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Taking Disability Public

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TAKING DISABILITY PUBLIC

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Antidiscrimination laws enforce the idea that no one should be forced or encouraged to hide their race, gender, sexuality, or other characteristics of their

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identity. So why is disability rights law the glaring exception? Other areas of antidiscrimination law have eschewed forms of enforced privacy about protected classes and, as a result, challenge privacy norms as problematic, anti-agentic, and, at times, counter to structural reform goals. In contrast, disability rights law values privacy norms to preempt discrimination; in other words, if you never reveal the information, no one can discriminate against you because of that information. This Article argues that this is a mistake, and that to truly discard stigma and false notions of disability as synonymous with incapacity, we need to fundamentally challenge and reconceive of how privacy applies to disability identity, legal status, the law's remedial role and, in some settings, redesign legal interventions to incentivize publicity values.

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INTRODUCTION

Disability law has a complicated relationship with privacy.¹ A central normative assumption is that, whenever possible, information related to disability should be kept confidential to avoid discrimination.² Antidiscrimination law and society have expressed a preference for privacy in the disability context. As a result, laws in this area often reinforce disability as a private, undesirable fact, and regulate its disclosure. In contrast, the relationship between privacy and publicity is more nuanced in other areas of antidiscrimination law. For example, the law is neutral on the position of whether an individual capable of concealing their Blackness ought to favor disclosure or nondisclosure.³ Partly a function of an accepted (albeit problematic) view that people can “see” race, many Black people lack the

¹ “Privacy” here includes primarily informational and bodily, intellectual, spatial, decisional, communicational, associational, proprietary, and behavioral privacy. Bert-Jaap Koops, Bryce Clayton Newell, Tjerk Timan, Ivan Škorvánek, Tomislav Chokrevski & Maša Galič, *A Typology of Privacy*, 38 U. PA. J. INT’L L. 483, 566-69 (2017). Privacy, as I argue in this Article, has individual and collective properties. See *infra* Part I. Scholars continue to debate existing and normative boundaries of “privacy.” See, e.g., Daniel J. Solove, *A Taxonomy of Privacy*, 154 U. PA. L. REV. 477, 490–91 (2006) (organizing privacy into four main categories and subcategories: (1) information collection (including surveillance); (2) information processing (including identification, insecurity); (3) information dissemination (breach of confidentiality, disclosure, appropriation, distortion); and (4) invasion (intrusion, overreaching, decisional interference)). This Article recognizes the theoretical and utilitarian complexities of this debate, but advancement of a normative position on the epistemological nature of privacy is beyond the scope of this paper. I assume privacy (and the rights and responsibilities that attach) is context-dependent and varies accordingly.

² People with more visible disabilities often do not have the luxury of wrestling with the question of disclosure because they visibly exhibit markers of disability, what I call the “aesthetics of disability” in a prior theoretical account. See generally Jasmine E. Harris, *The Aesthetics of Disability*, 119 COLUM. L. REV. 895 (2019). “Discrimination” here refers to differential treatment based on protected identity characteristics and not positive or neutral instances of socially/legally acceptable differential treatment such as differential treatment based on age that limits access to voting or, more mundanely, alcohol consumption.

³ Society’s preferences for “whiteness” and related performances of “whiteness” do nudge those capable of passing or covering race to do so. The point here is that disability law takes a notable normative position on disclosure.

choice of whether or not to claim Blackness.⁴ As a result, Black people might make different choices along a privacy–publicity continuum depending on the extent to which they manifest visible markers of difference.

Disability identity, however, finds itself clustered at the extreme privacy end of the same continuum. Disability laws nudge those capable of doing so toward passing or covering their less visible disabilities. While there are certainly benefits to disability law’s preference for privacy—most notably, avoiding discrimination based on antiquated biases about disability—this strong privacy norm also has costs which we have not fully considered. For example, disability is also a sociopolitical identity with increasing salience in contemporary political discourse and a growing voting bloc courted by political actors.⁵

This Article challenges this principal normative assumption in disability law that privacy best serves both individual and structural antidiscrimination goals.⁶ I argue that a preference for privacy-enforcing norms in disability law

⁴ Of course, skin color and other aesthetic markers associated with “Blackness” also exist along a continuum relative to perceived “whiteness.” Like people with less apparent disabilities, those with lighter skin color may be faced with opportunities for claiming “Blackness.” As Professor Lori Tharps has argued:

In the 21st century, as America becomes less white and the multiracial community—formed by interracial unions and immigration—continues to expand, color will be even more significant than race in both public and private interactions. Why? Because a person’s skin color is an irrefutable visual fact that is impossible to hide, whereas race is a constructed, quasi-scientific classification that is often only visible on a government form.

Lori L. Tharps, *The Difference Between Racism and Colorism*, TIME (Oct. 6, 2016, 3:49 PM), <https://time.com/4512430/colorism-in-america> [<https://perma.cc/BA4Q-XVVA>].

⁵ See, e.g., *The Biden Plan for Full Participation and Equality for People with Disabilities*, BIDEN HARRIS, <https://joebiden.com/disabilities> [<https://perma.cc/KV42-7XAW>] (discussing President Biden’s goals of “equality of opportunity, full participation, independent living, and economic self-sufficiency” for individuals with disabilities); Michelle Diament, *Biden Pandemic Strategy Puts Focus On People With Disabilities*, DISABILITY SCOOP (Jan. 25, 2021), <https://www.disabilitycoop.com/2021/01/25/biden-pandemic-strategy-puts-focus-on-people-with-disabilities/29163> [<https://perma.cc/Y4LA-UCA6>] (outlining President Biden’s attempts to support the disabled community particularly in light of the COVID-19 pandemic); Exec. Order No. 13,995, 86 Fed. Reg. 7193 (Jan. 26, 2021); Maggie Astor, *Elizabeth Warren Opens a New Front in Disability Policy*, N.Y. TIMES (Jan. 10, 2020), <https://www.nytimes.com/2020/01/10/us/politics/elizabeth-warren-disability-plan.html> [<https://perma.cc/K4XJ-5LNC>] (discussing then-presidential candidate Elizabeth Warren’s plans to assist individuals with disabilities, including free education and elimination of sub-minimum wage pay); LISA SCHUR & DOUGLAS KRUSE, FACT SHEET: DISABILITY AND VOTER TURNOUT IN THE 2018 ELECTIONS 1-2 (2019), https://smlr.rutgers.edu/sites/default/files/Documents/Centers/Program_Disability_Research/Fact%20Sheet%20Disability%20Voter%202018%20Elections.pdf [<https://perma.cc/A25K-SFBH>] (reporting that “[v]oter turnout surged” in the November 2018 election cycle among people with disabilities and comparing 14.3 million people with disabilities voting with an estimated 15.2 million Black people and 11.7 million Latinx people voting in the cycle).

⁶ I made a narrower claim in an earlier piece. See generally Jasmine E. Harris, *Processing Disability*, 64 AM. U. L. REV. 457 (2015) (arguing that a history of closed adjudicative proceedings created a public deficit of information about disabilities that would help challenge antiquated stigma

has generated Pyrrhic victories with underappreciated negative costs that stunt, rather than advance, the broader antidiscrimination mission of the law itself.⁷

Research on disability stigma and prejudice suggests that disability stigma is quite sticky, and while the built world has indeed changed, attitudinal shifts remain stagnant. For example, a recent longitudinal study of implicit and explicit discriminatory attitudes about sexuality, race, gender, skin tone, age, disability, and body weight revealed that, while explicit attitudes about all categories moved from negative to neutral and implicit attitudes about sexuality, race, gender, and skin tone shifted from negative to neutral or positive, implicit attitudes about disability and age remained static over the ten-year period studied.⁸ Researchers attributed the rapid attitudinal changes in the context of sexuality and race to the publicity and public debate (called “societal priority”) around these two areas of discrimination: “In the United States today, race and sexuality attitudes appear to be societally prioritized (e.g., through the Black Lives Matter movement or legislation about same-sex marriage) and therefore are more frequently discussed than other attitudes, such as age or disability.”⁹

The Center for Disease Control estimates that there are sixty-one million people with disabilities in the United States (one in four adults), the majority of whom are not readily identifiable as disabled individuals.¹⁰ Privacy masks

of incapacity associated with disability). Other disability and health law scholars have heavily invested in the opposite position—that we ought to invest more in a privacy approach to prevent disability discrimination. *See generally, e.g.*, Jessica L. Roberts, *Protecting Privacy to Prevent Discrimination*, 56 WM. & MARY L. REV. 2097 (2015).

⁷ Harris, *supra* note 2, at 916-31 (discussing the “logic of disability rights law” and its antidiscrimination mission (stylization omitted)). Scholars recognize the limitations of the Americans with Disabilities Act (ADA) and the persistence of disability discrimination. *See, e.g.*, Mark C. Weber, *The Common Law of Disability Discrimination*, 2012 UTAH L. REV. 429, 431 n.11; Arlene S. Kanter, *The Americans with Disabilities Act at 25 Years: Lessons to Learn from the Convention on the Rights of People with Disabilities*, 63 DRAKE L. REV. 819, 822 (2015); *see also* SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT 116-28 (2009) (noting underenforcement of the ADA as to public accommodations and employment and the limits of the ADA in promoting meaningful integration); Michael Ashley Stein & Michael E. Waterstone, *Disability, Disparate Impact, and Class Actions*, 56 DUKE L.J. 861, 885-93 (2006) (discussing remedial weakness such as the ability of the ADA to respond to serial employer-offenders); Michael Waterstone, *The Untold Story of the Rest of the Americans with Disabilities Act*, 58 VAND. L. REV. 1807, 1854 (2005) (discussing some commentators’ belief that Title II of the ADA “guarantees a secret and independent vote to people with disabilities” and that election administrators “are in utter noncompliance” with such a standard).

⁸ Tessa E. S. Charlesworth & Mahzarin R. Banaji, *Patterns of Implicit and Explicit Attitudes: I. Long-Term Change and Stability From 2007 to 2016*, 30 PSYCH. SCI. 174, 174 (2019).

⁹ *Id.* at 181; *see also id.* (“Societal priority corresponds to more frequent and repeated exposure to debate or counterarguments that may, in turn, induce greater attitude change.”).

¹⁰ CTRS. FOR DISEASE CONTROL & PREVENTION, DISABILITY IMPACTS ALL OF US (2020), https://www.cdc.gov/ncbddd/disabilityandhealth/documents/disabilities_impacts_all_of_us.pdf [<https://perma.cc/6DH4-845L>]. The number of people with less visible disabilities is difficult to assess with certainty for a number of reasons including reliance on self-selection and identification (which is

the prevalence, differentiation, and pervasiveness of disability in society. This allows nondisabled¹¹ people to continue to narrowly associate disability with socially constructed aesthetic markers, such as wheelchairs, missing limbs, prosthetics, non-normative speech and behavior.¹² For these individuals—collectively, those with less visible disabilities—law and society aggressively nudge them to *closet*, *pass*, or *cover* disability identity to meet able-bodied and neurotypical expectations at great costs to physical and mental health,¹³ relationships,¹⁴ employment opportunities, and financial success.¹⁵ Consequently, without a robust continuum of disability to draw on, the differences between people with and without disabilities are exaggerated and perceived to be immutable, tragic, and pitiful. This allows nondisabled people to claim visible and measurable distinctions that can delineate the deserving,

the subject of this Article), definitions of what counts as physical or visible or less apparent, etc. *See infra* Part IV. For the purpose of this Article, I will refer to individuals who manifest the aesthetics of disability (sensory and behavioral markers) interchangeably with physical or visible disability and those who do not manifest the aesthetic markers as people with less apparent disabilities.

¹¹ I use “nondisabled” and “people with disabilities” to make the point and ultimately demonstrate the fallacy of such rigid distinctions.

¹² *See* Harris, *supra* note 2, at 931 (coining the phrase “aesthetics of disability” to describe the aesthetic markers of disability that trigger affective responses in nondisabled people).

¹³ Caroline Reilly writes:

Resisting care . . . allows us to invoke normalcy and to pretend: We fight through the pain, mostly to prove to ourselves that we’re just like everyone else. And while that can feel like a triumph, we’re really just hurting ourselves. Pain is traumatic, and it stays with us—burrowing into our brain, our nervous system, and our skin. It’s for all these reasons that disclosure can be such a catharsis . . .

Caroline Reilly, *The Intimate Act of Performing Pain*, BITCH MEDIA (Feb. 12, 2020, 10:00 AM), <https://www.bitchmedia.org/article/privacy-and-disclosure-with-chronic-illnesses> [<https://perma.cc/H9U3-7CK9>].

¹⁴ Describing her experiences dating with an invisible disability, Amy Gaeta frames the problem as ableism—not disability:

[W]hat failed me the most was assumptions about disabled people and dating. First . . . assumptions that disability causes a tragic life, that dating us is a burden because we are “needy.” Dating us makes non-disabled people saints taking on a charity case. Second . . . the false notion that disability and sexiness are at odds. We might be “cute” in a pitiful sort of way, but never desirable. Lastly . . . the stereotype that disabled people have limited futures, so dating us is signing up for limited options and compromise.

Amy Gaeta, *Navigating Dating, Disability, and Disclosure*, ROOTED IN RTS. (Feb. 14, 2020), <https://rootedinrights.org/navigating-dating-disability-and-disclosure> [<https://perma.cc/7T9N-NCWN>].

¹⁵ ERVING GOFFMAN, STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY 102-04 (1963). *See generally* Kenji Yoshino, *Covering*, 111 YALE L.J. 769 (2002) (discussing this phenomenon for LGBTQ+ individuals).

legitimate minority of people with disabilities from those perceived to be malingering charlatans.¹⁶

Why should disability law be premised on catering to social norms? The answer is twofold. First, Congress identified the greatest barrier to inclusion for people with disabilities as antiquated attitudes and biases that associate disability with individual deficit, incapacity, and dependency.¹⁷ Second, the remedial impact of antidiscrimination law in this area cannot be realized unless we address these deeply rooted biases that are taken for granted as “normal” or “justified.”¹⁸ Legal actors argue, frame, and interpret existing antidiscrimination laws according to their common knowledge and experience. However, as this Article contends, privacy has prevented the development of meaningful public discourse to develop an accurate common base of knowledge about disability needed to advance antidiscrimination efforts.

So how do we do attend to the information deficits in society about disability that undermine antidiscrimination efforts? In my last Article, *The Aesthetics of Disability*, I said we need to move beyond known or visible markers of disability which effectively define the scope of legitimate claims to disability rights.¹⁹ Here, I take up the other end of the aesthetic spectrum, the overwhelming majority of people with disabilities in the United States who do not exhibit commonly accepted physical or behavioral markers associated with disability. I explore why publicity is central to the normative work that needs to be done, and how the design of disability laws can incentivize publicity while carefully balancing legitimate privacy interests. Dismissing publicity as contrary to individual self-determination, as lawmakers, courts, and society continue to do, ignores the structural constraints on choices available to people with less apparent disabilities as well as the negative individual and collective costs of “passing” or “covering.”²⁰

I join several current scholarly debates with transferrable insights for other areas of law and society. First, and principally, I challenge well-established assumptions about privacy and disability that permeate disability

¹⁶ See, e.g., N. Ann Davis, *Invisible Disability*, 116 ETHICS 153, 210 (2005) (“The presumption that there are deep and obvious differences between being ‘normal’ and being disabled is one that is deeply and dogmatically held: it is taken to be self-evident.”).

¹⁷ See 42 U.S.C. § 12101(a)(2) (“[H]istorically, society has tended to isolate and segregate individuals with disabilities, and . . . such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem . . .”).

¹⁸ Challenging the perceived neutrality of the status quo is central to the work of critical race theorists as well. See, e.g., *Introduction to CRITICAL RACE THEORY: THE KEY WRITINGS THAT FORMED THE MOVEMENT* xiii, xiv (Kimberlé Crenshaw, Neil Gotanda, Gary Peller & Kendall Thomas eds., 1995) (“The construction of ‘racism’ from . . . the ‘perpetrator perspective’ restrictively conceived racism as an intentional, albeit irrational, deviation by a conscious wrongdoer from otherwise neutral, rational, and just ways of distributing jobs, power, prestige, and wealth.”).

¹⁹ Harris, *supra* note 2, at 967.

²⁰ Cf. Yoshino, *supra* note 15, at 813 (“[P]assing, too, exacts its costs.”).

laws. Last year marked the thirtieth anniversary of the Americans with Disabilities Act (ADA), the central civil rights legislation for people with disabilities. Consistent with this milestone, I join disability law scholars in reflecting on the efficacy of the ADA and its remedies. While the ADA visibly transformed the architectural landscape for improved physical accessibility,²¹ it has experienced significantly less success in shifting social norms of disability, such as the association of disability with deficit.²² I part ways with scholars in this area by questioning the overreliance on privacy norms to do the antidiscrimination work without greater nuance. Second, and relatedly, this Article situates disability within the broader privacy literature by recognizing the collective interests at stake in this debate. I draw upon the privacy literature to argue for a more robust (and nuanced) analysis of privacy interests in the disability context. Third, this Article begins to explore the remedial value of publicity in disability law. In doing so, I join a broader discussion taking place in the civil rights and social movements literature where publicity continues to offer new possibilities for grassroots organizing, stigma reduction, and legislative reforms. I consider the #MeToo movement and the Dreamers as examples.

This Article unfolds in five parts. Part I argues that the law treats disability as private. Privacy was originally forced upon people with disabilities in an effort to segregate and render them invisible through legal regulation much like the experience of other marginalized communities in the United States.²³ Along the way, however, social progressives and some legal scholars have come to embrace the antidiscrimination properties of privacy as a more powerful prescription to address contemporary forms of discrimination—such as implicit biases, data mining, and surveillance—that are difficult to address through our existing antidiscrimination frameworks.

Part II then explains the logic of privacy norms in the disability context and places this discussion within broader debates among privacy and antidiscrimination scholars.

Part III argues that disability law has an overall preference for privacy and explains why this preference makes sense. Sometimes, disability law requires disclosure of disability, such as when a disabled individual wants to secure a

²¹ See Harris, *supra* note 2 at 896 (noting the ADA's focus on "access to employment, public services, and places of public accommodations").

²² See, e.g., Charlesworth & Banaji, *supra* note 8, at 174 (describing longitudinal, comparative analysis of patterns of long-term change in social-group attitudes (sexual orientation, race, skin tone, age, disability, and body weight) and finding that all explicit responses changed toward attitude neutrality but while implicit responses also changed toward neutrality for sexual orientation, race, and skin-tone attitudes, there was stability over time for age and disability attitudes).

²³ See *infra* Part V. (discussing the value of publicity).

reasonable accommodation.²⁴ Most other times, however, disability and related areas of law nudge privacy by establishing rights to confidential treatment of information about disability or regulating the effects of disclosure of that information. This proclivity for privacy stems from its relative effectiveness in preventing discrimination. Said differently, disability and related laws nudge individuals and institutions to protect information about disability identity either by creating incentives for individual nondisclosure or, when law requires its disclosure, ensuring that the disclosed information remains under lock and key. In this way, law incentivizes institutional actors to protect this information or face potential legal liability.

Part IV argues that the law's preference for privacy is not costless. First, privacy nudges obscure the pervasiveness and diversity of disability in society, reducing public perceptions of disability to a narrow set of aesthetic markers. Second, privacy nudges create "ambiguity aversion"²⁵ that can force discrimination underground and make people with less visible disabilities more susceptible to implicit biases. Third, and relatedly, these nudges privatize the costs of accommodations and mask the need (and opportunity) for broader structural reforms.

Finally, Part V contends that publicity²⁶ has underexplored benefits and argues that we should recalibrate disability law and policy to reflect these values. Part V concludes with a discussion of three concrete ways to incorporate publicity values in disability law and policy: data, institutional incentives, and law reforms.

Taking disability public requires a nuanced approach that surfaces the values and risks associated with legal designs that privilege privacy. Importantly, this approach does not signal the demise of existing privacy rights and individual agency. Legal scholars justify the current privacy nudges underwriting disability law in service of decisional autonomy, particularly for people with less apparent disabilities. Closer examination of the quality of available choices shows that meaningful protection from discrimination is often predicated on concealment of disability identity. A person without the aesthetics of disability can choose, for example, to self-accommodate

²⁴ See 42 U.S.C. § 12112(b)(5)(A) ("[T]he term 'discriminate against a qualified individual on the basis of disability' includes . . . not making reasonable accommodations to the *known* physical or mental limitations . . ." (emphasis added)).

²⁵ See *infra* Section IV.B.

²⁶ "Publicity" means institutional and individual public association with disability which includes, but is not limited to, personal disclosure. This concept is more than "visibility" as it requires an affirmative engagement with others and the process of adopting and disclosing. This Article argues that publicity should become a guiding normative principle shaping disability antidiscrimination laws. See *infra* Part V.

(assuming certain risks²⁷) and avoid the costs of disclosure including stigma and discrimination.²⁸ Alternatively, that person can disclose disability identity in the workplace, for example, to obtain a reasonable accommodation. The disabled individual, then, must rely on existing antidiscrimination frameworks to prevent and, where possible, remedy legally recognized harms if they arise.²⁹ Said differently, risk aversion warrants hiding to avoid disability stigma and discrimination (but it is the individual's choice). If, the person needs an accommodation or wants to disclose disability to someone, again, it is the individual's choice, but if there is a problem, the individual must rely on a legal structure designed to remedy forms of *explicit* discrimination that is ill-equipped to address contemporary manifestations of implicit biases. This Article challenges this narrow vision of agency. I argue that by reframing the stakes, we can have a more robust (and accurate) debate regarding the value of publicity not only to the individual but also to people with disabilities and society more broadly.

I. DISABILITY AS PRIVATE

Part I traces the construction of disability as a private fact. There are good reasons for advancing privacy norms in the context of disability. Disclosure of a concealable stigmatized social identity is risky. People who disclose can be exposed to discrimination, bias, negative stereotypes or, in some cases, violence.³⁰ The treatment of disability identity as private reflects a complicated history of deliberate state action to segregate, hide, rehabilitate, or eliminate disability.³¹

²⁷ Such risks include actual costs of self-accommodation. A person with a learning disability who may need extra time to process the written information may, for example, work longer hours but not report them to the employer. Over time, this may not only increase the emotional and physical stress on the individual but may place the person at a disadvantage financially since they have worked significant overtime without securing the financial benefit. This individual may be reluctant to seek out additional social or work-related opportunities because they simply do not have the time to do so.

²⁸ The extreme approach advanced by some disability law scholars is to avoid disclosure altogether as the only effective way to control the disclosure and secondary disclosure of information about disability. *See, e.g., infra* Part II.

²⁹ There may be additional permutations here. I am not suggesting a clean binary, rather one framing that descriptively accounts for the qualitatively poor choices under the current structure.

³⁰ *See, e.g.,* Debra McKinney, *The Invisible Hate Crime*, INTEL. REP., Summer 2018, <https://www.splcenter.org/fighting-hate/intelligence-report/2018/invisible-hate-crime> [<https://perma.cc/KT2K-MLQT>] (discussing the history, incidence, and nature of hate crimes against disabled persons).

³¹ There are places where disability rights law requires disclosure, namely, for purposes of requesting a reasonable accommodation and exercising rights under the ADA. The point is that there are many areas where privacy is the default and people are encouraged, if they can, to pass as nondisabled. *See infra* Part III.

A. Defining Privacy

Privacy is elusive.³² Part of the difficulty in defining privacy comes from its strategic deployment in public discourse as everything from an individual right to a dignity interest or to a well-established norm related to personal agency.³³ Privacy includes the substance of the data which, in turn, may signal different public and private interests in that information and, ultimately, who controls the data and regulates it (individual, public, or private actors).³⁴ In any formulation, privacy means more than personal data and more than individual interests in dignity and autonomy; privacy is about power, a set of rules used to regulate information that can control our lives.³⁵ Descriptive accounts of privacy—delineating what is, in fact, protected as private—differ in the legal scholarship from normative accounts of privacy: defending its value and the extent to which it should be protected. In these discussions, some treat privacy as an interest with moral value, while others refer to privacy as a legal right that ought to be protected by society or the law.³⁶ Still

³² Arthur Miller described privacy as “difficult to define” precisely because “it is exasperatingly vague and evanescent.” ARTHUR R. MILLER, *THE ASSAULT ON PRIVACY: COMPUTERS, DATA BANKS, AND DOSSIERS* 25 (1971); see also NEIL RICHARDS, *WHY PRIVACY MATTERS* (forthcoming) (manuscript at ch. 1, 3) (on file with author) (“[N]o one—not the general public, not policymakers, nor even scholars—can quite agree on what precisely we mean by ‘privacy.’”).

³³ See, e.g., Sjaak van der Geest, *Lying in Defence of Privacy: Anthropological and Methodological Observations*, 21 INT’L J. SOC. RSCH. METHODOLOGY 541, 541 (2018) (“[T]he concept of privacy defies a precise definition because it refers to experiences that are too close to look at objectively.”). This Article draws upon existing research and legal scholarship to define “privacy.” While I offer a normative view of privacy in the disability context, I do not weigh in on the more abstract discussion of the bounds and nature of privacy in U.S. law.

³⁴ See Neil Richards & Woodrow Hartzog, *Privacy’s Trust Gap: A Review*, 126 YALE L.J. 1180, 1182–83 (2017) (reviewing FINN BRUNTON & HELEN NIESSENBAUM, *OBFUSCATION: A USER’S GUIDE FOR PRIVACY AND PROTEST* (2015)) (arguing that conversations about the “digital divide” fail to capture that it is not just about access to the technology, but the power dynamics among those who create, monitor, and regulate the digital technology and the personal data that fuels them). References to privacy in the disability context can also mean that families rather than the state have to deal with it. Or, as I note in the text, it can also mean that a person’s disability status is private in that they do not have to disclose it to others. Finally, privacy could mean that certain people should not enter the public sphere, a frame originally used against women, Black, LGBTQ+, and Latinx communities.

³⁵ RICHARDS, *supra* note 32 (manuscript intro. at 4); see, e.g., Convention on the Rights of Persons with Disabilities art. 22, Dec. 13, 2006, 2515 U.N.T.S. 3 (defining privacy as freedom from state interference in private affairs and setting out the obligation of states to “protect the privacy of personal, health and rehabilitation information . . . on an equal basis with others”); *id.* art. 31(1)(a) (“The process of collecting and maintaining . . . information shall . . . [c]omply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities . . .”).

³⁶ See, e.g., ANITA L. ALLEN, *UNPOPULAR PRIVACY: WHAT MUST WE HIDE?* 23 (2011) (“[T]he actual, reliable experience of privacy is a moral imperative and can be a requirement of social justice.”). Critics of privacy, such as Richard Posner, claim that privacy interests are not distinctive because the personal interests they protect are economically inefficient. See, e.g., RICHARD POSNER, *THE ECONOMICS OF JUSTICE* 233–37 (1981); see also ROBERT H. BORK, *THE TEMPTING OF*

others, reframe the analysis away from protections the individual wants or those forms of privacy accepted by most as appropriate for protection (“popular privacy”) and those forms of privacy that are unwanted or unprotected (“unpopular privacy”) but which, nevertheless, may warrant the state denying the individual control over the disclosure decision because it concerns matters fundamental to our sense of self, agency, or dignity.³⁷

Privacy scholars generally believe in privacy’s instrumental (rather than intrinsic) value; that is, privacy ought to serve broader values and interests of society such as identity formation or democratic participation.³⁸ Similarly, our varied conceptions of privacy, however distinct, have certain consistent elements, namely, that individual dignity and autonomy interests drive discussions; responsibility is largely placed on the individual to police misuse; and the nature of the data, if involuntarily disclosed, is perceived to cause reputational harm and related costs.³⁹ First, conceptions of privacy elevate individual interests: “In the United States, information privacy has

AMERICA: THE POLITICAL SEDUCTION OF THE LAW 99-100 (1990) (arguing that the Supreme Court’s construction of “privacy” lacks a well-defined jurisprudential basis); CATHARINE A. MACKINNON, TOWARD A FEMINIST THEORY OF THE STATE 187-88 (1989) (advancing a feminist critique of privacy, namely, that special treatment of privacy can be harmful when used as a shield for violence against women).

³⁷ ALLEN, *supra* note 36, at 6, 10-13. Anita Allen’s robust, influential body of work has demonstrated the existence of beneficial forms of privacy and the importance of private choice for some historically marginalized communities such as women, people of color, and LGBTQ communities. *See, e.g., id.*; Anita L. Allen, *Privacy Torts: Unreliable Remedies for LGBT Plaintiffs*, 98 CALIF. L. REV. 1711, 1721-22 (2010) [hereinafter Allen, *Privacy Torts*] (examining the efficacy of the privacy tort in the context of LGBT rights); Anita L. Allen, *Gender and Privacy in Cyberspace*, 52 STAN L. REV. 1175 (2000); *see also* Danielle Keats Citron, *Sexual Privacy*, 128 YALE L.J. 1870, 1874-75 (2019) (arguing that “sexual privacy sits at the apex of privacy values because of its importance to sexual agency, intimacy, and equality,” particularly for women).

³⁸ RICHARDS, *supra* note 32 (manuscript intro. at 8) (exploring the value of privacy to advancing “identity, freedom, and protection”). Richards’s conception of “intellectual privacy” focuses on identity formation across multiple domains such as religious and political. *See id.* (manuscript intro. at 8-9) (noting that the notion of privacy as freedom to explore and define oneself is quite different from the views of privacy skeptics such as Richard Posner who believe that privacy allows people to be dishonest about their true selves).

³⁹ *See* ALAN F. WESTIN, *PRIVACY AND FREEDOM* 31-32 (1967). Professor Westin described four types of aspects of privacy with four related functions. The types or aspects of privacy include: solitude (being alone), intimacy (being alone with only one or a few close others), anonymity (being with others but unknown to them and unobserved, ‘lost in a crowd’), and reserve (being with others but having erected a ‘psychological barrier against unwanted intrusion’). *Id.* In terms of the goals or effects of privacy, Westin described personal autonomy (which includes self-identity and the ability to control communication and interaction with others); emotional release (the option of withdrawing and being free from observation by others); self-evaluation (the possibility of reflecting on one’s position vis-à-vis others); and protected communication (sharing confidential things with selected others). *See also* Koops et al., *supra* note 1, at 566 (building on Westin’s typology by describing eight basic types of privacy occurring in four zones (personal, intimate, semi-private, and public) with a ninth type, (informational privacy), which is described as “an overlay related to each underlying type”).

historically been defined as an individual concern rather than a general societal value or a public interest problem.”⁴⁰ Classically, this is Louis Brandeis and Samuel Warren’s notion of privacy as “the right to be let alone.”⁴¹ Second, and relatedly, legal and policy remedies emphasize harm to the individual.⁴² Legal doctrines such as informed consent become the primary means of describing and regulating offenses to individual autonomy. The responsibility for identification and redress of violations of informed consent rests with the individual. Third, the “private” label describes its substance or content and a belief that inadvertent disclosure could result in embarrassment, unnecessary social tension, or negative consequences to the individual or family members (such as one’s status as a sex offender, recipient of public welfare benefits, or survivor of sexual assault).

B. *How Disability Became a Private Fact*

Contemporary privacy norms are byproducts of at least four key historical ingredients: (1) a conceptual and regulatory divide between “public” and “private” spheres; (2) the rise of the public welfare system; (3) the development of health sciences, rehabilitation, and the medical profession; and (4) in employment, “scientific management” and, separately, the professionalization of human resources.

1. Separation of “Public” and “Private” Spheres

First, association of disability with the “private sphere” of family and care outside of the public (and state’s) interests has shaped its treatment as private information.⁴³ This fictitious binary treats legal and policy matters related to the home, relationships, the body, or caregiving (highly gendered) to be

⁴⁰ James P. Nehf, *Recognizing the Societal Value in Information Privacy*, 78 WASH. L. REV. 1, 5 (2003).

⁴¹ *Olmstead v. United States*, 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting) (“[The Founders] conferred, as against the Government, the right to be let alone—the most comprehensive of rights and the right most valued by civilized men.”). Interestingly, Justice Brandeis also valued transparency and “sunlight” for the public good. See Louis D. Brandeis, *What Publicity Can Do*, HARPER’S WKLY., Dec. 20, 1913, at 10 (“Publicity is justly commended as a remedy for social and industrial diseases. Sunlight is said to be the best of disinfectants . . .”).

⁴² See, e.g., Nehf, *supra* note 40, at 4 (describing survey results showing that while the public holds data and information privacy as a priority, “a great number of [people also] understand that [their] interests in privacy must be balanced against other interests, i.e., the multitude of benefits resulting from more efficient government, business, and law enforcement functions when information in digital form is readily accessible.”); see also Joseph I. Rosenbaum, *Privacy On the Internet: Whose Information is it Anyway?*, 38 JURIMETRICS 565, 566 (1998) (recognizing the difficulties of defining privacy and its continued elusive nature because it is highly dependent on technological capabilities and developments, and social norms and values).

⁴³ See SUSAN WENDELL, *THE REJECTED BODY: FEMINIST AND PHILOSOPHICAL REFLECTIONS ON DISABILITY* 40 (1996).

outside of a “public sphere,” the home of legitimate state interests, such as economic markets and state regulation.⁴⁴ Privacy was billed as protective, intended to shield the agency of individuals and households from state overreaching.⁴⁵ However, emphasis on legitimate zones of state regulation, at least initially, gave states license to avoid duties to protect historically vulnerable and marginalized groups (on the basis of race,⁴⁶ gender,⁴⁷ or sexual identity⁴⁸). For example, feminist legal theorists have well documented the ways in which attaching a privacy label has “operated to make violence against women legally and politically invisible.”⁴⁹ The care and support for people with disabilities through the mid-nineteenth century was left to families, churches, and charities, in part, a function of its ontological ties to moral depravity, punishment, and deviance.⁵⁰ The state intervened to police disability in public spaces through municipal ordinances and criminal laws and, in its *pater patriae* function, to assure control over property.⁵¹ The infamous “ugly laws,”⁵² for example, criminalized “unsightly beggar[s]” and

⁴⁴ As Bart van der Sloot writes:

Privacy is perhaps the oldest legal principle. It pertains to the separation of the public and private domain. Where that boundary lies exactly differs from culture to culture, epoch to epoch, and country to country, but there always is one. In ancient times, the ruler or king had authority over the public domain, while the household fell under the rule of the *pater familias*, the male breadwinner of the family, who reigned over his family members like a king. The separation of the public domain from the private domain, meant that public laws, in principle, held no sway over the household.

Bart van der Sloot, *Privacy from a Legal Perspective*, in THE HANDBOOK OF PRIVACY STUDIES: AN INTERDISCIPLINARY INTRODUCTION 68-70 (Bart van der Sloot & Aviva de Groot eds., 2018) (footnote omitted).

⁴⁵ *Id.* at 70.

⁴⁶ *E.g.*, Christopher W. Schmidt, *On Doctrinal Confusion: The Case of the State Action Doctrine*, 2016 BYU L. REV. 575, 582, 615-16 (discussing the state action doctrine’s distinction between public and private spheres and how the civil rights movement brought formerly “private” racial discrimination, for example, in places of public accommodations, within the purview of state regulation).

⁴⁷ See Frances Olsen, *Constitutional Law: Feminist Critiques of the Public/Private Distinction*, 10 CONST. COMMENT. 319, 322-23 (1993) (offering an overview of early feminist critiques of the “public/private distinction”).

⁴⁸ See *Bowers v. Hardwick*, 478 U.S. 186, 191 (1986) (“[T]he proposition that any kind of private sexual conduct between consenting adults is constitutionally insulated from state proscription is unworkable.”), *overruled by* *Lawrence v. Texas*, 539 U.S. 558 (2003).

⁴⁹ Sally F. Goldfarb, *Violence Against Women and the Persistence of Privacy*, 61 OHIO ST. L.J. 1, 5 (2000).

⁵⁰ See, e.g., Chai R. Feldblum, *Definition of Disability Under Federal Anti-Discrimination Law: What Happened? Why? And What Can We Do About It?*, 21 BERKELEY J. EMP. & LAB. L. 91, 94 (2000) (“In colonial America, people with disabilities were viewed primarily in terms of their dependency. Wherever possible, people with disabilities were cared for by their relatives, who often hid them out of shame.”).

⁵¹ See Harris, *supra* note 6, at 509-10 (discussing the evolution of guardianship proceedings as a means for managing the property of people believed to be legally incompetent).

⁵² Marcia Pearce Burgdorf and Robert Burgdorf Jr. coined this term in 1975, but Susan Schweik used it as the title of her book and expanded upon it greatly through her thorough discussion of the legal history in this area. See generally SUSAN M. SCHWEIK, THE UGLY LAWS: DISABILITY IN

forced people with disabilities from public spaces by imposing hefty fines on poor people who, when they expectedly could not pay, were confined to poorhouses and jails.⁵³ These laws remained on the books well into the twentieth century and were enforced (albeit infrequently) as late as 1974.⁵⁴ Institutions, therefore, regulated the appearance of disability (and its related marginalized identities).⁵⁵ Disability was as a social eyesore, a personal tragedy, and thus, a private fact to be hidden from those outside of the home. People with disabilities became invisible, and as a result, “pitied, excluded, and/or cared for outside of the mainstream of society.”⁵⁶

Furthermore, the public-private divide forms the basis for the Supreme Court’s privacy jurisprudence from *Griswold v. Connecticut* onward.⁵⁷ For example, in *Whalen v. Roe*, even as the Court upheld a New York law requiring people taking certain controlled prescription drugs to file their names with the state Health Department, it nevertheless recognized that these individuals had a legitimate privacy interest in their medical data.⁵⁸ Constitutional legal scholarship in the area of informational privacy is well-developed and beyond the scope of this project.⁵⁹ One upshot of the literature is that the Supreme Court understands information privacy as highly individualized and rooted in three interests: to avoid disclosure of personal matters; to maintain autonomy in personal decision-making; and to assimilate whenever possible.⁶⁰ Subsequent case law has shaped the scope of

PUBLIC (2009); Marcia Pearce Burgdorf & Robert Burgdorf Jr., *A History of Unequal Treatment: The Qualifications of Handicapped Persons as a “Suspect Class” Under the Equal Protection Clause*, 15 SANTA CLARA LAW. 855, 863 (1975) (coining the term “ugly laws”).

⁵³ SCHWEIK, *supra* note 52, at 26-27 (noting that these nuisance ordinances imposed hefty fines on offenders—for example, the equivalent of over \$350—but offered an alternative for those unable to pay: confinement in the Almshouses).

⁵⁴ *Id.* at 6.

⁵⁵ Disability, like poverty, was often used as a proxy to regulate other disfavored identities. Accordingly, no single explanation can account for the emergence of the policing of the unsightly beggar in American culture. *See id.* at 24 (identifying “the persistent nexus of disability and poverty at the heart of the ugly law, as well as . . . the complex interweaving of economic unrest, social policy and cultural (including aesthetic) imagination at work”). As Professor Schweik notes, disability is inherently intersectional, as the ugly laws were “a matrix of codes concerning local purity: decency and exhibition, gender and sexuality.” *Id.* at 144; *see also* Harris, *supra* note 2, at 897 (identifying sensory and behavioral markers associated with disability).

⁵⁶ Feldblum, *supra* note 50, at 95.

⁵⁷ 381 U.S. 479 (1965); *see* *Roe v. Wade*, 410 U.S. 113, 152-56 (1973) (extending the right of privacy to abortion). In part, the connection between privacy and health allowed disability status to move seamlessly into this framework. *See generally* Francis S. Chlapowski, Note, *The Constitutional Protection of Informational Privacy*, 71 B.U. L. REV. 133 (1991) (discussing the early development of the Court’s informational privacy jurisprudence); Jed Rubenfeld, *The Right of Privacy*, 102 HARV. L. REV. 737 (1989) (same).

⁵⁸ 429 U.S. 589, 598-600 (1977).

⁵⁹ *See generally, e.g.*, Scott Skinner-Thompson, *Outing Privacy*, 110 NW. U. L. REV. 159 (2015).

⁶⁰ *Whalen*, 429 U.S. at 598-600. As Robin Pierce summarizes it:

constitutional protection, including the importation of doctrinal principles such as “reasonable expectation of privacy” from the Fourth Amendment doctrine.⁶¹ Courts apply an intermediate standard of review in such an analysis and balance the privacy interests against the interests in disclosure of personal information.⁶²

2. Disability as Dependency

Second, the rise of the public welfare system, and state interest in its regulation, shaped the treatment of disability as private information. The “shameful” association of disability with state dependency caused many people to reject disability as antithetical to American identity. Legal historians mark the Civil War as a critical moment in the construction of disability as part of national rhetoric of disfavored identity.⁶³ The choice to “cast disabled veterans as primarily disabled and dependent rather than as

Such decisions exist within the “private sphere”. This seemingly simple concept frequently escalates in complexity when confronted with situations in which the decision would appear to lie with the patient, but the interests of others are implicated by the individual’s decision. This occurs, for example, in the case of infectious disease and, in some jurisdictions, decisions regarding abortion. The operation of decisional privacy can also be seen in the use of consent-substitutes such as advance directives for care or research, a mechanism that is intended to perpetuate autonomy even after the person loses the capacity to consent.

Robin Pierce, *Medical Privacy: Where Deontology and Consequentialism Meet*, in HANDBOOK OF PRIVACY STUDIES, *supra* note 44, at 327, 329 (internal citations omitted).

⁶¹ See *Nixon v. Admin’r of Gen. Servs.*, 433 U.S. 425, 457 (1977) (“[W]hen Government intervention is at stake, public officials, including the President, are not wholly without constitutionally protected privacy rights in matters of personal life unrelated to any acts done by them in their public capacity.”); see also Roger Doughty, *The Confidentiality of HIV-Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic*, 82 CALIF. L. REV. 111, 148-49 (1994) (discussing the importation by the Court of “the legitimate expectation of privacy” standard from Fourth Amendment search and seizure decisions into a case dealing with the violation of privacy interests through disclosure of personal information” (citing *Nixon*, 433 U.S. at 457-65)).

⁶² Doughty, *supra* note 61, at 149-50. Until recently, the abortion and gay rights jurisprudence relied on the right of the plaintiff to reveal no facts about themselves. Plaintiffs did not reveal facts in either *Roe* or *Bowers*. In recent years, that strategy has ended. There are now briefs including narratives about the lives of women who have had abortions or members of the LGBTQ+ community seeking to marry.

⁶³ See, e.g., Rabia Belt, *Ballots for Bullets?: Disabled Veterans and the Right to Vote*, 69 STAN. L. REV. 435, 439 (2017) (“War was not just an engine of democracy. It was a factory of death and disability. As it disabled, it transformed. Citizen-soldiers became dependent citizens. And this dependency carried oft-detrimental political, social, and legal consequences.”); Peter Blanck, *“The Right to Live in the World”: Disability Yesterday, Today, and Tomorrow*, 13 TEX. J. ON C.L. & C.R. 367, 370 (2008) (“The Civil War changed how Americans thought about disability. Attitudes were shaped about and by returning disabled veterans and their families as they engaged the Civil War pension system.”).

primarily veterans” worthy of public support had long-lasting effects.⁶⁴ The veterans’ pension scheme was, at the time, the “nation’s largest and most medicalized welfare scheme.”⁶⁵ Payments initially required a causal connection to war-related impairments as determined by means of a detailed medical rating system for compensating “legitimate” disabilities.⁶⁶ Veterans received payments regardless of socioeconomic status. Later, however, the federal government and states tied eligibility to pension benefits to the existence of a medically recognized disability *and* socioeconomic status as indigent.⁶⁷ Medical professionals and legal institutions—courts, public agencies—became the gatekeepers of one’s public identity as “disabled” and, by extension, access to limited pools of public benefits including social security, cash assistance, food stamps, and subsidized housing and health care. Physicians rated claimants’ disabilities in relation to their ability to participate in the labor market, sorting them by disease and severity.⁶⁸ “Pensioners with visible or ‘less obscure’ injuries from gunshot wounds” were subject to less attitudinal prejudice and were less likely to be rejected by the Pension Bureau, while veterans with less visible, less common, and, thus, less understood conditions faced attitudinal prejudice and skepticism, resulting in higher rates of outright denial.⁶⁹

Similarly, in the context of immigration law, disability was (and continues to be) grounds for exclusion from the United States because of the unquestioned assumption that disability means dependency.⁷⁰ Ellis Island

⁶⁴ Belt, *supra* note 63, at 443.

⁶⁵ Blanck, *supra* note 63, at 370-71.

⁶⁶ *Id.* at 371, 375-76. Later payments expanded to include disorders and diseases arising out of war that caused disability later on. *See, e.g.*, Act of Mar. 3, 1873, ch. 234, 17 Stat. 566; Act of June 27, 1890, ch. 634, 26 Stat. 182.

⁶⁷ William P. Quigley, *The Quicksands of the Poor Law: Poor Relief Legislation in a Growing Nation, 1790-1820*, 18 N. ILL. U. L. REV. 1, 50 (1997) (discussing a change to the revolutionary war pension scheme); Michael Waterstone, *Returning Veterans and Disability Law*, 85 NOTRE DAME L. REV. 1081, 1105-1108 (2010) (discussing contemporary varied veterans’ benefits programs including the means-tested Veterans Administration Pension Program).

⁶⁸ Blanck, *supra* note 63, at 370-72.

⁶⁹ *Id.* at 377.

⁷⁰ Immigration laws once included explicit exclusions for persons with disabilities. *See, e.g.*, Act of Aug. 3, 1882, ch. 376, § 2, 22 Stat. 214, 214 (excluding “lunatic[s], idiot[s], or any person unable to take care of himself or herself without becoming a public charge” from entry to the United States); *see also* Douglas C. Baynton, *Defectives in the Land: Disability and American Immigration Policy, 1882-1924*, 24 J. AM. ETHNIC HIST. 31, 33-34 (2005) (explaining how immigration laws denied admission to “mental or physically defective [persons]” and to anyone with “any mental abnormality whatever” (first quoting Act of Feb. 20, 1907, ch. 1134, § 2, 34 Stat. 898, 899; then quoting U.S. PUB. HEALTH SERV., REGULATIONS GOVERNING THE MEDICAL INSPECTION OF ALIENS 30 (1917))). While much of this exclusion has since been repealed, immigration law today explicitly maintains the “public charge” language, while also excluding persons with “physical and mental disorder[s]” who have “harmful behavior[s]” that pose a threat to oneself or others. *See* 8 U.S.C. § 1182(a)(4)(A) (“public charge”); *id.* § 1182(a)(1)(A)(iii)(II) (“physical or mental disorder”).

played a critical role in the construction of disability and its connotations. State-imposed labels of illness, insanity, and criminality tracked racist and xenophobic views of undesirability:

The social processing that Ellis Island engendered was all about identifying and sometimes manufacturing abnormal bodies: these elements are out of place; these bodies are disordered. . . . At Ellis Island, the categories of defect and disability that adhere today were strongly grounded if not created, as was the diagnostic gaze that allowed for the nebulous application of the stigma of disability as we know it⁷¹

For example, when immigrants passed through Ellis Island, they “became part of an indelible marking, [the immigrant] body was interrogated, written across, and read into.”⁷² Interestingly, the very design of Ellis Island as a series of stairs and pathways was a perfect mix of Jeremy Bentham’s panopticon and Henry Ford’s assembly line that offered agents at Ellis Island the opportunity to inspect immigrant bodies, behaviors, and minds with every step from multiple angles. In this way, the construction of a maze of stairs tested physical mobility, the requirement that they carry their luggage demonstrated strength and endurance, and the winding maze operated like one big catwalk for aesthetic inspection. Ellis Island also provided a testing ground for empirical and rhetorical social sorting tools (e.g., IQ tests); it was “a genetic experiment” facilitated by the expansion of medical science, as the next subsection explains.⁷³

3. Medical and Health Law Frames

Third, and relatedly, the increasing medicalization of disability in the late nineteenth century reduced disability identity to a sum of medical diagnoses defined and controlled by medical professionals. This “medical model” of disability locates the deficiency in the person rather than in relation to how social institutions respond to individual impairment.⁷⁴ In other words, a

⁷¹ Jay Dolmage, *Disabled upon Arrival: The Rhetorical Construction of Disability and Race at Ellis Island*, 77 CULTURAL CRITIQUE 24, 26 (2011).

⁷² *Id.* at 24.

⁷³ *Id.* at 27-28.

⁷⁴ See, e.g., Bradley A. Areheart, *When Disability Isn't "Just Right": The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma*, 83 IND. L.J. 181, 185-86 (2008) (footnote omitted) (“The medical model views the physiological condition *itself* as the problem. In other words, ‘the individual is the locus of [. . .] disability.’” (quoting Mary Crossley, *The Disability Kaleidoscope*, 74 NOTRE DAME L. REV. 621, 649 (1999))); Samuel R. Bagenstos, *Subordination, Stigma, and "Disability,"* 86 VA. L. REV. 397, 426-31 (2000) (describing the medical model of disability as one that “treat[s] disability as an inherent personal characteristic that should ideally be fixed, rather than as a characteristic that draws its meaning from social context”); Elizabeth F. Emens, *Framing Disability*, 2012 U. ILL. L. REV. 1383, 1401 (“The medical model is the idea, common

wheelchair user is disabled by the design choice of stairs rather than by a mobility impairment itself. The medical model describes disability as an abnormal, personal defect or impairment in need of medical correction, cure, or mitigation relative to an able-bodied, nondisabled “fit” or “healthy,” athletic male.⁷⁵ Medical professionals and researchers sought ways to identify, label, and diagnose disabilities. At times, the explicit goal was the eradication of disability⁷⁶ and, at other times, the goal was treatment, cure, or rehabilitation.⁷⁷ For example, the modern practice of fingerprinting and its related data collection comes from a eugenic policy initiative to track and mark disability.⁷⁸ In this way, medical diagnoses and medical data become synonymous (and conflated) with disability identity, placing its construction, evaluation, and legitimacy in the hands of medical professionals. While there is certainly a connection between someone who has a medical condition, for example, AIDS or status as HIV positive, this does not necessarily track whether the person identifies with disability as a sociopolitical identity.⁷⁹

The benefits of nondisclosure of disability (with invisible or less apparent disabilities), shaped directly by legislation, have outweighed the benefits of publicly claiming disability for many people. Consider the incentives for nondisclosure. Laws codified the gatekeeping role of the medical profession

to mainstream portrayals, that disability is an individual medical problem.”). Consider how the Hippocratic Oath itself developed and maintained to ensure candor and allow doctors to get the best most accurate information from patients to help with medical treatment. If doctors (like lawyers) did not offer this protection, the accepted wisdom goes, then people would be more reticent to offer embarrassing or damaging information and/or seek care.

⁷⁵ See ROSEMARIE GARLAND THOMSON, EXTRAORDINARY BODIES: FIGURING PHYSICAL DISABILITY IN AMERICAN CULTURE AND LITERATURE 12 (1997) (coining the notion of the “normate” or culturally constructed corporeal normativity); Lennard J. Davis, *Introduction: Normality, Power, and Culture*, in THE DISABILITY STUDIES READER 1, 6 (Lennard J. Davis ed., 4th ed. 2013) (discussing the fitness of the body and its connection to eugenics and national identity).

⁷⁶ See Davis, *supra* note 75, at 4 (“[O]ne of the inducements to making these inquiries into personal identification has been to discover independent features suitable for hereditary investigation . . . [I]t is not improbable, and worth taking pains to inquire whether each person may not carry visibly about his body undeniable evidence of his parentage and near kinships.” (citing DONALD A. MACKENZIE, STATISTICS IN BRITAIN, 1865-1930, at 65 (1981) (quoting Sir Francis Galton))).

⁷⁷ This was the driving ideology for the Rehabilitation Act of 1973—as the name suggests, it is spending clause legislation designed to provide a remedy for discrimination in federally funded employment, programs, and services to move people with disabilities into the formal economy and reduce reliance on public welfare. Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355 (1973) (current version at 29 U.S.C. §§ 701-18).

⁷⁸ Data collection dates back to the early efforts of Sir Francis Galton, a key figure in the international eugenics movements, to develop our modern system of fingerprinting, “a kind of serial number written on the body.” Davis, *supra* note 75, at 4. Fingerprinting then develops as a way to identify, track, and “out” criminals who wished to hide their flawed and deviant identities. *Id.*

⁷⁹ This is true even if the person meets the federal definition of disability under disability rights laws such as the ADA or the Rehabilitation Act. The term “disability” means, with respect to an individual, one who meets the federal threshold definition of disability—that is, “a physical or mental impairment that substantially limits one or more major life activities.” 42 U.S.C. § 12102(1)(A).

by requiring explicit diagnoses for eligibility for public benefits and “proof” from medical experts of deservedness. States embraced medical diagnoses as neutral, empirical proof of deservedness of a limited social safety net and the benefits of citizenship. Claiming disability could mean experiencing stigma, and more concretely, systemic exclusion from voting,⁸⁰ marriage,⁸¹ parenting,⁸² and even procreation.⁸³ In fact, involuntary sterilization laws advanced societal norms of disability as deficit and dependency with our nation’s highest Court’s blessing in *Buck v. Bell*.⁸⁴ Such views of disabled lives as sad, depressing, and lacking in value persist today.⁸⁵ A recent study of

⁸⁰ In thirty-nine states and the District of Columbia, persons deemed “incapacitated” or “incompetent” as a result of mental disorder may be stripped of their voting rights. Matt Vasilogambros, *Thousands Lose Right to Vote Under ‘Incompetence’ Laws*, PEW (Mar. 21, 2018), <https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2018/03/21/thousands-lose-right-to-vote-under-incompetence-laws> [<https://perma.cc/EZ2A-R4V4>]; see, e.g., ALA. CONST. art. VIII, § 177(b) (“No person . . . who is mentally incompetent . . . shall be qualified to vote until . . . removal of disability.”).

⁸¹ See, e.g., Robert E. Rains, *Disability and Family Relationships: Marriage Penalties and Support Anomalies*, 22 GA. ST. U. L. REV. 561, 567 (2006) (explaining that under 20 C.F.R. § 416.412, individuals with disabilities who marry lose money under social security programs).

⁸² See, e.g., ALA. CODE § 12-15-319(a)(2) (2019) (providing that “[e]motional illness, mental illness, or mental deficiency of the parent, or excessive use of alcohol or controlled substances, of a duration or nature as to render the parent unable to care for needs of the child” is a ground for terminating parental rights); NAT’L COUNCIL ON DISABILITY, ROCKING THE CRADLE: ENSURING THE RIGHTS OF PARENTS WITH DISABILITIES AND THEIR CHILDREN 16 (2012), https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_o.pdf [<https://perma.cc/2WL8-VLC8>] (“Fully two-thirds of dependency statutes allow the court to reach the determination that a parent is unfit (a determination necessary to terminate parental rights) on the basis of the parent’s disability. In every state, disability may be considered in determining the best interest of a child for purposes of a custody determination in family or dependency court.”); *id.* (“Removal rates where parents have a psychiatric disability have been found to be as high as 70 percent to 80 percent; where the parent has an intellectual disability, 40 percent to 80 percent. In families where the parental disability is physical, 13 percent have reported discriminatory treatment in custody cases.”). See generally CHILD’S BUREAU, GROUNDS FOR INVOLUNTARY TERMINATION OF PARENTAL RIGHTS (2017), <https://www.childwelfare.gov/topics/systemwide/laws-policies/statutes/groundtermin.pdf> [<https://perma.cc/9U7C-PBST>] (discussing state statutes providing for the termination of parental rights by a court).

⁸³ See generally David Pfeiffer, *Eugenics and Disability Discrimination*, 9 DISABILITY & SOC. 481 (1994) (documenting the history of involuntary sterilization laws targeting individuals with disabilities).

⁸⁴ 274 U.S. 200 (1927). For discussions of the implications of *Buck v. Bell*, see generally Jasmine E. Harris, *Commentary to Buck v. Bell*, 274 U.S. 200 (1927), in FEMINIST JUDGMENTS: REPRODUCTIVE JUSTICE REWRITTEN 15 (Kimberly M. Mutcherson ed., 2020), and Jasmine E. Harris, *Why Buck v. Bell Still Matters*, BILL OF HEALTH, HARV. L. SCH. PETRIE-FLOM CTR. (Oct. 14, 2020), <https://blog.petrieflom.law.harvard.edu/2020/10/14/why-buck-v-bell-still-matters> [<https://perma.cc/DZK7-EEA8>].

⁸⁵ See, e.g., Sarah Maslin Nir, *A Dozen Calls to Child Abuse Hotline Did Not Save 8-Year-Old Boy*, N.Y. TIMES (Feb. 23, 2020), <https://www.nytimes.com/2020/02/02/nyregion/nypd-cop-autistic-son.html> [<https://perma.cc/7YMT-F7TC>] (describing the horrific abuse of an autistic child by his father); Corina Knoll, *Sweethearts Forever. Then Came Alzheimer’s, Murder and Suicide*, N.Y. TIMES (Dec. 29, 2019), <https://www.nytimes.com/2019/12/29/nyregion/alzheimers-murder-suicide.html> [<https://perma.cc/PGB8-FLKG>] (framing husband’s murder of wife with Alzheimer’s as “a new love

physicians' perceptions of the quality of disabled lives, for example, found that 82.4% reported that people with a significant disability have a worse quality of life than nondisabled people and only 40.7% of physicians surveyed were "very confident" about their ability to provide the same quality of care to disabled and nondisabled patients.⁸⁶

4. "Scientific Management" and the Professionalization of HR

Two additional factors in the context of employment have also contributed to the treatment of disability as private and have increased the costs of claiming disability.⁸⁷ First, "scientific management," or the trend toward greater optimization, has created an environment where employers engineer one "best" method of job performance. In doing so, employers create the "ideal worker" who can perform those specific tasks in the method prescribed without deviation.⁸⁸ The very notion of disability accommodations requires flexibility with the methods of performing what are deemed the essential functions of the job title. Not only does scientific management remove discretion from the employees as to the process of accomplishing a stated work goal, it also removes discretion from supervisors in direct contact with employees to make small adjustments that might allow an employee with a disability to reach the ultimate goal of the position by following a different process.

Related to scientific management is the professionalization of human resources compliance duties, which has also left line supervisors with less discretion to accommodate disability. Like the scientific management trend, professionalization of human resources reduces manager autonomy and ownership over compliance responsibilities, albeit in different ways. Unlike scientific management which removes discretion in the name of overall

story"). Recent examples abound in state responses to the coronavirus pandemic. See generally Jasmine E. Harris, Essay, *The Frailty of Disability Rights*, 169 U. PA. L. REV. ONLINE 29 (2020); Samuel R. Bagenstos, *Who Gets the Ventilator? Disability Discrimination in COVID-19 Medical-Rationing Protocols*, 130 YALE L.J.F. 1 (2020).

⁸⁶ Lisa I. Iezzoni, Sowmya R. Rao, Julie Ressler, Dragana Bolcic-Jankovic, Nicole D. Agaronnik, Karen Donelan, Tara Lagu & Eric G. Campbell, *Physicians' Perceptions of People with Disability and Their Health Care*, 40 HEALTH AFFS. 297, 300 (2021). These statistics offer empirical support for claims of differential care by some people with disabilities during the pandemic. See, e.g., Joseph Shapiro, *One Man's COVID-19 Death Raises the Worst Fears of Many People with Disabilities*, NPR (Jul. 31, 2020, 3:29 PM) <https://www.npr.org/2020/07/31/896882268/one-mans-covid-19-death-raises-the-worst-fears-of-many-people-with-disabilities> [<https://perma.cc/6M56-P7TR>] (discussing the death of forty-six-year-old Michael Hickson, a Black man with quadriplegia in a Texas hospital).

⁸⁷ I thank Professor Danielle D'Onfro for her thoughts here.

⁸⁸ See Peter Cappelli, *Stop Overengineering People Management: The Trend Towards Optimization is Disempowering Employees*, HARV. BUS. REV., Sept.–Oct. 2020, at 56, 59 ("Labor is treated as a commodity, and the goal is to cut it to a minimum by replacing employees with contract and gig workers Ideal behaviors are dictated to the remaining employees, who are closely monitored for compliance.").

optimization, the professionalization of human resources has created a climate where managers are told to refer anything plausibly related to compliance issues to human resources.⁸⁹ Thus, whereas a request to a manager for time to go to a doctor's appointment might ordinarily be decided by the supervisor on the ground, the professionalization of human resources might now require that every such request be processed formally through their system and discussed through a privacy lens on behalf of the individual employee. Ironically, while compliance and human resource departments have expanded, there is often a mismatch between expertise and authority. By professionalizing compliance with the ADA and removing discretion at the local supervisory level, HR may have counterintuitively incurred costs and imposed greater administrative burdens that deter employees from pursuing and securing reasonable accommodations.

II. THE LOGIC OF PRIVACY

Part II explains why some legal scholars have called for greater privacy as a prophylaxis for contemporary forms of discrimination.⁹⁰ The argument that privacy advances individual liberties is well developed outside of the disability space and regularly imported into the disability context.⁹¹ Alan Westin, one of the early theorists on privacy law (pre-internet) framed privacy as control.⁹² Other proponents of privacy frame privacy as an interest held by the individual to control information as a way of controlling access to their lives; others emphasize the importance of privacy to the development of meaningful social relationships. Some scholars argue, therefore, that

⁸⁹ See Julia Borggraefe, *Human Resources Governance and Compliance: Introduction and Overview*, in HANDBOOK OF HUMAN RESOURCES MANAGEMENT 1051, 1056-57 (Matthias Zeuch ed., 2016) ("If HR therefore is responsible for creating HR compliance standards, HR also must be empowered to instruct executives and to conduct consequences in case the rules have not been complied with. Rules have to be binding and people—be it employees or executives—must be aware of this.").

⁹⁰ See, e.g., Joni Hersch & Jennifer Bennett Shinall, *Something to Talk About: Information Exchange Under Employment Law*, 165 U. PA. L. REV. 49, 56 & n.27 (2016) (listing scholars advocating for privacy protections in antidiscrimination laws but challenging blanket reliance on privacy); Sharona Hoffman, *The Importance of Immutability in Employment Discrimination Law*, 52 WM. & MARY L. REV. 1483, 1533-36 (2011) (highlighting the absence of protections in federal antidiscrimination law for marital and parental status); Noreen Farrell & Genevieve Guertin, *Old Problem, New Tactic: Making the Case for Legislation to Combat Employment Discrimination Based on Family Caregiver Status*, 59 HASTINGS L.J. 1463, 1465-66 (2007) (calling for federal law that explicitly proscribes discrimination on the basis of family status).

⁹¹ A detailed discussion about privacy debates among legal scholars is beyond the scope of this Article. However, the arguments advanced in this Article contribute to the broader debates by offering an anomaly—disability.

⁹² WESTIN, *supra* note 39, at 22-24; see also Paul M. Schwartz, *Internet Privacy and the State*, 32 CONN. L. REV. 815, 836 (2000) (mapping privacy along a continuum with "liberal" at one end representing privacy as individual control over personal information).

information control better serves the exercise of meaningful decisional agency for individuals.

More recent privacy scholarship, such as the work of Anita Allen, explores the “politics of sensitive data.”⁹³ Allen describes the absence of “racial privacy” and argues that race does not receive the same legal protections afforded health, education, or financial data and questions the reasoning for its exclusion from formal legal protection.⁹⁴ Rather than ban racial identification to help redress a history of racial subordination, indignity, and denial of fundamental rights, Allen states, U.S. law requires classification based on race.⁹⁵ However, strong privacy protections for racial data in a remedial system requiring statistical proof of disparate impact, for example, may undermine broader goals of antidiscrimination law.⁹⁶

Disability antidiscrimination scholars, building on this broader privacy literature, often advance four interrelated arguments in support of data privacy: self-determination, avoidance of disability stigma, algorithmic discrimination, and the imperfections of our current antidiscrimination safety net to remedy implicit and institutional biases.

A. Self-Determination and Decisional Autonomy

While some scholars assert a utilitarian view of privacy, others adopt a deontological position, arguing that privacy is critical for self-determination and self-care, both foundational components of the formation of the contemporary liberal subject.⁹⁷ Accordingly, some health and disability law scholars take a very aggressive position on privacy in the disability context. Professor Jessica Roberts, for example, astutely ties privacy law to antidiscrimination law, arguing that these two areas tend to be siloed given the focus of the former on individual autonomy and the latter on equality of groups.⁹⁸ The appeal of privacy law as part of the disability antidiscrimination

⁹³ ALLEN, *supra* note 36, at 123-24; *see also* Anita L. Allen, *Race, Face, and Rawls*, 72 *FORDHAM L. REV.* 1677, 1683-86 (2004) (“Government should not act so as to call attention to facts on record about a person [such as race] that will result in the person’s being an object of perhaps unwanted, perhaps negative scrutiny.”).

⁹⁴ ALLEN, *supra* note 36, at 124.

⁹⁵ *Id.* at 125.

⁹⁶ For an interesting discussion of racial privacy in the context of tax law, see Jeremy Bearer-Friend, *Should the IRS Know Your Race?: The Challenge of Colorblind Tax Data*, 73 *TAX L. REV.* 1, 37 (2019), which argues that the IRS’s colorblind data collection undermines broader equity goals because it fails to capture the ways tax policies have disparate impacts on racial minorities.

⁹⁷ *See* Julie E. Cohen, *Privacy, Visibility, Transparency, and Exposure*, 75 *U. CHI. L. REV.* 181, 189 (2008).

⁹⁸ *See, e.g.*, Bradley A. Areheart & Jessica L. Roberts, *GINA, Big Data, and the Future of Employee Privacy*, 128 *YALE L.J.* 710, 710 (2019) (arguing that privacy norms and legislation promote antidiscrimination); Roberts, *supra* note 6, at 2099-103 (calling for privacy and health law to come together as a means of promoting antidiscrimination). Professor Roberts’s work has focused on the

agenda, she argues, centers on two main points. First, privacy law is administratively simpler to enforce than a more complex and nuanced system of disclosure.⁹⁹ Second, strict privacy protections are preemptive, meaning that a potential plaintiff does not wait for harm to actualize before bringing a claim.¹⁰⁰ This, of course, works only when the disfavored identity trait can be masked or is not immediately apparent. Even scholars who might have historically questioned privacy are now more skeptical given the explosion of big data mining and algorithmic discrimination that seeks to make decisions based on select variables about a person's life, behavior, and history. These scholars, as a result, tend toward more explicit and comprehensive data protection for individuals as a shield against discrimination, particularly in the workplace.¹⁰¹

Other scholars, serious about the dangers of disclosure of disability, call for heightened tort protections as a way to supplement existing antidiscrimination laws. For example, greater recognition of the tort of invasion of privacy might offer greater employee protection for misuse of genetic information by employers.¹⁰² Broader tort liability may also enhance the dignity of people with disabilities (especially disabled people of color) as they are often the subject of state policing and surveillance.¹⁰³

B. *Avoidance of Disability Stigma*

Second, identification as a disabled person has subjected people with disabilities to inexplicable privacy invasions including involuntary

Genetic Information Nondiscrimination Act (GINA) and has framed GINA as an antidiscrimination statute because of the privacy protections in place. *See, e.g., id.* at 2101.

⁹⁹ *See* Roberts, *supra* note 6, at 2121 (“Because [antidiscrimination laws] simply prohibit decisions based on protected status, they do not seek to prevent the preceding differentiation or value assignment that makes those decisions possible.”).

¹⁰⁰ *See id.* (“Privacy law has the power to cut the process of discrimination short.”).

¹⁰¹ *See* Ifeoma Ajunwa, Kate Crawford & Jason Schultz, *Limitless Worker Surveillance*, 105 CALIF. L. REV. 735, 738-39, 772 (2017) (arguing that current laws are generally insufficient to guard against intrusive worker surveillance, the product of new technologies and the decreased costs of surveillance).

¹⁰² *See* William R. Corbett, *The Need for a Revitalized Common Law of the Workplace*, 69 BROOK. L. REV. 91, 154 (2003) (“Regarding genetic discrimination, tort theory could augment the coverage already provided by the Americans with Disabilities Act and state genetic discrimination laws.”); *see also* Mark P. Gergen, *A Grudging Defense of the Role of the Collateral Torts in Wrongful Termination Litigation*, 74 TEX. L. REV. 1693 (1996) (discussing common law claims brought in cases also alleging violations of various civil rights statutes). In fact, several cases allege violations of the ADA's confidentiality provisions and secondary claims for invasion of privacy under state tort law.

¹⁰³ *See, e.g.,* Rosa Ehrenreich, *Dignity and Discrimination: Toward a Pluralistic Understanding of Workplace Harassment*, 88 GEO. L.J. 1, 23 (1999) (“The intentional torts are not the only tort causes of action that protect dignitary interests. The torts of invasion of privacy and defamation do so as well.”); *see also* Jane Bowling, *Workplaces Fraught with Potential for Invasions of Privacy, Panel Finds*, DAILY REC. (Balt.), June 17, 1996, at 17 (suggesting that employers increasingly face invasion of privacy suits if they reveal medical information about employees with disabilities).

sterilization and medical testing;¹⁰⁴ continuous surveillance by the state, medical providers, and support personnel; and the denial of decisional agency.¹⁰⁵ This recent history offers strong incentives for those without the aesthetic markers to cover or pass as nondisabled and avoid the consequences of disability stigma in social and professional interactions.¹⁰⁶ The legislative history of the ADA, for example, highlights the impossible dilemma facing people with less apparent disabilities: “I wish to remind you that many of us have hidden disabilities. We often risk discrimination by the very act of disclosing our disability. Once disclosure is risked, we have little recourse when denial of accommodation and exclusion occur.”¹⁰⁷

In this sense, privacy law and policies insulate people with less visible disabilities from public scrutiny and prejudice.¹⁰⁸ When given a choice to disclose or not, even if it means forgoing legally mandated reasonable accommodations, a person capable of covering or passing as nondisabled has good reason to seek the protection of self-accommodation and nondisclosure. Erving Goffman’s classic work on stigma details how these social relations play out and how they limit the life choices of those subject to the explicit and implicit negative attitudes of others.¹⁰⁹

C. Algorithmic Discrimination

Third, nondisclosure of disability may avoid certain forms of algorithmic discrimination. Even when a person chooses not to disclose in the workplace, the ability to be selectively “out” in one’s social life is increasingly difficult. Machine-learning (and other artificial intelligence tools (AI)) allow

¹⁰⁴ Harris, *supra* note 2, at 919-20.

¹⁰⁵ See NAT’L COUNCIL ON DISABILITY, TURNING RIGHTS INTO REALITY: HOW GUARDIANSHIP AND ALTERNATIVES IMPACT THE AUTONOMY OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES 72-73 (2019), https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_o.pdf [<https://perma.cc/8TM4-9XJM>] (describing how people with intellectual and developmental disabilities experience “a regression of their decision-making abilities” after a guardian is appointed).

¹⁰⁶ GOFFMAN, *supra* note 15, at 102-04.

¹⁰⁷ *Oversight Hearing on H.R. 4498, Americans with Disabilities Act of 1988 Before the Subcomm. on Select Educ. of the Comm. on Educ. & Lab.*, 100th Cong. 80 (1988) (statement of Marcie Roth, Supervising Advocate, WE CAHR).

¹⁰⁸ See, e.g., J. Alexander Short, Opinion, *Stopping Stigma: The Necessity of Privacy Protections*, PATRIOT-NEWS (Feb. 11, 2020), <https://www.pennlive.com/opinion/2020/02/stopping-stigma-the-necessity-of-privacy-protections-opinion.html> [<https://perma.cc/WR4R-MJMN>] (“Unlike many other diseases, disclosure of [substance use disorder] regularly invokes unique repercussions. Whether it be the loss of parental rights, employment, housing, or insurance, the stakes are incredibly high. As such, protecting the privacy of such disclosures is imperative for this population to access healthcare without the devastating fear of negative repercussions.”).

¹⁰⁹ See GOFFMAN, *supra* note 15, at 104 (“[T]he hard of hearing learn to talk with the degree of loudness that listeners feel is appropriate . . . [T]he blind sometimes learn to look directly at the speaker . . .”).

institutional actors to amass consumer data that can identify individuals as disabled without their knowledge or consent.¹¹⁰

Predictive algorithms focused on “safety” or “dangerousness” present similar challenges. After the school shooting in Parkland, Florida, for instance, Governor Rick Scott signed the “Marjory Stoneman Douglas Public Safety Act,” a “red flag” law, which, among other provisions, directs the Florida Department of Education to work with the Florida Department of Law Enforcement and create a “centralized integrated data repository and data analytics resources.”¹¹¹ This repository collects data on students with mental disabilities and behavioral problems, among others, whom public agencies think are potential school safety risks. The types of information populating the database include “Good Samaritan” reports, state and local sources such as social media, district special education records, the Department of Children and Families, the Department of Law Enforcement, the Department of Juvenile Justice, and records from local law enforcement.¹¹² Government agencies and private contractors argue that there is a significant need to share confidential information quickly and, in emergency situations, they should be exempt from potential violations of federal and state privacy and education confidentiality laws.¹¹³ Civil liberty groups such as the Southern Poverty Law Center and the Florida chapter of the American Civil Liberties Union have raised concerns about erroneous predictions of risk and future violence that will negatively and disproportionately affect students with disabilities and those with disciplinary records who also are disproportionately male students of color.¹¹⁴

¹¹⁰ Mason Marks, *Algorithmic Disability Discrimination*, in *DISABILITY, HEALTH, LAW AND BIOETHICS* 242, 242 (I. Glenn Cohen, Carmel Shachar, Anita Silvers & Michael Ashley Stein eds., 2020) (“In the past, disability-related information flowed between people with disabilities and their doctors, family members, and friends. However, AI-based tools . . . allow corporations . . . to bypass the laws protecting people with disabilities and infer consumers’ disabilities without their knowledge or consent.”).

¹¹¹ Marjory Stoneman Douglas High School Public Safety Act, ch. 2018-3, § 21, 2018 Fla. Laws 6, 40.

¹¹² *Id.* The public discourse on mental and psychosocial disabilities, despite sound data to the contrary, continues to tie mental illness to violence, particularly gun violence. Jonathan M. Metzler & Kenneth T. MacLeish, *Mental Illness, Mass Shootings, and the Politics of American Firearms*, 105 *AM. J. PUB. HEALTH* 240, 247 (2015).

¹¹³ See generally Health Insurance Portability and Accountability Act of 1996, Pub. L. 104-191, 110 Stat. 1936; Family Educational Rights and Privacy Act of 1974, 20 U.S.C. § 1232g.

¹¹⁴ See *What Does the “Marjory Stoneman Douglas High School Public Safety Act” Mean for Students?*, ACLU FLA., <https://www.aclufll.org/en/what-does-marjory-stoneman-douglas-high-school-public-safety-act-mean-students> [<https://perma.cc/MU2Y-GCAJ>] (highlighting increased youth arrests and disparate treatment of minorities as risks); Greg Allen, *Florida Could Serve as Example for Lawmakers Considering Red Flag Laws*, NPR (Aug. 21, 2019, 5:00 AM), <https://www.npr.org/2019/08/21/752815318/florida-could-serve-as-example-for-lawmakers-considering-red-flag-laws> [<https://perma.cc/7ZT8-UT7R>] (discussing Florida’s red flag laws as examples for other states). Consider the effects of other identities such as class or immigration status on listing in the database.

Categorical nondisclosure, therefore, prevents inadvertent secondary disclosure and, as such, may permit the individual ongoing control of the information to make select disclosures as desired. In an age of data mining, sharing, and AI, however, the ability to control information about one's identity gets harder each day.¹¹⁵ For this reason, scholars equate privacy with dignity, autonomy, and stigma avoidance, even going so far as to frame privacy as a human right for people with disabilities.¹¹⁶

D. *The Imperfections of Existing Antidiscrimination Laws*

The prevalence of disability bias in society, according to some disability law scholars, demands a strong privacy preference to prevent discrimination.¹¹⁷ Consider the Equal Employment Opportunity Commission (EEOC) statistics tracking complaints filed correlating with type of disability. The EEOC data reflect the prevalence of less visible disabilities among EEOC complaints, suggesting that, "at least in getting hired, the apparent absence of disability makes a difference."¹¹⁸

Privacy laws, then, on balance, may be a more direct remedy for misuse of disability information than existing antidiscrimination laws that impose onerous burdens of proof that do not mirror contemporary forms of discrimination. For example, aggrieved plaintiffs need only show that the disability related information was either wrongfully obtained (without consent) or improperly disseminated. Privacy laws, in this respect, may better redress discrimination that is not captured by our equality laws. The prime example here is the difficulty of proving intent and causation in antidiscrimination laws, creating particular challenges for responding to unconscious biases. Privacy laws may avoid the challenge of investigating intent by engaging in a relatively

¹¹⁵ See Carsten Maple, *Security and Privacy in the Internet of Things*, 2 J. CYBER POL'Y 155, 155 (2017) ("The growth in the number of devices and the speed of that growth presents challenges to our security and freedoms . . .").

¹¹⁶ See, e.g., Jonathan Lazar, Brian Wentz & Marco Winckler, *Information Privacy and Security as a Human Right for People with Disabilities*, in DISABILITY, HUMAN RIGHTS, AND INFORMATION TECHNOLOGY 199, 202 (Jonathan Lazar & Michael Ashley Stein eds., 2017) (stating that the "human right to information privacy and security is critical for persons with disabilities" and thus framing privacy as a human right for people with disabilities).

¹¹⁷ See Areheart & Roberts, *supra* note 98, at 710 (contending that privacy protection promotes antidiscrimination); Roberts, *supra* note 6, at 2099-2103.

¹¹⁸ Mark C. Weber, *Privacy Protection and Disability Discrimination in a Social Context* 2 (2019) (unpublished manuscript) (on file with author); see also *ADA Charge Data by Impairment/Bases – Resolutions (Charges Filed with EEOC) FY 1997 – FY 2019*, U.S. EQUAL EMP. COMM'N, <https://www.eeoc.gov/eeoc/statistics/enforcement/ada-resolutions.cfm> [<https://perma.cc/4NCE-PA9R>] (presenting EEOC resolution statistics which show that those with less apparent disabilities consistently file the most complaints).

“straightforward factual inquiry” into whether a defendant attempted to obtain certain kinds of protected information.¹¹⁹

The ADA provides protection against preemployment conditional-offer medical exams and inquiries and limits post-employment examinations and inquiries.¹²⁰ These protections provided innovative solutions to disability discrimination at the hiring stage and, undoubtedly, have helped prevent discrimination in employment in many cases. However, some disability scholars remain skeptical that these provisions offer meaningful protection against disability discrimination in an age of big data.¹²¹ The use of predictive algorithms in employment settings weighs heavily against disclosure, particularly at the hiring stage, when the ADA is perhaps least effective at combating disability discrimination.

III. PRIVACY NORMS AS ANTIDISCRIMINATION LAW

The understanding that disability identity was and, normatively, should be a private matter continues to shape disability rights today. The law nudges privacy in two ways. Sometimes the law explicitly states that information about a person’s disability ought to be kept private. Other times, the law offers remedies that focus on the “harmful” consequences of disclosure. While modern iterations of privacy are not always direct shoves into the disability closet as they were during state-sponsored eugenics and institutionalization, contemporary disability law tips the scales in favor of covering and passing, for those who can do so, rather than creating the conditions for publicly claiming disability identity. This section offers some examples of privacy nudges operating in disability, procedural, education, and tort law.¹²²

A. Disability Antidiscrimination Law

I will discuss three main examples of privacy nudges in disability antidiscrimination law: (1) the ADA definition of disability, (2) the tension between disclosure and confidentiality provisions under the ADA, and (3) the

¹¹⁹ Roberts, *supra* note 6, at 2154.

¹²⁰ 42 U.S.C. § 12112(d)(2), (4); 29 C.F.R. § 1630.13 (2020).

¹²¹ Areheart & Roberts, *supra* note 98, at 764 (citing Mark A. Rothstein, *GINA at Ten and the Future of Genetic Nondiscrimination Law*, HASTINGS CTR. REP., May–June 2018, at 3, 6) (“Of course, in the age of big data, when employers can access information through a variety of sources other than medical examinations and inquiries, the ADA’s privacy protections look obsolete.”); see also Sharon Hoffman, *Big Data and the Americans with Disabilities Act*, 68 HASTINGS L.J. 777, 786–88 (2017) (describing the ADA’s shortcomings with big data).

¹²² Not all disability rights laws advance only privacy norms. Rather, this Part shows how some of the key celebrated aspects of these laws use privacy as part of their remedial mechanisms.

treatment of disability identity as proprietary under the Rehabilitation Act of 1973 (Rehab Act).

1. The ADA Definition of Disability

First, courts have struggled with the intended scope of coverage of the ADA which is, in part, a reflection of misperceptions about the incidence of disability in society and the scope of Congress's intended protection. The ADA defines a person with a disability as a person having a physical or mental impairment that substantially limits one or more major life activities; a person with a record of such an impairment; or someone regarded as having such an impairment.¹²³ The first eighteen years of the ADA cultivated judicial backlash as courts wrestled with the threshold category of disability and who could claim standing to sue under the ADA.¹²⁴ In 1999, the Supreme Court granted certiorari in three cases—the *Sutton* trilogy¹²⁵—seeking clarity on the legal definition of disabled under the ADA, specifically, the definition of “substantially limits” used to define “disability” under the statute.¹²⁶

This question required the Court to determine whether Congress intended to include in the definition of disability those individuals who could employ “mitigating measures”—defined as medication, assistive technology or other ameliorative devices.¹²⁷ If an individual self-accommodated and it

¹²³ 42 U.S.C. § 12102(1).

¹²⁴ See, e.g., Matthew Diller, *Judicial Backlash, the ADA, and the Civil Rights Model of Disability*, in *BACKLASH AGAINST THE ADA: REINTERPRETING DISABILITY RIGHTS* 62, 65-66 (Linda Hamilton Krieger ed., 2003) (“Judges view the ADA as a form of public benefit program for people with disabilities, rather than as a mandate for equality.”); Linda Hamilton Krieger, *Foreword—Backlash Against the ADA: Interdisciplinary Perspectives and Implications for Social Justice Strategies*, 21 *BERKELEY J. EMP. & LAB. L.* 1, 7 (2000) (describing a “powerful narrowing trend in the federal judiciary, especially on the foundational question of who was a ‘person with a disability’ entitled to protection under the Act”).

¹²⁵ *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 487 (1999) (holding that the determination of disability under the ADA should be made considering an individual's ability to mitigate the current impairment through corrective measures, which accords with the statutory language and history of the ADA); *Murphy v. United Parcel Serv., Inc.*, 527 U.S. 516, 521 (1999) (citing *Sutton* to hold that the determination of disability under the ADA is made considering available mitigating circumstances); *Albertson's, Inc. v. Kirkingburg*, 527 U.S. 555, 563-66 (1999) (holding that not all physical difficulties render an individual per se “disabled” under the ADA, but that disability is proven on an individual basis showing that an alleged disability substantially impacts a major life activity).

¹²⁶ The ADA as promulgated by Congress in 1990 defined disability as an “impairment that substantially limits one or more major life activities.” 42 U.S.C. § 12102(1)(A).

¹²⁷ Examples of such measures include:

- (I) medication, medical supplies, equipment, or appliances, low-vision devices (which do not include ordinary eyeglasses or contact lenses), prosthetics including limbs and devices, hearing aids and cochlear implants or other implantable hearing devices, mobility devices, or oxygen therapy equipment and supplies;
- (II) use of assistive

worked, but still experienced discrimination in the workplace on the basis of an actual, prior, or perceived disability, the Supreme Court held, Congress intended to exclude him from the legal definition of disability. The expressive value of these holdings signaled a pervasive public distrust with disability and a desire to ensure limited remedial access to those with “legitimate” disabilities, defined by the Supreme Court as unassimilable impairments, those a disabled person could not self-accommodate to achieve “normalcy.”¹²⁸

Congress promulgated the ADA Amendments Act (ADAAA) in direct response to the *Sutton* trilogy and instructed federal courts (especially, the highest court) to adopt a broad interpretation of the definition of disability in accordance with its original statutory intent.¹²⁹ The ADAAA also reiterates Congress’s intent to remedy what it deemed to be the core of disability discrimination: negative stereotypes of deficit and incapacity (and not always overt animus) that permeated all areas of interaction and association with disability. This insight is clearest in the “regarded as” prong of the definition of disability which extends protection under the ADA to people without actual or records of impairments who nevertheless face discrimination based on a perception that they have a disability.¹³⁰

2. The Tension Between Disclosure and Confidentiality

Second, the ADA sets up an awkward tension between disclosure and privacy. The baseline rule is that employers “shall not make inquiries of an employee as to whether such employee is an individual with a disability or as to the nature or severity of the disability, unless such examination or inquiry is shown to be job-related and consistent with business necessity.”¹³¹ In addition, Congress designed the process for requesting reasonable accommodations under Title I of the ADA to be interactive. “In *many* instances, both the disability and the type of accommodation required will be obvious, and thus there may be little or no need to engage in any discussion.”¹³²

technology; (III) reasonable accommodations or auxiliary aids or services; or (IV) learned behavioral or adaptive neurological modifications.

42 U.S.C. § 12102(4)(E)(i).

¹²⁸ See e.g., *Murphy*, 527 U.S. at 519 (describing the petitioner as someone who “can function normally and can engage in activities that other persons normally do” (quoting *Murphy v. United Parcel Serv., Inc.*, 946 F. Supp. 872, 875 (D. Kan. 1996))).

¹²⁹ See 42 U.S.C. § 12101 note (“The purposes of this Act . . . are . . . to reject the requirement enunciated by the Supreme Court in *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999) and its companion cases . . .”).

¹³⁰ *Id.* § 12101(a)(2), (8).

¹³¹ *Id.* § 12112(d)(4)(A).

¹³² U.S. EQUAL EMP. OPPORTUNITY COMM’N, EEOC-CVG-2003-1 ENFORCEMENT GUIDANCE: REASONABLE ACCOMMODATION AND UNDUE HARDSHIP UNDER THE AMERICANS WITH

The ADA streamlines the process for individuals who manifest the aesthetics of disability and instructs employers to presume statutory eligibility. Those without visible markers of disability, however, must undergo a process of proving eligibility by litigating the existence of a covered disability.

To obtain a reasonable accommodation in the workplace under Title I for those with less apparent disabilities, a person must first request an accommodation by disclosing their disability.¹³³ When the disability is “not obvious” an employer may ask the individual for “reasonable documentation” about functional limitations and the ability to perform the “essential functions” of the position.¹³⁴ Conversely, an employer may violate Title I if she requests documentation of a disability when “both the disability and need for reasonable accommodation are obvious,”¹³⁵ further demarcating the line between legitimate disabilities (those who bear the markers) and those who have to perform socially constructed perceptions of disability to access rights. The EEOC’s guidance explains that “[t]he employer is entitled to *know* that the individual has a covered disability for which s/he needs a reasonable accommodation.”¹³⁶

Legal doctrine signals that disclosure is potentially costly. For example, if an employee voluntarily discloses disability outside of the reasonable accommodations process and the employer learns about it, the employee may lose certain legal protections, such as the presumed confidentiality of that information, which may damage the employee’s case for disability discrimination under the ADA. In *Rohan v. Networks Presentation LLC*, the plaintiff claimed she was forced to disclose to her co-workers her mental impairment, history of trauma, and treatment in violation of the ADA’s confidentiality provisions.¹³⁷ The court held that because the disclosure was voluntary and not the result of a medical exam or inquiry initiated the employer, the ADA did not mandate confidentiality.¹³⁸ *Rohan* discourages disclosure because the person making such disclosure lacks the ability to control subsequent (and perhaps unintended) use of the information.

Similarly, the Seventh Circuit held, in *EEOC v. Thrivent Financial for Lutherans*, that disability related information voluntarily disclosed by an employee to an employer outside of a former medical inquiry did not preclude the former employer from providing this information to other potential

DISABILITIES ACT (2002) (emphasis added), <https://www.eeoc.gov/policy/docs/accommodation.html> [<https://perma.cc/XA88-B7HH>] [hereinafter ENFORCEMENT GUIDANCE].

¹³³ *Id.*

¹³⁴ *Id.* (defining “essential function” as a “fundamental duty” of a position).

¹³⁵ *Id.*

¹³⁶ *Id.* (emphasis added).

¹³⁷ 175 F. Supp. 2d 806, 813 (D. Md. 2001).

¹³⁸ *Id.* at 808, 813-14.

employers as part of a reference check.¹³⁹ The EEOC argued that the defendant, Thrivent, revealed information about plaintiff Messier's migraine condition to prospective employers in violation of the ADA's confidentiality requirement.¹⁴⁰ "The district court found that Thrivent learned of Messier's migraine condition outside the context of a medical examination or inquiry."¹⁴¹ Therefore, the confidentiality provisions of 42 U.S.C. § 12112(d)(3) did not apply, and Thrivent had no duty to treat knowledge of Messier's migraine condition as a confidential medical record in accordance with the ADA.¹⁴²

The ADA prohibits employers from making preemployment inquiries about disability, recognizing the difficulty in building a failure to hire claim as discussed above. People with more apparent disabilities, such as wheelchair users, may choose to disclose disability preemployment to ensure that the interview itself, if in person, is accessible. Similarly, a deaf person or someone with low hearing may disclose disability to ensure the availability of interpretation services. The EEOC agency guidance permits employers in the preemployment process, if a disability is obvious, known, or voluntarily disclosed, to ask the applicant if she requires a reasonable accommodation.¹⁴³ But consider a blind applicant's initial interview. Although disability is likely the elephant in the room and, in some cases, highly visible to the employer, the employer's risk aversion may prevail and dissuade the employer from asking about the need for reasonable accommodations. This leaves the employer to imagine the accommodations needed (and costs attached) and the blind person to wonder what effect a cane or other aesthetic markers will have on her chances of getting the job.

For some less visible disabilities, a person may not disclose at all because of concerns about bias at the hiring stage and the difficulty of proving that disability discrimination was the "but for" cause of the employer's failure to

¹³⁹ 700 F.3d 1044, 1046 (7th Cir. 2012).

¹⁴⁰ *Id.* at 1046; *see also* 42 U.S.C. § 12112(d) (requiring employers to treat information about an employee obtained from "medical examinations and inquiries" "as a confidential medical record").

¹⁴¹ *Thrivent*, 700 F.3d at 1046.

¹⁴² *Id.* Similarly, in *Hannah P. v. Coats*, the Fourth Circuit held that because the employee voluntarily disclosed her depression diagnosis to her supervisors, she could not sustain a claim against her employer for breach of confidentiality of medical information under the Rehabilitation Act, part of her antidiscrimination claims. 916 F.3d 327, 340 (4th Cir. 2019) ("The Rehabilitation Act does not protect information shared voluntarily."). The court reasoned that, in fact, the employee voluntarily shared information about her depression diagnosis with at least four of her supervisors and admitted to such in her interrogatory responses. *Id.*; *see also* *Reynolds v. Am. Nat'l Red Cross*, 701 F.3d 143, 155 (4th Cir. 2012) (finding the district court properly granted summary judgment on a confidentiality claim brought under the Rehabilitation Act because the record "clearly show[ed]" that the appellant "disclosed his medical condition voluntarily").

¹⁴³ ENFORCEMENT GUIDANCE, *supra* note 132. Anything that could reasonably justify an employer's reasonable belief that the person has a disability suffices. *See id.*

hire.¹⁴⁴ In fact, “[i]f an individual’s disability or need for reasonable accommodation is not obvious, and s/he refuses to provide the reasonable documentation requested by the employer, then s/he is not entitled to reasonable accommodation.”¹⁴⁵ Congress heard testimony from affected individuals leading up to the ADA:

[Tricia,] a bright young woman was interviewed for a position with a financial institution and was told that she could give notice to her present employer. The woman who interviewed her was to call Tricia with a starting date. Tricia decided to disclose that she had [multiple sclerosis]. Although Tricia was initially told that it made no difference, the woman who interviewed her failed to call with a starting date. When Tricia called to find out what had happened, she was told that someone else would be hired for the position. The lady who interviewed Tricia admitted that she had been denied the job because she had multiple sclerosis.¹⁴⁶

Now add the confidentiality provisions of the ADA that limit disclosure. Except under narrowly prescribed circumstances, employers must collect and maintain any information about disability—including medical records, results of medical examinations, or medical history of the employee, and requests for reasonable accommodations—separate from the general employee files and treat this information “as a confidential medical record.”¹⁴⁷ There is a disincentive for employers to request information about disability because of its association with medical data and their fear of incurring liability under the ADA, Genetic Information Nondiscrimination Act (GINA), and other privacy protections.¹⁴⁸

¹⁴⁴ See 42 U.S.C. § 12132 (“[N]o qualified individual with a disability shall, by reason of such disability, be excluded . . .”).

¹⁴⁵ ENFORCEMENT GUIDANCE, *supra* note 132.

¹⁴⁶ *Hearing on H.R. 2273, Americans with Disabilities Act of 1989 Before the Subcomm. on Select Educ. of the Comm. on Educ. & Lab.*, 101st Cong. 1802-03 (1989) (statement by JoAnn L. Shanks, Chapter Services and Equipment Coordinator, Indiana State Chapter, National Multiple Sclerosis Society).

¹⁴⁷ 29 C.F.R. § 1630.14(b)(1) (2020). Notable exceptions include: information shared with supervisors and managers regarding restrictions and necessary accommodations on a need-to-know basis; first aid and safety personnel in an emergency; and government officials investigating compliance with the employer’s responsibilities under the ADA and regulations. *Id.*

¹⁴⁸ For example, one district court held that a jury could hear such evidence that an employer breached its confidentiality requirements under the ADA by asking an employee to provide a doctor’s note after missing work. *Stark v. Hartt Transp. Sys., Inc.*, 37 F. Supp. 3d 445, 450, 452-55 (D. Me. 2014). *But see Lee v. City of Columbus*, 636 F.3d 245, 255 (6th Cir. 2011) (holding that such a policy did not violate the Rehabilitation Act or the Constitution because “there is no evidence that this inquiry is intended to reveal or necessitates revealing a disability”).

3. Treatment of Disability Identity as Proprietary Under the Rehab Act

Third, the Department of Labor (DOL), the organization responsible for regulating federal contractors' compliance with Section 503¹⁴⁹ of the Rehabilitation Act, treats disability identity as proprietary information belonging to the federal contractor. Section 503 and its implementing regulations require that federal contractors take "affirmative action to recruit, hire, promote, and retain" individuals with disabilities, with a goal of employing seven percent individuals with disabilities.¹⁵⁰ However, the DOL asserts that the number of people with disabilities hired by each federal contractor (in aggregate form without personally identifiable information) is not subject to public inspection.¹⁵¹ The DOL requires federal contractors to maintain detailed employment records that are subject to periodic compliance audits.¹⁵² Specifically, federal contractors are required to record:

(1) The number of applicants who *self-identified* as individuals with disabilities . . . or who are *otherwise known* to be individuals with disabilities; (2) [t]he total number of job openings and total number of jobs filled; (3) [t]he total number of applicants for all jobs; (4) [t]he number of *applicants with disabilities* hired; and (5) [t]he total number of applicants hired.¹⁵³

If the federal government and its contractors assert that publication of the very numbers required to assess compliance with Section 503 is exempted from public scrutiny, then how can the public know whether contractors comply with the applicable statutory and regulatory authority?¹⁵⁴ This is

¹⁴⁹ See generally Section 503, OFF. OF FED. CONT. COMPLIANCE PROGRAMS, U.S. DEP'T OF LAB., <https://www.dol.gov/ofccp/regs/compliance/section503.htm> [<https://perma.cc/G8SL-URNS>].

¹⁵⁰ 41 C.F.R. § 60-741.45(a) (2019) ("[Office of Federal Contract Compliance Programs] has established a utilization goal of 7 percent for employment of qualified individuals with disabilities for each job group in the contractor's workforce, or for the contractor's entire workforce . . .").

¹⁵¹ Letter from Jane Suhr, Reg'l Dir., Off. of Fed. Cont. Compliance Programs, Pac. Reg'l Off., U.S. Dep't of Lab., to Jasmine E. Harris, Professor, Univ. of Cal. Davis Sch. of L. 1 (June 19, 2019) (on file with author) (writing in response to and describing information requested in a May 29, 2019 Harris Freedom of Information Act (FOIA) request as "business confidential information" subject to the trade secret exception for FOIA requests). These claims to privacy also come after the Obama Administration directed the DOL to establish a default of disclosure and publication. See Memorandum on the Freedom of Information Act, 74 Fed. Reg. 4683, 4683 (Jan. 26, 2009) ("All agencies should adopt a presumption in favor of disclosure, in order to renew their commitment to the principles embodied in FOIA, and to usher in a new era of open Government."); see also Jamillah Bowman Williams, *Diversity as a Trade Secret*, 107 GEO. L.J. 1684, 1688 (2019) (noting President Obama's guidance to the DOL).

¹⁵² 29 U.S.C. § 793; 41 C.F.R. § 60-741.44(k) (2019).

¹⁵³ 41 C.F.R. § 60-741.44(k) (2019) (emphasis added).

¹⁵⁴ Imagine if the Department of Education refused to publish aggregate education data on public school compliance with federal education and special education laws on the same grounds. Note that Vocational Rehab (VR) programs, or supported employment, explicitly require disclosure because employers work with the VR specialist on hiring and setting up accommodations. Susan G.

especially problematic because of Section 503's remedial mission to address the unemployment and underemployment of people with disabilities in the formal economy.¹⁵⁵

B. Procedural Law

Contrary to our tradition of public adjudication, many disability-related proceedings unfold in informal spaces outside of public view because of a belief that the subject matter (disability) is itself embarrassing or stigmatizing, and that there is no public interest in disability related proceedings.¹⁵⁶ First, consider closed probate proceedings to appoint a conservator and restrict an individual's decisional autonomy. In some jurisdictions, not only are these proceedings closed to the public, but there is no requirement that the subject of the proceedings be physically present.¹⁵⁷ The public interest in transparency in these cases is high given repeated allegations of conservator abuse and overly broad grants of plenary conservatorship. Plenary conservatorships remain the default in many jurisdictions, effectively removing all decisional authority from the conservatee. This includes personal choices about where to live, how to allocate finances, or with whom to associate.¹⁵⁸ Even certain jurisdictions that have open probate proceedings and publish probate decisions online generally

Goldberg, Mary B. Killeen & Bonnie O'Day, *The Disclosure Conundrum: How People with Psychiatric Disabilities Navigate Employment*, 11 PSYCH. PUB. POL'Y & L. 463, 467 (2005).

¹⁵⁵ According to the Department of Labor, the 2019 unemployment rate of people with disabilities was over seven percent. *Office of Disability Employment Policy*, U.S. DEP'T OF LAB. (Jan. 2021), <https://www.dol.gov/odep> [<https://perma.cc/NK49-JLXR>]; see also Martha Ross and Nicole Bateman, *Only Four out of Ten Working-Age Adults with Disabilities Are Employed*, BROOKINGS (July 25, 2018), <https://www.brookings.edu/blog/the-avenue/2018/07/25/only-four-out-of-ten-working-age-adults-with-disabilities-are-employed> [<https://perma.cc/HGK6-YH8N>] (“Only 40 percent of adults with disabilities in their prime working years (age 25-54) have a job, compared to 79 percent of all prime-age adults.”)

¹⁵⁶ See, e.g., *J.W. v. District of Columbia*, 318 F.R.D. 196, 200-01 (D.D.C. 2016) (concluding in *Individuals with Disabilities Education Act* appeal that information about disability in the case is “a matter of a sensitive and highly personal nature” warranting deviation from strong norms of publicity in context of adjudication (quoting *Nat'l Ass'n of Waterfront Emps. v. Chao*, 587 F. Supp. 2d 90, 99 (D.D.C. 2008))); see also Harris, *supra* note 6, at 526. While it is true that some adjudicative spaces may be open to the public, the norm is privacy with the decision held, in theory, by the person with a disability. See, e.g., CAL. EDUC. CODE § 56501(c)(2) (Deering 2021) (stating that parents have the right to decide to open special education hearings with a default of closed proceedings).

¹⁵⁷ See, e.g., *In re Mental Health of L. K.*, 184 P.3d 353, 360-61 (Mont. 2008) (detailing a case in which a committee appeared from a hospital and had her microphone periodically muted during her commitment hearing).

¹⁵⁸ *Supported Decision Making & The Problems of Guardianship*, ACLU, <https://www.aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making> [<https://perma.cc/B3VT-PXME>].

remove litigation documents that deal with conservatorship for people with disabilities on privacy grounds.¹⁵⁹

Second, civil commitment hearings in many jurisdictions continue to be informal and closed to the public based on privacy concerns despite being “quasi-criminal” in nature. Among other questions, the judge must decide whether the person is a threat to self or others to warrant involuntary commitment (or continued commitment) at a psychiatric hospital or other institution. The judge reviews mental health information and hears testimony from medical professionals, law enforcement officers (where applicable), family, and community members. The liberty interests at stake here weigh in favor of greater sunlight and procedural protections, not less. However, because these proceedings are also considered therapeutic and associated with medical treatment, courts tend to tip the scale in favor of greater privacy.

Consider, for example, a recent opinion by the Massachusetts Supreme Judicial Court holding that civil commitment hearings held in rooms at psychiatric hospitals did not violate due process even when the subject of those proceedings requested that the hearing be moved to open court to allow greater public participation.¹⁶⁰ The lower court judge, in response to the respondent’s request that the proceedings be moved from a conference room in the hospital to municipal court, reminded the parties that “[t]hese proceedings are not open to the public. They are held here in a hearing[] room in the hospital where the public generally cannot walk into. They are conducted generally with the patient, attorneys, family members and needed security and medical personnel present.”¹⁶¹

The Massachusetts Supreme Judicial Court, however, despite affirming the lower court’s finding that proceedings in the psychiatric facility did not violate due process, had a different view about the privacy of the hearings. Specifically, the court found that “[a]ll civil commitment hearings, wherever conducted, must be recorded and must operate as open, public proceedings. These protections are critical to ensuring that civil commitment hearings safeguard individuals’ rights to due process and equal access to the courts.”¹⁶² The court noted that the record did not contain any evidence indicating that “members of the [general] public were prevented, or would have been prevented, from attending the civil commitment hearing” in the psychiatric

¹⁵⁹ *Records*, SUPERIOR CT. OF CAL., CNTY. OF ALAMEDA, <http://www.alameda.courts.ca.gov/Pages.aspx/Court-Records-1-#Probate> [<https://perma.cc/JY3Y-8NDD>] (noting that probate case records are available online “except for conservatorships, guardianships and confidential documents”).

¹⁶⁰ *In re M.C.*, 115 N.E.3d 546, 549 (Mass. 2019).

¹⁶¹ *Id.* at 557 n.8.

¹⁶² *Id.* at 549.

hospital.¹⁶³ Here, health privacy laws such as HIPAA complicate the court's desire to shift a well-established norm that proceedings held in hospitals are fundamentally private.¹⁶⁴ It is hard to imagine how the hospital would publicize the day's hearings and facilitate the flow of public traffic through an otherwise private, highly secured facility subject to medical privacy laws. Furthermore, the actual record from these civil commitment proceedings is not publicly available through legal databases or through public requests to the court even in redacted form.

Third, procedural rules themselves operate at times to reinforce privacy norms. Federal, state, and court-specific rules perpetuate the view that disability information should be private, for example, by sealing documents in disability cases, masking the identity of disabled litigants with initials, and enforcing nondisclosure agreements in disability cases. These rules and practices, particularly sealing litigation documents and entering into nondisclosure agreements—not only protect bad actors (think Harvey Weinstein in the context of sexual assault) but also mask the structural problems and potential institutional remedies available. Professional responsibility rules require lawyers to represent clients' interests and the client holds the waiver of confidentiality.¹⁶⁵ When defendants use nondisclosure agreements as central points of negotiation that can make or break a settlement, this places many civil rights lawyers in a tough position between the needs of the individual client and the desire for promoting broader social reforms and deterring repeat bad actors.¹⁶⁶

C. Education Law

Voluntary disclosure of disability is often thwarted by claims that privacy and education laws prohibit it even when the laws do not address this issue. As a policy matter, public schools (primary and secondary) are highly risk averse but not necessarily out of fear of violating applicable privacy laws regulating information on disability. More often, schools use privacy laws as a sword to enforce social norms of disability as deficient and stigmatizing, or,

¹⁶³ *Id.* at 557.

¹⁶⁴ See, e.g., Harris, *supra* note 6, at 526.

¹⁶⁵ See, e.g., MODEL RULES OF PRO. CONDUCT r. 1.6 (AM. BAR ASS'N 1983).

¹⁶⁶ Representatives from several disability rights organizations have conveyed to me that their impact litigation focuses on client education during pre-retention process to explain the value of publicity as it aligns with the broader mission of the organization. Cf. *Written Testimony of Debra S. Katz, Partner and Hannah Alejandro, Senior Counsel Katz, Marshall & Banks LLP*, EEOC, <https://www.eeoc.gov/written-testimony-debra-s-katz-partner-and-hannah-alejandro-senior-counsel-katz-marshall-banks-llp> [<https://perma.cc/UYD9-6HMY>] (discussing how nondisclosure agreements in the context of sexual harassment suits can be “harmful or beneficial to the degree that it respects the rights and autonomy of victims”).

paternalistically, in the best interests of young people to protect them against long-term risks associated with these social norms. Consider the following example. Eva and Madeline, two high school student editors, wanted to devote an issue of their school newspaper to the experiences of students with depression, including their own.¹⁶⁷ The school administration, however, prevented publication, citing student privacy rights. Eva and Madeline wanted to use their own and other students' actual names, with the consent of the students and their parents, as part of an effort to normalize mental disability among young people. The school administrators argued that disclosure would only lead to potential bullying, in the short term, and regret later in life¹⁶⁸—for example, in college admissions and employment applications—because the students would lose control over this “damaging” information if published. Ultimately, Eva and Madeline published an opinion piece in the *New York Times* and received national attention for their efforts to destigmatize mental disability.¹⁶⁹ Even after a public outpouring of support, however, the high school administration maintained its position against disclosure.

What explains the school's response to the possibility of publicity? School administrators regulated the disclosure of disability identity by framing their objections, in the first instance, as a violation of privacy, designed to protect confidential medical information.¹⁷⁰ However, this framing conflates disability identity with private medical information and masks paternalistic overreaching. Interestingly, the school's secondary objections used privacy as a favored prescription for disability discrimination, a way to protect the students who identified as people with mental and psychiatric disabilities from bullying, embarrassment, and bias, much like the arguments advanced by some disability rights scholars. The story illustrates the ways in which privacy regulates identity and, at times, can be misdirected to force people to be in the closet about their disabilities. The school's response denied the students an opportunity for individual and collective “coming out” and the personal (and collective) benefits that publicity brings.

Under the Individuals with Disabilities Education Act (IDEA), schools have an affirmative duty to locate and evaluate students with suspected

¹⁶⁷ Madeline Halpert & Eva Rosenfeld, Opinion, *Depressed, but Not Ashamed*, N.Y. TIMES (May 21, 2014), <https://www.nytimes.com/2014/05/22/opinion/depressed-but-not-ashamed.html> [<https://perma.cc/G9AD-6TLH>].

¹⁶⁸ *Id.*

¹⁶⁹ *Id.*; see also, e.g., Susan Antilla, *Let Teens Talk About Mental Illness*, CNN, <https://www.cnn.com/2014/05/27/opinion/antilla-mental-illness/index.html> [<https://perma.cc/7CNB-KH7S>] (May 27, 2014, 9:49 AM).

¹⁷⁰ Halpert & Rosenfeld, *supra* note 167; see also, e.g., Harris, *supra* note 6, at 526 (discussing the application of existing privacy laws).

disabilities who are eligible for special education services.¹⁷¹ Failure to identify can occur when the school knew or should have known about a potential disability. Like the employment context, if the student manifests the aesthetics of disability, the school is more likely to provide legally mandated services.

This duty must be carried out without broader disclosure and in accordance with the educational rights holders' (typically the parents') entitlement to nondisclosure of disability-related information. Thus, only school administrators and teachers know which students who attend the school have disabilities and this information is available only if the students receive special education services or have a 504 plan.¹⁷² As the IDEA limits the provision of special education services to students with a disability that negatively affects their ability to access a "free appropriate public education" (FAPE),¹⁷³ this is a much smaller percentage of the total number of students with disabilities in public schools.

The IDEA incorporates and, at times, surpasses the protections offered by FERPA and HIPAA. All three privacy laws shroud disability in cloak of privacy by regulating disability identity as medical diagnoses.¹⁷⁴ The IDEA also creates a "right to confidentiality of personally identifiable information" as a minimal procedural safeguard.¹⁷⁵ Informed consent principles determine whether the confidentiality requirements have been violated.¹⁷⁶ However, the message from federal and state education law is clear: disclosure should be on a "need to know basis" and solely for purposes of requesting accommodations because disclosure opens the individual to disability discrimination.¹⁷⁷

¹⁷¹ 20 U.S.C. § 1412(a)(3); 34 C.F.R. § 300.111 (2020).

¹⁷² Students with disabilities are not required to disclose their disabilities to anyone unless they request special education services under the Individuals with Disabilities Education Act (IDEA) or reasonable accommodations under Section 504 of the Rehabilitation Act of 1973. As part of the assessment process, schools obtain informed consent from the educational rights holder for special education services and from the individual with a disability seeking accommodations. Disability related information contained in a student's official education "record" is also subject to the protections of the Family Educational Rights Protection Act (FERPA). *See, e.g.*, 20 U.S.C. § 1417(c); *Catrone v. Miles*, 160 P.3d 1204, 1212 (Ariz. Ct. App. 2007) ("[FERPA and IDEA's] express statutory mandates recognize privacy interests in special education records.").

¹⁷³ 34 C.F.R. § 300.101 (2020).

¹⁷⁴ *See* 20 U.S.C. § 1417(c) ("The Secretary [of Education] shall take appropriate action . . . to ensure the protection of the confidentiality of any personally identifiable data, information, and records collected or maintained by the Secretary and by State educational agencies and local educational agencies . . .").

¹⁷⁵ *Id.* § 1439(a)(2).

¹⁷⁶ *Id.*; 34 C.F.R. § 300.9 (2020) (defining "consent").

¹⁷⁷ The Office of Disability Employment Policy at the Department of Labor explains:

To whom do you disclose your disability? Generally, you should only disclose your disability to those individuals who have a need to know because of the accommodation process. You may consider disclosing to the program's disability support service's staff,

Taken to the extreme, these principles can nudge schools to be risk averse with respect to *any* discussion about disability. For example, one parent wanted to visit her child's second grade classroom during disability awareness month¹⁷⁸ and discuss, alongside her son, his experience with autism. She hoped to give the class opportunities to ask questions and move past staring or ignoring her son's disability altogether. The son wanted to do this. The teacher said that the parent and son could not discuss his autism in class because it would reveal personal medical information and would risk bullying and other long-term discrimination. The school administration agreed with the classroom teacher, and the mother, instead, sent a non-specific book about autism to the school for the teacher to read to the class, losing an opportunity for potential norm shifts and engagement on disability.

Once a young person advances to higher education, the IDEA no longer applies (the ADA and Rehab Act apply) and any request for accommodations looks more like the interactive process discussed above in employment settings under Title I of the ADA.¹⁷⁹ Given the rising numbers of students with disabilities entering higher education, attention to accommodations is critical.¹⁸⁰ Interestingly, the number of students with university-approved

academic advisor, directly on your application, or to an admissions officer. Some programs discourage students with disabilities from disclosing directly to faculty and staff because of student confidentiality. It is a good idea to begin by disclosing to the disability support services office to learn what the specific procedures are for your program.

OFF. OF DISABILITY EMP. POL'Y, THE WHY, WHEN, WHAT, AND HOW OF DISCLOSURE IN AN ACADEMIC SETTING, AFTER HIGH SCHOOL (2007), https://ecommons.cornell.edu/bitstream/handle/1813/76652/The_Why_When_What_and_How_of_Disclosure_in_an_Academic_Setting.pdf?sequence=1&isAllowed=y [<https://perma.cc/VS68-X4PN>].

¹⁷⁸ There is no one "disability pride" month, but all are siloed. Amanda Burris, *2020 Diversity, Inclusion and Disability Awareness Calendar*, DISABILITY SOLS. (Dec. 31, 2019), <https://www.disabilitytalent.org/single-post/2019/12/31/2020-Diversity-Inclusion-Disability-Awareness-2020Calendar> [<https://perma.cc/D28R-J6LZ>]. For example, October is National Disability Employment Awareness Month, April is Autism Awareness Month, and November is Diabetes Awareness Month. *Id.*

¹⁷⁹ 42 U.S.C. § 12132 ("[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."); Rehabilitation Act of 1973, 29 U.S.C. § 701(c)(1), (4), (5) (emphasizing principles of "respect for individual dignity, personal responsibility, self-determination, and pursuit of meaningful careers . . . of individuals with disabilities" and "support for involvement of an individual's representative . . . and [the] community . . .").

¹⁸⁰ *People with Disabilities and Postsecondary Education—Position Paper*, NAT'L COUNCIL ON DISABILITY, <https://ncd.gov/publications/2003/people-disabilities-and-postsecondary-education-position-paper> [<https://perma.cc/NA3R-WDC6>] (documenting rising numbers of students with disabilities in post-secondary education); *see, e.g.*, Susan Grimes, Jill Scevak, Erica Southgate & Rachel Buchanan, *Non-Disclosing Students with Disabilities or Learning Challenges: Characteristics and Size of a Hidden Population*, 44 AUSTRALIAN EDUC. REP. 425, 427 (2017) ("International research has attempted to identify the true participation rates of the [students with disabilities] population and found that the population is significantly higher than institutional statistics indicate. In one US institution,

accommodations is inconsistent with university data on the number of students who anonymously and voluntarily identify as students with disabilities.¹⁸¹ “‘Disability’ is a stigmatised term and it is argued that few would [publicly] choose to associate themselves with the term for this reason.”¹⁸² Mental health, for example, is one of the fastest growing concerns students raise and yet there is very little discussion among students collectively and universities at the institutional level.¹⁸³ Federal and state privacy laws that treat disability identity as medical data postpone the development of institutional designs to normalize disability and investigate opportunities for structural reforms. Instead, university discussions often focus on streamlining accommodations, enhancing student privacy, and providing more individual counseling services.

D. Tort Law

Tort law continues to treat disability as a negative “private fact” that causes reputational harm when disclosed.¹⁸⁴ The expressive value of this legal

[researchers] reported that 8.4% of students identified as disabled although less than one percent had disclosed to the institution.” (citing Susan L. Gabel & Maja Miskovic, *Discourse and the Containment of Disabilities in Higher Education: An Institutional Analysis*, 29 *DISABILITY & SOC’Y* 1145 (2014))).

¹⁸¹ See *Students with Disabilities*, NAT’L CTR. FOR EDUC. STAT., <https://nces.ed.gov/fastfacts/display.asp?id=60> [<https://perma.cc/GMV7-QXCW>] (“Nineteen percent of undergraduates in 2015-16 reported having a disability.”). Notably, not all students with disabilities need accommodations. Similarly, some students who need accommodations choose not to use the formal accommodations process and prefer to work individually with professors to accommodate them ad hoc. In these cases, privacy may not be as big of an issue, or when weighed against the time consuming and uncertain process of formal accommodations, students choose to disclose to and directly negotiate with the professor. Some accommodations, however, like extended time on exams, may only be granted through the more formal accommodations process with a university’s disability center. See, e.g., *Alternative Testing Process for Students*, UNIV. OF WASH., <https://depts.washington.edu/uwdrs/current-students/accommodations/alternative-testing> [<https://perma.cc/8REK-DMYW>].

¹⁸² Grimes et al., *supra* note 180, at 428.

¹⁸³ See, e.g., *College Students’ Mental Health Is a Growing Concern, Survey Finds*, MONITOR ON PSYCH., June 2013, <https://www.apa.org/monitor/2013/06/college-students> [<https://perma.cc/QQ9W-DEEA>] (“Ninety-five percent of college counseling center directors surveyed said the number of students with significant psychological problems is a growing concern in their center or on campus.” (citing BRIAN J. MISTLER, DAVID R. REETZ, BRIAN KRYLOWICZ & VICTOR BARR, *THE ASSOCIATION FOR UNIVERSITY AND COLLEGE COUNSELING CENTER DIRECTORS ANNUAL SURVEY (2012)*)); see also *College Students (And Their Parents) Face a Campus Mental Health ‘Epidemic,’* NPR (May 28, 2019, 2:44 PM), <https://www.npr.org/transcripts/727509438> [<https://perma.cc/DZ2M-YGAE>].

¹⁸⁴ One Washington Supreme Court decision stated:

Every individual has some phases of his life and his activities and some facts about himself that he does not expose to the public eye, but keeps entirely to himself or at most reveals only to his family or to close personal friends. Sexual relations, . . . family quarrels, many unpleasant or disgraceful or humiliating illnesses . . .

doctrine communicates to people with and without disabilities the benefits of privacy. Courts have considered publication of disability status under both defamation and invasion of privacy branches of privacy torts.¹⁸⁵ Public disclosure of private facts generally requires that the fact (1) was publicized, (2) was a private fact, (3) that is “highly offensive to a reasonable person,”¹⁸⁶ and (4) is not of “legitimate concern” to the public.¹⁸⁷ Failure to meet any one of these elements defeats the claim. Not only have courts repeatedly held that “disability” is a “private fact,” but many state courts have also held that information about disability generally meets the offensiveness or embarrassment element without the need for legal analysis.¹⁸⁸ In *Cordts v.*

Cowles Publ'g Co. v. State Patrol, 748 P.2d 597 (Wash. 1988) (en banc) (quoting RESTATEMENT (SECOND) OF TORTS § 652D cmt. b (AM. L. INST. 1977)).

¹⁸⁵ William L. Prosser, *Privacy*, 48 CALIF. L. REV. 383, 389-407 (1960) (reviewing existing cases on the invasion of privacy tort, organizing the cases into four categories ((1) intrusion; (2) public disclosure of private fact; (3) false light in the public eye; and (4) appropriation of the image or likeness of the person), and discussing the elements of proof of and available defenses to each). The Restatement, memorializing Prosser's taxonomy, explains the elements of defamation:

To create liability for defamation there must be: (a) a false and defamatory statement concerning another; (b) an unprivileged publication to a third party; (c) fault amounting at least to negligence on the part of the publisher [with respect to the act of publication]; and (d) either actionability of the statement irrespective of special harm or the existence of special harm caused by the publication.

RESTATEMENT (SECOND) OF TORTS § 558. Public disclosure of private facts is the publication of the private affairs of another person when the disclosures would be highly offensive to a reasonable person. *See, e.g.*, *Smith v. Methodist Hosps. of Dall.*, 2008 U.S. Dist. LEXIS 103588, at *19 (N.D. Tex. Dec. 19, 2008) (“Publicity means that a matter is communicated to the public at large or disseminated to so many people that it becomes public knowledge.” (citing *Indus. Found. of So. v. Tex. Indus. Accident Bd.*, 540 S.W.2d 668, 683-84 (Tex. 1976))); *see also* *Yath v. Fairview Clinics, N. P.*, 767 N.W.2d 34, 42 (Minn. Ct. App. 2009) (recognizing two modes of publicity: communicating to the public and communicating to a number of individuals large enough to be deemed communication to the public); *see also* *Allen, Privacy Torts, supra* note 37, at 1721 (analyzing privacy tort case law in the context of LGBT plaintiffs and showing how plaintiffs often advanced legal claims based on more than one features of Prosser's privacy tort taxonomy).

¹⁸⁶ *See Cordts v. Chi. Tribune Co.*, 860 N.E. 2d 444, 450-51 (Ill. App. Ct. 2006) (“An invasion of a plaintiff's right to privacy is important if it exposes private facts to a public whose knowledge of those facts would be embarrassing to the plaintiff.” (quoting *Miller v. Motorola Inc.*, 560 N.E.2d 900, 902 (Ill. App. Ct. 1990))).

¹⁸⁷ *Taus v. Loftus*, 151 P.3d 1185, 1199 (Cal. 2007) (outlining the elements of public disclosure of private facts to include that the private fact is not of legitimate public concern). Note that it is not necessary to prove malice unless punitive damages are sought. *See, e.g.*, CAL. CIV. CODE § 3294 (Deering 2021).

¹⁸⁸ *See, e.g., Smith* at *19 (“The matter publicized must relate to the plaintiff's private life. There is a presumption under Texas law that the public has no legitimate interest in private, embarrassing facts about private citizens.” (citations omitted)). The court then proceeds to discuss whether the facts rise to the level of publication without engaging the question of disability as private. *See also* *White v. Twp. of Winthrop*, 116 P.3d 1034, 1038 (Wash. Ct. App. 2005) (“The employer argues that the information disclosed [that the plaintiff has epilepsy] was not highly offensive.”) Cases from other jurisdictions involving publication of the intimate details of an employee's medical health have met the “highly offensive” requirement. *See* *Blackwell v. Harris*

Chicago Tribune Co., for example, a plaintiff claimed that an employee of his benefits evaluator wrongfully disclosed his treatment to his ex-wife.¹⁸⁹ Cordts asserted that the confidential information disclosed (about his depression) was of the kind that would be “highly offensive to a reasonable person” and that the disclosure was especially devastating to him due to the “special relationship” he had with his ex-wife.¹⁹⁰

In another case, the Ninth Circuit Court of Appeals reversed a lower court ruling that disclosure of a law student’s disability accommodations did not involve a “private fact” that a reasonable person would find “offensive” if disclosed.¹⁹¹ The court reasoned that the plaintiff sufficiently alleged that the information disclosed by his law school regarding his accommodation “was not already public knowledge.”¹⁹² The lower court’s opinion focused, in part, on the fact that his disability was public when he failed to show up for the final exam with the rest of the class.¹⁹³ However, his absence alone did not constitute an explicit public disclosure and could be explained by a number of other possible reasons. The Ninth Circuit offered another reason for why disclosure of disability accommodations met the statutory element of “private fact” whose revelation would be “highly offensive.” Specifically, the court of appeals noted that disclosure of accommodations might reveal medical information courts unquestionably consider “private facts,” such as medical diagnoses, once again reaching for health privacy laws, regulations, and norms to reduce disability identity to medical data.¹⁹⁴

Interestingly, courts hearing claims for improper disclosure of disability status tend to focus the least on the elements of disability as “private” information and its “embarrassing” nature, assuming this is common knowledge and these are established norms.¹⁹⁵ “The right to privacy acknowledges that the reason a person wishes to keep his or her illness confidential is to avoid the pity [or rejection] that knowledge of such a disease

Chem. N. Am., Inc., 11 F. Supp. 2d 1302, 1310 (D. Kan. 1998) (holding alleged disclosure of personal medical information to other employees sufficiently met elements of private facts tort).

¹⁸⁹ *Cordts*, 860 N.E.2d at 447.

¹⁹⁰ *Id.*

¹⁹¹ *Tecza v. Univ. of S.F.*, 532 F. App’x 667, 669 (9th Cir. 2013).

¹⁹² *Id.*

¹⁹³ *Tecza v. Univ. of S.F.*, 2010 WL 1838778, at *2 (N.D. Cal. May 3, 2010).

¹⁹⁴ “[T]o the extent that [the University]’s disclosure indirectly revealed some underlying medical information—that Tecza likely had a disability and some additional information that might allow a person to make inferences about the general nature of Tecza’s disability—California courts have considered medical information to be a private fact.” *Tecza*, 532 F. App’x at 669 (citing *Jeffrey H. v. Imai, Tadlock & Keeney*, 101 Cal. Rptr. 4th 345, 920-21 (Cal. Ct. App. 2000)).

¹⁹⁵ Courts primarily focus on the “publication” of the private fact and whether it is of “legitimate concern” to the public. *See, e.g., Leach v. Dist. Bd. of Trs.*, 244 F. Supp. 3d 1334, 1339 (S.D. Fla. 2017) (focusing on the publication element of invasion of privacy and assuming without explanation that disability is a “private fact” under state law).

would engender in others.”¹⁹⁶ However, the law is not agnostic on this front. Failure to interrogate disability as negative, embarrassing, and pity inducing is highly normative and norm dependent.¹⁹⁷ It requires a conception of able-bodied as the preferred baseline such that one’s deviation from it inherently invokes shame or pity.¹⁹⁸

What constitutes a “private” fact under tort law is highly normative as well as norm reinforcing.¹⁹⁹ Courts used to treat a person’s identity as gay as presumptively private information whose disclosure could cause embarrassment and reputational harm. State cases from the late 1970s and 1980s illustrate how plaintiffs only had to show that one’s gay identity (and exposure to HIV) was made public without a requisite showing of actual damage because it was presumed harmful.²⁰⁰ Jenny Pizer of Lambda Legal Defense, for example, summarized the central problem: “It shouldn’t still be existing in the law that being gay is so horrible that when someone is falsely accused of it they don’t have to prove that it is damaging – that the accusation is seen as damaging on its face. People should have to *prove* that it’s bad.”²⁰¹ If the category or identity is not something that normatively people would find

¹⁹⁶ *White v. Twp. of Winthrop*, 116 P.3d 1034, 1038 (Wash. Ct. App. 2005).

¹⁹⁷ *See, e.g., Gill v. Hearst Publ’g Co., Inc.*, 253 P.2d 441, 445 (Cal. 1953) (discussing elements of a claim of invasion of the right of privacy including “portraying [something] to shock the ordinary sense of decency or propriety”). This criterion is undoubtedly relative to the “customs of the time and place, to the occupation of the plaintiff and to the habits of his neighbors and fellow citizens.” *Vassiliades v. Garfinckel’s, Brooks Bros.*, 492 A.2d 580, 588-89 (D.C. 1985) (quoting RESTATEMENT (SECOND) OF TORTS § 652D, cmt. c (AM. L. INST. 1977)); *Harris ex rel. Harris v. Easton Publ’g Co.*, 483 A.2d 1377, 1384 (Pa. Super. Ct. 1984) (dicta).

¹⁹⁸ *See, e.g., Deaton v. Delta Democrat Publ’g Co.*, 326 So.2d 471, 474 (Miss. 1976) (“It is difficult to conceive that any information can be more delicate or private in nature than the fact that a child has limited mental capabilities or is in any sense mentally retarded.”).

¹⁹⁹ Plaintiffs bringing tort claims against defendants for publication of a private fact without consent, for example, must prove that the fact was “private” and one whose disclosure would be “embarrassing to a reasonable person,” either of which might be perceived to be a concession of the stigma and shame of the nonnormative identity. Plaintiffs also would make more public a fact about sexual identity and increase the potential harm of the disclosure all in service of remedying the “harmful” publication.

²⁰⁰ *See Robert C. Ozer, P.C. v. Borquez*, 940 P.2d 371, 373-74 (Colo. 1997) (recognizing the tort of invasion of privacy in a case involving a plaintiff who was an associate at a law firm, disclosed to the president and shareholder of the law firm that he was gay, that his partner had been diagnosed with AIDS, and that the associate needed to get tested immediately only to be fired the following week and have this information shared with several people at the firm). However, at least one study of the cases from the 1960s through the early 2000s shows that although gay plaintiffs reached for the privacy torts seeking injunctive relief and damages, they did not achieve the anticipated success. Allen, *Privacy Torts*, *supra* note 37, at 1723-33 (surveying the case law).

²⁰¹ DAVID EHRENSTEIN, OPEN SECRET: GAY HOLLYWOOD—1928-2000, at 152 (1st perennial ed. 2000). Jennifer C. Pizer is the Law and Policy Director for Lambda Legal, the oldest and largest national legal organization committed to achieving full recognition of the civil rights of lesbian, gay, bisexual and transgender (LGBT) people and people living with HIV. *Jennifer C. Pizer*, LAMBDA LEGAL, <https://www.lambdalegal.org/about-us/staff/jennifer-c-pizer> [<https://perma.cc/9FLG-GDPL>].

automatically harmful or bad, the question of whether it is a “private fact” should go to a jury. The question before the jury would be whether the nature of the statement was such that a reasonable person hearing it would think badly about the person of whom it was said. This inquiry is highly contextual,²⁰² but courts largely skipped this step, almost taking judicial notice of the embarrassing nature of gay identity, then, and today, disability identity.

Moreover, the common law tort doctrine related to “outing” nudged people to cover or pass as heterosexual or lose viable legal defenses.²⁰³ If a person who identified as LGB was in a public place displaying same-sex affection, they could not later claim an invasion of privacy tort because they publicly “chose” to put their identity on display. Even if sexual identity was generally non-public, if it appeared in a public record, it could provide a reasonable defense to defendants in some courts.²⁰⁴ Similarly, in defamation cases, truth was an absolute defense,²⁰⁵ thus creating an incentive for those who could pass as heterosexual to do just that.

IV. THE COSTS OF PRIVACY

Part IV argues that disability law’s privacy defaults and nudges have costs that have not yet been explored and debated.²⁰⁶ Antidiscrimination laws have deployed privacy as a way for individuals to hide experiences or parts of

²⁰² See, e.g., *Selleck v. Globe Int’l Inc.*, 212 Cal. Rptr. 838, 844 (Cal. Ct. App. 1985) (providing the facts of a case in which plaintiff, father of actor Tom Selleck, brought an action against a publisher of a tabloid magazine that allegedly quoted him about insults he allegedly made about his son’s romantic character including that he was allegedly “ill at ease with women” and “he [is] just not the person they [women] think he should be” (second alteration in original)).

²⁰³ See, e.g., *Borquez*, 940 P.2d at 377 (“The disclosure of facts that are already public will not support a claim for invasion of privacy.” (citations omitted)).

²⁰⁴ See, e.g., *Crumrine v. Harte-Hanks Television, Inc.*, 37 S.W.3d 124, 127 (Tex. App. 2001) (affirming lower court decision denying plaintiff police officer’s invasion of privacy claim against news outlet because his sexual identity was the subject of a child custody proceeding and “once true information is disclosed in public court, there is no liability for giving publicity to that which is already public” (citations omitted)).

²⁰⁵ Eric K.M. Yatar, *Defamation, Privacy and the Changing Social Status of Homosexuality: Re-Thinking Supreme Court Gay Rights Jurisprudence*, 12 LAW & SEXUALITY 119, 122-23 (2003).

²⁰⁶ There are other costs to privileging privacy norms that I do not discuss in detail. For example, privacy masks the presence of disability in society and the contributions of people with disabilities historically. See, e.g., Sara White, *Crippling the Archives: Negotiating Notions of Disability in Appraisal and Arrangement and Description*, 75 AM. ARCHIVIST 109, 120-21 (2012) (discussing the barriers to documentation due to privacy laws and the effects on knowledge creation and historical work as a result); see also Yaron Covo, *Gambling on Disability Rights*, 43 COLUM. J.L. & ARTS 237, 243 (2020) (arguing that the expressive value of “anti-tipping” rules in sports prohibiting the disclosure of athletes’ psychosocial impairments may reinforce stigma associated with mental and psychosocial impairments and obscure their prevalence among athletes).

identity deemed normatively “bad” or embarrassing.²⁰⁷ But it has also become a tool of perpetuating discrimination by masking its incidence. This Part complicates the current discussions of privacy in the context of disability by surfacing and unpacking the costs of our current approach.

A. *Privacy Obscures Prevalence and Diversity of Disability in Society*

By overvaluing privacy, we do not have an accurate picture of the breadth of disability in society and, as a result, society limits disability to visible markers. The aesthetics of disability in the aggregate depict the most severe (visible) manifestations of incapacity and, as such, delineate the “deserving disabled.”²⁰⁸ These markers have become probative and, in some cases, dispositive evidence of eligibility for public benefits programs like Social Security and access to legal rights (such as standing) under disability laws.²⁰⁹ While not formally codified in any statute, the aesthetics of disability have become tools of statutory and regulatory interpretation used by judges, lawyers, and juries to decide cases.²¹⁰ Notably, the aesthetic markers—reinforced through limited media representations of disability as wheelchairs, canes, and dark glasses²¹¹—are normative guides for civilian vigilantes to

²⁰⁷ Early privacy scholars skeptical of the veil of privacy such as Richard Posner argued that privacy is actually a fraud on the market for personal reputation. Richard A. Posner, *Privacy, Secrecy, and Reputation*, 28 BUFF. L. REV. 1, 14 (1979) (“The market approach suggests in turn that whatever rules governing fraud are deemed optimal in ordinary product markets ought in principle to apply equally in labor markets, credit markets, and ‘markets’ for purely personal relationships as well.”). Similarly, some contemporary privacy scholars actively challenge the very construction of privacy as flawed and ill-conceived, particularly considering an algorithmic-driven world. See, e.g., Kate Crawford & Jason Schultz, *Big Data and Due Process: Toward a Framework to Redress Predictive Privacy Harms*, 55 B.C. L. REV. 93, 106-09 (2014) (challenging the capacity of existing privacy frameworks to meaningfully capture and remedy the harms of big data mining).

²⁰⁸ See, e.g., Doron Dorfman, *Fear of the Disability Con: Perceptions of Fraud and Special Rights Discourse*, 53 LAW & SOC. REV. 1051, 1070 (2019) [hereinafter Dorfman, *Fear*] (“[T]he visibility of disability plays an important role in signaling the deservingness of rights claimants. This clearly visible deservingness has been found to have a much bigger effect on the assessment for potential disability con than the purist of self-interest and loss of personal opportunities in situations of scarcity.” (citing Doron Dorfman, *[Un]Usual Suspects: Deservingness, Scarcity, and Disability Rights*, 10 UC IRVINE L. REV. 557 (2020))).

²⁰⁹ The ADA as promulgated by Congress in 1990 defined disability as an “impairment that substantially limits one or more major life activities.” 42 U.S.C. § 12102(1)(A); *Id.* § 12132 (“[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”).

²¹⁰ See, e.g., Harris, *supra* note 2, at 934-35 (discussing the impact of aesthetics of disability on juror decisionmaking).

²¹¹ See Whitney Friedlander, *How Hollywood Is Working to Improve Representation of People with Disabilities*, CNN, <https://www.cnn.com/2019/09/06/entertainment/disability-representation-in-hollywood/index.html> [https://perma.cc/8FQ8-7BFM] (Sept. 6, 2019, 2:54 PM) (“There’s also the

police disability in schools, movie theaters, parking lots, airports and other public places of accommodation.²¹² On the one hand, people who do not conform and exercise their legal rights may subject themselves to harassment, public shaming, and, in some cases, physical violence. On the other hand, those with the visible markers who excel and surpass low expectations for people with disabilities are perceived as exceptional, “super-crips” who have overcome disability.²¹³

This, in turn, leads to a false impression that the number of people with disabilities is lower relative to other protected classes, such as women or racial minorities when, in fact, people with disabilities represent the most populous minority group.²¹⁴ The number of people with disabilities in the United States continues to grow with longer life expectancies and, most recently, with the realization of the high percentage of people who will experience long-term health impairments as a result of COVID-19.²¹⁵ Though existing data on people with less visible disabilities is scarce or criticized as methodologically suspect,²¹⁶ it is possible to extrapolate this information from a recent data collection.²¹⁷

misunderstandings and stereotypes surrounding what constitutes a person with a disability and why their inclusion matters just as much as those of other minorities.”)

²¹² See Dorfman, *Fear*, *supra* note 212, at 1070 (referring to the phenomenon of public fear of “the disability con” and importing this frame into disability law and policy); see also ELLEN SAMUELS, *FANTASIES OF IDENTIFICATION: DISABILITY, GENDER, RACE* (2014). The COVID-19 pandemic has exacerbated fears of fraud associated with “anti-maskers” and vaccine “line jumpers.” See Ana Medaris Miller, *Anti-Maskers’ Say Medical Conditions Prevent Them from Wearing Masks, but Doctors Say That’s Not a Legitimate Excuse*; BUS. INSIDER (July 2, 2020, 7:36 AM), <https://www.businessinsider.com/anti-maskers-say-they-cant-wear-masks-because-medical-conditions-2020-5> [<https://perma.cc/9YXG-P9RL>] (describing how mask wearing has become a political act and insincere claims of health hardships and privacy protections create public distrust); Elisabeth Rosenthal, Opinion, *Yes, It Matters That People Are Jumping the Vaccine Line*, N.Y. TIMES (Jan. 28, 2021), <https://www.nytimes.com/2021/01/28/opinion/covid-vaccine-line.html> [<https://perma.cc/769M-8KLU>] (discussing public frustration with ineligible wealthy and politically connected individuals who have received vaccines in exchange for political favors, donations, or social status).

²¹³ See Sami Schalk, *Reevaluating the Supercrip*, 10 J. LITERARY & CULTURAL DISABILITY STUD. 71, 74 (2016) (describing the term “supercrip” as a “pejorative term for overachieving people with disabilities” that emphasizes narratives of over “compensation for the perceived ‘lack’ created by disability”); see also Jasmine E. Harris, Opinion, *The Hill We Climb’ to Overcome Stereotypes About Disabilities*, S.F. CHRON. (Jan. 25, 2021, 4:00 AM), <https://www.sfchronicle.com/opinion/openforum/article/The-Hill-We-Climb-to-overcome-stereotypes-15894496.php> [<https://perma.cc/3QZ2-54VW>] (describing the “disability inspiration porn” of Youth Poet Laureate Amanda Gorman overcoming her speech disability to perform at President Biden’s inauguration).

²¹⁴ The use of categorical identities also obscures the intersectionality of those identities, that is, people with disabilities are also women and people of color.

²¹⁵ Cf. CTRS. FOR DISEASE CONTROL & PREVENTION, *supra* note 10 (suggesting that the number of people with disabilities continues to grow because life expectancy has increased).

²¹⁶ Critics point to self-reporting as a central flaw of the disability data collection at the federal level.

²¹⁷ Thanks to Professor Dorfman for sharing data collected in a recent study. Dorfman, *Fear*, *supra* note 212, at 1063-64. Some of this data was used in a separate piece, however, I am taking raw

data from his collection and extrapolating from it to estimate the percentage of people with physical (more visible) and less apparent disabilities. Survey Sampling International (SSI) administered the survey. With respect to its sampling, SSI recruits participants through various online communities, social networks, and website ads. SSI makes efforts to recruit hard-to-reach groups, such as ethnic minorities and seniors. These potential participants are then screened and invited into the panel. When deploying a particular survey, SSI randomly selects panel participants for survey invitations. While there was no weighing of particular participants, Professor Dorfman asked SSI to recruit in order to roughly match the census numbers of adults with disabilities (roughly 23-27% of the U.S. population overall). *See id.*

Table 1: Breakdown by Type of Disability (n=245)²¹⁸

TYPES OF DISABILITY	FREQUENCY	PERCENT	CUMULATIVE
Physical	152	62.04	62.04
Mental	56	22.86	84.90
Developmental	3	1.22	86.12
Learning	2	0.82	86.94
Chronic Illness	20	8.16	95.10
Sensory	8	3.27	98.37
Other	4	1.63	100.0
TOTAL	245	100.0	

The data in Table 1 above allows for an estimate of the percentage of people with “more apparent” and “less apparent disabilities.” Of the people who responded to the survey as having a physical disability, half reported the use of an assistive device such as walkers, canes, prosthetic limbs, or wheelchairs (n=76).²¹⁹ Assistive devices themselves are aesthetic markers of disability and would represent the more apparent end of the disability continuum. The balance of people reporting physical impairments would map closer to the nonapparent end of the continuum (n=76). The non-physical, “other” categories of disability in Table 1 above largely fall closer to the less apparent end of the continuum (n=93).²²⁰ Thus, a fair estimate of those with less apparent, fewer aesthetic markers is 169 people in the data sample, which is approximately 69% (169/245) or two-thirds of the data sample.²²¹

The absolute number of adults with disabilities in the United States is significant (approximately 61 million).²²² The percentage of those with less apparent disabilities (those with few if any aesthetic markers) is approximately two-thirds, certainly more than a majority of all who identify as people with disabilities.²²³ Taken together, this is a much more nuanced

²¹⁸ See *id.*

²¹⁹ See *id.*

²²⁰ Behavioral manifestations of disabilities are not easily captured in this data set, nor are comorbid disabilities. Still, the data here roughly reflect broader estimates of non-apparent disabilities in society. The data also illustrate the flaws of current data collection and the need for more formal, consistent data collection, especially longitudinal, disaggregated data.

²²¹ Dorfman, *Fear*, *supra* note 212, at 1067 (“[I]t is fair to assume that the less visible the disability, the more likely it is suspected as fake. It is unsurprising that, of the narratives about situations in which respondents felt suspected of faking disability, 42% (43 out of 102) mentioned having ‘nonapparent’ disabilities or ‘not looking sick/disabled.’”).

²²² Press Release, Ctrs. for Disease Control & Prevention, CDC: 1 in 4 US Adults Live with a Disability (Aug. 16, 2018), <https://www.cdc.gov/media/releases/2018/p0816-disability.html> [<https://perma.cc/W7ZE-AFUF>].

²²³ See *supra* note 217.

and robust picture of people with disabilities that underscores the imperceptibility of disability in society. People with disabilities, like those of any identity group, may have different capabilities, but privacy norms that nudge people with less visible disabilities to cover or pass mask the sheer numbers of people with disabilities living their lives each day in public spaces.

Thus, privacy norms prevent the development of a nuanced picture of people with disabilities along a continuum and, instead, maintain a social norm of disability as severe, obvious, and visible. This affects not only the relationships between people with and without disabilities but also horizontal relationships between those with and without aesthetic markers. If the norm was a continuum rather than a binary, people might feel less entitled to police what are understood as “special benefits” for a minority group. This includes actions by people with more apparent disabilities who question the legitimacy of claims to disability identity (and the resources that may come with such identification) by those without visible markers of disability.²²⁴ This distorted view, in turn, prevents broader sociopolitical organizing around disability identity.

B. *Ambiguity Aversion*

Privacy norms also may push discrimination underground. Specifically, privacy nudges in disability antidiscrimination and other laws may work counterintuitively to make people with disabilities more susceptible to bias in some settings. Consider the hiring process in the employment setting. Professors Joni Hersch and Jennifer Shinall’s work on “ambiguity aversion”—that individuals prefer known risks over unknown risks²²⁵—offers insights about the cost of privacy in employment in the context of family status that extend analytically to disability status.²²⁶ Title VII of the Civil Rights Act and related regulations prohibit prospective employers from asking questions about marital status, and number and ages of children only of women and not men, or only of men and not women seeking employment, with the goal of mitigating sex discrimination.²²⁷

Professors Hersch and Shinall’s empirical study asked whether nondisclosure or active concealment of personal information lowers female

²²⁴ See JENNIFER L. ERKULWATER, *DISABILITY RIGHTS AND THE AMERICAN SOCIAL SAFETY NET* 16 (2006) (discussing how people with more visible disabilities are perceived as more deserving of benefits).

²²⁵ While the theory of ambiguity aversion is considered irrational in behavioral economics, it is still widely regarded as predictive. See generally Hersch & Shinall, *supra* note 90. Hersch and Shinall’s project is clear that the employer does not face ambiguity aversion when interviewing a male candidate because the caregiver work is assumed to be done by women. *Id.* at 56.

²²⁶ *Id.* at 52.

²²⁷ *Id.*

applicants' hiring prospects.²²⁸ They concluded, counterintuitively, that workplace information restrictions “may actually serve to stifle, rather than improve, workplace equity” between men and women.²²⁹ They found that otherwise identical applicants with a substantial gap in their work history (namely, college-educated women in their forties) who do not explain personal family circumstances surrounding their job search are far less likely to be hired than those who do disclose, regardless of the content of the reason provided.²³⁰ Workplace information restrictions in this context result in employers refraining from asking such questions, and employment applicants similarly refraining from offering this information.²³¹ The expressive value of law and perceptions that questions of disability, like questions of parental or family status are off-limits, creates a taboo space where parties on both sides feel constrained—the employer, not to ask questions, and the employee, not to give any information in those areas. Similar to the family status context, neither prospective hires nor existing employees are prohibited from discussing their disabilities or claiming a disability identity, however, the fact that employers may not ask questions pre-offer about disability nudges both employer and prospective employee to steer clear of disability discussions not only as taboo but also as illegal.

Consider how ambiguity aversion operates in the employment context for two people with disabilities—Natalia, who has multiple sclerosis and uses a cane as an assistive device, and Jenny, who has a chronic illness, fibromyalgia, but no external aesthetic markers of disability. Both candidates have a gap in their resumes of roughly one year that goes unexplained in any of the application documents. Both women have comparable qualifications and credentials on paper. A data management company interviews both women for an open position. Neither has requested reasonable accommodations for the interview and their resumes have no information that could identify them as people with disabilities.

Title I of the ADA, like Title VII after which it was modeled, provides preemployment protections for both job candidates. An employer “shall not conduct a medical examination or make inquiries of a job applicant as to whether such applicant is an individual with a disability or as to the nature or severity of such disability.”²³² For Natalia, whose cane is an aesthetic marker,

²²⁸ *Id.* at 49.

²²⁹ *Id.* at 55. “To investigate whether concealing family information actually improves women’s employment prospects, we conducted an original experimental study fielded on more than 3000 subjects.” *Id.* at 49.

²³⁰ *Id.* at 55, 72.

²³¹ *Id.* at 54.

²³² 42 U.S.C. § 12112(d)(2)(A). The employer is prohibited from asking questions about general health, past medical history, time off for health reasons, or the applicant’s worker’s

the challenge is not whether to disclose to the employer but when to do so (before, on the day of, or after an interview). She may need to disclose her disability before the interview if she needs to request reasonable accommodations—e.g., the company’s office in New York is on the tenth floor with no elevator. Natalia might request the interview be held somewhere else or virtually. If she waits to disclose, not only might she trigger the interviewer’s sensory or behavioral responses to disability aesthetics in real time, but the employer may also experience resentment, albeit unjustly, because the information was not shared previously, all of which could affect Natalia’s chances being hired.²³³ Because of restrictions on preemployment inquiries, the employer-interviewer will encounter the aesthetics of disability but will be unable to ask questions about it and, thus, experience ambiguity aversion with respect to future costs or work productivity.²³⁴

Although the experience may differ somewhat for Jenny, the same ambiguity aversion exists for the employer. For Jenny, assuming no reasonable accommodation was requested for the interview, the choice is whether to disclose at all (at the interview, post-offer if hired, or on the job) or pass as nondisabled which would require her to self-accommodate. When her fibromyalgia is active, without accommodations, she may need to create excuses why she cannot be at work or must work remotely. Although Jenny does not manifest readily apparent aesthetic markers, her gap year raises questions about either her family status or disability, each heightening the ambiguity aversion experienced by the employer-interviewer. Employers also have concerns about applicants with invisible disabilities who they will hire and may feel trapped to accommodate because of antidiscrimination laws. The reality of low to de minimus accommodation costs is not widely understood even among human resources professionals or corporate compliance officers.²³⁵ This, combined with ambiguity aversion may explain

compensation history. Employers are allowed to administer examinations after an offer of employment has been made but before the person begins her employment under certain conditions. See 42 U.S.C. § 12113(a); e.g., *id.* § 12113(e) (listing conditions, such as when someone has an infectious disease).

²³³ See, e.g., Melanie Whetzel, *If We Had Known . . .*, JOB ACCOMMODATION NETWORK (Nov. 28, 2018), <https://askjan.org/blogs/jan/2018/11/if-we-had-known.cfm> [<https://perma.cc/Z67R-YKEX>] (“Many employers expect job applicants to disclose their disabilities during the application/interview stage and feel deceived when they find out later on that an employee had a disability at the time of the hiring, but neglected to let the employer know. Some employers even go as far as to say if they had known about a disability, they wouldn’t have hired the employee.”).

²³⁴ Covering may also be an option, i.e., not actively hiding identity but also not flaunting or performing a stereotypical version of it. See Yoshino, *supra* note 15, at 837.

²³⁵ D.J. Hendricks, Linda C. Batiste & Anne Hirsh, *Cost and Effectiveness of Accommodations in the Workplace: Preliminary Results of a Nationwide Study*, DISABILITY STUD. Q., Fall 2005, <https://dsq-sds.org/article/view/623/800> [<https://perma.cc/PDF2-KYBG>] (reporting on Job Accommodation Network data and finding that the median accommodation cost to an employer is \$250); see, e.g., H.

why employment rates for people with disabilities actually fell after Congress passed the ADA in 1990.²³⁶

C. Privatizes the Costs of Disability

The continued reliance on faulty social norms of disability in decisionmaking have led organizations devoted to increasing opportunities for people with disabilities to discourage disclosure, particularly in employment during the hiring process.²³⁷ For example, consider a job candidate, Zuri, a person with a less apparent disability. She discloses her disability on employment applications over the course of four years and never receives a call back. As a result, Zuri believes that her disclosure must have deterred prospective employers, particularly because she either easily meets or exceeds the listed job qualifications. After consulting with the Job Accommodation Network (JAN),²³⁸ a federally funded contractor, Zuri decides not to disclose her disability.²³⁹

Zuri's decision to omit reference to her disability in the hiring process, and, potentially, in the workplace at all, illustrates a third category of costs of overvaluing privacy norms: privatizing the costs of disability. Rather than exercise one's rights in the workplace, for example, people with disabilities are opting out of exercising their rights or underaccommodating to downplay disability.²⁴⁰ Without disclosure, an employer has no legal obligation to accommodate those with nonobvious disabilities.²⁴¹

Stephen Kaye, Lita H. Jans & Erica C. Jones, *Why Don't Employers Hire and Retain Workers with Disabilities?*, 21 J. OCCUPATIONAL REHAB. 526, 533-34 (2011) (citing several studies finding "that the typical individual accommodation is inexpensive and more than pays for itself in increased productivity").

²³⁶ See, e.g., Christine Jolls, *Accommodation Mandates*, 53 STAN. L. REV. 223, 276 (2000) ("[E]mployment levels fell significantly for disabled workers aged 21-39 relative to nondisabled workers in this same age cohort." (citing Daron Acemoglu & Joshua Angrist, *Consequences of Employment Protection? The Case the Americans with Disabilities Act* 12-13 (Working Paper 1999))).

²³⁷ See Whetzel, *supra* note 233 ("If no accommodation is needed for the application or the interview process, you might seriously consider postponing the disclosure conversation until after you get a job offer.").

²³⁸ JAN is funded by the U.S. Department of Labor and the Office of Disability Employment Policy. *About JAN*, JOB ACCOMMODATION NETWORK, <https://askjan.org/about-us/index.cfm> [<https://perma.cc/4KNQ-7V9U>].

²³⁹ This hypothetical is based on an example found in Whetzel, *supra* note 233.

²⁴⁰ David C. Baldrige & John F. Veiga, *Toward a Greater Understanding of the Willingness to Request an Accommodation: Can Requesters' Beliefs Disable the Americans with Disabilities Act?*, 26 ACAD. MGMT. REV. 85, 85 (2001) ("[U]nderaccommodation continues to be a major barrier to equal employment opportunities for people with disabilities." (citing DAVID BRADDOCK & LYNN BACHELDER, *THE GLASS CEILING AND PERSONS WITH DISABILITIES* (1994))).

²⁴¹ See, e.g., *Taylor v. Principal Fin. Grp.*, 93 F.3d 155, 157 (5th Cir. 1996) (finding for the employer because the plaintiff failed to disclose to the employer "any limitations resulting from his disability, and . . . any need for a reasonable accommodation"), *cert. denied*, 519 U.S. 1029 (1996).

Thus, the ADA creates what disability scholars have dubbed “the Goldilocks dilemma” or the “double bind,” where the person with a disability has to show both the existence of an impairment that *substantially limits* one or more major life activities and, at the same time, that she is *qualified* to perform the essential functions of a job.²⁴² This places people with disabilities in an awkward position where “successfully performing as a worker, seem[s] to cast doubt on one’s disability, and vice versa,” requiring that they choose among two opposite normative performances.²⁴³ As a result, not only are the costs placed on the individual to assimilate, but privacy does nothing to populate the continuum of disability and challenge the legitimate/illegitimate binary. This creates an environment where “workers often struggle to conform to some imagined ideal of disability by downplaying or hiding their disability; or, by giving the impression that they are overcoming their disability through hard work and determination.”²⁴⁴ It also establishes an expectation that this is possible, desired, or the gold standard. Thus, “many workers view their ADA rights through the perspective of their coworkers; imagining how they are judged, accepted, or rejected as workers. For this reason, workers perform and adopt an attitude that downplays the effects of their disability and avoids relying too heavily on the ADA.”²⁴⁵

One study, based on qualitative interviews with workers with disabilities, captures the ways in which suspicions and public policing (and even the thought of exposure to it) alters workers’ behavior. For one employee who fell and injured her ankle, her supervisor’s suspicion and disbelief about her disability pushed her to contemplate finding a new job rather than exercise her rights to a reasonable accommodation under the ADA.²⁴⁶ The study illustrates the extent to which some employees with disabilities will go to “hide their disability, its impact on their bodies, or any visual reference to it.”²⁴⁷ Individuals with disabilities exist in siloes in the workplace with strong privacy norms. Those with the aesthetics of disability focus on either downplaying the disability or exaggerating the visible impairment to secure

²⁴² Areheart, *supra* note 74, at 181, 185-87. The ADA as promulgated by Congress in 1990 defined disability as an “impairment that substantially limits one or more major life activities.” 42 U.S.C. § 12102(1)(A); 42 U.S.C. § 12132; *see also* Paul R. Durlak, *Making Rights in the Workplace: Workers’ Perceptions of the Americans with Disabilities Act 19* (May 14, 2018) (Ph.D. dissertation, University of Buffalo, State University of New York) (on file with author) (“This dilemma frames the performance and outward appearance of disability as a seemingly contradictory thing: disabled, yet also able to work. As a result, many scholars accused the courts of maintaining an almost impossible standing for people with a disability seeking protection from the law.” (citations omitted)).

²⁴³ Durlak, *supra* note 242, at 19.

²⁴⁴ *Id.* at 21.

²⁴⁵ *Id.* at 30; *see also* Dorfman, *Fear*, *supra* note 212, at 1067-68 (discussing experiences with and fear of disability suspicion among people with invisible and visible disabilities).

²⁴⁶ Durlak, *supra* note 242, at 31-32.

²⁴⁷ *Id.* at 32.

a place among the “deserving disabled” and exercise rights to accommodations.²⁴⁸ At the other end of the continuum, people without the aesthetic markers seek to pass as nondisabled so as to not make waves even if it means forgoing legal rights. This approach may also place the disabled employee in a more precarious situation where nondisclosure means the person cannot access a needed accommodation to perform the essential functions of the position and, thus, become more susceptible to a negative employment action.²⁴⁹

In either case, privacy norms transfer the costs of accommodations to employees. This not only exacerbates the emotional and physical labor associated with performing disability, but also financially burdens employees rather than the employer or institution. People with disabilities experience a “disability tax,” the extra costs of daily living, such as additional medical expenses, personal assistance, retrofitting spaces for accessibility, food, clothing, or other personal care items. One study suggests that living with a disability may cost an additional estimated \$1000 to \$7000 per year, which, over time, becomes a considerable financial burden on households.²⁵⁰

This is particularly egregious when taking an employers’ costs into consideration. Research suggests that provision of reasonable accommodations costs most employers nothing and, when there is a cost, the typical expenditure to the employer is de minimis.²⁵¹ Interestingly, the employers surveyed in one study reported that they gain several advantages that greatly outweigh the costs, including direct benefits such as retention of employees, avoiding the costs of onboarding new employees, increased productivity, increased attendance, and greater diversity.²⁵² Indirect benefits noted by employers include improved interactions between co-workers and increased

²⁴⁸ Dorfman, *Fear*, *supra* note 212, at 1070 (discussing the role of disability visibility in “signaling the deservingness” of people with disabilities).

²⁴⁹ The design of disability antidiscrimination law here encourages disabled employees to “lead[]” with their value first and then, only if needed, disclose a disability. Rachel Casper, *Transitioning Reasonable Accommodations from Law School to the Workplace*, LAWS. CONCERNED FOR LAWS. (Jan. 30, 2020), <https://www.lclma.org/2020/01/30/transitioning-reasonable-accommodations-from-law-school-to-the-workplace-bba-event-on-february-3> [https://perma.cc/U34V-85YG].

²⁵⁰ Sophie Mitra, Daniel Mont, Hoolda Kim, Michael Palmer & Nora Groce, *The Hidden Extra Costs of Living with A Disability*, CONVERSATION (July 25, 2017, 9:45 AM), <https://theconversation.com/the-hidden-extra-costs-of-living-with-a-disability-78001> [https://perma.cc/S7Q8-WRH3].

²⁵¹ JOB ACCOMMODATION NETWORK, *WORKPLACE ACCOMMODATIONS: LOW COST, HIGH IMPACT* 2 (2020), <https://askjan.org/publications/TopicDownloads.cfm?pubid=962628&action=download&pubtype=pdf> [https://perma.cc/Y588-MWQ2].

²⁵² *Id.* at 2,4.

company morale.²⁵³ Moreover, employers can use certain state and federal tax benefits to offset the costs of providing reasonable accommodations.²⁵⁴

Finally, when individual employees absorb the costs of accommodation, this relieves pressure for public entities to change structures, practices, and policies that presume “typical” bodies and minds. Consider corporate diversity, equity, and inclusion (DEI) efforts: while ninety percent of companies claim to invest in and value diversity, only four percent include disability as part of their DEI efforts.²⁵⁵ Nevertheless, the case for disability as diversity exists not only as a potential customer base but also with respect to corporate social responsibility and best practices for employee hiring and retention.²⁵⁶ Companies such as Virgin Media have set hiring goals much like those under Section 503 of the Rehabilitation Act to increase the number of employees with disabilities at their organizations, in part, by paying attention to the ways that disability biases infect hiring and may weed out qualified applicants.²⁵⁷

To the extent that corporations advance disability as a part of DEI, and even set hiring goals, DEI data is often kept confidential even in the aggregate (with no personally identifying information). As a result, companies are not held accountable for their inclusion initiatives. Even more troubling, under Section 503 of the Rehabilitation Act where federal contractors have a duty to design and implement affirmative action and produce data to show compliance, both the contractors and government agencies have claimed, for example, that this information is proprietary to the contracting organization and thus not subject to Freedom of Information Act requests.²⁵⁸

V. THE VALUE OF PUBLICITY

Part V takes up the natural question of how to address the negative privacy costs discussed in Part IV. First, I introduce the value of publicity, in part, by offering a more nuanced framing of privacy to include the collective interests in disability identity. Second, I explain how and why publicity plays a starring role in contemporary social movements such as #MeToo and Dreamers.

²⁵³ *Id.* at 4.

²⁵⁴ *See, e.g.*, I.R.C. § 44(c) (detailing tax benefits for small businesses for architectural changes, equipment, or services); *id.* § 190 (detailing tax benefits for businesses of any size that make architectural and transportation modifications).

²⁵⁵ Caroline Casey, *Do Your DEI Efforts Include People with Disabilities?*, HARV. BUS. REV. (Mar. 19, 2020), <https://hbr.org/2020/03/do-your-di-efforts-include-people-with-disabilities> [<https://perma.cc/N6HM-8QG9>].

²⁵⁶ *Id.*

²⁵⁷ *See id.*

²⁵⁸ *See supra* note 151. This is a disturbing trend happening also in other spaces. *See, e.g.*, Bowman, *supra* note 151, at 1690 (discussing the use of trade secret arguments to control information in litigation and noncompete agreement contexts).

Finally, I offer three concrete steps we can take to recalibrate: disability data, law reform, and strategic nudges to incentivize publicity of disability identity.

A. *Theoretical Re-Framing of the Interests/Stakes*

Privacy conceptions that focus solely on the individual are insufficient to capture the varied interests at play in disability antidiscrimination law. Outside of disability law, several privacy law scholars have moved away from a narrow framing of privacy as purely an individual right to self-determination by recognizing public interests at stake in the production and circulation of information. These discussions among scholars can help us better understand why some degree of privacy must exist in the context of disability identity and status but, perhaps most relevant to the disability space, why privacy is not absolute nor simply a matter of individual choice. For example, in addition to baseline constitutional arguments in favor of privacy under the First and Fourth Amendments,²⁵⁹ Priscilla Regan argues that while privacy is valuable for the individual, it also is critical for society. All, or at least the vast majority of, individuals value some degree of privacy (of information, home, or body), and this privacy is essential for both individual and social existence.²⁶⁰

First, Professor Regan contends that privacy is effectively a “collective or public good, as used in economics” because both technology and market forces make it more difficult for any one person to have privacy without all persons having a similar minimum level of privacy.²⁶¹ Because technology and automation require some disclosure to allow the individual to participate in society—receive health care, apply for employment, maintain a bank account, attain a mortgage, etc.—it is not realistic to think that the individual could exit the market completely. If an individual did go “off the grid,” accessing goods and services for the individual would be more difficult and the imbalance would make the market more inefficient.²⁶² Second, some level of privacy is fundamental to the development of commonality—namely, our democratic political system and process.²⁶³ People can express divergent political opinions and construct individual identities vis-à-vis the body politic; as a result, privacy itself is intrinsically linked to publicity and

²⁵⁹ Specifically, the First Amendment right entails freedom of speech and the Fourth Amendment right protects against unwanted government intrusion.

²⁶⁰ See *supra* Section I.A.

²⁶¹ Priscilla Regan, *Legislating Privacy: Technology, Social Values, and Public Policy*, in *THE HANDBOOK OF PRIVACY STUDIES*, *supra* note 44, at 57, 57-61 (citation omitted).

²⁶² *Id.* at 59.

²⁶³ *Id.*; see also Paul M. Schwartz, *Privacy and Democracy in Cyberspace*, 52 *VAND. L. REV.* 1609, 1610-11 (1999) (arguing that privacy protections are important to protect individuals seeking to explore and understand their identities and discuss those identities with others online).

defining *what is public* because it ensures that people are not “over-differentiated,” an important point in the context of disability.²⁶⁴

We have a conception of privacy that is not absolute. Most notable exceptions to personal control and strong privacy as the basis for autonomy are rooted in public safety or health where an individual’s rights to the information or the decision may be trumped if the public value is strong enough, as we have experienced during COVID-19. Everything from HIV/AIDS and partner notification, respecting personal privacy may run counter to the well-being of others (biological relatives for certain types of genetic risk or sexual partners in the case of STIs). While there are strict edicts about the need to protect privacy in the medical sphere, well-recognized exceptions exist and continue to emerge when nondisclosure is likely to result in harm to others. This is baked into professional responsibility duties and ethics such as the exception to the requirement that lawyers keep their clients’ secrets, including in an ongoing investigation where the crime has not been solved.²⁶⁵ The rules say that the lawyer “may” disclose if the public interest is strong enough, and the threat must be “imminent[.]”²⁶⁶

Thus, the question is not limited to privacy or publicity, disclosure or nondisclosure. Rather, discussions about privacy in the context of disability should be malleable and are highly contextual. This Article offers principles or criteria that should be used in designing disability antidiscrimination interventions to allow for a robust accounting of the stakes of disclosure and the relevant stakeholders. The next subsection defines “publicity” and offers places where strategic nudges in disability law and policy can introduce publicity values into the privacy debates. Rather than the opposite of privacy, publicity is intrinsically connected to it.²⁶⁷

B. *Publicity Values in Social Movements*

“Publicity” here means a strategic communications approach to systematically change problematic social norms. Publicity requires that public and private institutions create spaces for individuals with less apparent disabilities to claim disability as a sociopolitical identity while paying attention to individual interests in privacy. Unlike existing privacy norms in

²⁶⁴ Regan, *supra* note 261, at 59 (quoting PRISCILLA M. REGAN, LEGISLATING PRIVACY: TECHNOLOGY, SOCIAL VALUES, AND PUBLIC POLICY 226-27 (1995)). For example, if a social media platform extracts data to deliver targeted political messages, the democratic process, writ large, would be harmed, hence the broader public interests at stake.

²⁶⁵ MODEL RULES OF PRO. CONDUCT r. 1.6(b) cmt. ¶¶ 7-8 (AM. BAR ASS’N 1983).

²⁶⁶ *Id.* ¶ 6.

²⁶⁷ See, e.g., JENNIFER E. ROTHMAN, THE RIGHT OF PUBLICITY: PRIVACY REIMAGINED FOR A PUBLIC WORLD 30 (2018) (“The creation of a right of publicity and its divergence from the right of privacy were not driven by essential differences.”).

disability law that place the onus on the individual to control and protect her interests in disability status and identity, the introduction of publicity recognizes the remedial role institutional actors must play. Just as privacy scholars tout the collective value of privacy for democratic participation, publicity values offer key organizing principles for the development of disability as a sociopolitical identity.²⁶⁸ Publicity, therefore, refers to more than individuals with less apparent disabilities “coming out” as disabled.²⁶⁹

Individual decisions to conceal disability identity or status, where possible, respond to structural-level social stigma; however, concealment does nothing to change the problematic structures themselves.²⁷⁰ Similarly, while coming out as a person with a disability has the potential for individual and, in the aggregate, group movement-building, this alone is insufficient to solve the structural problem of institutionalized ableism and neurotypicality that is so pervasive in society.

Three critical features link contemporary movements such as the Dreamers (undocumented Americans) and #MeToo (survivors of sexual violence and harassment) with the early LGB movement in the 1970s and 1980s and the evolving disability rights movement.²⁷¹ First, and most prominently, publicity is at the core of the movement. In fact, these movements appropriate the master schema of the “closet” and “coming out” not because it is a perfect metaphor, rather, because it is a well-known one that can generate broader support.²⁷² Although, retrospectively, some sexuality scholars have questioned the utility of the “closet” metaphor for the gay rights

²⁶⁸ Jodi Dean, *Publicity's Secret*, 29 POL. THEORY 624, 624-25 (2001).

²⁶⁹ The closet as a metaphor and foil to coming out have been critiqued by scholars such as Judith Butler and Eve Sedgwick for its reliance on binary oversimplification. Danielle Bobker, *Coming Out: Closet Rhetoric and Media Publics*, 5 HIST. PRESENT 31, 34 (2015). Michael Warner's work, for example, critiques the mantra “the personal is political”—that is, that issues of personal identity provide an ideal focus for political action—as dangerously reinforcing the individual as the subject and one that is solely responsible for their invisibility. MICHAEL WARNER, *PUBLICS AND COUNTERPUBLICS* 52 (2002).

²⁷⁰ See Michael H. Pasek, Gabrielle Filip-Crawford, & Jonathan Cook, *Identity Concealment and Social Change: Balancing Advocacy Goals Against Individual Needs*, 73 J. SOC. ISSUES 397, 398 (2017).

²⁷¹ The first generation included the grassroots organizers and protestors such as Judith Heumann, Ed Roberts, and Justin Dart. See generally FRED PELKA, *WHAT WE HAVE DONE: AN ORAL HISTORY OF THE DISABILITY RIGHTS MOVEMENT* 183-226 (2012); JUDITH HEUMANN & KRISTEN JOINER, *BEING HEUMANN: AN UNREPENTANT MEMOIR OF A DISABILITY RIGHTS ADVOCATE* (2020). There are a number of disability rights priorities today that were not a part of the early movement, for example, understanding how race and class intersect with movement leaders and priorities. See, e.g., Letter from Disability Rts. Laws. & Activists to the Steering Comm., tenBroek Disability L. Symp., Nat'l Fed'n for the Blind (Apr. 5, 2019) (on file with author) (highlighting the lack of diversity among the movement's leaders and the need to contend with race and transphobia within the disability legal community).

²⁷² This is the subject of a working book manuscript on the role of publicity in social movements and will not be built out in this piece.

movement and thus, its applicability to other movements,²⁷³ other social movement scholars note the transposability of the metaphor as its legacy:

Coming out was, for the first time, set up in explicit relation to the metaphor of the closet. A hostile, homophobic mainstream culture was blamed for the creation of the closet but individuals, including gay individuals, were blamed for its maintenance. Thus, the mantra “Come Out, Come Out, Wherever You Are” of the 1980s and 1990s can be understood as *just as much of a demand for gays and lesbians to publicly declare their sexuality as an assurance of safety and community*. This new formulation of coming out asserts “the public relevance of what others deem private.”²⁷⁴

Second, the movements organized around, at least in part, the ways in which laws and regulations contributed to their marginalization by forcing them to “hide in the shadows.” For example, in the gay rights context, Professor Kenji Yoshino has argued that laws forced sociopolitical invisibility, such as “Don’t Ask Don’t Tell.”²⁷⁵ Social action and calls from Harvey Milk to come out of the closet forged a movement that led to legal victories and legislative victories such as the death of anti-sodomy laws targeting the gay community.²⁷⁶ Survivors of sexual violence organized the #MeToo movement

²⁷³ See, e.g., Janet E. Halley, *The Politics of the Closet: Towards Equal Protection for Gay, Lesbian, and Bisexual Identity*, 36 UCLA L. REV. 915, 958 (1989) (arguing that LGB individuals “would rather switch than fight” if they are able to blend in with their heteronormative counterparts, limiting the LGB movement).

²⁷⁴ Abigail C. Saguy & Anna Ward, *Coming Out as Fat: Rethinking Stigma*, 74 SOC. PSYCH. Q. 53, 59 (2011) (emphasis added) (citation omitted) (quoting JOSHUA GAMSON, FREAKS TALK BACK: TABLOID TALK SHOWS AND SEXUAL NONCONFORMITY 200 (1998)).

²⁷⁵ Yoshino, *supra* note 15, at 778; see also Letter from Eric H. Holder, Jr., U.S. Att’y Gen., to John A. Boehner, Speaker, U.S. House of Reps., Letter from the Attorney General to Congress on Litigation Involving the Defense of Marriage Act (Feb. 23, 2011), <http://www.justice.gov/opa/pr/letter-attorney-general-congress-litigation-involving-defense-marriage-act> [<https://perma.cc/7BVM-3YAB>] (“[A] growing scientific consensus accepts that sexual orientation is a characteristic that is immutable; it is undoubtedly unfair to require sexual orientation to be hidden from view to avoid discrimination.” (citations omitted)).

²⁷⁶ In one of Milk’s more famous speeches about the ideal of equality, he professed:

Gay people, we will not win our rights by staying quietly in our closets. . . . We are coming out to fight the lies, the myths, the distortions. We are coming out to tell the truths about gays, for I am tired of the conspiracy of silence, so I’m going to talk about it. And I want you to talk about it. You must come out.

The Official HARVEY MILK Biography, MILKFOUNDATION.ORG, <https://milkfoundation.org/about/harvey-milk-biography> [<https://perma.cc/W7D4-WSZT>]. Dan White, also a member of the San Francisco Board of Supervisors, assassinated Harvey Milk and San Francisco Mayor George Moscone on November 27, 1978. White vehemently opposed a city antidiscrimination ordinance introduced to protect gays and lesbians from discrimination in employment, public services, and places of public accommodations. Les Ledbetter, *Bill on Homosexual Rights Advances in San Francisco*, N.Y. TIMES (Mar. 22, 1978), https://timesmachine.nytimes.com/timesmachine/1978/03/22/110810981.pdf?pdf_redirect=true&cip=0

in response to the inability of law to provide protection or justice for survivors. This included a frontal attack on the use of nondisclosure agreements in private settlements with survivors that obscured real structural issues around power and sexual violence.²⁷⁷ Moreover, advocates are calling for Congress to introduce bills that restrict the use of mandatory arbitration agreements in harassment disputes and require employers to disclose harassment claims.²⁷⁸

Similarly, the Dreamers organized around moving “out of the shadows” where punitive immigration law and policies forced undocumented immigrants to hide or face deportation.²⁷⁹ Professor Rose Cuison Villazor, for example, explains that “[t]o lessen the chances of deportation [undocumented immigrants] live in society in largely unnoticed ways and avoid calling attention to their very existence, despite the burdens of living concealed lives.”²⁸⁰ In addition to the threat of or actual deportation, undocumented immigrants face legal obstacles in a variety of other circumstances pertaining to detention, re-entry, and employment. For example, undocumented immigrants can be arrested and detained pending a decision on whether the individual is to be removed from the United States.²⁸¹ If an undocumented immigrant is removed from the United States, that individual will likely face barriers to re-entry.²⁸² Both despite and because of these barriers for undocumented immigrants, many undocumented immigrants have revealed their undocumented status as they “seek to acquire recognition of their existence from society” and change the “shadow” narrative.²⁸³ Professor

[<https://perma.cc/7K6Y-TQXF>]. In fact, Dan White “feared” that his constituents would “move out of the city or ‘react punitively,’” in statements later used as evidence of his animus toward gay men, including Harvey Milk. Tim Fitzsimons, *Forty Years After His Death, Harvey Milk’s Legacy Still Lives On*, NBC NEWS (Nov. 27, 2018, 9:10 AM), <https://www.nbcnews.com/feature/nbc-out/forty-years-after-his-death-harvey-milk-s-legacy-still-n940356> [<https://perma.cc/TE2U-BTRM>] (quoting Ledbetter, *supra*).

²⁷⁷ Melissa Murray, *Consequential Sex: #MeToo, Masterpiece Cakeshop, and Private Sexual Regulation*, 113 NW. U. L. REV. 825, 858, 866-70 (2019).

²⁷⁸ See Elizabeth C. Tippet, *The Legal Implications of the MeToo Movement*, 103 MINN. L. REV. 229, 235 (2018) (describing the current state and federal laws legislators are considering that restrict the use of mandatory arbitration agreements).

²⁷⁹ See, e.g., Rose Cuison Villazor, *The Undocumented Closet*, 92 N.C. L. REV. 1, 1 (2013) (drawing from the “coming out” metaphor to describe how undocumented individuals go through a version of this when they reveal their immigration status).

²⁸⁰ *Id.* at 29.

²⁸¹ See 8 U.S.C. § 1226(a) (“On a warrant issued by the Attorney General, an alien may be arrested and detained pending a decision on whether the alien is to be removed from the United States.”).

²⁸² See *id.* § 1182(a)(9) (stating provisions for excluding undocumented individuals who were previously removed from the United States).

²⁸³ Cuison Villazor, *supra* note 279, at 29, 52.

Cuison Villazor suggests that the change in social narrative may prompt a change in the law,²⁸⁴ a common thread connecting these social movements.

In this respect, the disability rights movement parts ways with its contemporaries. Neither the Rehabilitation Act of 1973 nor the Americans with Disabilities Act came about as a result of a highly publicized and contested social movement. This is not to say that disability rights advocates did not contribute to the promulgation of these disability antidiscrimination laws; their legacies are clear. Rather, when we think about the major social movements of the twentieth and twenty-first centuries such as civil rights movements for racial and gender equality, or the gay rights movement, publicity was a major part of the strategy to gain access to rights. There were relatively fewer nationally televised protests (perhaps other than the occupation of the HEW office in San Francisco to force HEW Secretary Califano to issue regulations for the Rehabilitation Act of 1973),²⁸⁵ there was no publicly visible mass political or social contestation that produced the ADA similar to that which produced the Civil Rights Act of 1964. In fact, legislative advocates involved with the ADA's promulgation explicitly relied on public inattention to the ADA which allowed it to pass without the common partisan negotiations and in-fighting. The next subsection offers initial prescriptions—both legal and policy reforms—that emphasize the role of institutions and not just individuals in advancing publicity values to shift social norms of disability.

C. *The Prescriptive Path Ahead*

The primary contribution of this Article is to challenge an assumption in disability law that privacy best serves antidiscrimination efforts. The operative prescription or set of prescriptions must ask how we make disability more visible; not how do we hide it better. We want to find a way to best incentivize publicity and visibility while mitigating or eliminating its costs.

The recalibration of privacy and publicity values in disability law is a massive, long-term project. However, I offer a few initial prescriptions in

²⁸⁴ See *id.* at 61 (explaining how the Dreamers' coming out movement has pushed for more favorable immigration policies, including President Barack Obama instituting the Deferred Action for Childhood Arrivals (DACA) program).

²⁸⁵ Other publicized protests include the 1990 Capitol Crawl and the "Deaf President Now" protest by deaf students at Gallaudet University. Becky Little, *When the 'Capitol Crawl' Dramatized the Need for Americans with Disabilities Act*, HISTORY (July 24, 2020), <https://www.history.com/news/americans-with-disabilities-act-1990-capitol-crawl> [<https://perma.cc/L9W4-XM4C>] ("Though reporters and photographers covered the Capitol Crawl . . . it didn't receive a huge amount of media attention at the time."). See generally JOHN B. CHRISTIANSEN & SHARON N. BARNARTT, *DEAF PRESIDENT NOW!: THE 1988 REVOLUTION AT GALLAUDET UNIVERSITY* (1995).

service of reframing the current conversations. On the front end, data collection and institutional subsidies can help advance visibility.

1. Disability Data

We need to understand the scope and diversity of disability in society to populate a disability continuum advanced in this Article. Similarly, we need to track investment in disability rights laws, policies, and interventions, and, more broadly, to understand the impact of laws and policies on people with disabilities. Thus, we need to create a structure for disclosure and data gathering that does not only go to diversity departments at universities or human resources departments in the private sector, but also has greater public value.

This Article identified the absence of reliable data on disability in public circulation and attributed this to the construction of disability identity as private. Federal and state governments do collect information on disability,²⁸⁶ however, these data collections are not designed to track and meaningfully measure disability identity. The three main federal disability surveys ask about the same six disability categories of impairment: hearing, vision, cognitive, ambulatory, self-care, and independent living.²⁸⁷

The U.S. Census tracks demographic information on race and ethnicity, but it does not include disability in its main data reporting.²⁸⁸ Instead, the American Community Survey (ACS), a project of the U.S. Census, does gather disability data based on functional impairments tied to daily living. The ACS replaced the Census “long-form” as way of streamlining the formal data collection process.²⁸⁹ The ACS, however, does not survey the same breadth of the population included in the Census; instead, the Census is a decennial count focused on “a basic headcount and minimal demographic data.”²⁹⁰

To align disability with other identity classifications listed, we could include three questions about disability on the short-form census. First, “Do

²⁸⁶ See, e.g., *How Disability Data Are Collected from the American Community Survey*, U.S. CENSUS BUREAU, <https://www.census.gov/topics/health/disability/guidance/data-collection-ac.html> [<https://perma.cc/6H2P-FZF5>] (Feb. 23, 2021).

²⁸⁷ *Id.*

²⁸⁸ While disability questions on the Census originated in 1830, the short-form Census no longer includes questions about disability. See *American Community Survey*, U.S. CENSUS BUREAU, <https://www.census.gov/acs/www/about/why-we-ask-each-question/disability> [<https://perma.cc/CX8Z-SVPT>]; NAT'L DISABILITY RTS. NETWORK, WHY ARE THERE NO DISABILITY-RELATED QUESTIONS ON THE 2020 CENSUS? (2020), <https://www.ndrn.org/resource/why-are-there-no-disability-related-questions-on-the-2020-census> [<https://perma.cc/2VPW-3NPP>]; cf. Brief of Historians and Social Scientists Margo Anderson, Andrew Beveridge, Rachel Buff, Morgan Kousser, Mae Ngai, and Steven Ruggles as Amici Curiae in Support of Respondents at 18, *Dept of Com. v. New York*, 139 S. Ct. 2551 (2019) (No. 18-966).

²⁸⁹ *How Disability Data Are Collected*, *supra* note 286.

²⁹⁰ *Id.*

you identify as a person with a disability?” Second, “Do you believe your disability is visible to others?” Third, “I believe my disability is visible to others because. . .” Followed by answer choices: “(a) I use an assistive device such as a wheelchair, prosthetic, cane, communication board, (b) my speech or behavior is atypical (e.g., physical tics, hyperactivity, speech impairments), or (c) I have been told my disability is visible, or (d) None of the above.” We would still benefit from the data collected by the ACS, however, Census data on disability identity with the seal of the federal government has both expressive and practical value. Data collected on disability should be disaggregated along other demographic lines such as gender or age, city/state, education level, employment status, family status, income, publicly funded supports received (e.g., Medicaid or Medicare) as examples of desired disaggregation. Importantly, definitions of disability listed should address the ways in which people struggle with self-identification as well as the purpose of the data collection and why this information is important to report. This priming may increase the number of people who claim disability identity and allows us a centralized source for capturing intersectional identities.

What effect might such changes have? Interestingly, when the Census first expanded the available categories for race, civil rights organizations such as the NAACP worried about the dilution of the benefits extended to particular minority groups. Specifically, the NAACP claimed that “the creation of a multiracial classification might disaggregate the apparent numbers of members of discrete minority groups, diluting benefits to which they are entitled as a protected class under civil rights laws.”²⁹¹ To what extent might people with more apparent disabilities argue the same point if people can simply self-identify on the Census form as disabled?

Developing the institutional capacity and scaffolding for meaningful data collection could include several pilot projects in public institutions that already have systems in place to collect demographic data. One larger data collection option is to add this question to the Social Security Administration’s data collection, which could help us better understand how people who receive social security disability insurance (SSDI) benefits perceive their connection to disability identity.²⁹²

²⁹¹ Kenneth Prewitt, *Racial Classification in America: Where Do We Go from Here?*, 134 DAEDALUS 5, 10 (2005) (quoting *Federal Measures of Race and Ethnicity and the Implications for the 2000 Census: Hearings Before the Subcomm. on Gov’t Mgmt., Info., & Tech. of the Comm on Gov’t Reform & Oversight*, 105th Cong. 578-79 (1997) (statement of Harold McDougall, Dir., Washington Bureau, NAACP)).

²⁹² Doron Dorfman conducted a qualitative study to better understand the disconnect between perceptions of disability by social security benefits recipients and those narratives created by social security laws. See Doron Dorfman, *Disability Identity in Conflict: Performativity in the U.S. Social Security Benefits System*, 38 T. JEFFERSON L. REV. 47 (2015). The inclusion of a disability question in existing data collection to a broader sample of benefits recipients under certain conditions could be an example of a relatively lower cost data collection that builds on existing institutional structures.

2. Choice Architecture and Publicity Nudges

The balance between privacy and publicity values as structural antidiscrimination devices should vary based on several factors.²⁹³ First, and most important in designing laws and policies with the right balance of privacy and publicity, we need to understand which settings have the greatest potential to shift social norms. Here, the social science literature emphasizes two settings where a person with a less visible marginalized identity can “come out” and impact the attitudes that underwrite discrimination: employment and higher education.²⁹⁴ People choose not to disclose because of the danger (physical, workplace or educational achievement, economic, health) of sharing this information. Assume, for example, that research indicates that employment is the best environment for shifting social norms of disability. Possible institutional responses include legislative efforts to strengthen the antidiscrimination safety net so people who come out know that if they experience bias (both explicit and implicit) as a result of coming out, they receive litigation benefits such as favorable presumptions or reductions in applicable burdens of production or persuasion.²⁹⁵

At the employer level, several potential institutional responses exist. Employers need to change workplace climates, which requires a long-term commitment. This could include required publication of disability antidiscrimination complaints filed with the EEOC against the employer, final opinions, and, if settled, disclosure of the policy changes to be implemented. The employer can commit to public settlements and reject the use of nondisclosure provisions as part of the settlement negotiation. While the person with a disability would have control over their name, there is no reason why the employer cannot publish statistics in the aggregate, particularly for larger organizations. The places of publication could be employee breakrooms or monthly newsletters and meetings where employees would hear about litigation. These statistics would also be made available on the company’s website to ensure public accountability. Another benefit would be to regularly identify opportunities for structural reforms rather than individual accommodations such as when the data shows, for example, that 30% of employees have carpal tunnel. Instead of individually assessing each

²⁹³ See RICHARDS, *supra* note 32 (manuscript intro. at 7-8) (advancing the idea that the design of privacy rules can help mitigate inequities in the balance of power between those who possess disproportionate access to both the means of data control as well as the data itself and those whose data is the oil that runs the data-dependent machinery).

²⁹⁴ See generally GORDON W. ALLPORT, *THE NATURE OF PREJUDICE* (1954) (listing the conditions shown to contribute to greater norm shifts which include equal status, common goals, intergroup cooperation, and support of authorities, law, or customs).

²⁹⁵ The presumptions should be more than Title VII disparate impact presumptions. See generally 42 U.S.C. §§ 2000e–2000e-17.

employee (which can be costly), employers can invest in ergonomic assistive technology that will benefit those with and without carpal tunnel. While one concern is that publicity may increase fear and reluctance to come out, over time, the greater information in circulation can reduce overall costs of disclosure to the individual.²⁹⁶

Second, we need to better understand if the impact and effectiveness of disclosure on social norms varies depending on other factors such as who is disclosing (demographics on age, race, gender, socioeconomic status).²⁹⁷ For example, if we knew that greater normative shifts occurred when well-established, middle-aged, white, men came out as disabled, we might design a top-down approach to disclosure, that creates incentives for people who are well established in their careers and who might even have a public presence to come out. One way might be through financial incentives, direct grants to do this, positions of authority, or being the public face of the organization. In this way, if the data supported it, we could develop the disability “brand” by incentivizing people like Justice Sotomayor (who came out as a person with diabetes), or David Boies (a nationally renowned litigator) and actor Henry Winkler, both who came out as people with learning disabilities. Consider how singer-songwriter-actor Lady Gaga’s coming out as a person with fibromyalgia is changing public discourse on its legitimacy as a chronic illness.²⁹⁸ While placing the risks associated with disclosure on the few with the least to lose, a danger here would be exceptionalism, treating famous people with disabilities as exceptions and not the norm.

Third, we have a first actor problem here. The costs of disclosure are highest, and often are, for first actors in any setting as they are when attempting to nudge disclosure and develop publicity norms. Institutional actors—employers, educators—could consider what Professor Ian Ayres and Cait Unkovic call “information escrows,” or “mechanism[s] of conditional, intermediated communication[s].”²⁹⁹ Ayres and Unkovic argue that the first actor problem in sexual assault and whistleblower cases can be addressed through information banking, or “allegation escrows” that “allow people to

²⁹⁶ Other policy interventions include investing in the creation of an affinity group and commitment to making disability a part of the institution’s overall diversity efforts.

²⁹⁷ I do not list all of the potentially relevant variables here; however, one might consider the effect on norm shifts of types of invisible disabilities disclosed—for example, mental health disabilities might have less of an impact relative to learning disabilities.

²⁹⁸ She made it more prevalent and a part of human difference rather than incapacity. See Laura Hensley, *Lady Gaga on Her Fight with Fibromyalgia: ‘Chronic Pain Is No Joke,’* GLOB. NEWS (Sept. 11, 2018, 1:07 PM), <https://globalnews.ca/news/4438236/what-is-fibromyalgia-lady-gaga> [<https://perma.cc/GB7H-XJWB>] (discussing Lady Gaga’s ongoing struggle with fibromyalgia, a brief history of the chronic illness, and where it stands today as a verified physical illness).

²⁹⁹ Ian Ayres & Cait Unkovic, *Information Escrows*, 111 MICH. L. REV. 145, 150 (2012) (emphasis omitted).

place actionable claims into escrow that will only be filed against a potential defendant by the escrow agent if a prespecified number of allegations are lodged against the same defendant.”³⁰⁰ The primary function of this model, in sexual assault cases, is to respond to the possibility that there will be a first-mover disadvantage in claiming sexual assault or harassment.³⁰¹ Victims are often more reluctant to bring an initial claim because they face a higher risk of retaliation from accused harassers, their credibility is more prone to attack, and some potential claimants may be unsure about whether they incorrectly labeled their experiences as sexual assaults.³⁰² Information escrow allows victims “to transmit claims information to a trusted intermediary, a centralized escrow agent, who forwards the information to proper authorities if (and only if) certain prespecified conditions are met.”³⁰³

Building on this idea to balance interests in privacy and publicity, institutional actors could develop what I call “disability identity escrow,” with an independent intermediary between the employer and the employee who owes fiduciary duties to employees with disabilities. The employer, to encourage disclosure, could allocate funds for the operation of a disability affinity group to engage in such activities as networking, socializing with colleagues, or accessing professional development opportunities.³⁰⁴ This is the strategic nudge. However, the employee maintains control over whether to participate and sets conditions of disclosure with the disability identity escrow agent. Because the intermediary is a fiduciary of the employee, the identity escrow agent can work with the employee to set the trigger for disclosure. For example, Employee A says: “You may disclose to the employer if four other employees also participate and disclose.” The employee does not have to reveal (but may do so voluntarily) the specific diagnosis to participate and the employer cannot require medical documentation as a condition of participation. Assume employees B, C, and D have already deposited their disability identity in escrow and set the same trigger and conditions as A. The identity escrow agent then releases the information to the employer who allocates the funding to the affinity group. In terms of remedies, if the identity escrow agent breaches the duty of loyalty or care, an employee has standing to bring a tort action in state court. If the employee with a disability experiences discrimination because of their association with and membership in the affinity group, or other discrimination based on disability since the

³⁰⁰ *Id.* at 159.

³⁰¹ *Id.* at 188-91.

³⁰² *Id.* at 160-61.

³⁰³ *Id.* at 147.

³⁰⁴ Another possibility is to use information escrow concepts more in line with Ayres and Unkovic by banking disability discrimination complaints or hostile work environment claims.

person disclosed, current antidiscrimination remedies would apply with potential amendments providing for litigation incentives.³⁰⁵

3. Disability Law Reforms

Data collection and choice architecture are front-end interventions to encourage greater visibility for those with less apparent disabilities. But we also need to think about back-end interventions, that is, when people do come out, what protections are in place sufficient to reduce costs on the front-end nudges discussed above?

Here, we can consider potential reforms to disability laws that advance greater publicity of disability identity. I will offer milder and more intense interventions here. Consider the elimination of the disability definition in the ADA as a nudge. Rather than exerting resources on the litigation of whether someone has a legal disability, we might repeal that portion of the ADA and have plaintiffs address discrimination and causation from the start. That is, rather than have a person with a less visible disability expend time and money to secure an expert, complete the necessary forms, engage in the interactive process, we might decide that like race or gender, the adjudicative focus should be the substantive discrimination claim.

If we eliminate the threshold question of whether the individual meets the disability definition, people may fear fraud. Questions about the nature of disability and extent of functional impairment will likely be addressed, in the employment context, for example, when pleading and proving the failure to provide a reasonable accommodation, improper discharge, or disparate impact. The benefit of eliminating this step is its signal to people with disabilities that personal claims to disability deserve a certain degree of deference to the individual disabled plaintiff.

If we want to incentivize publicity, we might place a greater burden on the individual in the first instance to disclose disability more publicly. To do this, we need to develop a stronger antidiscrimination safety net to help capture potential discrimination after disclosure. We want to get to the point where people with disabilities no longer need the privacy protections in the ADA because our antidiscrimination efforts (both front- and back-end) are working effectively. However, until then, the risks and potential costs to individuals are great. To mitigate these risks, we should consider litigation benefits and procedural rule reforms that could help incentivize individuals and institutional actors to promote visibility. Consider, for example, a shift of the burden of proof, specifically the burden of persuasion: a plaintiff who comes out in the workplace and experiences an adverse employment action

³⁰⁵ See *supra* Part II.

based on disability (or perceived as such) might show that she was public about her otherwise less apparent disability. This would be a low burden of persuasion where she might show that she wore a “Mad Pride” shirt celebrating neurodiversity and psychosocial disabilities during the employee summer outing. With this evidentiary showing, the burden might then shift to the employer to show that the alleged adverse employment action was not motivated by disability.

CONCLUSION

Disability law has a privacy problem. Taking disability public may appear counterintuitive, at least initially, but, as this Article has argued, maintaining existing privacy preferences in disability laws without interrogation and public debate is not costless. Specific prescriptions require public debate about the value of privacy and publicity in a given context, the stakes of disclosure and nondisclosure, and the role of the state in advancing publicity or privacy in those areas. In this sense, this Article opens the conversation by challenging an untested assumption and offering an analytical framework for analysis and discussion. After three decades and with such a significant public information deficit about the prevalence and diversity of capabilities under the umbrella of “people with disabilities,” we cannot afford to ignore this debate any longer.