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## Overcoming Fragmentation in Disability and Health Law

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# OVERCOMING FRAGMENTATION IN DISABILITY AND HEALTH LAW

Ani B. Satz\*

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## INTRODUCTION

Legal structures respond to human need by defining situations in which specific rights or entitlements attach. Legal protections usually depend on

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whether an individual is operating within a particular time period,<sup>1</sup> physical space,<sup>2</sup> or other context.<sup>3</sup> The assumption underlying this targeted approach to state response is that the law must make distinctions between individuals that both determine eligibility for legal protections and possible remedies. In litigation, this approach may be perceived as necessary to promote fairness amongst adversarial parties.<sup>4</sup> Targeted approaches may also facilitate desired judicial outcomes, by expanding, contracting, or reframing liability.<sup>5</sup> Laws structuring social welfare programs or other access to material resources may target certain populations to control public expenditures.<sup>6</sup>

The major weakness of this targeted legal approach is that individuals' experiences and needs are not viewed holistically across civic and social realms, but in fragments defined by certain legally protected contexts. By varying protection based on context, the law fragments the human experience. The legal subject experiences a condition, harm, or other circumstance that the

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<sup>1</sup> Statute of limitation periods are the most obvious example of time period limitations. Statutes may also apply to individuals of a certain age, such as the Age Discrimination in Employment Act or sections of the Social Security Act that authorize Medicare and the Children's Health Insurance Program (CHIP). Age Discrimination in Employment Act of 1967, 29 U.S.C. §§ 621–634 (2006) (amended 2009); Health Insurance for the Aged Act (Medicare Act), Pub. L. No. 89-97, tit. XVIII, 79 Stat. 290 (1965) (codified as amended in scattered sections of 26, 42, and 45 U.S.C. (2006)); Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009, Pub. L. No. 111-3, tit. XXI, 123 Stat. 8 (codified in scattered sections of 26, 29, and 42 U.S.C.). For a discussion of the effects of time-framing in assessing conduct in criminal law, see generally Mark Kelman, *Interpretive Construction in the Substantive Criminal Law*, 33 STAN. L. REV. 591 (1981).

<sup>2</sup> Statutes typically cover particular places in the public realm, such as the workplace, public transportation, and places of public accommodation. See Ani B. Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, 83 WASH. L. REV. 513, 541–43 (2008) [hereinafter Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*]; see also Ani B. Satz, *Fragmented Lives: Disability Discrimination and the Role of "Environment-Framing,"* 68 WASH. & LEE L. REV. (forthcoming 2011) [hereinafter Satz, *Fragmented Lives*] (discussing the effects of judicial "environment-framing" on disability eligibility and remedy).

<sup>3</sup> See, e.g., Daryl J. Levinson, *Framing Transactions in Constitutional Law*, 111 YALE L.J. 1311, 1317 (2002) (discussing how frames in constitutional law either "creat[e] or negat[e] individualized harm" or "direct judicial attention to the types and patterns of government behavior that are significant for purposes of implementing particular constitutional norms").

<sup>4</sup> Fairness concerns underlie statute of limitation periods as well as laws that limit private firm liability to particular contexts. For example, an employer's liability for the actions of her employees is limited to harm caused by employee actions undertaken within the scope of their employment. See, e.g., William O. Douglas, *Vicarious Liability and Administration of Risk* (pt. 1), 38 YALE L.J. 584, 585 (1929) ("Compensation for an injured party comes first, but that cannot be considered separately from the capacities of the parties, to whom the loss is allocated, to bear it. Only when those capacities are measured, can the scope of the right of the injured party be intelligently determined.").

<sup>5</sup> See *supra* note 1, 3–4, and accompanying text.

<sup>6</sup> Health benefit programs impose age limitations for this reason. See statutes cited *supra* note 1 and accompanying text. Similarly, the Americans with Disabilities Act limits accommodation to that which is "reasonable," and does not impose an "undue hardship" on the firms making and affected by the accommodation. Americans with Disabilities Act (ADA) of 1990, 42 U.S.C. § 12111(9)–(10) (2006).

law fails to recognize adequately. Legal protections start and stop in various places within the public realm and may not afford the continuity necessary for meaningful civic or social participation. Further, laws conferring material benefits are rarely extended into the private sphere, failing to respond to the fact that some individuals require assistance to leave their homes or otherwise enter the public realm.<sup>7</sup>

Legal structures fragment protections across almost every field of law, by addressing only certain time periods, environments, issues, or persons. Legal fragmentation is perhaps most consequential, however, in the context of disability and health law. In this context, the human condition itself is at stake. Individuals who are disabled or seriously ill (i.e., who have a condition that impairs functionality and requires intensive and extended medical care) may not be able to enter the public realm to benefit from the protections and privileges that exist in that domain.<sup>8</sup> Thus, a fragmented approach to law fails to recognize or appreciate that barriers arising in an environment the law does not address, such as the home, may impact participation in other environments where the law does provide protections, such as the workplace.

Unsurprisingly, dominant political, economic, and social theories influencing the law assume that individuals are able to enter society and participate on equal ground. For example, the “liberal subject” of Rawlsian contractarian theory is one who does not experience profound periods of

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<sup>7</sup> Lack of accommodation in the private realm is the consequence of the well-known public-private distinction, which views the proper role of government as regulating only what is considered public or inside the marketplace. MARTHA ALBERTSON FINEMAN, *THE AUTONOMY MYTH: A THEORY OF DEPENDENCY* 38–39, 208 (2004) [hereinafter FINEMAN, *THE AUTONOMY MYTH*]; cf. MARTHA ALBERTSON FINEMAN, *THE NEUTERED MOTHER: THE SEXUAL FAMILY AND OTHER TWENTIETH CENTURY TRAGEDIES* 162 (1995) [hereinafter FINEMAN, *THE NEUTERED MOTHER*] (discussing the characterization of caretaking as private labor); ROBIN L. WEST, *RE-IMAGINING JUSTICE: PROGRESSIVE INTERPRETATIONS OF FORMAL EQUALITY, RIGHTS, AND THE RULE OF LAW* 7 (2003) (same); Robin West, *From Choice to Reproductive Justice: De-Constitutionalizing Abortion Rights*, 118 *YALE L.J.* 1394, 1415–16 (2009) [hereinafter West, *From Choice to Reproductive Justice*] (same). Affirmative protections in the private realm are largely restricted to limited criminal protections against violence occurring within the home.

<sup>8</sup> The definition of *seriously ill* is not meant to be precise. It refers generally to the type of illness that prevents an individual from participating in society and benefitting from the protections and resources that exist in the public domain. The conditions I am imagining are those that are both severe enough, and of sufficient duration, to undermine the ability to obtain or retain employment or otherwise participate meaningfully in society. Such conditions are likely to exceed six months. The ADA, as amended, uses a similar time frame to distinguish between conditions that may be “regarded as” disabilities and those that are “transitory and minor,” which are “impairment[s] with an actual or expected duration of 6 months or less.” ADA § 12102(3)(A)–(B) (Supp. II 2008).

disability or illness, but rather is fully functional over her lifetime.<sup>9</sup> Libertarian theorists assume that individuals are capable of laboring for wages.<sup>10</sup> Law and economics scholars view individuals as possessing the ability to form and order certain preferences in ways that allow them to participate actively and efficiently in the market.<sup>11</sup> Legal rights and protections premised on these assumptions fail to reach some disabled and seriously ill individuals who face barriers to entry into the workforce, barriers to service and facility accessibility, or significant medical expenditures. Indeed, it is likely that many laws—and most of the arguments put forth in law review articles adopting the foregoing theories—begin with assumptions about social participation that exclude disabled and seriously ill individuals.

This Article explores the previously underappreciated problem of legal fragmentation for individuals who are disabled or seriously ill. I examine such fragmentation at the macro- and micro-levels. At the macro-level, I discuss how legal structures—namely legislatures and government agencies and the laws and regulations they respectively create—respond to disability and illness. I also discuss fragmentation in disability law at the micro-level, or how judicial construction of laws further undermines protections for individuals

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<sup>9</sup> See JOHN RAWLS, *POLITICAL LIBERALISM* 20 (expanded ed. 2005) (“I put aside for the time being these temporary disabilities and also permanent disabilities or mental disorders so severe as to prevent people from being cooperating members of society in the usual sense.”); John Rawls, *A Kantian Conception of Equality*, *CAMBRIDGE REV.*, Feb. 1975, at 94, reprinted in JOHN RAWLS: *COLLECTED PAPERS* 254, 259 (Samuel Freeman ed., 1999) [hereinafter Rawls, *A Kantian Conception of Equality*]; John Rawls, *Social Unity and Primary Goods*, in *UTILITARIANISM AND BEYOND* 159, 168 (Amartya Sen & Bernard Williams eds., 1982) [hereinafter Rawls, *Social Unity and Primary Goods*]. While Rawls argues that health care resources for “normal health and medical needs” could be provided at the “legislative stage” (i.e., after the principles to guide just resource allocation are chosen), his theory does not account for services for “special health care” needs, or those that extend beyond acute illness or injury. See John Rawls, *Some Reasons for the Maximin Criterion*, 64 *AM. ECON. REV. (PAPERS & PROC.)* 141 (1974), reprinted in JOHN RAWLS: *COLLECTED PAPERS*, *supra*, at 225, 227; Rawls, *Social Unity and Primary Goods*, *supra*, at 168. Rawls argues that anything beyond acute care is a “hard case[] [that] can distract our moral perception by leading us to think of people distant from us whose fate arouses pity and anxiety.” Rawls, *A Kantian Conception of Equality*, *supra*, at 259.

<sup>10</sup> See, e.g., ROBERT NOZICK, *ANARCHY, STATE, AND UTOPIA* 246–52 (1974) (assuming the ability to work when discussing “meaningful work”). Many libertarians believe antidiscrimination mandates and publically provided state disability and health benefits disrupt the efficiency of the marketplace. See, e.g., RICHARD A. EPSTEIN, *MORTAL PERIL: OUR INALIENABLE RIGHT TO HEALTH CARE?* 81–120, 147–84 (1997) (discussing the distribution of disability and health care benefits as falling outside the competitive market). See generally RICHARD A. EPSTEIN, *FORBIDDEN GROUNDS: THE CASE AGAINST EMPLOYMENT DISCRIMINATION LAWS* (1992) (arguing that antidiscrimination laws violate freedom of contract and impose transaction, agency, political, and other costs on private firms by mandating hiring practices that discourage homogeneity and expose firms to liability for firing practices).

<sup>11</sup> See, e.g., A. MITCHELL POLINSKY, *AN INTRODUCTION TO LAW AND ECONOMICS* 124–27 (2d ed. 1989); RICHARD A. POSNER, *ECONOMIC ANALYSIS OF LAW* 504–07 (7th ed. 2007).

with disabilities.<sup>12</sup> Part I of the Article presents my theory of fragmentation. Fragmentation occurs when the lived experience of an individual with an impairment differs from what is recognized by the law. This disrupts legal protections and impedes access to material resources. Parts II and III explore the implications of this theory for fragmentation in disability and health law, respectively.

Part IV challenges the legal assumptions that give rise to fragmentation in disability and health law as well as the philosophical underpinnings of those assumptions. I argue that the current legal approach fails to recognize universal vulnerability to disability and serious illness and the social disadvantage that may follow from each of those states. I assert that the law must better align with the human experience of disability and serious illness, by recognizing that many individuals are not fully functioning, and their impairments extend beyond discrete statutorily protected realms.<sup>13</sup> I suggest at a minimum that an individual must be viewed holistically, across the full range of environments in which she functions, to assess her level of impairment and need for accommodation or other modification. To best address disability and serious illness, the state may need to restructure legal and social institutions. Moving toward universal approaches to disability and health benefits will increase participation in the civic and social realms by individuals who are disabled or ill. The Article then concludes by remarking on the implications of my findings for an era of re-regulation.

## I. A THEORY OF FRAGMENTATION

Most succinctly stated, fragmentation occurs when law separates or breaks apart the experience of the legal subject.<sup>14</sup> This happens because the actual experience of living with a disability or illness differs from the legally recognized one.<sup>15</sup> The disjunction between the actual and legal experience manifests itself in two ways. First, an individual may identify as ill or disabled but not be legally recognized as such. As a result, she may not be entitled to

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<sup>12</sup> I introduce my theory of environment-framing and micro-level fragmentation in Satz, *Fragmented Lives*, *supra* note 2.

<sup>13</sup> In this Article, I distinguish between individuals with disability and serious illness. The categories may overlap when serious illness becomes disabling. *Individuals with impairments* may refer to either individuals with disability or serious illness, depending on the context in which it is used.

<sup>14</sup> I introduce my theory of fragmentation in Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 2.

<sup>15</sup> I use *illness* to mean *serious illness*, as defined in the Introduction. See *supra* note 8 and accompanying text.

protections or material resources. Second, an individual who is recognized as ill or disabled may experience inappropriate limitations to the protections or resources she receives.

Fragmentation occurs on both macro- and micro-levels. At a macro-level, fragmentation results from statutes and regulations that address impairment as exceptional rather than as part of the human condition. Impairment is treated as legally relevant only in certain contexts, in the sense that protections and benefits attach to particular individuals within specific situations. On a micro-level, fragmentation occurs (and is exacerbated) due to judicial construction of legal rules or policies about impairment. In other words, individuals with disability and illness are disadvantaged by the plain language of laws as well as the manner in which those laws are construed and applied.

At both the macro- and micro-levels, fragmentation may be linked to the state's response to two inquiries, namely, whether an individual is disabled or ill, and, if so, whether she is entitled to protections or benefits.<sup>16</sup> In both cases, there is a disconnection between the experience of living with disability or illness and the legal recognition of that experience. In the initial context of eligibility, an individual may subjectively experience disability or illness but not be legally recognized as having such. This may be damaging to one's self-conception and deeply offensive.<sup>17</sup> This is particularly so in the case of laws with the stated purpose of promoting access for, or providing benefits to, individuals with disabilities.<sup>18</sup> Fragmentation may also be experienced by

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<sup>16</sup> I argue in other work that the U.S. Supreme Court conflates in some instances three distinct and sequential inquiries within disability analysis: (1) Is an individual disabled? (2) Is she entitled to an accommodation? and (3) What is the nature of her accommodation? See Ani B. Satz, *A Jurisprudence of Dysfunction: On the Role of "Normal Species Functioning" in Disability Analysis*, 6 YALE J. HEALTH POL'Y L. & ETHICS 221 (2006). The Court's historic narrow interpretation of disability likely resulted in the blurring of these inquiries. Since the ADA Amendments Act (AAA) allows a larger protected class, it is possible that the Court will begin to treat the first and second (and possibly the third) inquiries as more distinct.

<sup>17</sup> Cf. SUSAN WENDELL, *THE REJECTED BODY: FEMINIST PHILOSOPHICAL REFLECTIONS ON DISABILITY* 25–28, 175–77 (1996) (discussing disabling illness as part of self-identity); Susan Wendell, *Unhealthy Disabled: Treating Chronic Illnesses as Disabilities*, HYPATIA, Fall 2001, at 17, 30–32 (“[A]lthough I would joyfully accept a cure if it were offered me, I do not need a cure and I do not regret having become ill. I suppose many people suspect I am making the best of a miserable fate, but then they probably think something very similar about other expressions of disability pride.” (citation omitted)).

<sup>18</sup> Disability advocates argue that the voices of individuals living with disabilities are not heard during policy and law development. As a result, laws are passed that fail to appreciate the experience of living with a disability. See generally JAMES I. CHARLTON, *NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT* (2000) (discussing disability oppression and the need for individuals with disabilities to inform disability policy). Fragmentation deepens this criticism. Additionally, it may be offensive to individuals with disabilities to have individuals without disabilities determine their needs.

individuals who are legally recognized as disabled or ill, when the law fails to appreciate that their needs extend throughout the life course or to unprotected environments. In this situation as well, the lived experience of disability or illness differs from the legal one.

Fragmentation in disability and health law occurs most notably in four contexts: eligibility for disability antidiscrimination protections, eligibility for disability and health care benefits, determination of the scope of accommodation or other modification under antidiscrimination mandates for individuals legally recognized as disabled, and determination of the scope of material resources available to individuals with disabilities and illnesses under social benefits regimes. For individuals with disabilities, eligibility for antidiscrimination protections and benefits under social welfare programs depends on the degree and nature of their impairments. Eligibility for public health benefits for individuals without disabilities is typically contingent on age or membership in a targeted group. Such individuals may qualify for benefits if they are indigent, federal employees, military personnel, veterans, or the dependents of individuals within those categories. The scope of accommodation or other modification under disability antidiscrimination mandates is affected by the range of environments covered by statute. The scope of health benefits for disabled and ill individuals alike is determined largely by what is viewed as “medically necessary.”

In this Article, I focus on the first three contexts of fragmentation: eligibility for disability antidiscrimination protections, eligibility for disability and health benefits, and accommodation or other modification under antidiscrimination mandates. I also discuss some issues of health care delivery that result in fragmentation of protections for individuals who are ill. The determination of medically necessary or minimum health benefits is a significant issue that requires further attention; I offer suggestions in other work for increasing the range of basic health care benefits available to individuals through private and public insurance.<sup>19</sup>

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<sup>19</sup> See, e.g., Ani B. Satz, *The Limits of Health Care Reform*, 59 ALA. L. REV. 1451 (2008) (discussing how the “basic minimum” approach to health care does not allow meaningful access to basic health care services); Ani B. Satz, *Toward Solving the Health Care Crisis: The Paradoxical Case for Universal Access to High Technology*, 8 YALE J. HEALTH POL’Y L. & ETHICS 93 (2008) (arguing that some forms of high technology medicine support the goals of basic health care).



## II. FRAGMENTATION IN DISABILITY LAW

Fragmentation in disability law occurs when the human experience of disability differs from the one recognized in the law: Laws deny protections or benefits to individuals with impairments who do not qualify as “disabled” or limit such protections or benefits to certain contexts. In the sections that follow, I examine disability civil rights protections as well as disability benefits statutes. At the macro-level, disability civil rights statutes fail to recognize that disability may extend to all areas of the public sphere and into the private realm. Disability benefits statutes restrict eligibility based on income and ability to work. At the micro-level, judicial interpretation of antidiscrimination statutes results in further fragmentation, when courts frame environments for assessing impairment in a manner that limits both disability eligibility and injunctive relief.

### A. *Civil Rights Protections*

Antidiscrimination laws protect individuals with certain characteristics, who qualify for protected class status. These laws are based on a conception of formal equality, or the idea that individuals must be treated in the same manner in a given context. Thus, disability antidiscrimination mandates facilitate access for individuals with disabilities into parts of the public sphere accessible to individuals without disabilities.

By nature, a formal equality approach to legal protection excludes individuals who do not possess the requisite characteristics to qualify for the protected class. Individuals with impairments that do not qualify them for the protected class are without legal entitlement to accommodation or other modification to promote access and, consequently, may be unable to participate in the civic and social realms. These individuals subjectively experience lives with disabilities but are not protected by law as individuals with disabilities. The law fragments their experience of living with disabilities because it denies them protections based on disability altogether. Individuals recognized as disabled may also experience fragmentation, when accommodation or other modification is limited to certain contexts. In subsection 1 below, I discuss both of these forms of fragmentation as macro-level fragmentation because they occur as a result of statutory mandates.

Additionally, fragmentation occurs at a micro-level when courts interpret disability civil rights statutes. Courts construct environments in which to assess impairments in ways that may deny eligibility for statutory protections

or, even if individuals are considered legally disabled, limit or deny accommodation or other modification needed for access. I discuss micro-level fragmentation in subsection 2 of this Part.

### 1. *Macro-Level Fragmentation*

Individuals with disabilities experience fragmentation, or a disjunction between their lived experience of disability and their legally recognized one, at the macro-level under civil rights statutes and their supporting regulations. Civil rights statutes require protected class status for protection against disability discrimination, which denies coverage to some individuals who self-identify as disabled. Further, disability is addressed only in statutorily designated environments.

#### a. *Eligibility for Protected Class Status*

At the federal level, the Americans with Disabilities Act (ADA) of 1990 protects individuals who qualify as part of the disability class.<sup>20</sup> The ADA is, in fact, the only federal civil rights statute with an eligibility test that has excluded most individuals seeking protection.<sup>21</sup> For almost twenty years, class membership functioned as one of the most significant hurdles to ADA protection.<sup>22</sup> This difficulty in qualifying for protection led to the enactment of the ADA Amendments Act (AAA) of 2008.<sup>23</sup>

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<sup>20</sup> ADA, 42 U.S.C. §§ 12101–12213 (2006), amended by ADA Amendments Act (AAA) of 2008, Pub. L. No. 110-325, 122 Stat. 3553. Most states have statutes that parallel the ADA; some afford greater protections than the ADA. See Alex Long, *State Anti-Discrimination Law as a Model for Amending the Americans with Disabilities Act*, 65 U. PITT. L. REV. 597, 625–33 (2004).

<sup>21</sup> See Ruth Colker, *The Americans with Disabilities Act: A Windfall for Defendants*, 34 HARV. C.R.-C.L. L. REV. 99, 100 n.7, 108–10 (1999) [hereinafter Colker, *Windfall for Defendants*] (finding that courts refuse to defer to agency regulations that would favor disability status, and many cases are dismissed on summary judgment; approximately 94% of plaintiffs in employment cases lose at the trial level, and 84% of the cases that proceed fail on appeal; and 82.8% of plaintiffs lose in cases against public entities). But see Ruth Colker, *Speculation About Judicial Outcomes Under 2008 ADA Amendments: Cause for Concern*, 2011 UTAH L. REV. (forthcoming) (finding in a new study using the PACER electronic database of filed cases that the greatest limitations to plaintiffs succeeding in disability discrimination cases are the inability to retain adequate counsel and the limits in the legal knowledge of pro se plaintiffs; 78% of pro se plaintiffs experienced significant legal difficulties, including failure to comply with EEOC requirements and neglecting to file their cases in time, and only 5% of pro se plaintiffs enjoyed a favorable case outcome); Sharon Hoffman, *Settling the Matter: Does Title I of the ADA Work?*, 59 ALA. L. REV. 305, 309–11 (2008) (discussing settlements and informal agreements not accounted for in Colker's 1999 study).

<sup>22</sup> See Colker, *Windfall for Defendants*, supra note 21, at 108.

<sup>23</sup> AAA § 2(b)(1), (5) (“The purposes of this Act [include] . . . reinstating a broad scope of protection . . . under the ADA; . . . and . . . convey[ing] that the question of whether an individual’s impairment is a disability under the ADA should not demand extensive analysis . . .”).

Under both the original and amended Act, to be part of the protected class an individual must: (1) have “a physical or mental impairment” that “substantially limits” her in “one or more major life activities,” (2) have “a record of such an impairment,” or (3) “be[] regarded as having such an impairment.”<sup>24</sup> Prior to the AAA, courts narrowly interpreted “substantially limits” and “major life activities” for all three of these prongs of the disability threshold test.<sup>25</sup> For example, courts interpreted “substantially limits” to mean “significantly restricts.”<sup>26</sup> In addition, an individual’s impairment was assessed following measures to mitigate disability, such as the use of drugs or assistive devices.<sup>27</sup>

The AAA significantly broadens the definition of “disability.”<sup>28</sup> It eliminates the requirement that an individual’s impairment be assessed after mitigating measures.<sup>29</sup> Further, the Act lowers the threshold for demonstrating a “substantial” limitation,<sup>30</sup> expands the range of “major life activities” considered,<sup>31</sup> and clarifies that limitation is required in only one major life activity.<sup>32</sup> Episodic impairments, such as epilepsy and cancers in remission or managed through chemotherapy, which were previously not recognized as

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<sup>24</sup> ADA § 12102(2) (2006 & Supp. II 2008).

<sup>25</sup> These prongs include actual, “record of,” and “regarded as” impairment. *Id.* For cases pertaining to judicial interpretation of “substantially” and “major life activities” in the context of actual impairment prior to the AAA, see, for example, *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*, 534 U.S. 184, 201 (2002) (finding that a factory worker who could perform some household manual tasks may not be “substantially limited” in the major life activity of performing manual tasks); *Albertson’s, Inc. v. Kirkingburg*, 527 U.S. 555, 564–65 (1999) (finding that a truck driver with monocular vision was not substantially limited in the major life activity of seeing); *Murphy v. UPS, Inc.*, 527 U.S. 516, 521–25 (1999) (finding that a mechanic with severe hypertension was not substantially limited in any major life activity or “regarded as” so limited in the major life activity of working); *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 481–94 (1999) (finding that twin sister pilots with severe myopia were not substantially limited in any major life activity or “regarded as” so limited in the major life activity of working).

<sup>26</sup> *Toyota*, 534 U.S. at 198; see also 29 C.F.R. § 1630.2(j) (2008) (stating that an individual is “substantially limited” if she is “unable to perform . . . [or is] [s]ignificantly restricted as to the condition, manner or duration under which [she] can perform a particular major life activity as compared to . . . the average person in the general population”).

<sup>27</sup> See, e.g., *Kirkingburg*, 527 U.S. at 556 (plaintiff was not disabled because his brain compensated for his monocular vision); *Murphy*, 527 U.S. at 516 (plaintiff was not disabled when he was medicated for severe hypertension); *Sutton*, 527 U.S. at 471 (plaintiffs were not disabled when they were wearing their eyeglasses).

<sup>28</sup> AAA §§ 2(b)(4)–(6), 4(a).

<sup>29</sup> *Id.* §§ 2(b)(2), 4(a).

<sup>30</sup> *Id.* § 2(b)(4)–(6).

<sup>31</sup> *Id.* §§ 2(b)(4), 4(a); see also *infra* note 66 and accompanying text.

<sup>32</sup> *Id.* § 4(a).

disabilities by many courts,<sup>33</sup> are now considered disabilities if they meet the threshold level of disability when active.<sup>34</sup> The AAA also eliminates the requirement that an individual “regarded as” disabled demonstrate that the alleged disability, if actual, would meet the threshold test.<sup>35</sup> This is significant because some individuals regarded as disabled may experience discrimination on the basis of impairments that do not fall within the legal definition of disability; these individuals would not otherwise be protected.

While the AAA broadens the definition of disability for claimants under the eligibility test, it does not fully address the disjunction between the lived experience of impairment and the legal one. Expanding the definition of disability may protect more individuals with disabilities, but it fails to respond to the vulnerability of individuals to discrimination outside the protected class. The exception is for individuals regarded as disabled. Here, Congress took a universal rather than a targeted approach to eligibility for ADA protection. All individuals regarded as disabled, and who experience discrimination on that basis, qualify for ADA protection. However, “regarded as” plaintiffs, including those with actual impairments that do not rise to the legal level of disability, are no longer entitled to accommodation or other modification.<sup>36</sup>

Further, parts of the original Act continue to pose limitations with respect to class eligibility. The ADA measures eligibility with regard to current or episodic impairment. It does not account for the vulnerability of some individuals with impairments who may become unable to function if their workplaces or other environments change. Further, the ADA requires that individuals are (or were) strongly symptomatic for disabling illness; it does not view individuals who are mildly symptomatic or asymptomatic for such conditions as disabled, though they could certainly encounter discrimination or other barriers to access.<sup>37</sup> These individuals might be able to bring “regarded

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<sup>33</sup> See, e.g., *Landry v. United Scaffolding, Inc.*, 337 F. Supp. 2d 808, 816 (M.D. La. 2004) (finding that a plaintiff with epilepsy was not disabled); *Breech v. Becon Constr.*, No. 02-404, 2002 U.S. Dist. LEXIS 19702, at \*14 (E.D. La. Oct. 16, 2002) (same); *Dinsdale v. Wesley*, No. C98-0123, 2000 U.S. Dist. LEXIS 12015, at \*4-5, 12-13 (N.D. Iowa Apr. 13, 2000) (finding that a woman with colon cancer who was able to work following surgery and chemotherapy was not disabled); *Farmer v. Nat'l City Corp.*, No. C-2-94-966, 1996 U.S. Dist. LEXIS 20941, at \*16-17 (S.D. Ohio Apr. 5, 1996) (finding that a man in remission from prostate cancer with lingering incontinence and impotence was not disabled).

<sup>34</sup> AAA § 4(a).

<sup>35</sup> *Id.* §§ 2(b)(3), 4(a) (returning to the standard articulated in *Sch. Bd. of Nassau Cnty. v. Arline*, 480 U.S. 273, 282-86 (1987)).

<sup>36</sup> *Id.* § 6(a)(1).

<sup>37</sup> ADA, 42 U.S.C. § 12102 (2006 & Supp. II 2008) (“physical or mental impairment” assumes current impairment). *But cf.* Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881

as” claims, though they would not be entitled to accommodation or other modification. In addition, the ADA does not account for the effects of an individual’s willpower or resilience in overcoming functional impairment, which may undermine disability status.<sup>38</sup>

The protected class approach of the ADA is mirrored in other disability statutes. For example, the ADA’s disability threshold test is adopted by the Federal Rehabilitation Act (FRA),<sup>39</sup> which applies to entities that receive federal funds, and the Federal Fair Housing Act (FHA), which seeks to prevent discrimination in housing sales, rentals, and related transactions and services.<sup>40</sup> Many states also have statutes that parallel the ADA.<sup>41</sup>

In sum, a targeted approach to disability necessarily excludes some individuals with impairments from the protected class. In Part IV, I address the question of how the state should respond to impairment and vulnerability to discrimination outside the protected class. I argue in the next part that the scope of accommodation or other modification for class members may be limited by a situational view of the vulnerability associated with disability discrimination. This situational view leads to fragmentation, when the experience of living with a disability throughout a range of environments does not match the legally recognized view of disability as relevant in only particular environments.

#### *b. Disability Accommodation and Other Modification*

Even for individuals covered under an antidiscrimination mandate, protections are commonly limited. Impairment is recognized as legally relevant only in statutorily designated environments. Under the ADA, accommodation or other modification is available to promote access to the workplace,<sup>42</sup> public services,<sup>43</sup> and places of public accommodation.<sup>44</sup> This

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(codified in scattered sections of 26, 29, and 42 U.S.C.) (prohibiting discrimination in work and health insurance coverage based on genetic information, including discrimination against individuals who are asymptomatic or mildly symptomatic for genetic conditions or diseases); *Bragdon v. Abbott*, 524 U.S. 624, 637 (1998) (recognizing HIV or “pre-symptomatic AIDS” as a physical impairment); *see also infra* note 66 and accompanying text discussing *Bragdon*.

<sup>38</sup> An exception exists for “learned behavioral or adaptive neurological modifications.” ADA § 12102(4)(1)(E)(i)(IV).

<sup>39</sup> Rehabilitation Act (FRA) of 1973, 29 U.S.C. §§ 705(20), 794 (2006).

<sup>40</sup> Fair Housing Act (FHA), 42 U.S.C. §§ 3602(h), 3604 (2006).

<sup>41</sup> *See Long, supra* note 20, at 625–33.

<sup>42</sup> ADA § 12111(9) (2006).

<sup>43</sup> *Id.* §§ 12142, 12143(a), 12144, 12146, 12147.

includes public transportation operated by both public and private entities.<sup>45</sup> The same environments are covered by parallel state statutes and the FRA.<sup>46</sup> The FHA applies only to housing and related services.<sup>47</sup>

The scope of accommodation or other modification under antidiscrimination mandates, which seek to promote formal equality, is narrow.<sup>48</sup> Promoting formal equality requires only a limited range of disability accommodation or other modification within the environments that are designated as protected.<sup>49</sup> While this accommodation or other modification may involve the resources of private firms, any injunctive relief available is not intended as a mechanism to redistribute resources or address substantive inequality.<sup>50</sup>

This approach to accommodation and other modification under civil rights mandates results in fragmentation—again, a disjunction between the lived experience of disability and the legally recognized view of it—in two ways. First, disability access extends only to particular environments, not the activities the environments support.<sup>51</sup> This is a significant limitation to promoting inclusion. For instance, an individual may be able to enter a workspace, board a public bus, or enter a shopping mall, but that does not mean that she will be able to work, travel to a desired destination, or shop

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<sup>44</sup> *Id.* §§ 12182(a)–(b), 12183.

<sup>45</sup> *Id.* §§ 12142, 12143(a), 12144, 12146, 12147, 12182(b)(2)(B)–(C), 12184(a)–(b).

<sup>46</sup> The FRA applies to employment and “federal grants and programs.” FRA, 29 U.S.C. §§ 791, 794 (2006). The latter includes places of service and public accommodation, such as universities and commercial entities. *Id.* § 794(b).

<sup>47</sup> FHA, 42 U.S.C. §§ 3604–3606 (2006).

<sup>48</sup> *See, e.g., Americans with Disabilities Act of 1989: Hearings on S. 933 Before the Subcomm. on the Handicapped of the S. Comm. on Labor & Human Res.*, 101st Cong. 7 (1989) (statement of Rep. Tony Coelho) (“We are not looking for welfare . . . We just want an opportunity to be able to live and be able to have an opportunity to work . . . to be productive citizens. We know that there is [sic] going to have to be accommodations to give us our basic civil rights.”); *see also* Michael Ashley Stein, *Same Struggle, Different Difference: ADA Accommodations as Antidiscrimination*, 153 U. PA. L. REV. 579, 636–70 (2004) (discussing the reasonable accommodation mandate as a remedy to problems of formal equality rather than access to material resources for workers with disabilities).

<sup>49</sup> *See, e.g., ADA* § 12111(9) (discussing modifications to the physical workplace environment, job-restructuring, and other workplace-specific alterations); *see also* Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 37 (2004) (describing an “access/content distinction”: individuals with disabilities have access to the same benefits as individuals who are not disabled, though the content of the benefit is not altered to meet the needs of individuals with disabilities).

<sup>50</sup> Stein, *supra* note 48, at 660–70; *cf.* Bagenstos, *supra* note 49, at 23–54 (discussing the current formal equality approach to reasonable accommodation as well as an alternative broader approach).

<sup>51</sup> Bagenstos, *supra* note 49, at 37 (discussing limitations in workplace accommodation under the formal equality approach).

effectively. In terms of accessing the workplace, if one does not have reliable, accessible transportation to work and the ability to perform vital tasks at home (e.g., meal preparation, dressing, and laundry), one may face barriers to working. Accommodation within the physical workplace or adjusted work schedules may be insufficient. Similar barriers may arise in accessing public services or places of public accommodation, such as shopping malls. Additionally, individuals may be able to access physical spaces but not enjoy meaningful access to the services provided therein.<sup>52</sup> In the case of public transportation, the ADA only requires that “key stations” are disability accessible.<sup>53</sup>

Second, current antidiscrimination law does not recognize the need to move effectively between protected environments and other places in the public sphere, much less the need to move from the private to the public sphere. This is a problem of both limiting disability protections to statutorily protected contexts and inadequate public transportation. Individuals with disabilities experience protections in physical spaces only when the environments in which they move are considered places of “employment,”<sup>54</sup> “public service,”<sup>55</sup> “public accommodation,”<sup>56</sup> or “public transportation.”<sup>57</sup> If an establishment is not considered a place of public accommodation, for example, the ADA’s accessibility mandate does not apply.<sup>58</sup> Most importantly, the mandate does not cover any aspects of the private sphere, which means that individuals receiving accommodation at work are not eligible for accommodation that may serve a dual purpose—namely, benefitting them at home and at work. Some tools assisting with communication, mobility, or grasping or manipulating

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<sup>52</sup> See, e.g., Nondiscrimination on the Basis of Disability in State and Local Government Services, 73 Fed. Reg. 34,466, 34,469 (proposed June 17, 2008) (codified with some differences in language at 28 C.F.R. pt. 35) (“[M]ore than seventeen years after the enactment of the ADA, as facilities are becoming physically accessible to individuals with disabilities, the Department [of Justice] needs to focus on second-generation issues that ensure . . . accessible elements . . . [such as] ticketing in assembly areas and reservations of boat slips.”); see also Samuel R. Bagenstos, *The Perversity of Limited Civil Rights Remedies: The Case of “Abusive” ADA Litigation*, 54 UCLA L. REV. 1, 4 (2006) (“[T]estimony from advocates across the country affirms that many if not most businesses remain inaccessible, even in circumstances where it would be easy to remove barriers.”).

<sup>53</sup> ADA § 12147(b)(1).

<sup>54</sup> *Id.* § 12111(2), (5) (defining “covered entity” and “employer”).

<sup>55</sup> *Id.* § 12131 (defining “public entity” providing services).

<sup>56</sup> *Id.* § 12181(7) (defining “public accommodation”).

<sup>57</sup> *Id.* §§ 12131(1)(C), 12181(10) (defining “public entity” providing transportation services and “specified public transportation,” respectively).

<sup>58</sup> The ADA exempts private clubs and religious organizations, including places of worship, from the definition of places of “public accommodation.” *Id.* § 12187.

objects, for example, may be critical for personal tasks that relate to the ability to work.

Lack of transportation also precludes effective movement between protected environments. Large portions of the United States are without reliable public transportation for anyone, and cities with public transportation are decreasing or eliminating services as well as imposing significant fare increases.<sup>59</sup> Even in cities with public transportation, portions of a metropolitan area may be inaccessible to individuals with disabilities. Paratransit services, which seek to provide special on-demand services for individuals with impairments, are also lacking. Paratransit services are experiencing increasing strain as the U.S. population ages and non-elderly individuals with disabilities are competing with elderly individuals, who may or may not be disabled, for services.<sup>60</sup>

## 2. *Micro-Level Fragmentation: Judicial Environment-Framing*

Fragmentation also occurs beyond the face of relevant statutes and regulations. Micro-level fragmentation results when judges interpret statutes and regulations in a manner that creates a disconnection between the lived experience of disability and the legal one. Federal disability law and parallel state statutes require tests—both at the threshold (eligibility) and remedy (accommodation or other modification) stages—that implicitly demand the assessment of an environment. By constricting or expanding the environments used for disability assessment at these points, courts limit disability protections.

I develop such a theory of environment-framing in other work.<sup>61</sup> Environment-frames are the physical spaces in which individuals are assessed for legal protection. Constructing a frame broadly allows for a holistic view of an individual's functional capacities, though under current judicial construction of the ADA, functioning in any part of a broad environment might undermine a

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<sup>59</sup> TRANSP. FOR AM., STRANDED AT THE STATION 8–9 (2009), available at <http://www.cfte.org/StrandedReport082009.pdf> (citing and discussing a survey by the American Public Transportation Association revealing that approximately 90% of existing transit services have either reduced services or raised fares in the last two years, and almost 50% of those service providers have taken both actions).

<sup>60</sup> See, e.g., *Liberty Res., Inc. v. Se. Pa. Transp. Auth.*, 155 F. Supp. 2d 242, 244, 257–58 (E.D. Pa. 2001), vacated, 54 F. App'x 769 (3d Cir. 2002) (finding liability under Title II for a transportation authority that effectively split Paratransit rides between elderly and disabled riders).

<sup>61</sup> Satz, *Framged Lives*, *supra* note 2.



disability claim.<sup>62</sup> By contrast, a narrow environment-frame provides a snapshot view of an individual's ability to function and may not capture the degree of a functional impairment or the extent to which accommodation or other modification is needed to promote access. While courts have never addressed the role of environment-framing in disability protections, judicial trends since the passage of the ADA indicate the construction of unfavorable environments for both eligibility for membership in the protected class and injunctive relief involving accommodation or other modification.<sup>63</sup>

In the protected class context, courts typically invoke large environment-frames to assess eligibility for disability protections.<sup>64</sup> In order to demonstrate that one has an actual (rather than a perceived) disability under the ADA, one must show a (1) "physical or mental impairment" that (2) "substantially limits" (3) a "major life activity."<sup>65</sup> The larger the environment-frame, the more likely an individual will be able to perform a major life activity in some portion of her environment and will not be considered disabled.<sup>66</sup>

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<sup>62</sup> I revisit this issue in Part IV.E.

<sup>63</sup> See *infra* notes 64 and 67.

<sup>64</sup> Compare *Fikes v. Wal-Mart, Inc.*, 322 F. App'x 882 (11th Cir. 2009) (broad environment; not substantially impaired in a major life activity), and *Lord v. Arizona*, 286 F. App'x 364 (9th Cir. 2008) (same), and *Gruener v. Ohio Cas. Ins. Co.*, 510 F.3d 661 (6th Cir. 2008) (same), and *Singh v. George Wash. Univ. Sch. of Med. & Health*, 508 F.3d 1097 (D.C. Cir. 2007) (same), and *Rolland v. Potter*, 492 F.3d 45 (1st Cir. 2007) (same), and *Ashton v. AT&T Co.*, 225 F. App'x 61 (3d Cir. 2007) (same), and *Hill v. Steven Motors, Inc.*, 97 F. App'x 267 (10th Cir. 2004) (same), with *Adams v. Rice*, 531 F.3d 936 (D.C. Cir. 2008) (narrow environment; substantially impaired in a major life activity), and *Gribben v. UPS, Inc.*, 528 F.3d 1166 (9th Cir. 2008) (same), and *Chalfant v. Titan Distrib., Inc.*, 475 F.3d 982 (8th Cir. 2007) (same).

<sup>65</sup> ADA, 42 U.S.C. § 12102(1) (2006 & Supp. II 2008). The ADA also covers individuals with "a record of such an impairment" or who are "regarded as having such an impairment." *Id.* § 12102(1)(B)–(C). Individuals with a record of a disability must prove that their disability meets the requirements for actual disability. *Id.* § 12102(1)(B). Thus, the arguments about environment-frames in this subsection apply to the "record" prong as well. After the AAA, "regarded as" plaintiffs are no longer required to meet the standard for actual disability, so environment-frames are less likely to play a role in "regarded as" cases. See *id.* § 12102(3)(A). However, plaintiffs are not entitled to accommodation for "regarded as" discrimination under the AAA. *Id.* § 12201(h).

<sup>66</sup> See cases cited *supra* note 64. The proposed EEOC regulations seem to recognize the difficulty of adopting a large environment-frame for assessing disability eligibility, though they arguably extend beyond the statute. The proposed regulations state: "In determining whether an individual has a disability, the focus is on how a major life activity is substantially limited, not on what an individual can do in spite of an impairment." Regulations to Implement the Equal Employment Provisions of the ADA, as Amended, 74 Fed. Reg. 48,431, 48,440 (proposed Sept. 23, 2009) (to be codified at 29 C.F.R. pt. 1630). This inquiry could involve an assessment of an individual across a range of environments that does not discount an impairment if an individual is able to function in some portion of a broad environment. However, the example provided does not directly address environments: A student with a learning disability who "has achieved a high level of academic success, such as graduating from college" may be viewed as disabled in the major life activity of learning. *Id.* at 48,442.

In the accommodation or other modification context, courts take the opposite approach and routinely use narrow environment-frames.<sup>67</sup> The narrower the environment assessed, the greater the possibility that an individual will be viewed as functional within that environment and denied a remedy.<sup>68</sup> Plaintiffs recognized legally as disabled are frequently denied accommodation or other modification on this basis.<sup>69</sup> For example, an individual who is able to function in her office cubicle may not be entitled to accommodation that would enable functioning in other parts of her office building.

Thus, on both ends of disability analysis—the threshold test and the remedy stage—protections are interrupted and fragmentation occurs.

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The ADA covers a broad range of “major life activities,” including “caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, . . . working,” and “major bodily functions.” ADA § 12102(2). “Major bodily functions” are defined as “including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.” *Id.* § 12102(2)(B).

Typically “impairment” is not an issue in demonstrating disability because the “environment” examined is a person’s own body (rather than the external environment assessed with respect to major life activities). Impairment has been an issue in only one of over twenty U.S. Supreme Court cases decided under the ADA. In that case, the Court deemed the relevant environment-frame to be the cells within one’s own body. *Bragdon v. Abbott*, 524 U.S. 624, 637 (1998) (holding that HIV, which affected an individual’s CD4+ (white cell) counts, constituted a “physical impairment”).

<sup>67</sup> Compare *Shannon v. Postmaster Gen. of U.S. Postal Serv.*, 335 F. App’x 21 (11th Cir. 2009) (particular workplace; no accommodation required), and *Mobley v. Allstate Ins. Co.*, 531 F.3d 539 (7th Cir. 2008) (same), and *Molski v. Foley Estates Vineyard & Winery, LLC*, 531 F.3d 1043 (9th Cir. 2008) (interior of wine-tasting room; modification of room but not ramp to room required), and *Tucker v. Tennessee*, 539 F.3d 526 (6th Cir. 2008) (single jail; no modification required), and *Norman v. Tex. Dep’t of Criminal Justice*, 293 F. App’x 285 (5th Cir. 2008) (single prison; no modification required), and *Brown v. City of Cleveland*, 294 Fed. App’x 226 (6th Cir. 2008) (particular workplace; no accommodation required), and *Bircoll v. Miami-Dade Cnty.*, 480 F.3d 1072 (11th Cir. 2007) (specific location of police stop, single police station; no modification required in either location), and *Ozlek v. Potter*, 259 F. App’x 417 (3d Cir. 2007) (particular workplace; no accommodation required), and *Gathright-Dietrich v. Atlanta Landmarks, Inc.*, 452 F.3d 1269 (11th Cir. 2006) (particular theater; no modification required), with *Simmons v. N.Y.C. Transit Auth.*, 340 F. App’x 24 (2d Cir. 2009) (all jobs within a company; accommodation required), and *Doran v. 7-Eleven, Inc.*, 524 F.3d 1034 (9th Cir. 2008) (7-Eleven store 550 miles from plaintiff’s residence; standing to challenge access barriers), and *Am. Council of the Blind v. Paulson*, 525 F.3d 1256 (D.C. Cir. 2008) (all users of money, not only sighted individuals; modification required), and *Miller v. Cal. Speedway Corp.*, 536 F.3d 1020 (9th Cir. 2008) (spectator “line of sight” throughout speedway rather than in designated areas; modification required), and *Schwarz v. City of Treasure Island*, 544 F.3d 1201 (11th Cir. 2008) (city of Treasure Island; modification required), and *Woodruff v. Sch. Bd. of Seminole Cnty., Fla.*, 304 F. App’x 795 (11th Cir. 2008) (entire school district; accommodation may be required), and *Bacon v. City of Richmond*, 475 F.3d 633, 645 (4th Cir. 2007) (entire school district; accommodation may be required under settlement agreement), and *Woodruff v. Peters*, 482 F.3d 521 (D.C. Cir. 2007) (workplace and home; accommodation required).

<sup>68</sup> See cases cited *supra* note 67.

<sup>69</sup> *Id.*

Significantly, the AAA, which expands the definition of disability, does not address the environment to be assessed for disability eligibility. Cases decided after the enactment of the AAA indicate that courts will continue to use broad environment-frames to determine eligibility, generating mixed results.<sup>70</sup> As I argue in Part IV.E., using a broad environment-frame to determine eligibility and accommodation or other modification affords a more accurate view of functional impairment, but an individual's ability to function in some portion of a broad environment must not be used by courts to undermine her disability status. The next section returns to macro-level fragmentation, with a discussion of disability benefits statutes.

### *B. Eligibility for Social Security Disability Benefits*

Social welfare statutes addressing disability pertain to wage and health benefits.<sup>71</sup> As with civil rights protections, disability benefits statutes require

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<sup>70</sup> See, e.g., *Rohr v. Salt River Project Agric. Improvement & Power Dist.*, 555 F.3d 850, 853, 858 n.5 (9th Cir. 2009) (discussing an environment-frame that included “major life activit[ies] in daily life” and stating that “the ADA, if applicable, would provide additional support for [the plaintiff’s] claims”); *Franchi v. New Hampton Sch.*, 656 F. Supp. 2d 252, 255, 257–60 (D.N.H. 2009) (applying the AAA and discussing an eating disorder as having affected life inside and outside a boarding school and indicating a possible disability); *Grizzle v. Macon Cnty.*, No. 5:08-CV-164 (CAR), 2009 U.S. Dist. LEXIS 73769, at \*19, 26–27 (M.D. Ga. Aug. 20, 2009) (stating that “major life activities are broadly defined as those that are of central importance to daily life” and that the application of the AAA would not change the plaintiff’s inability to establish disability status); *Moen v. Genesee Cnty. Friend of the Ct.*, No. 2:08-cv-12824, 2009 U.S. Dist. LEXIS 57177, at \*16–17 (E.D. Mich. July 6, 2009) (referring to an “active lifestyle” with respect to a question about substantial limitation in the major life activity of walking and stating that the application of the AAA would not change the plaintiff’s inability to establish disability status); *Menchaca v. Maricopa Cmty. Coll. Dist.*, 595 F. Supp. 2d 1063, 1069 (D. Ariz. 2009) (applying the AAA and describing various major life activities, including “interacting with others,” as having affected personal and work relationships and indicating a possible disability).

<sup>71</sup> Disability supports are also provided to children under the Individuals with Disabilities Education Act (IDEA) in the form of Individual Education Programs (IEP). IDEA, 20 U.S.C. §§ 1400, 1401(2)(A) (2006) (amended 2010). The IDEA has its own disability qualification standards, defining a student with a disability as having one of the impairments listed in the statute and, “by reason thereof,” needing special education. *Id.* Students without listed impairments will not qualify for benefits, and other students who are considered to have a listed impairment may be excluded if they are able to pass their grade level or their poor academic performance is attributed to something other than their disability. See, e.g., *Hood v. Encinitas Union Sch. Dist.*, 486 F.3d 1099, 1107–08 (9th Cir. 2007) (holding that a student with a qualifying disability was not entitled to benefits under the IDEA if she can progress to the next grade under the general curriculum); *M.P. v. Ne. Indep. Sch. Dist.*, No. SA-07-CA-004-XR, 2007 U.S. Dist. LEXIS 87239, at \*2–4 (W.D. Tex. Nov. 27, 2007) (holding that a student with violent outbursts and Attention Deficit Hyperactivity Disability demonstrated poor academic performance due to his behavioral choices rather than his disability). The U.S. Department of Education regulations permit states to define what it means for a disability to “adversely affect[] a child’s educational performance” and warrant an IEP. See 34 C.F.R. § 300.8(c) (2007). A child in one state who receives passing grades but is unable to participate in extracurricular activities may receive benefits under the IDEA, whereas that same child in another state might not. Compare *Mr. I. v. Me. Sch.*

eligibility for disability status and take a targeted approach to legal benefits. Certain individuals with impairments are denied initial coverage, resulting in macro-level fragmentation for those individuals.<sup>72</sup> For other individuals, benefits will terminate when they attain employment, due to the mutually exclusive requirements for job retention and benefits eligibility.

Unlike civil rights approaches, benefits statutes seek to provide material resources to address disability discrimination. They are social welfare statutes and are intended to be redistributive in nature. Social welfare statutes restrict disability status to limit expenditures, rather than to limit protected class status to those with a history of oppression.<sup>73</sup> Perhaps as a result, the definition of *disability* is more restrictive under benefits statutes than under civil rights statutes.

Two types of Social Security wage supports are available for individuals with disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Both have corresponding health benefits. Under Title II of the Social Security Act, SSDI is paid to individuals with sufficient previous payroll contributions.<sup>74</sup> Individuals receive monthly wage support<sup>75</sup> and are eligible for Medicare.<sup>76</sup> Dependents may also be

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Admin. Dist., 480 F.3d 1, 6–7, 12 (1st Cir. 2007) (holding that a student with Asperger’s disorder who became increasingly withdrawn, could not form relationships, engaged in self-destructive behavior, skipped school, and eventually attempted suicide was entitled to IDEA benefits despite passing grades), *with* Dale M. v. Bd. of Educ. of Bradley-Bourbonnais High Sch. No. 307, 237 F.3d 813, 814, 817–18 (7th Cir. 2001) (holding that a student with passing grades who had a conduct disorder requiring custodial confinement was not entitled to IDEA benefits). Once a student graduates high school, coverage under the IDEA ends. IDEA § 1401(9) (defining “free and appropriate public education” as including “an appropriate preschool, elementary school, or secondary school education in the state involved”). But extended coverage may be granted as an equitable remedy to students over the age of entitlement if they can show that the school failed to provide required adequate education during years of entitlement. *See* Bd. of Educ. of Oak Park v. Ill. State Bd. of Educ., 79 F.3d 654 (7th Cir. 1996); *Parents of Student W. v. Puyallup Sch. Dist.*, 31 F.3d 1489 (9th Cir. 1994).

<sup>72</sup> My examination of Social Security cases in other work did not reveal the micro-level fragmentation caused by environment-framing seen in disability antidiscrimination cases. Satz, *Fragmented Lives*, *supra* note 2. This result may be attributed to the holistic view taken by courts in Social Security cases, which examines an individual’s functioning across all environments. *See infra* Part IV.E. Of course judges may limit disability benefits through narrow construction of the Social Security Act. If such trends are identified, they would be examples of micro-level fragmentation as I am interpreting it.

<sup>73</sup> As I have argued in other work, however, courts may narrowly construe disability antidiscrimination mandates to limit the cost of accommodation and other modification borne by private firms. Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 2; Satz, *Fragmented Lives*, *supra* note 2.

<sup>74</sup> *See* SOC. SEC. ADMIN., 2010 RED BOOK: A SUMMARY GUIDE TO EMPLOYMENT SUPPORTS FOR PERSONS WITH DISABILITIES UNDER THE SOCIAL SECURITY DISABILITY INSURANCE AND SUPPLEMENTAL SECURITY INCOME PROGRAMS 12 (2010), available at [http://www.ssa.gov/redbook/eng/2010 Red Bookpdf.pdf](http://www.ssa.gov/redbook/eng/2010%20Red%20Book.pdf).

<sup>75</sup> Monthly support varies according to previous earnings. *See id.* at 13.

<sup>76</sup> *Id.*

eligible for health care benefits, depending on previous earnings.<sup>77</sup> Title XVI of the Social Security Act provides SSI as a means-tested program, which pays a monthly wage support to adults and children.<sup>78</sup> Individuals receiving SSI are eligible for Medicaid.<sup>79</sup> Individuals with disabilities may receive both SSDI and SSI benefits, though SSDI benefits are included in SSI eligibility calculations.<sup>80</sup> Both SSDI and SSI benefits are predicated on an inability to work.<sup>81</sup>

For both SSDI and SSI, disability is evaluated in a five-step sequential process that considers whether the claimant<sup>82</sup>: (1) is engaged in substantial gainful employment,<sup>83</sup> (2) has a medically severe impairment or combination of impairments that significantly limits her ability to perform basic work activities,<sup>84</sup> and (3) has an impairment that is the same as, or equivalent to, a listed impairment.<sup>85</sup> An Administrative Law Judge assesses “severe impairment” by considering an individual’s overall ability to function or “the combined effect of all of the individual’s impairments without regard to whether any such impairment, if considered separately, would be of such severity.”<sup>86</sup> A disability that prevents substantial gainful employment is generally one that will either result in death or that will exist without interruption for a period of twelve months or longer.<sup>87</sup> If these three criteria are met, an individual is considered disabled. If an impairment is not listed, an

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<sup>77</sup> *Id.* at 12.

<sup>78</sup> *Id.* In 2010, the supplement was \$674 for an individual and \$1,011 for a couple per month. *Id.* at 13. Some states also provide supplements. *Id.*

<sup>79</sup> *See id.* at 12–13.

<sup>80</sup> *Id.*

<sup>81</sup> *Id.*

<sup>82</sup> Determining Disability & Blindness, 20 C.F.R. § 404.1520(a)(4) (2010). A federal appeals court may review the decision of an Administrative Law Judge (ALJ) to see whether it is supported by substantial evidence and the proper legal standards were employed. *See* 42 U.S.C. § 405(g) (2006); Tonapetyan v. Halter, 242 F.3d 1144, 1147 (9th Cir. 2001); Plummer v. Apfel, 186 F.3d 422, 427 (3d Cir. 1999); Andrade v. Sec’y of Health & Human Servs., 985 F.2d 1045, 1047 (10th Cir. 1993); Brainard v. Sec’y of Health & Human Servs., 889 F.2d 679, 681 (6th Cir. 1989); Rodriguez v. Sec’y of Health & Human Servs., 647 F.2d 218, 222 (1st Cir. 1981).

<sup>83</sup> 20 C.F.R. § 404.1520(a)(4)(i) (2010). “Substantial gainful [employment] activity” assumes compensated labor that “involves doing significant physical or mental activities.” *Id.* § 404.1572.

<sup>84</sup> *Id.* § 404.1520(a)(4)(ii). Impairments are listed in Appendix A of the regulation. The “ability to do basic work activities” is defined as “the abilit[y] and aptitude[] necessary to do most jobs.” *Id.* § 404.1521(b).

<sup>85</sup> *Id.* § 404.1520(a)(4)(iii).

<sup>86</sup> Social Security Act, 42 U.S.C. § 423(d)(2)(B) (2006); *see also* Webb v. Barnhart, 433 F.3d 683, 688 (9th Cir. 2005).

<sup>87</sup> *See* SOC. SEC. ADMIN., *supra* note 74, at 14.

individual must prove (4) an inability to perform past relevant work.<sup>88</sup> If such impairment is established, the burden shifts to the agency to establish (5) that the claimant retains sufficient residual functional capacity to permit her to engage in other substantial gainful employment.<sup>89</sup> Residual functional capacity measures a claimant's highest sustainable level of functioning in a work setting.<sup>90</sup>

Fragmentation may occur with respect to Social Security benefits at the initial eligibility stage as well as after enrollment. Demonstrating initial inability to partake in substantial gainful employment may prove quite difficult. If an individual earns \$1,000 per month (\$1,064 for individuals who are blind), she is considered gainfully employed and not entitled to SSDI or SSI.<sup>91</sup> The cost of medical equipment and support pertaining to disability that is not covered by insurance is deducted from this amount, but *support* is narrowly construed; for example, the cost of assistance to complete household tasks to facilitate employment is specifically excluded.<sup>92</sup>

Once an individual is covered by SSDI or SSI and begins to earn \$1,000 or more per month, her disability is considered to “cease.”<sup>93</sup> SSDI enrollees may receive six months of temporary wage benefits within a five-year period after their benefit termination, if their income drops below \$1,000 per month.<sup>94</sup> Medicare benefits may be continued for SSDI recipients for a maximum of seven years and nine months; after that time, Medicare may be purchased.<sup>95</sup> Individuals receiving SSI are subject to a different means assessment. If wages and SSI benefits are above \$674 per month, wage support will end.<sup>96</sup>

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<sup>88</sup> 20 C.F.R. § 404.1520(a)(4)(iv) (2010).

<sup>89</sup> *Id.* § 404.1520(a)(4)(v).

<sup>90</sup> *Id.* § 404.1545. Residual functional capacity is also measured at step (4), though if an individual is unable to perform past relevant work her claim will proceed to step (5). In assessing an individual's residual functional capacity, the agency or reviewing court considers the aggregate effect of all impairments by examining the claimant in different environments and over an extended period of time. Factors include: (1) daily activities; (2) location, duration, frequency, and intensity of pain and other symptoms; (3) factors that precipitate or aggravate symptoms; (4) effects of medication; (5) effects of treatments other than medication; and (6) any other factors concerning an individual's functional limitations and restrictions. *Glomski v. Massanari*, 172 F. Supp. 2d 1079, 1083–84 (E.D. Wis. 2001). Biological as well as socially constructed impairments and exertion levels may be considered. *Kelly v. Sec'y of Health & Human Servs.*, 871 F. Supp. 586, 592 (W.D.N.Y. 1994) (impairments); SSR 96-8p, 1996 WL 374184, at \*5 (July 2, 1996) (exertion levels).

<sup>91</sup> See SOC. SEC. ADMIN., *supra* note 74, at 14.

<sup>92</sup> *Id.* at 23–25.

<sup>93</sup> *Id.* at 16.

<sup>94</sup> *Id.* at 28.

<sup>95</sup> *Id.* at 32–34.

<sup>96</sup> *Id.* at 13.

Individuals receiving SSI who return to work may be eligible for Medicaid, but only if they do not earn enough to exceed what their state spends per capita on Medicaid.<sup>97</sup>

Medical improvement will also terminate benefits under SSDI and SSI, which may pose a problem for individuals with impairments that are episodic.<sup>98</sup> While individuals may be entitled to temporary benefits under SSDI if their wages drop, no such benefits are available for SSDI recipients with variable medical conditions.<sup>99</sup> Individuals receiving SSI are eligible for a three-month grace period, but only if they meet the wage requirements for SSI.<sup>100</sup>

The Social Security Act fragments the disability experience in another significant way. Individuals with disabilities must often choose between employment (and civil rights protections in employment) and social support.<sup>101</sup> Under the ADA, individuals must demonstrate that they are able to fulfill the “essential functions” of their jobs “with or without reasonable accommodation.”<sup>102</sup> Under Social Security benefit programs, individuals must show that they are unable to maintain gainful employment.<sup>103</sup> With some limited exceptions discussed below, individuals may not work and receive SSDI or SSI benefits.

Individuals may continue to receive wage supports while working only if they attempt a “Trial Work Period,” receive SSI and have income that is at the gainful employment level but otherwise meets disability eligibility requirements, or pursue vocational training.<sup>104</sup> Under the Trial Work Period,

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<sup>97</sup> *Id.* at 43.

<sup>98</sup> *Id.* at 16.

<sup>99</sup> *Id.* at 28.

<sup>100</sup> *Id.* at 17. Benefits may also be extended until the end of certain vocational training programs. *Id.* at 27.

<sup>101</sup> See Bagenstos, *The Future of Disability Law*, *supra* note 49, at 32–34 (discussing this tension); Michael E. Waterstone, *Returning Veterans and Disability Law*, 85 NOTRE DAME L. REV. 1081, 1083, 1085–96 (2010) (same). However, veterans with service-related disabilities enjoy wage supports under the Uniformed Services Employment and Reemployment Rights Act (USERRA), even if employed. See Waterstone, *supra*, at 1105–06.

<sup>102</sup> ADA, 42 U.S.C. § 12111(8) (2006 & Supp. II 2008).

<sup>103</sup> The Social Security Act does not offer vocational training until *after* a claimant has demonstrated an inability for substantial gainful employment. Paul Armstrong, *Toward a Unified and Reciprocal Disability System*, 25 J. NAT'L ASS'N ADMIN. L. JUDGES 157, 163 (2005).

<sup>104</sup> SOC. SEC. ADMIN., *supra* note 74, at 29, 40; Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999, Pub. L. No. 106-170, 113 Stat. 1860 (1999) (codified as amended in scattered sections of 42 U.S.C.).

individuals receiving SSDI may attempt gainful employment for nine months while receiving benefits; during this period, benefits are not terminated, despite income levels that may exceed \$1,000 per month.<sup>105</sup> SSI recipients may file for “Section 1619(a)” payments when their income is at the gainful employment level, though their means assessment must remain below \$674 per month.<sup>106</sup> Under the Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999, individuals who return to work may be able to maintain limited health care coverage and cash payments during their vocational training.<sup>107</sup> Medicare beneficiaries may keep their insurance for eight and a half years.<sup>108</sup> Medicaid coverage may be extended or available for purchase, though the TWWIIA does not mandate that states receiving Medicaid funding provide options for individuals returning to work under the program.<sup>109</sup> These options have not been successful in allowing individuals to receive sufficient benefits and return to work, which has, unfortunately, perpetuated the view that individuals with disabilities are better off not working.<sup>110</sup>

Thus, macro-level fragmentation may occur at a number of junctures for individuals who identify as disabled and seek Social Security benefits. These individuals may be denied initial supports. Individuals receiving benefits may have them withdrawn, once they become gainfully employed or experience medical improvement. Though some government programs provide wage and health care supports to individuals with impairments who have varying income, individuals often must choose between employment and supports.

The next Part focuses on fragmentation caused by health law structures. While the issues of fragmentation in disability law I discuss in this Part overlap with those discussed in the next Part, I examine health law separately for two reasons. First, individuals who are ill may not be disabled. They consequently face different eligibility requirements and barriers to access to care under

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<sup>105</sup> SOC. SEC. ADMIN., *supra* note 74, at 29.

<sup>106</sup> *Id.* at 40.

<sup>107</sup> Pub. L. No. 106-170, 113 Stat. 1860.

<sup>108</sup> *Id.* § 202(a).

<sup>109</sup> *Id.*

<sup>110</sup> See DAVID C. STAPLETON ET AL., DISMANTLING THE POVERTY TRAP: DISABILITY POLICY FOR THE 21ST CENTURY 1-3 (2005), available at <http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1124&context=edicollect>; see also Carrie Griffin Basas, *Indulgent Employment? Careers in the Arts for People with Disabilities*, 40 RUTGERS L.J. 613, 661 (2009) (“Even with the growth of such governmental programs as Ticket to Work, the joblessness of people with disabilities has persisted. The attitudes and goals transmitted by vocational counselors, policymakers, and even legal scholars are informed by these realities. They do not want to advise people with disabilities to pursue a fruitless goal, but in playing it safe, they may be binding the potential growth of disabled artists.”).



current federal programs than individuals with disabilities. Second, health care delivery itself may cause fragmentation.

### III. FRAGMENTATION IN HEALTH LAW

The term *fragmentation* is not new to discussions of health care delivery, though its usual meaning differs from my use of the term in this Article. In health law scholarship, *fragmentation* is taken to mean “having multiple decision makers make a set of health care decisions that would be made better through unified decision making.”<sup>111</sup> Thus, focus is on the coordination of health care delivery, involving everything from doctor visits to patient records.<sup>112</sup> My discussion of fragmentation is broader in scope and considers how legal structures create a disjunction between the lived experience of illness and legal understandings of illness. Laws are structured to respond to illness as an exception to, rather than as part of, the typical human experience. Laws pertaining to access to health care target only particular individuals or aspects of the life cycle, interrupting care. Lack of coordinated care also may result in the fragmentation about which I am concerned, when a patient experiences a single illness but does not enjoy cohesive treatment. However, it is possible to coordinate care for sick individuals (addressing the typical, narrower issue of fragmentation) without viewing and responding to illness as part of the human condition (my view of fragmentation). The sections that follow discuss fragmentation both in terms of eligibility for targeted programs and coordination of care.

As a preliminary matter, it is necessary to distinguish between the health care needs and experiences of individuals with disabilities and those of individuals who are ill but not disabled. I have argued in other work that illness is not a “disability issue.”<sup>113</sup> Individuals who are sick may not be disabled, and vice-versa. Further, access to adequate health care, in terms of both coverage and the range of medical services available, is a problem for individuals with and without disabilities. While disability may seem to raise some complicating factors—including a possible higher consumption of health care resources than most individuals, health care rationing schemes that disfavor those with medical impairments, and difficulty moving between

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<sup>111</sup> Einer Elhauge, *Why We Should Care About Health Care Fragmentation and How to Fix It*, in *THE FRAGMENTATION OF U.S. HEALTH CARE* 1, 1 (Einer Elhauge ed., 2010).

<sup>112</sup> *See generally* *THE FRAGMENTATION OF U.S. HEALTH CARE* (Einer Elhauge ed., 2010) (discussing fragmentation in various facets of health care delivery).

<sup>113</sup> Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 2, at 561–67.

public assistance programs that include health care and the workforce—these are problems that individuals without disabilities face as well. Elderly individuals and premature infants are the greatest consumers of health care resources, with high costs for care during the last and the first few months of life, respectively.<sup>114</sup> In addition, any individual with a health impairment may be disadvantaged by the metrics used to ration care and segregate risk. Disabled, elderly, and seriously ill individuals alike may be viewed as having a shorter or lower quality of life, and may consequently not be entitled to health care resources due to their perceived lesser benefit from them. Also, many indigent individuals experience difficulty moving between social welfare programs and the workforce, as their circumstances change. Because individuals with disabling illness face similar challenges to individuals with illness who are not disabled in these contexts, I do not distinguish between these groups below. Relevant legal distinctions for benefit programs targeting individuals with disabilities are discussed in Part III above.

#### A. *Eligibility for Health Benefits*

The most dramatic example of fragmentation in the health care context occurs with respect to access to health care services under government programs. Access is dependent on age, income, federal employment, or military service. Individuals are covered at both ends of life, i.e., as children (Children’s Health Insurance Program (CHIP)<sup>115</sup> and Medicaid<sup>116</sup>) and when

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<sup>114</sup> In 2004, health care expenditures for people sixty-five years and older were \$531.46 billion. *2004 Age Tables*, CTRS. FOR MEDICARE & MEDICAID SERVS., <http://www.cms.gov/NationalHealthExpendData/downloads/2004-age-tables.pdf> (last visited Feb. 1, 2011). The per capita health care expenditure for adults age sixty-five and older was 5.6 times the per capita expenditure for children and 3.3 times that for adults under age sixty-five. *Id.* The report does not discuss what proportion of these individuals would be legally considered disabled. In 2005, the estimated “social cost” (“medical, education, and lost productivity”) of preterm births was \$26.2 billion. *Prematurity*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/Features/PrematureBirth> (last updated Nov. 15, 2010).

<sup>115</sup> CHIP provides basic medical coverage to children ineligible for Medicaid; its target population is children in families with incomes around 200% of the federal poverty line. CHIPRA, Pub. L. No. 111-3, sec. 111(a), § 2112(b)(1)(B), tit. XXI, 123 Stat. 8, 26 (2009) (codified at 42 U.S.C. § 1397 (Supp. III 2009)). Participating states may either expand their Medicaid program or fund a new CHIP program. CHIP differs from Medicaid because states may collect co-payments and premiums from enrollees and have greater flexibility in implementing their plans. For these reasons, CHIP is technically a grant, not a federal entitlement, program.

<sup>116</sup> Medicaid provides “medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services.” 42 U.S.C. § 1396-1 (Supp. III 2009). After the Patient Protection and Affordable Care Act, states are required to provide Medicaid to individuals at or below 133% of the federal poverty line by 2014, but may do so before then. Patient Protection and Affordable Care Act (PPACA), Pub. L. No. 111-148,

they are over age sixty-five (Medicare).<sup>117</sup> Indigent or lower income individuals may receive Medicaid or support to purchase insurance under the Patient Protection and Affordable Care Act (PPACA).<sup>118</sup> Military service personnel and their dependents are covered under TRICARE, when they are actively serving in or retired from the military, and the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA), as veterans.<sup>119</sup> Federal employees and their dependents receive insurance through the Federal Employee Benefits Program.<sup>120</sup>

Fragmentation also results from the way in which these programs operate. For example, various Medicaid plan options—fully capitated (prepaid per individual), partially capitated (limited to certain services), managed fee-for-service, etc.—result in inconsistent standards for eligibility and disparities in access to services.<sup>121</sup> Additional inconsistencies may occur within a chosen option. Eligibility for Medicaid after disabling illness is different for children and adults, although both may have the same condition.<sup>122</sup> Under Medicare and Medicaid, individuals in debilitating pain may not be considered “truly and justifiably in need,” while other individuals with debilitating conditions are viewed as meeting the standard.<sup>123</sup>

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§ 2001(a), 124 Stat. 119 (2010) (to be codified at 20, 21, 25, 26, 29 and 42 U.S.C.). In 2011, the poverty line for a family of four is an annual income of \$22,350. Annual Update of HHS Poverty Guidelines, 76 Fed. Reg. 3637, 3638 (Jan. 14, 2011). Medicaid is a program of last resort; when membership in another government assistance program like Medicare overlaps with Medicaid, the other program’s resources are exhausted first. See S. REP. NO. 99-146, at 312 (1985), *reprinted in* 1986 U.S.C.C.A.N. 42, 279.

<sup>117</sup> Medicare provides “basic protection against the costs of hospital, related post-hospital, home health services, and hospice care” for all individuals age 65 or over as well as for certain individuals with disabilities, government and railroad employees, and individuals suffering from end stage renal disease. 42 U.S.C. § 1395c (2006).

<sup>118</sup> PPACA §§ 1401(a), 2001(a). The insurance premium credit provisions take effect in 2014. *Id.*

<sup>119</sup> 10 U.S.C. §§ 1071–1110 (2006) (TRICARE); 38 U.S.C. §§ 1701–1785 (2006) (CHAMPVA).

<sup>120</sup> 5 U.S.C. §§ 8901–8914 (2006).

<sup>121</sup> Ian Hill et al., *Achieving Service Integration for Children with Special Health Care Needs: An Assessment of Alternative Medicaid Managed Care Models*, 5 J. HEALTH CARE L. & POL’Y 208, 210–11 (2002) (“[S]ome rely on commercial ‘mainstream’ health plans, while others utilize Medicaid-only plans that draw extensively on safety net providers more experienced with serving low-income families; some place responsibility for all services with [a managed care organization], while others ‘carve out’ clusters of services to be delivered by separate systems . . . .”); see also Cynthia R. Schuster et al., *Partially Capitated Managed Care Versus FFS for Special Needs Children*, HEALTH CARE FINANCING REV., Summer 2007, at 109, 109 (“Results show that special needs children enrolled in the partially capitated MCP [managed care programs] are significantly more likely to obtain occupational and physical therapy at school relative to their FFS [fee for service] counterparts.”).

<sup>122</sup> SOC. SEC. ADMIN., *supra* note 74, at 14.

<sup>123</sup> Timothy S. Jost, *Public Financing of Pain Management: Leaky Umbrellas and Ragged Safety Nets*, 26 J.L. MED. & ETHICS 290, 290 (1998).

### B. *Lack of Coordinated Care as a Barrier to Access*

Fragmentation also results from health care delivery when a patient experiences one illness but health care is disjointed due to lack of coordination. The absence of coordinated care makes it difficult to provide consistent, continuous, quality care. Fragmentation from lack of coordinated care occurs at the regulatory level as well as within the provision of health care services directly to patients.

Fragmentation occurs at the regulatory level because care is not coordinated within the health care “system,”<sup>124</sup> given the large number of legal and medical authorities governing the actions of health care providers.<sup>125</sup> The mixture of federal, state, self, and professional regulation prevents cohesiveness in health care delivery.<sup>126</sup> At a federal level, regulatory agencies address specific problems but do not have the knowledge or authority to solve system-wide issues.<sup>127</sup> At the state level, the corporate practice of medicine doctrine does not allow hospitals, which are firms without medical licenses, to direct the practice of medicine by their physicians.<sup>128</sup> The governance structure of hospitals supports this approach, stressing physician independence rather than coordinated care.<sup>129</sup> Further, state law may prohibit or discourage the employment of physicians directly by hospitals, limiting the ability of patients who are harmed by medical care to seek recourse against hospitals providing care through independent contractors.<sup>130</sup>

As a result of current regulatory structures, physicians continue to practice individually or in small groups, organized separately from hospitals and health

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<sup>124</sup> I place “system” in quotations because it refers to a collection of actors rather than a cohesive organization—regulators, institutions, providers, payors, and patients.

<sup>125</sup> William M. Sage, *Over Under or Through: Physicians, Law, and Health Care Reform*, 53 ST. LOUIS U. L.J. 1033, 1034–35 (2009).

<sup>126</sup> *Id.*

<sup>127</sup> Louise G. Trubek & Maya Das, *Achieving Equality: Healthcare Governance in Transition*, 7 DEPAUL J. HEALTH CARE L. 245, 263 (2004).

<sup>128</sup> *Id.*

<sup>129</sup> James Blumstein, *Of Doctors and Hospitals: Setting the Analytical Framework for Managing and Regulating the Relationship*, in THE FRAGMENTATION OF U.S. HEALTH CARE, *supra* note 111, at 146, 158–59; see also M. Gregg Bloche, *The Emergent Logic of Health Law*, 82 S. CAL. L. REV. 389, 452 (2009) (discussing how hospitals exercise minimal control over medical practice and remain institutionally independent from health plans); Randall D. Cebul et al., *Organizational Fragmentation and Care Quality in the U.S. Healthcare System*, J. ECON. PERSP., Fall 2008, at 93, 100 (discussing how physicians are largely independent from hospital management, resulting in lack of coordination between physicians, nurses, and hospital staff).

<sup>130</sup> Cebul et al., *supra* note 129, at 103.

plans.<sup>131</sup> Care is not standardized, and the range of services varies unpredictably by provider.<sup>132</sup> This “cottage industry” approach causes fragmentation in health care delivery and generates enormous inefficiencies.<sup>133</sup> A patient seeking care for a single ailment may need to attend appointments in a physician’s office, a specialty care center, and a hospital, each with its own operating rules. While from a patient’s perspective she is seeking care for one condition, each treating physician is likely to have separate required medical and billing procedures.<sup>134</sup> For example, Medicare adopts a “silo” approach to health care payment, which imposes separate participation requirements, cost-sharing requirements, and payment systems for recipients of hospital services (Medicare Part A) and physicians’ services (Medicare Part B).<sup>135</sup>

The next Part examines the ontology of legal structures causing fragmentation in disability and health law, questions the validity of the assumptions that underlie these structures, and proposes a shift from a targeted to a universal approach to address impairment.

#### IV. CHALLENGING ASSUMPTIONS ABOUT THE HUMAN EXPERIENCE

This Part challenges legal assumptions about human functioning, beginning with the philosophical underpinnings of dominant legal approaches. It then attacks the false premises themselves, foremost that all but exceptional individuals are fully functioning over their lifetimes, capable of laboring for wages, and able to form and order preferences and to participate in the market. An alternative view of the human experience, one of universal vulnerability, is then presented. According to this view, individuals are universally vulnerable to disability and illness; to subsequent disability and illness; and to social disadvantage based on those states, including isolation and discrimination. If the law is to consider universal vulnerability, human functioning must be viewed on a continuum, rather than assumed to be at a certain “normal” level. I propose that law- and policy-makers formally acknowledge disability and illness as part of the human experience and move toward structures that

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<sup>131</sup> Bloche, *supra* note 129, at 452; Sage, *supra* note 125, at 1038 (arguing that medical professionals are not organized efficiently, and “[t]he U.S. health care system [is] the world’s most expensive cottage industry”).

<sup>132</sup> Stephen J. Swensen et al., *Cottage Industry to Postindustrial Care—The Revolution in Health Care Delivery*, 362 NEW ENG. J. MED. e12 (2010).

<sup>133</sup> *Id.*

<sup>134</sup> Cebul et al., *supra* note 129, at 100.

<sup>135</sup> Timothy Stoltzfus Jost, *Medicare: What Are the Real Problems? What Contribution Can Law Make to Real Solutions?*, 1 ST. LOUIS U. J. HEALTH L. & POL’Y 45, 63 (2007).

support universal rather than targeted approaches to those states. Universal approaches do not fragment the human experience and provide more meaningful access to the civic and social realms.

### A. *Philosophical Assumptions*

Certain key assumptions about human functioning underlie the conception of the “liberal subject” in political philosophy.<sup>136</sup> Most importantly, the liberal subject is viewed as one who is fully functioning and capable of laboring for wages and participating in the market.<sup>137</sup> This section examines the role of the liberal subject in social contract theory, to illuminate the philosophical assumptions that support current legal approaches to disability and illness.<sup>138</sup>

Social contract theory involves an initial bargaining situation in which individuals consent to give power or authority to government.<sup>139</sup> While the process and results of these negotiations vary amongst theorists, it is assumed that the individuals participating are without significant impairments.<sup>140</sup> John Rawls sets aside the issue of impairment in the bargaining scenario he imagines.<sup>141</sup> David Gauthier discusses individuals with disabilities as unable

<sup>136</sup> See generally THOMAS HOBBS, *LEVIATHAN* (J.C.A. Gaskin ed., Oxford Univ. Press 1998) (1651); JOHN LOCKE, *TWO TREATISES OF GOVERNMENT* (Peter Laslett ed., Cambridge Univ. Press 1960) (1689); NOZICK, *supra* note 10; JOHN RAWLS, *A THEORY OF JUSTICE* (1971) [hereinafter RAWLS, *A THEORY OF JUSTICE*]; RAWLS, *POLITICAL LIBERALISM*, *supra* note 9.

<sup>137</sup> NOZICK, *supra* note 10; RAWLS, *POLITICAL LIBERALISM*, *supra* note 9.

<sup>138</sup> I do not intend to provide a detailed analysis of social contract theory in this section, but rather to highlight insights from social contract theory for understanding fragmentation.

<sup>139</sup> See, e.g., HOBBS, *supra* note 136, at 115 (“A commonwealth is said to be instituted, when a multitude of men do agree, and covenant, every one, with every one, that to whatsoever man, or assembly of men, shall be given by the major part, the right to present the person of them all (that is to say, to be their representative).”); LOCKE, *supra* note 136, at 349 (noting that a political society begins with consent); JEAN-JACQUES ROUSSEAU, *THE SOCIAL CONTRACT* 152 (Maurice Cranston trans., Penguin Books 1968) (1762) (same).

<sup>140</sup> See, e.g., MARTHA NUSSBAUM, *FRONTIERS OF JUSTICE: DISABILITY, NATIONALITY, AND SPECIES MEMBERSHIP* 98 (2006); Eva Feder Kittay, *When Caring Is Just and Justice Is Caring: Justice and Mental Retardation*, 13 *PUB. CULTURE* 557, 559 (2001) (noting that “liberalism” conceives of a person as “independent, rational, and capable of self-sufficiency” and society as “an association of such independent equals”).

<sup>141</sup> RAWLS, *POLITICAL LIBERALISM*, *supra* note 9, at 20 (“I put aside for the time being these temporary disabilities and also permanent disabilities or mental disorders so severe as to prevent people from being cooperating members of society in the usual sense.”); see also NUSSBAUM, *supra* note 140, at 98 (commenting that under a Rawlsian framework, individuals with disabilities “are not among those for whom and in reciprocity with whom society’s basic institutions are structured”). John Rawls’s dominant version of social contract theory envisions an initial bargaining situation—the “original position”—from which the principles of justice are chosen behind a “veil of ignorance.” RAWLS, *A THEORY OF JUSTICE*, *supra* note 136, at 12, 19. Behind the veil, individuals have limited knowledge about themselves, including class membership, personal

to contribute to, or to participate in, society.<sup>142</sup> Robert Nozick, one of the foremost modern libertarians, assumes that the state should not redistribute assets to assist individuals with disability or illness (or other needs) because doing so would upset preexisting entitlement to those assets.<sup>143</sup>

Thus, a critique of social contract theory must begin by challenging the conception of the persons in the initial bargaining position. For Rawls, as for nearly every social contract theorist, the legitimacy of government finds its roots in notions of rational choice and consent.<sup>144</sup> Social contract theory thus minimally assumes a bargaining paradigm wherein rational individuals come together and make reasoned decisions about the role of the state.<sup>145</sup> Individuals participating in the bargaining process have the capacity to reason, to determine and articulate their interests, and to cooperate fully in society.<sup>146</sup> Social contract theory also relies on notions of mutual advantage or reciprocity.<sup>147</sup> Individuals are assumed to have a “capacity for engagement” and cooperation in society.<sup>148</sup> But not all individuals with disability or illness will have these capacities, given biological and social constraints.<sup>149</sup>

Within social contract theory, disability and illness are not viewed as part of the human experience, but rather as exceptional. To the extent that social contract theory considers impairment at all, it does so indirectly, rather than requiring that the foundational structures of society be designed to recognize

wealth, talents, and intelligence. *Id.* at 12. The principles of justice chosen thus are considered the result of a fair agreement. *Id.*

<sup>142</sup> DAVID GAUTHIER, *MORALS BY AGREEMENT* 18, 18 n.30 (1986) (“[O]ur society . . . make[s] possible an ever-increasing transfer of benefits to persons who decrease that average [level of well-being]. . . . The primary problem is care for the handicapped. Speaking euphemistically of enabling them to live productive lives, when the services required exceed any possible products, conceals an issue which, understandably, no one wants to face.”).

<sup>143</sup> NOZICK, *supra* note 10, at 235. However, Nozick assumes that rights exist prior to, rather than as a result of, social contract. *Id.* at 89, 131–32.

<sup>144</sup> GAUTHIER, *supra* note 142, at 9 (“A person is conceived as an independent centre of activity, endeavouring to direct his capacities and resources to the fulfillment of his interests.”); RAWLS, *supra* note 136, at 12 (“[J]ustice as fairness . . . conveys the idea that the principles of justice are agreed to in an initial situation that is fair.” (internal quotation marks omitted)).

<sup>145</sup> See RAWLS, *A THEORY OF JUSTICE*, *supra* note 136, at 10–11; RAWLS, *POLITICAL LIBERALISM*, *supra* note 9, at 20.

<sup>146</sup> See RAWLS, *A THEORY OF JUSTICE*, *supra* note 136, at 11; see also EVA FEDER KITTAY, *LOVE’S LABOR: ESSAYS ON WOMEN, EQUALITY, AND DEPENDENCY* 83–99 (1999) (discussing Rawls).

<sup>147</sup> These terms are discussed interchangeably as well as distinctly, depending on the philosopher.

<sup>148</sup> Christie Hartley, *Justice for the Disabled: A Contractualist Approach*, 40 *J. SOC. PHIL.* 17, 28 (2009).

<sup>149</sup> Even a broad concept such as “capacity for engagement” excludes some disabled and ill individuals. *Id.* at 30.

disability and illness as part of the human condition.<sup>150</sup> Given the dominance of social contract theory in western political thought, it is perhaps unsurprising that legal structures treat disability and illness as deviations from the norm.

Commentators consider a number of alternative theoretical approaches. Eva Kittay criticizes the common conception of the liberal subject and argues that the state must account for fundamentally dependent persons.<sup>151</sup> On a practical level, this translates into supporting publically funded dependent care.<sup>152</sup> Anita Silvers and Leslie Francis advocate abandoning the bargaining framework of social contract theory.<sup>153</sup> They argue that the social contract should be founded instead on the idea of building trust between individuals in society,<sup>154</sup> shifting the social contract from mutual advantage to a cooperative scheme.<sup>155</sup> Lawrence Becker argues for a more general reciprocity, which entails recognizing the need for disability supports, including health care.<sup>156</sup> Becker believes bargainers will recognize that it is to their advantage to consider the possibility of having disabled loved ones.<sup>157</sup> Martha Nussbaum argues for a departure from social contract theory, suggesting that the state must support a threshold level of certain basic capabilities.<sup>158</sup> In her view, the selected capabilities would be supported by overlapping consensus, the choice of “reasonable citizens.”<sup>159</sup>

Each of these approaches has limitations in terms of addressing fragmentation. Kittay’s view does not address the value of participation of individuals with disabilities in society. While the approach suggested by

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<sup>150</sup> For example, Rawls’s theory of justice requires that any redistribution of assets benefit the least advantaged. RAWLS, *A THEORY OF JUSTICE*, *supra* note 136, at 132–42; *see also* KITTAY, *supra* note 146, at 77 (discussing this aspect of Rawls). Friedrich Hayek discusses minimum wage support. *See* 2 FRIEDRICH A. HAYEK, *LAW, LEGISLATION AND LIBERTY* 87 (1978).

<sup>151</sup> Kittay, *supra* note 140, at 574–75 (“Inevitable dependencies, the dependencies of our early years, old age, disability, and illness . . . have been privatized, so that we have come to discount them and the integral part of social life they in fact constitute. Doing so permits us to avoid our collective responsibility to maintain dependents.”); *cf.* sources cited *infra* note 182 and accompanying discussion in Part IV.C.

<sup>152</sup> Kittay, *supra* note 140, at 575–76.

<sup>153</sup> Anita Silvers & Leslie Pickering Francis, *Justice Through Trust: Disability and the “Outlier Problem” in Social Contract Theory*, 116 *ETHICS* 40, 59 (2005).

<sup>154</sup> *Id.* at 60 (“Social contract theory aims fundamentally at an account of how social cooperation (far more than simply sharing resources) justly may be sustained. In this light, it seems counterproductive to construe the foundational contracting process as essentially adversarial.”).

<sup>155</sup> *Id.* at 45.

<sup>156</sup> Lawrence C. Becker, *Reciprocity, Justice, and Disability*, 116 *ETHICS* 9, 32, 35 (2005).

<sup>157</sup> *Id.* at 17.

<sup>158</sup> NUSSBAUM, *supra* note 140, at 71.

<sup>159</sup> *Id.* at 182.



Becker considers the role of individuals with disabilities in society, it does not address their exclusion. Disabled persons may remain ill-equipped to participate in the bargaining process and reliant on the beneficence of other, self-interested bargainers. Nussbaum's model appears to exclude severely disabled and ill individuals who lack certain capacities.<sup>160</sup> Silvers and Francis come closest to realizing the inclusion of individuals with disabilities, though it is unclear how their theory would apply in practice. It is possible, however, that it would support the universal vulnerability approach I posit in section C. Prior to turning to that discussion, it is useful to revisit the dominant legal assumptions about human functioning that result in fragmentation and thereby limit the protections and benefits for individuals with disabilities and illness.

### *B. Legal Assumptions*

The philosophical assumptions discussed in section A are mirrored in the law. The law incorporates a narrow view of the human subject as functioning over a lifetime, which fails to capture the lived experience of disability and illness. When laws do not address the barriers to the civic and social realms that individuals with disability and illness experience, such individuals may be excluded from the public domain. When individuals with disability and illness are able to participate in society, they do so within workplaces, programs, and other contexts that operate under the assumption that they function without impairment (unless they request an accommodation or other modification). Such individuals often do not have meaningful access to work and services, and lack substantive equality.

The current organization of legal structures addressing disability and illness embraces the following three assumptions:

A1: Individuals are fully functioning over a lifetime.

A2: Individuals are capable of laboring for wages.

A3: Individuals are able to form and order preferences and to participate in the market.

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<sup>160</sup> See Cynthia A. Stark, *Respecting Human Dignity: Contract Versus Capabilities*, 40 METAPHILOSOPHY 366, 378 (2009) (discussing Nussbaum's view of the need for capacity for reasonable agreement and her rejection of trusteeship for individuals without that capacity); see also Michael Ashley Stein, *Disability Human Rights*, 95 CALIF. L. REV. 75, 105 (2007) (discussing that under Nussbaum's capabilities model, individuals with profound impairments may not be able to realize the capabilities she suggests a state must maximize to promote human dignity).

Under Assumption One, individuals are viewed as capable of entering the workforce and other areas of the public realm, and obtaining (minimal) health care without support. Legal structures are not arranged to anticipate or respond to impairment to functioning. Disability and illness are not considered part of the human experience but as discrete occurrences to be addressed through targeted benefit programs that reach only some individuals with impairments. The same targeted approach limits eligibility for disability protections under antidiscrimination mandates for individuals with impairments. Individuals with disabilities who are able to participate in society are often held at the margins, with low-paying work that is not considered to violate antidiscrimination provisions.<sup>161</sup> Additionally, individuals with disabilities may face structural barriers when they have physical access to places of public accommodation or services but are unable to enjoy what they offer.<sup>162</sup>

A similar critique may be applied to Assumption Two—that individuals are capable of laboring for wages. For workers deemed “unproductive,” *no* civil rights protections attach.<sup>163</sup> Aside from limited government-subsidized work experiences, which are insufficient to support independent living, unproductive workers are largely excluded from the workforce.<sup>164</sup> Productive workers also face formidable challenges, both with barriers to entry into the workforce and job retention. Individuals with disabilities who are working but who earn wages that are insufficient to support independent living, and who consequently supplement their income through Social Security, are effectively taxed at 50%.<sup>165</sup> No workplace protections exist for individuals with illnesses that do not rise to the level of disability, other than limited, unpaid leave.<sup>166</sup> Workers with disabilities are protected against discrimination, but employment rates for individuals with legally recognized disabilities are either the same or

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<sup>161</sup> Many individuals with disabilities live in poverty. See STAPLETON ET AL., *supra* note 110, at 1 (“Poverty rates for people with at least one disability are more than twice as high [23.3% versus 8.9%] as for those with no disabilities.”); U.S. DEP’T OF LABOR, CREATING A ROADMAP OUT OF POVERTY FOR AMERICANS WITH DISABILITIES 5 (2009), available at [http://www.dol.gov/odep/documents/197953\\_DeptLabor.pdf](http://www.dol.gov/odep/documents/197953_DeptLabor.pdf) (“[T]he Adjusted Gross Income of a taxpayer with a disability was \$19,100 compared to \$33,800 for a worker without a disability and . . . wages for a taxpayer with a disability were \$15,000 compared to \$39,300 for a worker without a disability.”).

<sup>162</sup> See *supra* Part II.A.

<sup>163</sup> Under the ADA, individuals must be able to fulfill “the essential functions of [their] job” as described by their employer. ADA, 42 U.S.C. § 12111(8) (2006 & Supp. II 2008); William G. Johnson, *The Future of Disability Policy: Benefit Payments or Civil Rights?*, 549 ANNALS AM. ACAD. POL. & SOC. SCI. 160, 164 (1997) (discussing how the ADA does not address workers with limited productivity).

<sup>164</sup> Johnson, *supra* note 163, at 164.

<sup>165</sup> STAPLETON ET AL., *supra* note 110, at 2.

<sup>166</sup> Family and Medical Leave Act of 1993, 29 U.S.C. § 2612(a) (2006).

lower than before the passage of the ADA.<sup>167</sup> Since most individuals in the United States obtain health benefits through their employer, individuals who are not working must qualify for one of a patchwork of government programs to receive health insurance.<sup>168</sup> The inability to work also deprives individuals with impairments of valuable social interaction and a sense of belonging that promotes well-being.<sup>169</sup> Arguably, the low employment rates of individuals with disabilities undercut the ADA's goal of decreasing isolation for individuals with disabilities.<sup>170</sup>

It should also be noted that some commentators believe that employers choose not to hire individuals with disabilities because they fear accommodation costs.<sup>171</sup> This highlights the problem with legal structures that do not support universal vulnerability to disability (and illness). Because impairment is viewed as exceptional, government support for accommodation is extremely limited. As a result, private firms must fund accommodation, creating a potential disincentive to hire employees with disabilities. The view that disability is exceptional also likely affects employer attitudes about disability hiring more generally.

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<sup>167</sup> Compare Kathleen Beegle & Wendy A. Stock, *The Labor Market Effects of Disability Discrimination Laws*, 38 J. HUM. RESOURCES 806, 850 (2003) (finding state disability antidiscrimination laws did not result in a decrease in employment for persons with disabilities prior to the enactment of the ADA), with DAVID C. STAPLETON ET AL., HAS THE EMPLOYMENT RATE OF PEOPLE WITH DISABILITIES DECLINED? 1–4 (2004), available at <http://digitalcommons.ilr.cornell.edu/edicollect/92> (discussing a decline in the employment of working age individuals with disabilities based on Current Population Survey data), and Daron Acemoglu & Joshua D. Angrist, *Consequences of Employment Protection? The Case of the Americans with Disabilities Act*, 109 J. POL. ECON. 915, 929 (2001) (finding a sharp decline in 1993 in the employment of men with disabilities between twenty-one and thirty-nine years old, and in 1992 a decline for women of the same age; both measurements are relative to the employment of workers without disability within the same age ranges), and Christine Jolls & J.J. Prescott, *Disaggregating Employment Protection: The Case of Disability Discrimination* 5 (Nat'l Bureau of Econ. Research, Working Paper No. 10740, 2004) (finding a causal relation between unemployment and the ADA in the years immediately following its enactment). Cf. John J. Donohue, III & James J. Heckman, *Re-Evaluating Federal Civil Rights Policy*, 79 GEO. L.J. 1713 (1991) (arguing that civil rights protections decreased employment of persons of color).

<sup>168</sup> See, e.g., KAISER FAMILY FOUND. & HEALTH RESEARCH & EDUC. TRUST, EMPLOYER HEALTH BENEFITS: 2007 SUMMARY OF FINDINGS 1 (2007), available at <http://www.kff.org/insurance/7672/upload/Summary-of-Findings-EHBS-2007.pdf> (finding that in 2007, 158 million Americans received health insurance through their employer). Employers pay 69.7% of health care expenses for their employees. 2009 Summary and Updated Tables, CTRS. FOR MEDICARE & MEDICAID SERVS., <http://www.cms.gov/NationalHealthExpendData/downloads/bhg09.pdf> (last visited Feb. 1, 2011).

<sup>169</sup> U.S. DEP'T OF LABOR, *supra* note 161, at 5 (“Working individuals and family members with disabilities recognize that work fulfills the need to be productive, enhances self-esteem, and expands opportunities for community participation.”).

<sup>170</sup> ADA § 12101(a)(2) (2006) (“[H]istorically, society has tended to isolate and segregate individuals with disabilities . . .”).

<sup>171</sup> See, e.g., Jolls & Prescott, *supra* note 167, at 2.

Assumption Three—that individuals are capable of forming and ordering preferences and participating in the market—may also be false.<sup>172</sup> Individuals with mental impairments (illness, disabling illness, or other mental impairment) may not be able to participate actively in the market. The same may be true for individuals who undergo treatments for physical illness, such as some forms of chemotherapy for cancer, which may impair mental capacity.<sup>173</sup> Individuals with physical impairments also may not be able to participate in the marketplace, due to barriers to accessing physical spaces or services. Information may be presented in an inaccessible manner, for example, when Braille is not available for blind individuals, audio for deaf persons, and the like.

The next section argues that addressing these false legal assumptions requires state recognition of, and response to, universal vulnerability. Individuals are not “liberal subjects” without impairments, but rather “vulnerable subjects,” with bodies and minds that may experience limitations throughout their life cycles.<sup>174</sup>

### C. *Recognizing Universal Vulnerability*

Martha Fineman’s theory of universal vulnerability views individuals as “vulnerable subjects” who may experience social, economic, or biological loss throughout their lives.<sup>175</sup> All individuals are vulnerable, in the sense that they have the potential to suffer these losses. As a result of social, economic, or biological limitations, individuals may become “dependent.”<sup>176</sup> The ontology

<sup>172</sup> Some scholars challenge this assumption with respect to individuals without impairments. *See, e.g.*, Ehud Guttel & Alon Harel, *Probability Matching and the Law: A Behavioral Challenge to Law & Economics* (Hebrew Univ. of Jerusalem, Discussion Paper No. 368, 2004), available at <http://ratio.huji.ac.il/dp/dp368.pdf> (“Contrary to the conventional assumption that individuals maximize payoffs, robust experimental studies show that individuals who face repeated choices involving probabilistic costs and benefits often make sub-optimal decisions by applying the strategy of ‘probability matching.’”); *see also* Alex Stein, *A Liberal Challenge to Behavioral Economics: The Case of Probability*, 2 N.Y.U. J.L. & LIBERTY 531 (2007).

<sup>173</sup> *Chemo Brain: Definition*, MAYOCLINIC.COM, <http://www.mayoclinic.com/health/chemo-brain/DS01109> (last updated Oct. 9, 2010) (“Chemo brain is a common term used by cancer survivors to describe thinking and memory problems that can occur after cancer treatment. Chemo brain can also be called chemo fog, cognitive changes or cognitive dysfunction.”).

<sup>174</sup> *See* Martha Albertson Fineman, *The Vulnerable Subject: Anchoring Equality in the Human Condition*, 20 YALE J.L. & FEMINISM 1, 11–14 (2008) [hereinafter Fineman, *Anchoring Equality*] (discussing the vulnerable subject); Martha Albertson Fineman, *The Vulnerable Subject and the Responsive State*, 60 EMORY L.J. 251 (2011) [hereinafter Fineman, *Responsive State*] (same).

<sup>175</sup> Fineman, *Anchoring Equality*, *supra* note 174, at 11–14; Fineman, *Responsive State*, *supra* note 174, at 266–69.

<sup>176</sup> Fineman, *Anchoring Equality*, *supra* note 174, at 12.

of dependency will necessarily vary, but possible sources include natural disaster, war, financial hardship, violence, disability, and illness.<sup>177</sup>

Fineman's theory rests on the view that vulnerability is a "universal, inevitable, enduring aspect of the human condition."<sup>178</sup> All individuals are vulnerable, and vulnerability remains constant throughout the life cycle.<sup>179</sup> This concept of vulnerability moves past views of "vulnerable populations" that focus on specific deprivations and dependencies (often resulting in stigmatization),<sup>180</sup> to one that views the human experience as one of vulnerability.<sup>181</sup>

While Fineman focuses on vulnerability more generally, and I focus on vulnerability realized as "impairment," Fineman's theory has clear application to disability and illness. The vulnerable subject may become a disabled or ill subject based on biology or environment. Vulnerability to disability and illness is universal and constant. We are susceptible to disability and illness as part of the human condition.

Fineman's concept of dependency is also relevant to understanding disability and illness as part of the human condition. Fineman conceptualizes dependency as encompassing both inevitable and derivative dependencies.<sup>182</sup> While disability and illness may not give rise to dependency, they are part of

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<sup>177</sup> *Id.* at 11–12.

<sup>178</sup> *Id.* at 8.

<sup>179</sup> *Id.*

<sup>180</sup> See, e.g., Janet E. Lord et al., *Natural Disasters and Persons with Disabilities*, in *LAW AND RECOVERY FROM DISASTER: HURRICANE KATRINA* 71, 80 (Law, Property & Society Ser., 2009) ("Subsuming disability under the rubric of vulnerable groups at particular risk and in need of protection may also serve to reinforce outmoded conceptions of people with disability as objects to be acted upon, thereby perpetuating medical models of disability."). However, policy-makers must develop comprehensive and inclusive policies, avoiding "[v]ague frameworks, which purport to address the vulnerability of all populations groups [that] do more harm than good insofar as they create the sense that 'something is being done.'"). *Id.*

<sup>181</sup> *Id.*

<sup>182</sup> Fineman has developed the concept of dependency over the last twenty years in an impressive volume of work. She understands "inevitable dependency" as "developmental and biological in nature" and involving care we receive as infants and elderly persons as well as that provided for some illness or disability. Fineman, *Responsive State*, *supra* note 174, at 264. "Derivative dependency" is "*neither* inevitable, *nor* . . . universally experienced . . . [I]t is socially imposed through our construction of institutions such as the family, with roles and relationships traditionally defined and differentiated along gendered lines." *Id.* While Fineman focuses on dependency within the family, she acknowledges other forms of dependency, including economic and psychological. *Id.* at 264 n.43; see also FINEMAN, *THE AUTONOMY MYTH*, *supra* note 7 (discussing her theory of dependency); MARTHA ALBERTSON FINEMAN, *THE ILLUSION OF EQUALITY: THE RHETORIC AND REALITY OF DIVORCE REFORM* (1991) (introducing her theory of dependency); FINEMAN, *THE NEUTERED MOTHER*, *supra* note 7 (discussing the role and inter-relationship of inevitable and derivative dependency).

the human condition like certain inevitable dependencies, such as dependency at the beginning and end of life.<sup>183</sup> Illness is inevitable at some point during one's life, and disability is possible and even likely toward the end of life.<sup>184</sup>

Under my application of Fineman's vulnerability thesis to disability and illness, an individual becomes disabled or ill when her vulnerability to impairment is realized. In this sense, an individual with a disability or illness experiences vulnerability more acutely than an individual without impairment.<sup>185</sup> A disabled or ill individual, moreover, remains vulnerable to further disability and illness. Disability and illness have the potential to result in dependency or disadvantage, the latter including isolation and discrimination.<sup>186</sup>

Fineman's vulnerability theory highlights the deleterious effects of fragmentation that I identify in this Article. It also provides a valuable theoretical basis from which to critique targeted as opposed to universal legal approaches to disability and illness. My application of Fineman's arguments suggests the need for legal structures that recognize and respond to the following three premises:

P1: All individuals are vulnerable to disability and illness.

P2: Individuals with disability and illness remain universally vulnerable to further disability and illness.

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<sup>183</sup> FINEMAN, *THE NEUTERED MOTHER*, *supra* note 7, at 162 (recognizing infancy and childhood as involving "inevitable dependencies"). For an insightful examination of the possible legal basis for a right to care, see Robin West, *The Right to Care*, in *THE SUBJECT OF CARE: FEMINIST PERSPECTIVES ON DEPENDENCY* 88 (Eva Feder Kittay & Ellen K. Feder eds., 2002).

<sup>184</sup> MATTHEW W. BRAULT, U.S. DEP'T OF COMMERCE, *AMERICANS WITH DISABILITIES: 2005*, at 4 (2008), available at <http://www.census.gov/prod/2008pubs/p70-117.pdf> (reporting that more than half of individuals age sixty-five or older have a disability, and 70% of individuals over age eighty have a disability).

<sup>185</sup> Fineman, *Anchoring Equality*, *supra* note 174, at 10 ("Undeniably universal, human vulnerability is . . . particular [and] is experienced uniquely by each of us . . .").

<sup>186</sup> Fineman prefers to speak in terms of *disadvantage* instead of *discrimination*, as she believes the former better captures the ills of privilege. *Id.* at 16. Further, *discrimination* invokes the protected class status of formal equality that she rejects as harmful to the very individuals it is designed to protect. However, Fineman acknowledges that disadvantage may give rise to discrimination. *Id.* at 4 n.7 ("I acknowledge that discrimination does exist, and I do recognize that . . . personal characteristics might work to complicate the experience of vulnerability for any individual. My claim is merely that discrimination models based on identity characteristics will not produce circumstances of greater equality and may in fact lead to less in many circumstances.").

P3: All individuals are vulnerable to disadvantage, including isolation and discrimination; however, individuals with disability and illness may experience such disadvantage more acutely based on their impairments.

If legal structures are to respond to universal vulnerability to disability and illness, these premises must replace the assumptions discussed in section B of this Part.

The premises have direct implications for both the macro- and micro-level fragmentation discussed in Parts II and III. All three premises suggest that universal approaches to addressing disability and illness offer the greatest possibility for responding to macro-level fragmentation. Laws that provide protections or benefits to only certain groups of individuals with impairments fail to recognize the ongoing vulnerability to disability and illness that all individuals experience. Premise Three underscores the need for legal protections across a range of environments for individuals with impairments. To address micro-level fragmentation, all three premises indicate that courts must assess individuals' impairments holistically and throughout their daily environments to gain an accurate view of impairment and required accommodation or other modification. I turn to each of these proposals for overcoming fragmentation—universal approaches to protections and benefits and a holistic assessment of impairment—below.

#### *D. Universal Versus Targeted Approaches*

At the macro-level, fragmentation is the product of targeted rather than universal legal approaches to disability and illness. Targeted approaches establish criteria for eligibility for protections or entitlement to resources, intending to limit or exclude individuals from certain rights or benefits. Targeted approaches may be strong or weak in terms of exclusivity. Civil rights laws, which require membership in a protected class, are strongly exclusive. Laws that provide benefits may range from weakly exclusive (e.g., Medicare for all individuals over age sixty-five) to strongly exclusive (e.g., disability education benefits only for qualifying children). Regardless of where a targeted approach falls on the spectrum, there will be some fragmentation between the lived experience of disability or illness and what the law recognizes or supports as disability or illness.

Universal approaches, by contrast, seek to provide a set of protections or benefits to all individuals. The strongest response to disability and illness as part of the human condition would be to restructure our legal and social

institutions to provide universal protections against certain forms of employer behavior (such as termination without cause), universal access to health care, and wage supports for individuals unable to work.<sup>187</sup> This would capture the largest range of impairments and would likely decrease stigma associated with “special” benefits for disability.<sup>188</sup> It might also change negative social attitudes about funding and receiving state support, as such support would be premised on the recognition of universal vulnerability to disability and illness.

In other work, I have variously argued for universal access to health care, but only for an expanded targeted approach (or a mixed antidiscrimination/social welfare approach) to employment.<sup>189</sup> With respect to employment, I suggest basing disability protections on membership in the protected class but expanding disability accommodation beyond what is required by the ADA.<sup>190</sup> I stop short of a universal work program because, unlike universal health care, I do not believe it is politically feasible. Under my work proposal, the disabled subject would still be considered more holistically than under current law. Protections would extend across environments in the public realm as well as into the private sphere. I argue

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<sup>187</sup> This restructuring would entail legislative action. Robin West is author of an important corpus of work examining the affirmative duties of legislatures to address social welfare issues. See, e.g., West, *From Choice to Reproductive Justice*, *supra* note 7 (discussing the possible advantages of a right to abortion through “ordinary political” rather than adjudicatory means); Robin West, *Katrina, the Constitution, and the Legal Question Doctrine*, 81 CHL-KENT L. REV. 1127 (2006) (introducing the “legal question doctrine,” which she defines as the treatment of constitutional questions as legal ones to be resolved by the judiciary, and proposing legislative responses in the poverty and other contexts); Robin West, *The Missing Jurisprudence of the Legislated Constitution*, in THE CONSTITUTION IN 2020, at 79 (Jack M. Balkin & Reva B. Siegel eds., 2009) (arguing that legislatures are better equipped to promote equality and achieve progressive goals such as addressing poverty); Robin West, *Unenumerated Duties*, 9 U. PA. J. CONST. L. 221 (2006) (arguing courts should abandon jurisprudence supporting the “legal question doctrine,” which she introduces in other work).

<sup>188</sup> See Bagenstos, *The Future of Disability Law*, *supra* note 49, at 73.

<sup>189</sup> Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 2, at 555–58. Mark Weber identifies the value of social welfare programs for addressing disability discrimination in significant early work. See Mark C. Weber, *Disability and the Law of Welfare: A Post-Integrationist Examination*, 2000 U. ILL. L. REV. 889, 940–56. Samuel Bagenstos explores the value of universal approaches to social welfare (particularly health care) coupled with antidiscrimination protections for individuals with disabilities in a path-breaking article. See Bagenstos, *The Future of Disability Law*, *supra* note 49, at 59–70. The concepts in his article are expanded in part of his 2009 book, *Law and the Contradictions of the Disability Rights Movement*, which will likely set the agenda for disability law reform in decades to come. In an insightful new article, Michael Waterstone explores the benefits of a mixed civil rights/social welfare approach in the context of disabled veterans. See Waterstone, *supra* note 101, at 1109–10 (“[V]eterans programs provide support for both a broader conception of antidiscrimination law and complementing it with social welfare programs that reduce structural barriers to employment. . . . [T]he USERRA implicitly recognizes that strict antidiscrimination, even with a reasonable accommodation requirement, may not go far enough”).

<sup>190</sup> Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 2, at 555–58.



that the ADA's reasonable accommodation mandate should be expanded, with government support to allow workers with disabilities accommodation that facilitates employment by improving functioning both at home and in the workplace.<sup>191</sup>

To further this goal, it is necessary to create funding structures that shift much of the financial burden from private firms to the government. A ceiling should be determined for the percentage of annual earnings an employer is required to spend on accommodating employees with disabilities. Thus, employer responsibility for accommodation would be capped. Government subsidies would close the gap between the employer cap and the remaining cost of a reasonable accommodation to facilitate work. The "undue hardship" defense would remain for an employer failing to make an accommodation, though I propose that the measure of the employer's burden should include the government subsidies for which the employer is eligible, even if the firm fails to seek them.<sup>192</sup> A standard such as "undue hardship" might also be used to assist the state in determining reasonable expenses for funding accommodation that exceeds the maximum amount required from private firms.

Before turning to possible ways to address micro-level fragmentation, it should be noted that universal approaches to accessibility may also assist in creating or re-creating physical spaces and altering service provision. Universal Design (UD) is a movement in architecture to "design . . . products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design."<sup>193</sup> UD responds to impairments that may not be considered disabilities under law. UD relies on seven principles: "equitable use," "flexibility in use," "simple and intuitive" use, "perceptible information," "tolerance for error," "low physical effort," and "size and space" appropriate for use.<sup>194</sup> I argue in previous work that UD

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<sup>191</sup> Home modifications are not available under the ADA. Veterans disabled in the line of duty may receive up to \$4,100 for home and vehicle modifications under USERRA. See Waterstone, *supra* note 101, at 1114, 1114 n.173.

<sup>192</sup> ADA, 42 U.S.C. § 12111(10) (2006) (defining "undue hardship" as "requiring significant difficulty or expense," measured by "the nature and cost of the accommodation" and the financial resources and impact of the accommodation on the facility making the accommodation as well as the covered entity, if different).

<sup>193</sup> *About UD*, CTR. FOR UNIVERSAL DESIGN, [http://www.ncsu.edu/www/ncsu/design/sod5/cud/about\\_ud/about\\_ud.htm](http://www.ncsu.edu/www/ncsu/design/sod5/cud/about_ud/about_ud.htm) (last visited Feb. 1, 2011); see also ROBERT F. ERLANDSON, UNIVERSAL AND ACCESSIBLE DESIGN FOR PRODUCTS, SERVICES, AND PROCESSES 17 (2008).

<sup>194</sup> *Universal Design Principles*, CTR. FOR UNIVERSAL DESIGN (Apr. 1, 1997), [http://www.ncsu.edu/www/ncsu/design/sod5/cud/about\\_ud/udprincipletext.htm](http://www.ncsu.edu/www/ncsu/design/sod5/cud/about_ud/udprincipletext.htm); see also ERLANDSON, *supra* note 193, at 67 (stating relevant UD design factors as "ergonomically sound, perceptible, cognitively sound, flexible, error-managed (proofed), efficient, stable and predictable [as well as] equitable").

should be encouraged through government support, though not mandated.<sup>195</sup> It is likely that UD at the construction stage will prove efficient, requiring fewer workspaces and other buildings to be retrofitted for disability access. UD principles may also be applied to the provision of services.<sup>196</sup>

### *E. Holistic Look and Micro-Level Fragmentation*

The solution to the problems of micro-level fragmentation (environment-framing) is a meaningful assessment of the broader environment in which an individual functions. While courts currently look to a broad environment for determining whether someone is disabled, the conclusions drawn fragment protections. Courts must adopt a holistic view of impairments, but not penalize someone for being able to function in a portion of her environment. With respect to remedy, courts need to move from a narrow to a broad assessment of environment. An individual should not be denied an accommodation or other modification because she is able to function in a small area of her environment.

Social Security disability cases provide a useful insight into the method of assessing environment for disability eligibility purposes. I want to emphasize that I am concerned with the method of environment assessment, not the

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<sup>195</sup> Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 2, at 560–61.

<sup>196</sup> For example, universal design principles are applied in education, both at the school and classroom levels. School-wide projects range from “inclusive schools,” which assist teachers working individually with all students regardless of perceived or diagnosed disabilities, to more modest approaches that seek to provide a level of benefits and services to students who might not otherwise meet the threshold for “child with a disability” under the IDEA. See MARY KONYA WEISHAAR ET AL., *INCLUSIVE EDUCATIONAL ADMINISTRATION* 17–18 (2d ed. 2007); see also IDEA, 20 U.S.C. § 1413(f) (2006). In addition, the IDEA allows school districts to spend up to 15% of the special education funds they receive from the federal government to “develop and implement coordinated, early intervening services.” *Id.* § 1413(f). These services target any student who begins to show signs of slipping grades or other interruptions in educational performance, regardless of potential eligibility under the IDEA. *Id.* Universal Design Learning (UDL), which is applied within individual classrooms, involves altering teaching to allow students “multiple means . . . to access and respond to the content [of the curriculum].” Suk-Hyang Lee et al., *Impact of Curriculum Modifications on Access to the General Education Curriculum for Students with Disabilities*, 76 *EXCEPTIONAL CHILD*, 213 (2010). UDL may involve a combination of lecturing, PowerPoint and other visual media, and class participation. *Id.* at 214. While UDL is currently used only in special education settings, it could be extended to general classrooms. *Id.* at 229. Mark Weber argues that this should be the point of special education, that it is “not so much special as part and parcel of the education enterprise as a whole.” Mark C. Weber, *Reflections on the New Individuals with Disabilities Education Improvement Act*, 58 *FLA. L. REV.* 7, 9 (2006). Classroom materials themselves may be universally designed. Some textbooks are available in alternative formats for students with visual impairments. Resources such as Bookshare.org maintain databases of books that may be converted to audio, large print, or Braille. Ann Harrison, *Bookshare.org: Accessible Texts for Students with Print Disabilities*, 24 *J. SPECIAL EDUC. TECH.*, no. 2, 2009, at 38, 38–40.

definition of disability employed in these cases. I do not believe the definition of disability under the ADA should change, only the way in which courts assess environment under that definition.

Social Security cases require a more holistic view of an individual's impairments. In the physical disability context, "severe impairment" is assessed by considering an individual's overall ability to function, or "the combined effect of all of the individual's impairments without regard to whether any such impairment, if considered separately, would be of such severity."<sup>197</sup> All credible limitations are assessed, including exertion levels at work.<sup>198</sup>

The method of assessing mental disability limitations is perhaps even more useful for overcoming fragmentation. The Social Security Administration is required "to consider . . . all relevant evidence to obtain a longitudinal picture of [the claimant's] overall degree of functional limitation."<sup>199</sup> The claimant's impairment is assessed in four functional areas: (1) activities of daily living; (2) social functioning; (3) concentration, persistence, or pace; and (4) episodes of decompensation (temporary increase in symptoms followed by a loss of functioning).<sup>200</sup>

Using a broad environment to assess individuals' functional impairments for Social Security disability purposes does not generate the negative results for plaintiffs that using the same environment produces in ADA litigation. In Social Security litigation, a broad environment is used to gain a more complete view of impairment, not to impede benefits coverage. The ability to perform tasks at home is not equated with the lack of disability.<sup>201</sup> The Social Security

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<sup>197</sup> 42 U.S.C. § 423(d)(2)(B) (2006); *see also* Webb v. Barnhart, 433 F.3d 683, 688 & n.1 (9th Cir. 2005).

<sup>198</sup> SSR 96-8p, 1996 WL 374184, at \*5 (July 2, 1996).

<sup>199</sup> 20 C.F.R. § 404.1520a(c)(1) (2010).

<sup>200</sup> *Id.* at § 404.1520a(c)(3).

<sup>201</sup> *See, e.g.*, Gaylor v. Astrue, 292 Fed. App'x 506, 513 (7th Cir. 2008) (holding that the claimant's ability to care for her own needs and those of her children did not demonstrate the ability to have gainful employment); Ford v. Astrue, 518 F.3d 979, 983 (8th Cir. 2008) (holding that the claimant's ability to wash dishes, iron clothing, and make several meals a week did not show that she can work); Wagner v. Astrue, 499 F.3d 842, 851 (8th Cir. 2007) (holding that the claimant's ability to cook, clean, and enjoy a hobby at home did not constitute substantial evidence of the capacity for gainful employment); Mendez v. Barnhart, 439 F.3d 360, 362 (7th Cir. 2006) (cautioning against "placing undue weight on a claimant's household activities in assessing the claimant's ability to hold a job outside the home"); Swope v. Barnhart, 436 F.3d 1023, 1026 n.4 (8th Cir. 2006) (noting that "the ability to do activities such as light housework and visiting with friends provide[d] little or no support" for the ALJ's conclusion that the claimant was capable of work (quoting Hogg v. Shalala, 45 F.3d 276, 278 (8th Cir. 1995)) (internal quotation marks omitted)); Gentle v. Barnhart, 430 F.3d 865, 867 (7th Cir. 2005) (finding that the claimant's ability to perform housework and take care of an infant did not equal the

Administration and judges considering Social Security claims consider the frequency and independence of activities performed by claimants, and their ability to sustain the activities over a period of time.<sup>202</sup> As recognized by one court, caring for one's children may be the product of desperation to retain custody, not an indicator of actual functionality as measured from a baseline of normal functioning.<sup>203</sup> As the court stated, "[a] person can be totally disabled for purposes of entitlement to social security benefits even if, because of . . . circumstances of desperation, he is in fact working."<sup>204</sup>

The same holistic approach could be used to overcome the fragmentation of disability protections under the ADA. An individual could be assessed in a broad environment at both the eligibility and remedy stages of disability analysis. While this would impose a broader environment for accommodation or other modification than is currently used, in the eligibility context it would require only a refinement of judicial analysis. Functionality in some portion of an individual's daily environment would be insufficient to preclude membership in the protected class.

My intention in this and the preceding sections is not to provide all of the "answers" to fragmentation. Rather, I seek to begin a conversation about moving toward more holistic, universal approaches to disability and illness as a potential response to fragmentation. Such reform, one might expect, could be achieved incrementally.

## CONCLUSION

The present era of government re-regulation presents a rare opportunity to reexamine how legal and social structures respond to disability and illness. Fragmentation is a typical, harmful government response to regulation. With respect to disability and illness, however, it is experienced by the legal subject

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ability to work in the labor market); *Smolen v. Chater*, 80 F.3d 1273, 1284 n.7 (9th Cir. 1996) ("[M]any home activities may not be easily transferable to a work environment where it might be impossible to rest periodically or take medication."); *Salts v. Sullivan*, 958 F.2d 840, 846 (8th Cir. 1992) (finding that the claimant's ability to garden, mow a lawn, build model cars, play cards, and drive did not disprove disability); *Murphy v. Sec'y of Health & Human Servs.*, 872 F. Supp. 1153, 1159 (E.D.N.Y. 1994) (holding that the claimant's ability to read and watch television did not prove that he can perform sedentary work).

<sup>202</sup> See *Reed v. Barnhart*, 399 F.3d 917, 923 (8th Cir. 2005).

<sup>203</sup> *Gentle*, 430 F.3d at 867.

<sup>204</sup> *Id.*

perhaps most acutely, when civic and social participation is severely limited or precluded.<sup>205</sup>

The role of the state in overcoming fragmentation may take different forms. I posit that more universal approaches to disability and illness would mitigate, if not overcome, the effects of fragmentation. This would entail broadening eligibility for disability protections and extending those protections to more environments. A range of disability and health benefits would also be made available to all individuals with functional impairments and illness.

Restructuring legal institutions to overcome fragmentation in any area undoubtedly requires state intervention. The state must be active in legislating and implementing legal change. The state must also concentrate on defining and developing tools that enable individuals to be resilient in the event of disability or illness.<sup>206</sup> Some of these tools may be directly related to disability and health—such as medical care, personal assistance, or accessible transportation—but others may be indirectly related, such as job training or wage supports.

I cast government intervention and enhanced public programs as optimal. One might conceptualize the state making these changes as a strong, responsive state.<sup>207</sup> However, the state may respond to fragmentation without such robust intervention.

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<sup>205</sup> Some may argue that fragmentation in education or work should be considered on similar grounds. While primary and secondary education is compulsory, children experience disparities in accessing quality, appropriate education. Not all primary and secondary students with impairments qualify for an IEP under the IDEA. For all students with impairments, certain UD approaches may be useful. See, e.g., DAVID H. ROSE & JENNA W. GRAVEL, NAT'L CTR. ON UNIVERSAL DESIGN FOR LEARNING, GETTING FROM HERE TO THERE: UDL, GLOBAL POSITIONING SYSTEMS, AND LESSONS FOR IMPROVING EDUCATION (2010), available at <http://www.udlcenter.org/sites/udlcenter.org/files/GPSarticle.pdf>; Douglas K. Rush & Suzanne J. Schmitz, *Universal Instructional Design: Engaging the Whole Class*, 19 WIDENER L.J. 183 (2009); *supra* note 196 and accompanying text. Barriers to job entry and retention are well documented. To resolve these problems, William Darity argues for a universal work program. See William A. Darity, Universal Work Program, Address at the *Emory Law Journal's* Randolph W. Thrower Symposium: The New New Deal: From De-Regulation to Re-Regulation (Feb. 11, 2010); cf. LOTTE BAILYN, BREAKING THE MOLD: REDESIGNING WORK FOR PRODUCTIVE AND SATISFYING LIVES (2d ed. 2006) (discussing work schedules that account for familial duties).

<sup>206</sup> See PEADAR KIRBY, VULNERABILITY AND VIOLENCE: THE IMPACT OF GLOBALISATION 54–76 (2006) (discussing the role of state institutions in providing resilience to violence); Fineman, *Anchoring Equality*, *supra* note 174, at 19 (discussing the role of the state in responding to vulnerability by providing tools for resilience); Fineman, *Responsive State*, *supra* note 174, at 255–56.

<sup>207</sup> Fineman, *Anchoring Equality*, *supra* note 174, at 19–22; Fineman, *Responsive State*, *supra* note 174.

Indeed, if one conceptualizes the state as functioning on two axes—one of state intervention and one of attention to vulnerability to disability and illness—a variety of possible combinations emerge. A state may be strong, intermediate, or weak in terms of intervention. A state may also be responsive or unresponsive in terms of reacting to vulnerability to disability and illness. I believe an intermediate, responsive state is similar to what we have now, with targeted approaches to disability and illness.<sup>208</sup> I say “similar” because a responsive state must recognize and address disability and illness as part of the human condition, and current laws do not do so. Targeted approaches fall on a spectrum of intervention themselves, meanwhile, with recent expansions to the definition of disability and to health care benefits expanding the targeted approach to perhaps its fullest extent.<sup>209</sup>

A weak, responsive state might be one where disability and illness are recognized as part of the human experience, and state intervention brings individuals who can be easily brought into the market and other public realms into those spheres. This intervention might be something akin to the limited assistance Friedrich Hayek speaks of within his otherwise non-interventionist, libertarian regime.<sup>210</sup> In the medical context, one could imagine such a minimalist state providing emergency medical care. Any responsive approach

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<sup>208</sup> Fineman argues that antidiscrimination (targeted) approaches do not address substantive inequalities. Fineman, *Responsive State*, *supra* note 174, at 275 n.20. This is because some individuals enjoy the privilege of protections and benefits while others do not. *Id.* at 253–54. However, antidiscrimination and other targeted approaches have decreased the disparities between individuals with disability and illness and those without such conditions. The former also serves as a formal statement of government commitment to equality, which may hinder discriminatory conduct. My position is that targeted programs may be responsive to vulnerability to disability and illness, but they do not go far enough.

<sup>209</sup> AAA, Pub. L. No. 110-325, §§ 2(b)(4)–(6), 4(a), 122 Stat. 3553, 3554, 3555 (2008) (expanding the range of “major life activities” that may be considered limited, lowering the standard for “substantial limitation,” and considering an individual in an unmitigated state); PPACA, Pub. L. No. 111-148, 124 Stat. 119 (2010) (to be codified at 20, 21, 25, 26, 29 and 42 U.S.C.) (expanding health insurance coverage through Medicare, Medicaid, and subsidized private insurance to include an additional 32 million individuals (over 92% of the population) by 2019). For a detailed summary of PPACA’s provisions, including program implementation dates, see KAISER FAMILY FOUND., FOCUS ON HEALTH REFORM: SUMMARY OF NEW HEALTH REFORM LAW (2010), available at <http://www.kff.org/healthreform/upload/8061.pdf>.

In a thoughtful article, Michael Ashley Stein and Michael E. Waterstone address expanding the formal equality or targeted approach to disability discrimination through class actions. See Michael Ashley Stein & Michael E. Waterstone, *Disability, Disparate Impact, and Class Actions*, 56 DUKE L.J. 861, 893–921 (2006) (presenting a “pandisability” theory of group-based discrimination).

<sup>210</sup> HAYEK, *supra* note 150, at 87 (noting that government should provide protection against severe deprivation, which may include “a uniform minimum income . . . outside the market to all those who, for any reason, are unable to earn in the market an adequate maintenance”).

would address fragmentation of the human experience of disability and illness, to varying degrees.

What must be avoided under any political regime is a state that is unresponsive to vulnerability to disability and illness, regardless of whether it is strong, intermediate, or weak in terms of intervention. A strong, unresponsive state might be one that enacts laws limiting protections against unequal treatment based on disability as well as access to health benefits, the latter through prohibitive pricing structures or other means. Public benefits would probably not be provided. An intermediate, unresponsive state would regulate private firms but would likely remain neutral with respect to antidiscrimination mandates or benefits. Such a state might enact laws that do not encourage the provision of disability and health benefits, such as tax structures lacking incentives for employers to offer health insurance to their employees. A weak, unresponsive state would be one that largely does not regulate private firms (i.e., regulation would likely address only safety) and probably provides no antidiscrimination mandates or public health or disability benefits.

Only an unresponsive state would fail to take any steps to align the human experience of disability and illness with the legal experience. By contrast, the responsive state at any level of intervention could challenge traditional notions of the human experience as one without physical or mental impairment. State acknowledgement of the experience of disability and illness as part of the human condition—even without any provision of material support—would help combat the stigma, segregation, and isolation of individuals that impede their social activity. Outmoded views of disability and illness invoke pity, fear, and discomfort that work against a more inclusive society and give rise to prejudice and discrimination.

In an era of re-regulation, the state must at a minimum be responsive. While the strong, responsive state best addresses fragmentation by restructuring legal and supporting social institutions, change may also occur in increments within the confines of existing legal structures. It is possible, for example, to expand gradually the environments covered under the ADA to better capture the experience of disability. Similarly, extensions of health care coverage may be incremental. In 1965, Congress enacted Medicare and

Medicaid for the elderly and indigent, respectively.<sup>211</sup> Coverage for children was expanded under the CHIP in 1997.<sup>212</sup> Prescription drug benefits were added in 2003.<sup>213</sup> Seven years later, Congress sought to expand these targeted approaches to health care through the PPACA.<sup>214</sup> These changes could ease the way to complete restructuring. Only with an understanding of disability and illness as part of the human experience may society begin to overcome the effects of fragmentation in disability and health law.

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<sup>211</sup> See Health Insurance for the Aged Act (Medicare Act), Pub. L. No. 89-97, tit. XVIII, 79 Stat. 290 (1965) (codified as amended in scattered sections of 26, 42, and 45 U.S.C.); Medicaid Act, Pub. L. No. 89-97, tit. XIX, 79 Stat. 343 (1965) (codified as amended in scattered sections of 42 U.S.C.). Also, in 1986, the Emergency Treatment and Active Labor Act expanded emergency care to all individuals who arrive in an emergent state at a hospital that receives Medicare funds and operates an emergency room. See 42 U.S.C. § 1395dd (2006).

<sup>212</sup> CHIPRA, Pub. L. No. 111-3, tit. XXI, 123 Stat. 8 (2009) (codified in scattered sections of 26, 29, and 42 U.S.C.). CHIP was formerly called “SCHIP,” the State Children’s Health Insurance Program.

<sup>213</sup> Medicare Prescription Drug, Improvement, and Modernization Act of 2003, Pub. L. No. 108-173, tit. XVIII, 117 Stat. 2066 (codified as amended in scattered sections of 26 and 42 U.S.C.).

<sup>214</sup> PPACA, Pub. L. No. 111-148, 124 Stat. 119 (2010) (to be codified at 20, 21, 25, 26, 29 and 42 U.S.C.); see also *supra* note 209 and accompanying text..