerbation of impairment such that a person is made to feel disabled due to a "set of social choices that [have] created a built environment that confines [them] to their homes."[321] Reframing disability within disablement, as a result, "equips disability activists with a rich language to articular why people with disabilities are victimized by prejudice rather than fate."[322]

Some past legal mechanisms seeking to provide a more expansive view of disability have employed the social model. For example, in enacting the EAHCA and IDEA, Congress has acknowledged the role of cultural and environment

---

[316] *Id.* at 142.

[317] *See* Steele, *supra* note 301, at 85.

[318] *See* Porter, *supra* note 147, at 1873–84.

[319] *See* Areheart, *supra* note 315, at 348.

[320] Adam M. Samaha, *What Good is the Social Model of Disability?*, 74 U. CHI. L. REV 1251, 1258–59 (2007).

[321] *See* Areheart, *supra* note 315, at 188; *see* Porter, *supra* note 147, at 1874 (quoting Samuel R. Bagenstos, *Subordination, Stigma, and "Disability,"* 86 VA. L. REV. 397, 429 (2000)).

[322] *See* Jonas-Sébastien Beaudry, *Welcoming Monsters: Disability as a Liminal Legal Concept*, 29 YALE J.L. & HUMS. 291, 295 (2017). In stating the benefits of the acknowledgement of the interrelation of power, stigma, and oppression with disability, Beaudry argues that, "[m]oral and legal claims can then be articulated as a demand for redress, similar to other oppressed minorities, rather than as a plea for charity. (This traditional plea, in contrast, would only provide [people with disabilities] a right to medical treatment on the basis that they should not be held responsible for having drawn a short genetic straw or undergone a disease or accident resulting in disability through no fault of their own)."

factors that shape the experience of impairment.[323] Another example of the implementation of the social model of disability is the ADAAA. By setting aside the mitigation trilogy and *Toyota* and expanding the parameters of disability, Congress acknowledged the many external factors that contribute to disablement. Subsequent iterations of disability law, as such, should continue this trend toward understanding the variety of factors, both social and medical, that disable.

Given these broader considerations in our advance of the ICBIR, we must caveat that we understand that creating a new interagency committee to focus on brain injuries is, inherently, an expansion of biopower from the state, something that scholars like Foucault warn come with risks and tradeoffs. While Foucault himself might have conflicting thoughts concerning such an expansion of biopower, in order to balance this appropriation, we have endeavored to design the AWAA to be as "person centered" as possible. This "person-focused" approach is present in the ICBIR's focus on family and in the design of individualized recovery plans. This allows individual goals to be realized, without trying to fit all people into particular types of pre-ordained boxes. Most importantly, we have designed a helpful administrative body, the ICBIR, to assist those with brain injuries in recovering in the way that is best suited for their goals and personal trajectory. We recognize that much of what holds individuals with disabilities back results from the unwillingness of society to change its practices to become more inclusive. Therefore, we have designed the AWAA to build a more inclusive environment and foster social scaffolding for the AT that is so important for rehabilitation and reintegration of those with a brain injury.

Furthermore, while Foucault was critical of the ways in which biopower can lead to the normalization and regulation of individuals, he was also interested in how it could be harnessed to promote positive outcomes. While he critiqued biopower's potential for controlling and disciplining individuals, he also highlighted instances where biopower could be used to improve well-being and provide support. An interagency committee, by pooling resources, expertise, and knowledge from different sectors, should lead to more holistic, individualized care for brain injury survivors. This approach resonates with Foucault's interest in mechanisms that genuinely enhance the lives of individuals, rather than work to simply exert control.

Moreover, Foucault's writing about disciplinary power highlighted that institutions often operate in isolated silos, leading to fragmented care and oversight. An interagency committee could break down these barriers by fostering collaboration among various sectors involved in brain injury care. This collaborative effort aligns with Foucault's critique of the compartmentalization

---

[323] Wendy F. Hensel, *Sharing the Short Bus: Eligibility and Identity Under the IDEA*, 58 HASTINGS L.J. 1147, 1180 (2006) (noting how Congress has highlighted the ways in which institutional environments and stigma may result in greater obstacles to the educational success of a child).

of power and his call for more interconnected, comprehensive, approaches that treat individuals as complex beings rather than isolated cases. Foucault also emphasized the importance of individual agency within power structures, highlighting that individuals possess the capacity to resist and negotiate power dynamics, even within systems of control. In the context of brain injury care, an interagency committee that values the input of survivors, their families, and advocacy groups would recognize individual agency and a commitment to incorporating their perspectives into any decision-making processes.

Ultimately, an interagency committee focused on brain injury care, guided by principles of collaboration, individual agency, and comprehensive support, would align with Foucault's belief in the potential for institutions to positively influence society. Such a committee, if designed and operated with transparency, accountability, and a genuine commitment to well-being, could mitigate some of the negative aspects often associated with biopower expansion.

Importantly, as discussed above, the AWAA itself must also emerge as the *product* of deliberation in which those most affected have a meaningful voice. As the phrase "Nothing About Us, Without Us"[324] reminds us, facilitating the involvement of people who will be most affected by the AWAA in the act's design is a moral imperative. Involving people with brain injuries in the AWAA's design will also foster an abilities approach rather than a negative rights approach. Policymakers, organizers, and families will need to expend the necessary resources to develop and recognize people with brain injury's capability to build out the program. Our hope is that the outline provided above serves as a starting point for those deliberations. However, legislation and improved interagency coordination is just one element of our call to improve the situation of those with disabilities.

As the history of the ADA shows us, new legislation is only a starting point. Proposed legislation can help catalyze a new focus on the ways that society can better serve all its members, helping design a more inclusive vision of community and society that allows increased engagement, participation, and flourishing from all members of society. This is the real work of the ICBIR and the true goal of the AWAA.

CONCLUSION

Over the last few years, we have worked to design the AWAA in a comprehensive and holistic manner, drawing on the expertise of individuals in medicine, law, sociology, government and industry. As discussed when we proposed the AWAA in the Boston College Law Review,[325] the AWAA can help actualize the potential of medical progress by scaffolding scientific advance into the lived experiences of those with brain injuries. Building on our proposal,

---

[324] Phrase popularized by James Charlton's book, NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT (Univ. of Cal. Press ed. 1998).

[325] *See generally AWAA*, *supra* note 1.

our focus here on improved interagency coordination, through the creation of a dedicated ICBIR, will ultimately allow individuals with disabling brain injuries to better access relevant programs to help their lives, while allowing their individuality and uniqueness to be respected and considered throughout their recovery process.

The time to design the ICBIR is now, as the rapid pace of technological advance will soon force us to legislate reactively, rather than proactively. Indeed, as we move toward an era of unprecedented progress in neuroscience, it is especially important to engage in thoughtful anticipatory governance. While we may not yet have all the tools we need to fully understand and harness the power of the brain, scientific progress marches on, and it is imperative that we begin to start planning for the future.

The promotion of capabilities is one key theme that must be central to any anticipatory governance framework in the realm of neuroscience. While rights are an essential component of any ethical and legal framework, they are not sufficient on their own. Instead, a focus on capabilities can help to ensure that individuals prospectively have the tools they need to fully realize their potential and live meaningful lives. This is particularly relevant in the context of brain injury and other neurological conditions, where patients and their families need support to navigate a complex and evolving landscape.

By adopting our capabilities approach to anticipatory governance in neuroscience, it is possible to achieve a homeostatic balance between negative and positive rights.[326] This means not only protecting individuals from harm, but also providing them with the resources they need to flourish. This is particularly important in the context of brain injury and other neurological conditions, where recovery and rehabilitation can be a long and difficult process.

This paper seeks to meet this need by proposing the creation of an Interagency Committee for Brain Injury Recovery, highlighting what such an effort could achieve and articulating its philosophical basis. We hope this analysis at the interface of law, neuroscience and public policy serves as a model for the next generation of disability rights legislation, so that society can build upon this framework to create a better future for individuals with brain injury and others with disability.

---

[326] *See generally id.*