

FRAGMENTATION AFTER HEALTH CARE REFORM

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ABSTRACT

In this Article, I argue that while the Patient Protection and Affordable Care Act of 2010 (PPACA and the Act) addresses health care fragmentation, it does not go far enough. In doing so, I further develop my theory of health care fragmentation—the disjunction between the legally-represented and lived experience of patients—as well as examine the meta-level issues absent from legal scholarship about the social assumptions that shape health care legislation and contribute to fragmentation. These social views fail to recognize vulnerability to illness as universal and constant across a lifetime and are reflected in legal responses to health care delivery. I examine fragmentation both before and after PPACA and offer suggestions to bring the lived and legal experiences of patients into alignment. My conception of the lived experience fits within the public policy debate about patient-centered health care, since vulnerability to illness—while universal—is experienced and often best addressed on an individual level.

INTRODUCTION

The Patient Protection and Affordable Care Act of 2010 (PPACA and the Act) is the first major federal expansion of health care coverage since President Lyndon B. Johnson signed Medicare and Medicaid into law in 1965. PPACA was enacted during a period of financial crisis in the United States. Personal bankruptcy rates resulting from medical costs were high, and the media were replete with stories of illness and death due to lack of insurance or underinsurance. Meanwhile, health care costs were rising, and medical outcomes often were not improving despite, and sometimes due to, medical technology. Medical error also was on the rise.

Congress intended PPACA to fill gaps in health care coverage as well as to improve the quality and outcomes of patient care.¹ PPACA seeks to accomplish this through governmental and private expansion of health insurance;² individual and employer mandates to purchase and to provide insurance, respectively;³ and reforms that target the type, manner, and circumstance of health care delivery.⁴ The reforms pertaining to health care delivery in part seek to coordinate better the way in which health care is provided and billed.⁵ Such coordination is believed to improve health care outcomes as well as to generate administrative cost savings that may be passed on to health care consumers.

Thus, PPACA speaks to remedying health care fragmentation as it is commonly understood, namely, lack of coordinated care or payment. PPACA contains many initiatives to address this type of fragmentation, including: streamlining enrollment for public health insurance,⁶ improving coordination of health care services for individuals enrolled in both Medicare and Medicaid,⁷ providing bonuses for Medicare Advantage (Medicare private insurance) plans

¹ See Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010).

² *Id.*

³ *Id.* §§ 1501, 1513.

⁴ *Id.* §§ 3001-3027.

⁵ See, e.g., *id.* §§ 3021-3027 (discussing new patient care models).

⁶ *Id.* § 1413.

⁷ *Id.* §§ 2601-2602.

based on health care coordination,⁸ requiring Health and Human Services (HHS) to establish a national strategy for improving health care delivery,⁹ and establishing new patient care models to coordinate health care better.¹⁰

PPACA also bears on health care fragmentation as I interpret it in this Article and elsewhere, that is, as the disjunction between the actual and legally-recognized experience of illness.¹¹ This disjunction may occur in a number of ways. Some health insurance plans and institutions are structured in a manner that fails to respond to patients' health care needs across a lifetime. Others may not otherwise adequately address patients' needs, for example, by providing inappropriate diagnostic services, treatment, or support. As a result, individuals may become unable due to illness to participate in social and civic realms. PPACA addresses this type of fragmentation by closing gaps in needed health care coverage, when the law fails to appreciate an on-going need for health services, as well as recognizing health care needs with more accuracy in other ways. These reforms take at least two forms: providing more comprehensive care and more appropriate services to meet patients' needs.

PPACA provides more comprehensive care by funding care, facilitating enrollment in health insurance, and improving physical access to medical services, largely in rural or underserved areas.¹² The Act funds health care by providing or subsidizing health insurance,¹³

⁸ *Id.* § 3011.

⁹ *Id.* §§ 3011-3015.

¹⁰ These include Accountable Care Organizations, medical homes, and pilot programs involving bundled payments for medical treatment and coordinated home-based primary care for chronically ill patients. *Id.* §§ 2703, 3022-3024.

¹¹ See Ani B. Satz, *Disability, Vulnerability, and Fragmented Protections: Accessing Education, Work, and Health Care*, in *RIGHTING EDUCATIONAL WRONGS: DISABILITY STUDIES IN LAW AND EDUCATION* 265, 271-72, 290-93 (Arlene S. Kanter & Beth A. Ferri eds., 2013); Ani B. Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, 83 WASH. L. REV. 513, 513 (2008); Ani B. Satz, *Fragmented Lives: Disability Discrimination and the Role of "Environment-Framing,"* 68 WASH. & LEE L. REV. 187, 233 (2011); Ani B. Satz, *Overcoming Fragmentation in Health and Disability Law*, 60 EMORY L. J. 277, 281 (2010).

¹² Patient Protection and Affordable Care Act §§ 5602, 7101-7103 (creating a floor for Medicare payments based on geography and bonus payments for ambulance services in rural areas).

¹³ PPACA includes voluntary extension of Medicaid up to 133% of the federal poverty level,

mandating that private employers with more than fifty employees provide insurance,¹⁴ and requiring insurance market reforms to extend and to provide continuity within insurance¹⁵—insuring an additional forty-three million United States citizens and documented immigrants. PPACA creates a demonstration program that allows hospice patients to receive Medicare¹⁶ and reauthorizes funding of state and medical school support for children’s emergency and critical care treatment and research.¹⁷ Additionally, it limits co-insurance and deductibles.¹⁸ It also addresses access to pharmaceuticals as a form of health care by reducing gaps in prescription drug coverage for adults and providing drug discounts for children and underserved communities.¹⁹ Enrollment in health insurance is mandated for most individuals, and employers with more than 200 employees must enroll their employees in health plans automatically.²⁰ Enrollment in government programs is facilitated through a website as well as a year-long enrollment period for disabled veterans and their dependents.²¹

Additionally, PPACA seeks to respond better to patient needs through a number of initiatives. It aims to ensure a range of necessary health care services in a less restrictive environment, namely, community-assisted living over institutionalization. To this effect, the Community First Choice Option provides community-based services for individuals with disabilities and grants to combine primary and

continuation of the Children’s Health Insurance Program through 2019, insurance through government-subsidized health insurance exchanges, tax breaks for individual purchase of insurance, long-term care services and supports, and the extension of dependent coverage under private parental policies until age 26. *Id.* §§ 1001, 1311, 1401, 2001(a), 2101(a), 2401.

¹⁴ *Id.* § 1513.

¹⁵ These include prohibiting discrimination and rescission of health insurance based on health status; eliminating lifetime and most annual caps on essential benefits; eliminating pre-existing condition clauses; and requiring coverage of preventative health care, including immunizations. *Id.* §§ 1001, 1201.

¹⁶ *Id.* § 3140.

¹⁷ *Id.* §§ 3504, 5603.

¹⁸ *Id.* §§ 1302, 1402(c)(1). Deductibles cannot exceed \$2,000 for an individual or \$4,000 for a family. *Id.* § 1302.

¹⁹ This is through the 340B program. *Id.* § 7101.

²⁰ *Id.* §§ 1511, 1513.

²¹ *Id.* § 1311(c)(6); HEALTHCARE.GOV, <http://www.healthcare.gov> (last visited Oct. 8, 2015).

specialty care in community-based mental and behavioral health facilities.²² The Act also requires governmentally-sponsored health insurance exchanges²³ and “essential health benefits” for insureds with individual and small group plans.²⁴ It increases access to preventative health care services in schools and for Medicare and Medicaid recipients (if states opt to participate in the expansion of the latter program)²⁵ as well as provides support for workplace health promotion and infectious disease and pain management.²⁶ PPACA further provides programs within nursing homes to prevent abuse and to educate care-givers about dementia²⁷ as well as to protect elderly patients generally (the latter is known as the “Elder Justice Act”).²⁸

Nevertheless, the degree to which PPACA addresses fragmentation—as both traditionally understood and as I conceptualize it—has not yet been explored in the legal literature. This Article is intended to begin that discussion. The Article examines the concept of health care fragmentation and the ways in which PPACA seeks to respond to it. I conclude that while PPACA remedies fragmentation in part, it does not go far enough. Part I of this Article defines and describes health care fragmentation. Parts II and III explore some meta-level issues associated with fragmentation, namely, social expectations and legal assumptions about health care, respectively, that contribute to the misalignment between the actual and legally-recognized patient experience. Part IV discusses the legal assumptions about the patient experience within PPACA specifically.

²² Patient Protection and Affordable Care Act § 2401. The Community Living Assistance Services and Support (CLASS) program, which was repealed, would have provided cash payments to individuals with disabilities to support community living services. *See* American Taxpayer Relief Act of 2012, Pub. L. No. 112-240, § 642, 126 Stat. 2313, 2358 (2012).

²³ Patient Protection and Affordable Care Act § 1311.

²⁴ “Essential benefits” include: emergency services; hospitalization; maternity and newborn care; mental health and substance abuse disorder services; behavioral health treatment; prescription drug treatment; rehabilitative services and devices; laboratory services; preventive and wellness services as well as chronic disease management; and pediatric services, including oral and vision care. *Id.* § 1302.

²⁵ *Id.* §§ 4101-4108.

²⁶ *Id.* §§ 4303-4305, 10408.

²⁷ *Id.* § 6121.

²⁸ *Id.* §§ 6701-6703.

Part V proposes some steps towards solutions to account better for the lived experience of patients after federal health care reform.

I. CONCEPTIONS OF HEALTH CARE FRAGMENTATION

First, it is necessary to interrogate what I mean by “fragmentation” in health law. In the following subparts, I distinguish it from the more common conception of fragmentation in the field and situate it within the broader theoretical construct of vulnerability theory.

A. Fragmentation as Lack of Coordination

Fragmentation in health law most commonly is understood as “having multiple decision makers make a set of health care decisions that would be made better through unified decision making.”²⁹ Thus, it is viewed as a problem stemming from lack of coordinated care and payment, which may be remedied by increasing such coordination.³⁰ This type of fragmentation could occur on different levels, as a result of individual medical practitioner, institutional, or regulatory policies.

A number of aspects of PPACA—including health homes³¹ and Accountable Care Organizations (ACOs), under Medicare’s Shared Savings Program—are regulatory policies designed to improve coordination of care and billing.³² In response to some of these and other coordination provisions of the Act, fragmentation also may be addressed at the institutional level by changing bylaws to integrate better health care delivery and payment within delivery systems. Similar policies that organize care and billing for patients may be developed at the individual practitioner level.

To be sure, increasing coordination of health care delivery and billing may improve patient care and health outcomes as well as

²⁹ Einer Elhauge, *Why We Should Care About Health Care Fragmentation and How to Fix It*, in *THE FRAGMENTATION OF U.S. HEALTHCARE* 1, 1 (Einer Elhauge ed., 2010).

³⁰ *Id.* at 8, 10. Deeper structural problems may underlie fragmentation as it is commonly understood, including disincentives to coordinate providers and billing practices that promote ease of switching providers and providing less medical care. *Id.*

³¹ Patient Protection and Affordable Care Act § 2703.

³² *Id.* § 3022.

lower administrative costs. But coordinating care and payment—and even remedying the larger structural problems that underlie lack of coordination—will remedy only one part of a much broader problem of fragmentation caused by laws that fail to represent the lived experience of patients.

B. Fragmentation as the Disjunction Between the Lived and Legally-Recognized Experience

Under my view, fragmentation occurs when the lived experience of an individual with an illness differs from what is recognized or assumed by the law. At the most basic level, this may happen when an individual experiences illness but is not recognized as eligible for health care services, or, alternatively, qualifies for insufficient services. Fragmentation as I understand it also may occur when the law responds to a health care need in a manner that fails to appreciate the patient's actual need. For example, insurance structures may provide more support for a patient to be institutionalized than to live in a community-based home, even when the latter better serves the patient's needs and is likely to generate a better health outcome.

Eligibility typically is an issue with benefits that apply to only certain time periods in a lifecycle, such as federal and state programs for children, pregnant women, and older Americans, when health care needs remain constant throughout life. Benefits also may attach only in particular circumstances, such as when an individual serves in or is retired from the armed forces, or impairment rises to the level of legally-recognized disability. Sometimes eligibility depends on strong political forces, such as coverage for end-stage renal disease for individuals of any age under Medicare, a statute otherwise targeting individuals age 65 or older.³³ While insufficient health care services may stem from such eligibility problems, they also may be the result of underinsurance (lack of sufficient health insurance coverage for individuals who have health insurance) or the inability to access health care services due to discrimination based on race, disability, or other personal characteristics; geographic location; or inadequate physician services or equipment. In each of these and the

³³ Medicare, 42 U.S.C. § 1395c (2006).

eligibility contexts, laws fail to support access to health care in ways that fully appreciate or respond to health care needs.

C. Comparing and Situating Fragmentation

Health care fragmentation as I conceptualize it may, like the traditional notion of fragmentation, occur on an individual, institutional, or regulatory level. My conceptualization of fragmentation, while encapsulating the standard definition, goes beyond it. It includes the standard conception in so far as laws do not create incentives for providers to coordinate health care or billing for such services, and this results in a difference between the legally-recognized and actual patient experience. These laws support practices that fail to appreciate treatment for an illness as the single episode that it is, and, consequently, divide care amongst multiple providers or employ disparate billing requirements. Fragmentation as I understand it extends beyond these limits, though, to capture other instances of misalignment between laws and the lived patient experience, based on the inability to access services across the lifecycle and the inappropriate nature of services provided.

Perhaps most important is the foundational difference between my notion of fragmentation and the traditional one. The theoretical underpinnings of the traditional concept are unclear and likely varied—possibly including economic, fairness, and individual freedom considerations. My concept is rooted in emerging vulnerability theory,³⁴ which seeks in part to re-conceptualize both the individual and the state based on certain factors about the human condition.³⁵ Namely, vulnerability is viewed as universal, constant, and extending across the lifecycle.³⁶ In these ways, vulnerability theory takes a fundamentally different view of the human experience that embraces interdependence and calls for legal and social

³⁴ Emory University is home to the global Vulnerability and the Human Condition Initiative directed by Martha Fineman, where I serve as affiliated faculty. See *Vulnerability and the Human Condition*, EMORY U., <http://web.gs.emory.edu/vulnerability/> (last visited Oct. 8, 2015). Fineman's path-breaking scholarship on vulnerability was first introduced in Martha Albertson Fineman, *The Vulnerable Subject: Anchoring Equality in the Human Condition*, 20 YALE J.L. & FEMINISM 1 (2008).

³⁵ See Fineman, *supra* note 34, at 11-12. Vulnerability theory also recognizes that institutions may be vulnerable. *Id.*

³⁶ *Id.* at 8.

structures that consider the entire lifecycle, rather than discrete moments of legal or other injury.³⁷ Vulnerability theory calls on the state to be active and responsive to the human condition and to provide tools for resilience that may prevent vulnerability from becoming realized.³⁸

Vulnerability theory thus grounds a number of arguments I make about fragmentation in this Article. First, vulnerability to illness is universal and constant, affecting the entire population, not only certain “vulnerable populations.” As a result, access to health insurance and other supports for illness, should it manifest, are universally required throughout life. To be sure, not all individuals need the same level of health care services in their life, but that does not change the fact that everyone is constantly vulnerable to illness on some level. Second, and relatedly, health care needs must be addressed across the lifecycle, rather than at discrete moments in time. This requires an investment in health care services over a lifetime, not only in a time of crisis or when an individual becomes a patient. Normative arguments from consequentialism that I provide in Part II also support this view, though this Article is not intended as a global defense of that approach. Third, and relatedly, the state—as reflected in health law and policy—should respond to these human characteristics, providing health insurance and other supports for illness.

Another clarification may be useful. In previous writing, I introduce fragmentation at the regulatory and judicial levels.³⁹ I refer to fragmentation created by statutes and regulations as “macro-level” fragmentation. I refer to “micro-level” fragmentation as fragmentation that results from judicial interpretation of such statutes and regulations, and further restricts health care benefits or exacerbates uncoordinated care or payment. I intend to explore “micro-level” fragmentation in more detail elsewhere, as the role of courts is complex in interpreting health care laws. While courts

³⁷ I am grateful to Martha Fineman for conversation on this point.

³⁸ Fineman, *supra* note 34, at 19-22.

³⁹ See, e.g., Satz, *Fragmented Lives: Disability Discrimination and the Role of “Environment-Framing,”* *supra* note 11 (discussing judicial or “micro-level” fragmentation); Satz, *Overcoming Fragmentation in Health and Disability Law,* *supra* note 11 (introducing fragmentation at the legislative (macro) and judicial (micro) levels).

contribute to further fragmentation—stemming, for example, from rulings rendering expansion of the Medicaid program under PPACA voluntary,⁴⁰ holding PPACA’s premium tax credits fail to apply to federal as opposed to state health insurance exchanges,⁴¹ and restricting patient claims under the Employee Retirement Income Security Act⁴² for denial of access to health care services—courts also readily seek to repair the damage caused by laws that fragment the human experience of illness.⁴³

My goal in this piece is to shed light on health care fragmentation created by legislatures and administrative agencies after PPACA. Remedies will require that health care benefits better reflect patients’ needs and experiences and are available across the lifecycle. This typically will include a move from targeted to more universal approaches to health care services. While the most obvious universal approach would be a single-payor health care program, this Article is not a direct defense of universal health care. Rather, I seek to uncover fragmentation under our current patchwork system of health care programs and to begin a discussion about how it might be remedied

⁴⁰ See Nat’l Fed’n of Indep. Bus. v. Sebelius, 132 S. Ct. 2566 (2012) (holding mandatory Medicaid expansion unconstitutional).

⁴¹ See *Halbig v. Burwell*, 758 F.3d 390 (D.C. Cir. 2014), *vacated en banc*, No. 14-5018, 2014 U.S. App. LEXIS 17099 (D.C. Cir. 2014), *overruled in part by* *King v. Burwell*, 135 S. Ct. 2480 (2015); see also Timothy Jost, *Implementing Health Reform: Decisions Split on Tax Credits in ACA Federal Exchange*, HEALTH AFF. BLOG (July 23, 2014), <http://healthaffairs.org/blog/2014/07/23/implementing-health-reform-appellate-decisions-split-on-tax-credits-in-aca-federal-exchange/> (noting that under the original *Halbig* ruling, five million Americans might have lost their health insurance without premium tax credits, and the individual market could have collapsed in thirty-four to thirty-six states).

⁴² See, e.g., *Aetna Health Inc. v. Davila*, 542 U.S. 200, 208-09 (2004) (interpreting Employee Retirement Income Security Act of 1974 § 502 as imposing complete field preemption and preempting plaintiffs’ torts claims for denial of benefits under Texas Healthcare Liability Act).

⁴³ This is especially true in the disability context. See, e.g., *Parents League for Effective Autism Serv. v. Jones-Kelley*, No. 2:08-cv-421, 2008 WL 2796744 (S.D. Ohio June 30, 2008) (denying motion to stay an injunction against enforcement of new Ohio Administrative Rules that would withhold medically necessary benefits from children by classifying them as habilitative (capable of learning new skills) instead of rehabilitative (capable of regaining lost skills), a distinction without much relevance for children born with disabilities); cf. *Walker v. Bowen*, 889 F.2d 47 (4th Cir. 1989) (holding in the disability income benefits context that claimants impairments should be viewed in the aggregate, so as not to “fragmentize” them).

within those programs. In some cases, this might occur through expansion of existing targeted programs, or, in others, by challenging and changing legal assumptions about the patient experience.

In order to begin to understand health care fragmentation and why these solutions are favorable for addressing it, it is helpful to uncover the reasons why lawmakers might create a misalignment between the actual and lived patient experience. In the next part, I examine how social expectations about health care support fragmentation.

II. SOCIAL ASSUMPTIONS ASSOCIATED WITH FRAGMENTATION

Patients often are concerned about preventing fragmentation in access to health care in terms of eliminating gaps in health insurance coverage and ensuring access to desired health care services under health plans. Paradoxically, certain social assumptions about health care align with fragmentation in health law. These views generate expectations about the availability of health care resources that are reflected in laws that fragment health care.

This part will focus on four such social assumptions: medical rationing is detrimental to patient care, patients benefit from directing their own health care, patients benefit by accessing the most advanced medical technology, and the best patient care requires medical specialization. These views rely on the respective false premises that fairness requires health care resources be delivered in response to acute illness rather than over the course of a lifetime, patients are able to coordinate and to otherwise manage their own care, and the most advanced medical technology and medical specialization result in the best patient outcomes.

A. Rationing Is Detrimental to Patient Care

Citizen opposition to rationing in the United States is well-established, as demonstrated by public criticism of nationalized health care in other countries based on long wait-lists for non-urgent hospital services;⁴⁴ Oregon's Medicaid plan, which rank-orders health

⁴⁴ Sharon Wilcox et al., *Measuring and Reducing Waiting Times: A Cross-National Comparison of Strategies*, 26 HEALTH AFF. 1078, 1085-86 (2007).

care services and determines eligibility for them;⁴⁵ and, more recently, end-of-life care conversations between Medicare recipients and medical providers viewed as “death panels.”⁴⁶ In each of these contexts, opponents argue that access to health care services should not be based on estimated health outcomes, where preference is given to those who are anticipated to benefit most from a particular health care service. Rather, they argue, individuals should have access to medical services when they need them, regardless of whether they stand to benefit less than someone else from the same service.⁴⁷

Stated most simply, “rationing” is a method by which access to something is restricted by limiting eligibility for it based on certain criteria.⁴⁸ Rationing in health care limits consumption of health care services, either by apportioning them or otherwise limiting access to them.⁴⁹ Rationing may be direct, in the sense that someone may be

⁴⁵ See OR. HEALTH AUTH., HEALTH EVIDENCE REVIEW COMM’N, PRIORITIZED LIST OF HEALTH SERVICES, 1 (Sept. 11, 2015), <http://www.oregon.gov/oha/herc/PrioritizedList/1-1-2015%20Prioritized%20List%20of%20Health%20Services.pdf> (“Providers,” “Prioritized List,” and “Current Prioritized List”). In 2015, 669 services are listed in rank priority, ranging from prenatal care to treatment for gastrointestinal and other conditions where no treatment is necessary or effective. *Id.*

⁴⁶ See America’s Affordable Health Choices Act of 2009, H.R. 3200, 111th Cong. § 1233(a); Payment Policies Under the Physician Fee Schedule, 75 Fed. Reg. 73,170, 73,406 (Nov. 29, 2010).

⁴⁷ This viewpoint captures the difference between rationing and a more common health care distribution approach in the United States—a “basic minimum approach”—which provides a certain level of health care services, usually a narrower range of services, across a population based on medical need and regardless of anticipated health outcome. I examine this and other health care distribution paradigms in earlier work. See Ani B. Satz, *The Limits of Health Care Reform*, 59 ALA. L. REV. 1451 (2008) (discussing the theoretical limitations of basic minimum and rationing approaches and proposing distribution to support basic capability equality); 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) (developing a theory of basic capability equality to distribute high technology health care).

⁴⁸ See, e.g., Simona Grassi & Ching-to Albert Ma, *Public Sector Rationing and Private Sector Selection*, 14 J. PUB. ECON. THEORY 1, 34 (2010) (discussing two different rationing rules, one that takes into account consumer wealth and the other that considers both consumer wealth and cost information).

⁴⁹ See Barbara J. Russell, *Health-Care Rationing: Critical Features, Ordinary Language, and Meaning*, 30 J.L. MED & ETHICS 82 (2002) (discussing five conceptions of health care rationing: apportionment through allowance, limited care with expected benefit, deliberate choices about sharing health care resources, social toleration of inequitable access to necessary services, and allocation of goods in scarcity).

denied access to a service, or indirect, if barriers such as co-payments and deductibles are intended to discourage uptake of services.⁵⁰

Opposition to rationing in the United States based on the view that it impedes patient care often is premised on the false assumption that rationing does not already occur. Private insurers ration in the sense that they make decisions about what services to cover for insured populations as well as what is “medically necessary” in individual patient situations. While these decisions certainly are challenged by some patients, the fact that insurers must make them in providing patient care is not. Individuals may even “self-ration,” to the extent that they restrict their own medical services and expenses. Thus, it seems that what people oppose is not rationing *per se* or rationing in these initial contexts, but further rationing or limits on services, especially those that are outside their control.

Evidence suggests that people want access to services when they desire them, even if those services are believed to be of limited or no efficacy or will consume a disproportionate share of health care resources per individual. As a result of this anti-rationing perspective, resources often are distributed to those who need them until funding is exhausted, instead of distributing them to those who would benefit most over the course of a lifetime. In other words, resources are consumed dealing with the immediate health needs of fewer people as opposed to distributed more equally over more people’s lifetimes.

The anti-rationing perspective is based on a specific notion of equality (and health care justice) that requires health care services be provided at any given point in time to those who require them, as opposed to thinking about equal claims to such services over a lifetime for a given individual or population. Individuals who prefer equality in the former sense may be understood to hold a “time-slice” rather than a lifetime view of equality. These individuals may perceive health care service allocations measured over the lifecycle as unjust, when acute health care problems go unaddressed. In fact, it is this desire for more equality in particular instances that motivated

⁵⁰ See Elizabeth Weeks Leonard, *Death Panels and the Rhetoric of Rationing*, 13 NEV. L.J. 872, 875-76 (2013) (citing Daniel Callahan, *Must We Ration Care for the Elderly?*, 40 J.L. MED. & ETHICS 10, 12 (2012)) (discussing indirect rationing, which Leonard terms “self-rationing,” using a different understanding than the one I present in this section).

the changes to the original Oregon Medicaid rationing plan to provide a greater number of basic services to everyone regardless of predicted health outcome.⁵¹

The time-slice view of health care justice is reflected in PPACA, not only by the notable absence of discussions about end-of-life care, but by the Act's silence with respect to changing the way in which health care allocations currently are made. Under both public and private insurance as conceived under the Act, health care coverage determinations are based on a time-slice view. In fact, PPACA furthers this view by removing lifetime and most annual caps on essential benefits, thereby eliminating any incentive to move from a time-slice to a lifetime view of access to scarce health care resources.⁵² While such caps might unfairly deprive individuals with chronic or terminal illness of access to needed care, arguably some limits on care are warranted to prevent expenditures on health care services with minimal to no value, particularly at the end of life.

The time-slice view embraced by PPACA likely will contribute to health care fragmentation. In the death panel context, the inability to consider options at the end of life ranging from resuscitation to palliative care may create significant gaps in care for terminally ill patients.⁵³ For patients who would choose less medical care at the end of life, failure to be informed about end-of-life care options could

⁵¹ See, e.g., JON ELSTER, LOCAL JUSTICE: HOW INSTITUTIONS ALLOCATE SCARCE GOODS AND NECESSARY BURDENS 71 (1992) (discussing limitations on rationing to promote equality under the Oregon Plan); John Oberlander, *Health Reform Interrupted: The Unraveling of the Oregon Health Plan*, 26 HEALTH AFF. 96, 97 (2007) (“[F]ears of rationing’s impact on Medicaid patients were allayed by [the Oregon’s Health Plan’s] generous benefit package and the absence of extensive rationing.”); Jonathan Oberlander et al., *Rationing Medical Care: Rhetoric and Reality in the Oregon Health Plan*, 164 CAN. MED. ASS’N J. 1583, 1586 (2011) (“Although initial rankings were based in large part on mathematical values, controversies around the list forced administrators to make political concessions and move medical services ‘by hand’ to satisfy constituency pressures and the federal government.”); Philip A. Perry & Timothy Hotze, *Oregon’s Experiment with Prioritizing Public Health Care Services*, 13 AM. MED. ASS’N J. ETHICS 241, 245 (2011) (discussing the Oregon Plan as “not the purest example of rationing”).

⁵² Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1001, 124 Stat. 119, 130 (2010). Exceptions exist for non-essential benefits and grandfathered plans. *Id.*

⁵³ Paul Westfall, *Ethically Economic: The Affordable Care Act’s Impact on the Administration of Health Benefits*, 14 DEPAUL J. HEALTH CARE L. 99, 109 (2001). The initiative also would have included discussions about advance directives, including living wills and durable power of attorney. *Id.*

result in medical waste and lower quality of life. As the over twenty-year studies of the Dartmouth Atlas Project demonstrate, Medicare patients who saw more physicians and received a greater number of medical interventions experienced worse health outcomes than those with less access to physicians and health care services.⁵⁴ Further, the inability to discuss the extraordinary costs of end-of-life care impedes some of the financial savings possible under PPACA.⁵⁵ If health care costs cannot be controlled at the end of life, benefits may be reduced during other periods of life or across all periods, creating gaps in coverage of some health care services outside the minimal level of benefits required by the Act. But this cost-control problem is not unique to health care provided at the end of life. It results from the anti-rationing or time-slice perspective generally taken with respect to health care coverage decisions as discussed above, and it is a historic cause of underinsurance in the United States.⁵⁶

Additionally, the anti-rationing perspective creates internal conflict within PPACA, given provisions stressing outcome-based health care that rely on the maximization of favorable health outcomes rather than a time-slice view of equality. These outcome-based programs include funding for comparative effectiveness research (measuring costs and benefits of health care services);⁵⁷ the Hospital Value-Based Purchasing Program that bases Medicare

⁵⁴ See generally DARTMOUTH ATLAS OF HEALTH CARE, <http://www.dartmouthatlas.org> (documenting the Dartmouth Atlas studies) (last visited Oct. 9, 2015); see also DARTMOUTH ATLAS PROJECT, THE CARE OF PATIENTS WITH SEVERE CHRONIC ILLNESS: AN ONLINE REPORT ON THE MEDICARE PROGRAM (2006), http://www.dartmouthatlas.org/downloads/atlas/2006_Chronic_Care_Atlas.pdf (last visited Oct. 9, 2015); Elliott S. Fisher et al., *The Implications of Regional Variations in Medicare Spending. Part I: The Content, Quality, and Accessibility of Care*, 138 ANN. INTERNAL MED. 273 (2003); John E. Wennberg et al., *Use of Hospitals, Physician Visits, and Hospice Care During Last Six Months of Life Among Cohorts Loyal to Highly Respected Hospitals in the United States*, 328 BRIT. MED. J. 607 (2004).

⁵⁵ See Westfall, *supra* note 53, at 111 (“Having end-of-life discussions decreases those end-of-life costs by 35% because the discussions lead to less invasive and less costly procedures.”).

⁵⁶ Similarly, some Oregon Medicaid recipients experienced a reduction in health care funding following the state’s departure from a traditional rationing scheme. See generally Oberlander, *Health Reform Interrupted: The Unraveling of the Oregon Health Plan*, *supra* note 51 (discussing Oregon’s unsuccessful move to cost-sharing for some Medicaid recipients in order to reduce costs after departing from a rationing scheme).

⁵⁷ Patient Protection and Affordable Care Act § 6302.

payments on performance for cardiac, surgical, and pneumonia care,⁵⁸ and patient care models and Medicare Part C incentives that reward institutions and insurers with a share of savings based on certain cost-saving and quality measures.⁵⁹ In fact, all of the reforms under Title III of PPACA, which emphasize quality and efficiency, may be viewed as adopting a maximization over a time-slice approach.

The time-slice view of health care justice is likely grounded in the belief that equality is an intrinsically important ethical goal.⁶⁰ This view discounts (rightly or wrongly) the importance of maximization of favorable health outcomes. At least one international study of 551 participants supports the preference for greater equality in access to health care services over the maximization of health outcomes.⁶¹ The study examined preferences for providing high cost services to fewer people or lower cost services to more people. The latter option approximates a rationing scheme, whereby services are distributed according to cost and anticipated benefit with the goal of covering more people. Eighty-one percent of individuals surveyed rejected cost as a basis for establishing allocative priority, meaning fewer patients might receive health care services over time.⁶² Over a hundred follow-up interviews confirmed these results. When presented with a compromise scenario, 53% chose to give partial priority to low cost patients, but only 14% of the remaining 47% of the people surveyed chose to maximize resources by giving low cost patients priority.⁶³ When asked to divide a set amount of resources between treatments for two illnesses at different costs, 94% of the

⁵⁸ *Id.* § 3001.

⁵⁹ *Id.* § 3201.

⁶⁰ Helga Kuhse et al., Rational Decision-making in Ethics of Health Care, QALYs: Some Methodological and Ethical Issues 10 (unpublished discussion paper) (on file with author). The preference for equality in the distribution of health care resources also might be based on the belief that such access is a means to better social consequences than other approaches. This approach may be viewed as an intuitive acceptance of an indirect form of utility as a prior notion of the good. The approach is based on a false belief, if one accepts that health care resources are scarce and needed throughout a lifetime. Erik Nord et al., *Who Cares About Cost? Does Economic Analysis Impose or Reflect Social Values?*, 34 HEALTH POL'Y 79, 90-94 (1995).

⁶¹ Nord et al., *supra* note 60, at 79.

⁶² *Id.* at 84.

⁶³ *Id.* at 86.

people surveyed chose a more equal distribution of treatment for both diseases over the treatment of a larger number of patients.⁶⁴

One possible response to this study and other anti-rationing views is that individuals do not reflect sufficiently before choosing equality over maximization. R. M. Hare argues, for example, that there are two different levels of moral thinking: intuitive and critical.⁶⁵ The intuitive level represents a choice when individuals employ “firm” and “simple principles” in everyday affairs, while the critical level involves more reflection, that is, consideration of the details of a situation or what one would do “in a cool hour.”⁶⁶ The view that one always should aid someone experiencing illness might be a principle applied in everyday affairs, while allocating health care resources over a lifetime could be preferred upon reflection. An informal 2012 National Public Radio poll in the end-of-life care context lends some support to this possibility. Prior to a fifty-minute panel discussion during the *Intelligence Squared* program about the benefits and burdens of rationing end-of-life care, 22% of the audience opposed rationing.⁶⁷ After the program, 12% remained in opposition.⁶⁸

Thus, a preference for equality over maximization may reflect a lower rational preference made in a situation of “crisis.” This may be because individuals have knowledge of their current health needs and ignorance of their future ones. As a result, they may lack the ability to separate themselves from a time-slice view of life—a preference for health care for what is wrong now—and to think in terms of rational, ethical ends—that is, health care over a lifetime.⁶⁹

If the choice of a time-slice approach results from this confusion, respect for individuals’ autonomous decision-making in resource allocation must be weighed against conceptions of justice that

⁶⁴ *Id.* at 87.

⁶⁵ R. M. HARE, MORAL THINKING: ITS LEVELS, METHOD AND POINT 25 (1981).

⁶⁶ *Id.* at 38-39, 52.

⁶⁷ Sherrie Dulworth, *From Schiavo to Death Panels: How Media Coverage of End-of-Life Issues Affects Public Opinion*, 58 N.Y.L. SCH. L. REV. 391, 398 (2013-2014) (citing *Should We Ration End-of-Life Care?*, NPR (Oct. 16, 2012, 1:15 PM), <http://www.npr.org/2012/10/12/162831800/should-we-ration-end-of-life-care>) (last visited Oct. 5, 2015).

⁶⁸ *Id.* at 399.

⁶⁹ Kuhse et al., *supra* note 60.

embody more rational ends. Public opinion, after all, is often based upon common misperceptions and prejudices that may be discarded once the public is informed or educated sufficiently. Changing views about the importance of nutrition and avoiding smoking serve as examples.

Alternatively, maybe anti-rationing views can be changed through political framing. One commentator suggests “benefits should be framed as providing ‘a mechanism for pooling our premium dollars so that health care will be available when we need it because no one has the private resources to fund a lifetime of health care on their own.’”⁷⁰ This framing, he argues, demonstrates loyalty and respect for people.⁷¹ In the context of rationing at the end of life, he states that “portraying death panels . . . as a cost-cutting measure [] portrays the government as a harsh, disciplinarian punisher . . . [one must instead] evoke values of cooperation and mutual aid, a morality of empathy for others and responsibility for oneself and others.”⁷²

B. Patients Benefit from Directing Their Own Health Care

Another social assumption that may be underlying health care fragmentation is that patients benefit from directing their own care. Since the late 1990s, patients have embraced consumer-driven health care (CDHC), or health care approaches that favor less coordination of benefits by insurers and providers and more patient choice in purchasing health care services. CDHC is care that is managed by patients themselves, in the sense that they determine which health care services to purchase and from whom to purchase them. Consumer-directed health plans (CDHP) may take many forms, including high deductible health plans (HDHP) with health savings accounts, health reimbursement accounts, and health plans that allow more patient choice in providers. When these choices produce gaps in care, legal structures that support CDHC contribute to fragmentation under both the traditional and expanded notions.

The goal of CDHC is to benefit health care consumers and

⁷⁰ Westfall, *supra* note 53, at 111 (quoting Sidney D. Watson, *Metaphors, Meaning, and Health Reform*, 54 ST. LOUIS U. L.J. 1313, 1327 (2010)).

⁷¹ *Id.* at 111-12.

⁷² *Id.* at 111.

insurers alike. On the patient side, it increases the patient's role in medical decision-making and therefore furthers patient autonomy. Such self-determination⁷³ in medical decision-making is widely viewed by patients and medical ethicists as instrumentally, if not intrinsically, valuable.⁷⁴ On the insurer side, CDHC is intended to decrease health care costs by setting aside a finite set of resources in health savings accounts from which patients pay medical expenses. Ideally, "patients will demand less care if they are burdened with a greater responsibility for paying [for it rather than having the costs] borne by public or private health insurance with little patient cost sharing."⁷⁵ According to one source, CDHPs could save \$57.1 billion per year if enrollment in such plans increases from 13% to 50% of employer-sponsored health insurance in the next decade.⁷⁶ For this reason, the American Medical Association favored PPACA to the extent that it supports CDHC, even though the organization historically opposed health care reform.⁷⁷

CDHC frequently involves high deductible health plans with health savings accounts used for out-of-pocket medical expenses. The funds in these accounts roll over each year and may even be passed to one's estate. Once these funds are exhausted, a patient is responsible for out-of-pocket costs. Patients also may direct their care by participating in health care reimbursement accounts, which are pre-tax dollars set aside for out-of-pocket medical expenses that serve as an insurance supplement rather than as a health plan. Under PPACA, these accounts are capped at \$2,500 pre-tax dollars per year and may be used only for medical services and prescription drugs

⁷³ Autonomy may be understood in many ways; here, I am generally speaking of self-determination. See, e.g., Lars Sandman, *On the Autonomy Turf: Assessing the Value of Autonomy to Patients*, 7 MED. HEALTH CARE & PHIL. 261 (2004) (discussing autonomy in terms of self-determination, freedom, desire-fulfillment, and independence).

⁷⁴ See, e.g., Jukka Varelius, *The Value of Autonomy in Medical Ethics*, 9 MED. HEALTH CARE & PHIL. 377 (2006) (arguing for the instrumental as opposed to intrinsic value of autonomy).

⁷⁵ Russell Korobkin, *Comparative Effectiveness Research as Choice Architecture: The Behavioral Law and Economics Solution to the Health Care Cost Crisis*, 112 MICH. L. REV. 523, 526 (2014).

⁷⁶ Amelia M. Haviland et al., *Growth of Consumer-Directed Health Plans to One-Half of All Employer-Sponsored Insurance Could Save \$57 Billion Annually*, 31 HEALTH AFF. 1009, 1010 (2012), available at <http://content.healthaffairs.org/content/31/5/1009.abstract>.

⁷⁷ Jill Quadagno, *Interest-Group Influence on the Patient Protection and Affordability Act of 2010: Winners and Losers in the Health Care Reform Debate*, 36 J. HEALTH POL. POL'Y & L. 449, 452 (2011).

and devices.⁷⁸

High deductible health plans and health savings accounts are subject to controversy because they function as primary health insurance, and, by definition, cap health care expenditures. While these plans do appear to save insurers money by allocating a finite level of resources for health care services to each plan participant,⁷⁹ evidence suggests that patients are not well served by these plans. Either the health plan's funds are too limited to cover needed services,⁸⁰ or patients are unable to make the decisions necessary to manage their own care.⁸¹ Funds certainly could be increased, so the key question is whether patients could become better consumers of health care. If not, fragmentation may be unavoidable under health care laws favoring CDHC.

Decision theory and empirical evidence suggest that patients incorrectly believe that placing them in charge of their own health care best protects their autonomy. Insights from decision theory strongly imply that this is not the case. In order to make rational decisions about their health care, patients "must be able to interpret complex, probabilistic information concerning the consequences of various treatment alternatives (including forgoing treatment) in an unbiased manner. [And then] given the differences in attributes of different treatment alternatives . . . select the alternative with the combination of attributes, including price, that will provide the most

⁷⁸ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 10902, 124 Stat. 119, 1016 (2010). Prior to PPACA, health care reimbursement accounts could be used for over-the-counter drug purchases.

⁷⁹ See *Consumer-Directed Health Care Plans 'Positive Force' in Marketplace, Aetna Says*, 10 HPPR (BNA) 214 (2004) (on file with author).

⁸⁰ While the effect of CDHP on health outcomes was not examined, one study found that patients with CDHP sought expensive care like emergency room care less often and had fewer diagnostic tests and more limited prescription drug use. Amy R. Wilson et al., *More Preventative Care, and Fewer Emergency Room Visits and Prescription Drugs—Health Care Utilization in a Consumer-Driven Health Plan*, 24 BENEFITS Q. 46, 50-51 (2008). Studies also show a disproportionate impact of CDHC on women, who have insufficient funds for pap smears, birth control, and mammography; they pay \$1,000 more out-of-pocket annually than men. *Consumer-Directed Plans Cost Women \$1,000 More Per Year than Men*, 13 HPPR (BNA) 394 (2007) (on file with author).

⁸¹ Lale Iskarpatyoti, *What's Next for Consumer-Directed Health Plans?*, 26 BENEFITS Q. 39, 41-42 (2010) (discussing a reduction in costs but no increase in consumer health knowledge).

overall utility.”⁸²

Most people do not have the ability to make such complex choices. As one commentator explains, “a patient would need to learn and understand the cost, inconvenience, mortality, and morbidity implications of each choice (along a variety of metrics).”⁸³ Decision theory suggests that when patients have difficulty comparing options, they make comparisons based on less important, easier to compare information or seek middle-of-the-road choices (a phenomenon termed “extremeness aversion”).⁸⁴ These options may not align with the best health outcomes or patients’ values. Further, even if patients could make such complex decisions, decision-making studies demonstrate that people choose not to make them because they are mentally taxing, and instead make decisions based on a simplified criterion, such as whether a health care service has the best chances of extending life or promoting a higher quality of life.⁸⁵

Compounding the problem, people have difficulty making medical decisions without prior experience considering the same options.⁸⁶ This situation is common, given one-time treatments as well as treatments for chronic or terminal illness that place patients on singular treatment paths, foreclosing other options along the way. Decision theory suggests that patients’ choices in these scenarios are often the product of context rather than patients’ values.⁸⁷ Ease of treatment in terms of geographic location, family obligations, or a favored physician, for example, might trump pursuing the treatment option with the best-predicted outcome, however a patient measures that.

When you add to this the fact that people do not feel comfortable placing a price on health care under the time-slice view (as addressed in the previous subsection on rationing), CDHC becomes burdened with what seem like insurmountable hurdles to benefitting patient autonomy. While empirical studies examining patient knowledge

⁸² Korobkin, *supra* note 75, at 532.

⁸³ *Id.* at 533.

⁸⁴ *Id.* at 536-37.

⁸⁵ *Id.* at 533-34.

⁸⁶ *Id.* at 534-35.

⁸⁷ *Id.*

and choice under CDHP are limited, those that exist support this conclusion. Studies show that patients have limited understanding of health options (that is, low “health literacy”), they have difficulty valuing health care services, and their preferences are inconsistent over time, perhaps due to the contextual effects previously discussed.⁸⁸ One study even demonstrated that patients with HDHP were unaware of how the plan itself works. Over half of the 465 patients surveyed were unaware that preventative health care visits were exempt and free of charge, and about 19% avoided or delayed such care.⁸⁹

Based on these limitations, it may be that CDHC is not in patients’ interests if only because of their inability to make the decisions it requires. As a general matter, poor patient choice may result in interruptions in care or inconsistent or substandard care. Poor health decisions also may be socially costly, especially if they result in emergency or extended care. Some patients may continue to believe, though, that CDHC best supports their autonomy. And this may be a preference—like equity under the time-slice view—that is paradoxically misaligned with overall patient goals. As in the rationing context, CDHC patients may fail to view their care over a lifetime. Just as patients prefer equity in distribution at any point in time but desire health care over a lifetime (mutually inconsistent desires with finite resources), patients desire autonomy at any given point in time but may exercise it in a manner that restricts autonomy over their lifetimes.

A distinction from philosophy is useful here. Philosophers recognize a difference between present (current or occurrent) and future (dispositional) autonomy.⁹⁰ Current or occurrent autonomy is autonomy, in this context choice based on self-determination, exercised at a given moment.⁹¹ Future or dispositional autonomy is self-determination that is realized at a future point in time.⁹² While

⁸⁸ *Id.* at 539.

⁸⁹ Mary E. Reed et al., *In Consumer-Directed Health Plans, A Majority of Patients Were Unaware of Free or Low-Cost Preventive Care*, 31 HEALTH AFF. 2641, 2644 (2012).

⁹⁰ See, e.g., ROBERT YOUNG, PERSONAL AUTONOMY: BEYOND NEGATIVE AND POSITIVE LIBERTY (1986).

⁹¹ *Id.*

⁹² *Id.*

future goals may change over time, they are understood to be long-term in nature. Occurrent autonomy may support dispositional autonomy, but it may not.

The distinction between occurrent and dispositional autonomy is salient in the medical context where certain medical or behavioral decisions (such as smoking or drinking) may impact future health, or one treatment decision may foreclose others. Physicians may act paternalistically or exercise what is sometimes called “high therapeutic privilege” to try to shape a patient’s treatment or other health-related decisions, in hopes of preserving the patient’s dispositional autonomy. If a patient makes a choice that conflicts with what the physician advocates at that time, the physician’s actions may be viewed as a violation of the patient’s occurrent autonomy. This violation of autonomy may be accepted by the physician (and retroactively by the patient) as necessary to preserve the patient’s dispositional autonomy.

The same arguments could be made in the CDHC context. Even if CDHC furthers patients’ occurrent autonomy, it might limit their dispositional autonomy. While CDHC patients, like all patients, may benefit from their physicians’ advice in choosing health care services, physicians—who are facing decreasing patient counseling time—are unable to assist patients with weighing complex variables regarding the selection and financing of their health care. For patients with medical savings accounts, their health insurance does not serve as a coverage guide for selecting services (a proxy for what might be medically necessary) or as a limiting factor on spending for any particular health occurrence. As a result, under CDHC funds may be exhausted prematurely due to unwise decisions. Alternatively, individuals may be afraid of exhausting their funds and avoid care they need to save resources. Like in the rationing context, failure to make decisions that take into account one’s health over a lifetime may result in gaps in needed health care. Thus, while legal structures supporting CDHC are designed to provide continuous care, the actual patient experience may be different.

C. Patients Benefit from Accessing the Most Advanced Medical Technology

Patient demand for ready access to advanced medical technology also is based on assumptions that are reflected in laws that fragment

health care. Patients often falsely assume that advanced medical technology will bring about the best health outcomes, and, as a result, should be provided at any cost. Given this view and the expectation that high technology health care will be available within a short time period and at a small geographic distance, advanced medical technology is one of the greatest contributors to health care costs.⁹³ When costs rise, insurers look to reduce spending in other ways, creating gaps in care.

Patients desire access to sophisticated or “high” technology health care, which has no rigid definition, but is commonly understood as technology offering an advanced means of analysis, imaging, diagnosis, or treatment.⁹⁴ They expect this technology, such as MRIs, to be available within a short distance⁹⁵ and without a substantial waiting period.⁹⁶ While it is difficult to fault patients for this, these expectations have significant financial costs. MRIs, for example, often need to be run continuously to pay for themselves, providing a powerful incentive for overuse. Compounding cost

⁹³ See Timothy Stoltzfus Jost, *Methodological Introduction*, in HEALTH CARE COVERAGE DETERMINATIONS: AN INTERNATIONAL COMPARATIVE STUDY 1, 1 (Timothy Stoltzfus Jost ed., 2005) (“Most experts . . . agree [] that the leading contributor to increases in health care costs in developed countries is the constant introduction of new health care technologies.”); Timothy Stoltzfus Jost, *The American Difference in Health Care Costs: Is There a Problem? Is Medical Necessity a Solution?*, 43 ST. LOUIS U. L.J. 1, 9-12 (1999).

⁹⁴ See, e.g., Jost, *Methodological Introduction*, *supra* note 93, at 2 (“Health care technology” is understood as “new drugs, devices, and medical procedures,” including technologies that utilize “high-tech equipment.”); see also Susan Bartlett Foote, *Frontiers of Medical Technology: Reflections on the Intersection of Innovation and the Health Care System*, 7 MINN. J.L. SCI. & TECH. 79, 80-81 (2005–2006) (describing “medical innovation” as including biologics, stents, medical lasers, magnetic resonance imaging, computerized tomography, positron emission tomography, and genomic medicine); Michael S. Mireles, *States as Innovation System Laboratories: California, Patents, and Stem Cell Technology*, 28 CARDOZO L. REV. 1133, 1135 (2006) (discussing stem cell technologies that “could lead to . . . treatments for . . . cancer, heart disease, diabetes, Alzheimer’s, Parkinson’s, HIV/AIDS, multiple sclerosis, and lung diseases” as “technological innovation”).

⁹⁵ See, e.g., Reed Abelson, *An M.R.I. Machine for Every Doctor? Someone Has to Pay*, N.Y. TIMES (Mar. 13, 2004), available at <http://www.nytimes.com/2004/03/13/business/13IMAG.html> (discussing patient demand for MRIs within small geographic areas).

⁹⁶ See, e.g., Hoangmai H. Pham et al., *Rapidity and Modality of Imaging for Acute Low Back Pain in Elderly Patients*, 169 ARCHIVE INTERNAL MED. 972, 978 (2009) (finding patient satisfaction to be a driver in rapid imaging); see also Richard J. Carroll et al., *International Comparison of Waiting Times for Selected Cardiovascular Procedures*, 25 J. AM. C. RADIOLOGY 557, 557 (1995) (finding significantly less waiting time in United States for cardiac imagery than in Canada, U.K., and Sweden).

problems is the fact that medical technology varies dramatically in price based on geography and despite demographics, so price variation does not necessarily reflect value.⁹⁷

Further, medical technology is of varied effectiveness. Ineffective technology may negatively impact health outcomes and result in costly follow-up care. PPACA contains provisions to provide assessments of technology, though they are not intended to be binding on insurers.⁹⁸ And what is ineffective for one patient may prove effective for another, which is something that scientists and physicians are beginning to understand more as we move toward personalized medicine. Decisions to limit patient choice with respect to technology are particularly fraught with issues when a patient is seeking last resort therapies, and conventional options are limited.

High technology health care does save lives. For example, a drug and radiation combination called Bexxar—which was approximately \$30,000 a treatment in 2003 when approved by the Food and Drug Administration (FDA) (cancer treatment prices today may be more than triple)—proved more effective than less costly traditional chemotherapy in treating some forms of leukemia.⁹⁹ Due to cost, a number of private insurers did not cover Bexxar at the time, and Medicare reduced reimbursement by approximately half in 2007, after competing drugs entered the market.¹⁰⁰ For some, lack of coverage literally meant the difference between life and death.

As a general matter, access to high technology health care may be limited by a cost containment mechanism called reference pricing, which allows insurers to cap the amount they will pay for a

⁹⁷ Randal Cebul et al., *Organizational Fragmentation and Care Quality in the U.S. Health Care System*, in *THE FRAGMENTATION OF U.S. HEALTHCARE*, *supra* note 29, at 37.

⁹⁸ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 3014, 124 Stat. 119, 384 (2010).

⁹⁹ Bexxar was removed from the market in 2014, when sales dropped to seventy-five patients. See Luke Timmerman, *Why Good Drugs Sometimes Fail: The Bexxar Story*, XCONOMY (Aug. 26, 2013), <http://www.xconomy.com/national/2013/08/26/why-good-drugs-sometimes-fail-in-the-market-the-bexxar-story/>. The story of Bexxar is an interesting one, as sales dropped after equally effective drugs entered the market that did not require a referral to an often competing institution for the radiation component. *Id.*

¹⁰⁰ See Alex Berenson, *Medicare Cuts Payment on Two Cancer Drugs*, N.Y. TIMES (Dec. 7, 2007), available at <http://www.nytimes.com/2007/12/07/business/07drug.html>.

particular procedure.¹⁰¹ For example, the reference price for an MRI might be \$2,000, but if the hospital charges the patient \$4,000, the patient will be responsible for the additional \$2,000. The extra \$2,000 is treated as an out-of-network expense and does not count toward the limits on the patient's annual out-of-pocket expenses. Even if patients had the ability to shop for lower-priced MRIs or other high technology health care, lower price options may not exist. Quality differences also may be a concern at lower price-points.

While other drivers of health care costs such as medical waste, ineffective health care services, and medical error may in theory be reduced, it is unlikely that access to high technology health care—unless it is grossly ineffective—will be limited due to social constraints. Patient demand is great for these technologies, particularly when it comes to potentially life-saving treatments.¹⁰² When the costs of health care increase, it is well known that insurers engage in a number of practices to try to recapture those expenditures, including reducing plan coverage and raising premiums. With some restrictions, both of these practices continue to be allowed after PPACA.

To be sure, PPACA eliminates lifetime and most annual limits on essential benefits as well as limitations on coverage for pre-existing conditions.¹⁰³ It requires that essential benefits are provided to plan participants in the health insurance exchanges as well as those

¹⁰¹ See, e.g., Ricardo Alonso-Zaldivar, *Feds Approve Cost-Control Strategy for Expensive Health Procedures*, PBS NEWSHOUR (May 15, 2014, 6:07 PM), <http://www.pbs.org/newshour/rundown/feds-approve-cost-control-strategy-expensive-health-procedures/>.

¹⁰² See Daniel Callahan, *Health Care Costs and Medical Technology*, in FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING BOOK FOR JOURNALISTS, POLICYMAKERS, AND CAMPAIGNS 79, 80 (Mary Crowley ed., 2008) (discussing patient demand for high technology health care, particularly at the end of life); see also BIPARTISAN POLICY CTR., WHAT IS DRIVING U.S. HEALTH CARE SPENDING? AMERICA'S UNSUSTAINABLE HEALTH CARE COST GROWTH (Sept. 2012), available at <http://bipartisanpolicy.org/wp-content/uploads/sites/default/files/BPC%20Health%20Care%20Cost%20Drivers%20Brief%20Sept%202012.pdf> (discussing patient demand for high technology health care and doctor provision of it, even when ineffective if not harmful, including at the end of life); Thomas J. Smith & Dan L. Longo, *Talking with Patients about Dying*, 367 NEW ENG. J. MED. 1651 (2012) (discussing patients' unrealistic expectations about treatments at the end of life).

¹⁰³ Patient Protection and Affordable Care Act § 1001 (annual limits). PPACA strengthens the prohibitions on pre-existing conditions contained in the Health Insurance Portability and Accountability Act of 1996. *Id.* § 1201; see 42 U.S.C. §§ 300gg-1, 300gg-3–300gg-4 (2012).

covered by individual and small group plans.¹⁰⁴ It also places some restrictions on premiums¹⁰⁵ and requires most people to purchase health insurance, which may prevent some gaps in coverage caused by higher premiums.¹⁰⁶ But premiums may be increased within certain thresholds and for actuarially sound reasons.¹⁰⁷ Quite a bit of room remains in the interpretation of “essential benefits,” and no requirements are imposed for coverage outside those benefits. Post-PPACA, some employees in fact experienced a reduction in their health plans, as large employers began to provide skeletal plans they argue comply with the law.¹⁰⁸ Further, businesses of fifty or more full-time employees providing health insurance for the first time under the Act’s mandates may provide minimal plans.

Social expectations about accessing high technology health care are deeply embedded in the legal structures that support public and private health insurance. These expectations do not contribute as directly to fragmentation as those that arise from a time-slice view of health care justice or from poor patient choices under CDHC, but they are likely to continue to drive costs up and ultimately to force reductions in coverage and higher premiums down the road. To the extent this occurs, health insurance that is designed to be comprehensive may fall short, creating fragmentation under both the traditional and my expanded definition.

D. Medical Specialization Is Required for the Best Patient Care

Though their reasons differ, both patients and medical providers seem to prefer narrow medical specialties, and this preference supports legal structures that fragment health care. At the most basic level, more specialists means more care and billing to coordinate.

¹⁰⁴ Patient Protection and Affordable Care Act § 1302.

¹⁰⁵ *Id.* § 1201; *see* 42 U.S.C. § 300gg.

¹⁰⁶ Patient Protection and Affordable Care Act § 1501. Exclusions exist for individuals with incomes below the federal tax threshold and qualifying religious objections as well as for Native Americans, undocumented immigrants, and incarcerated people. 26 U.S.C. § 5000A(d)-(e) (2013).

¹⁰⁷ Patient Protection and Affordable Care Act § 1201; *see* 42 U.S.C. § 300gg.

¹⁰⁸ Christopher Weaver & Anna Wilde Mathews, *Employers Eye Bare-Bones Health Plans Under New Law*, WALL ST. J. (May 29, 2013), available at <http://www.wsj.com/articles/SB10001424127887324787004578493274030598186>.

Nobody is charged with that task for the privately insured. PPACA provides for Medicare coordinators,¹⁰⁹ but it is unclear how well they will work, especially since Medicare requires separate billing for physician, hospital, and most other services.¹¹⁰ At a more complex level, patients' preference for specialists and practitioners' preference for specializing are reflected in legal structures in the informed consent area that may impose more legal liability on practitioners with less experience performing specialized tasks. Patients' and physicians' preferences are examined in turn.

The sense among many patients is that a specialist is more of a medical expert than a generalist. For example, patients may prefer an orthopedic instead of a general surgeon, an endodontist versus a general dentist, a urologist over an internal medicine doctor, or even an internal medicine doctor instead of a general practitioner, though each set of medical providers may be legally able and trained to perform the same tasks. The same also is true amongst other medical staff like nurses, where distinctions are made between specialty nurses like obstetrical-gynecological nurses and Registered Nurses, and between Registered Nurses and Licensed Practical Nurses.

These preferences are rational to the extent that specialists have more training, certifications, or experience treating certain conditions and performing particular procedures. The perception that a specialist is likely to bring about better health outcomes, though, may be false. At least one study in the mental health area shows that individuals receiving mental health care services from mental health providers instead of general practitioners did not have better health outcomes.¹¹¹ Although the reason for the result in this study is unclear, it might be the case that someone looking at a patient's health as a whole may be in a better position to treat a specific ailment.

Patients' views about specialists as medical experts are

¹⁰⁹ Patient Protection and Affordable Care Act § 3021.

¹¹⁰ Medicare has a "silo" approach to health care payment that imposes separate participation and cost-sharing requirements as well as payment systems for recipients of hospital services (Medicare Part A) and physicians' services (Medicare Part B). Elhauge, *supra* note 29, at 7.

¹¹¹ Barak Richman et al., *Fragmentation in Mental Health Benefits and Services: A Preliminary Examination into Consumption and Outcomes*, in *THE FRAGMENTATION OF U.S. HEALTHCARE*, *supra* note 29, 279, 292-99.

supported by legal and insurance structures. Legal structures require informed consent about physician-specific risks, including background and experience performing certain procedures.¹¹² Generalists are likely to have less experience than specialists with respect to performing some procedures and may be more prone to actions for breach of informed consent duties when medical harm occurs. Further, the standard of care in medicine determines whether a physician breaches her duty of care to a patient.¹¹³ Thus, if a physician deviates from standard (typically national) practice, she will be viewed as having breached her duty of care to her patient.¹¹⁴ The standard of care may vary between specialists and generalists, with specialists being held to a higher standard.¹¹⁵ But if patients expect a consistent skill level between generalists and specialists, courts could apply the standard of a specialist to a generalist performing the same task, increasing liability for generalists.

Insurance structures may afford more patient choice in selecting physicians and offer broader networks of specialists under health insurance plans. These structures include CDHC and other insurance arrangements like Point-of-Service and Preferred Provider Organizations, which typically do not require approval for specialist care. Health Maintenance Organizations (HMOs), physician-hospital organizations (PHOs), and other more tightly managed health care provider structures have fallen into disfavor, either because health care benefits are viewed as inadequate (which is the case with respect

¹¹² See, e.g., *Johnson v. Kokemoor*, 545 N.W.2d 495, 498 (Wis. 1996) (holding that evidence of a physician's experience performing a particular type of aneurysm clip was admissible at trial).

¹¹³ See, e.g., *Johnson v. Riverdale Anesthesia Assocs., P.C.*, 563 S.E.2d 431, 432 (Ga. 2002) (holding that the standard for breach in medical malpractice cases is that which is adopted by the medical profession generally).

¹¹⁴ *Id.* at 433.

¹¹⁵ See, e.g., *Aves v. Shah*, 997 F.2d 762, 765 (10th Cir. 1993) ("A doctor is entitled to be judged according to the standards of the particular school of medicine to which he belongs. If a doctor is a specialist and the patient accepts treatment with that understanding, it is the generally accepted rule that a physician, surgeon or dentist who holds himself out to be a specialist is bound to bring to the discharge of his professional duties as a specialist that degree of skill, care, and learning ordinarily possessed by specialists of a similar class, having regard to the existing state of knowledge in medicine, surgery and dentistry, that is, a higher degree of skill, care, and learning than that of the average practitioner." (internal citations omitted)).

to HMOs) or integration is insufficient to control costs or to increase quality (as with PHOs).¹¹⁶

Physicians and other medical personnel have distinct reasons for preferring specialization. These include the desire to focus academically and in practice on certain medical areas (perhaps based on intellectual interest or a lifestyle preference) as well as higher salaries. Specialists arguably believe they provide better care than nonspecialists in most circumstances.

Physician specialization is supported by medical school and residency program curricula, as well as the aforementioned legal structures that may impose greater liability on a generalist performing a specialized task than a specialist in certain circumstances, even though both are legally authorized to perform the same task. Additionally, legal structures that promote physician independence in medical practice exacerbate the fragmentation caused by medical specialization and are worth noting here. Physicians practice individually or in small groups organized separately from hospitals and health plans, and care varies by provider. No insurance or other law requires that physician care is coordinated by a particular physician or case manager.¹¹⁷ Most physicians, including specialists performing services at a hospital, are independent contractors who are not overseen by the hospital (or anyone) and who have separate billing practices. In fact, it is illegal in every state for physicians to split their fees with other physicians with whom they are not in partnership.¹¹⁸ Further, the corporate practice of medicine doctrine precludes a hospital, HMO, or other health care institution—entities that are not licensed physicians themselves—from interfering with the medical decisions of physicians who practice within their walls or otherwise directing the practice of medicine.¹¹⁹ State licensing laws impose similar restrictions.¹²⁰ With respect to public health insurance, Medicare laws

¹¹⁶ James F. Blumstein, *Of Doctors and Hospitals: Setting the Analytical Framework for Managing and Regulating the Relationship*, in *THE FRAGMENTATION OF U.S. HEALTHCARE*, *supra* note 29, at 135, 156.

¹¹⁷ Elhauge, *supra* note 29, at 3.

¹¹⁸ *Id.* at 12.

¹¹⁹ *Id.* at 7.

¹²⁰ *Id.* at 12.

do not allow the government to supervise medical providers or to choose them.¹²¹ Medicare patients also are billed separately for physician services.¹²²

How do patient and physician preferences for specialization affect health care delivery? The reality is that Medicare patients with chronic illnesses see about thirteen physicians a year; typical Medicare patients see five specialists and two generalist physicians annually.¹²³ Medicare patients with heart disease see an average of ten physicians within six different specialties.¹²⁴ Because few specialists are in multi-specialty practices, patients are likely traveling to separate physician offices for each specialist appointment, which does not comport with what one might expect for treatment of a single medical episode.¹²⁵

It is well documented that when care becomes decentralized, as it does amongst uncoordinated medical specialists, fragmentation in the traditional sense occurs. Lack of coordinated care may produce many problems, including inconsistency and redundancy in care. With respect to redundancy, independent specialists do not have available, or fail to trust, test results from other specialists' offices.¹²⁶ Repeating tests may have physical (especially in the case of CAT or PET scans, where radiation is used), mental, and financial consequences for patients as well as result in medical waste, which has costs for insurers and society. While electronic health records—which play a substantial role in PPACA—will improve availability of patient test results, they do not address physician mistrust.¹²⁷

Fragmentation also occurs under my expanded notion when the patient experience of a single episode of illness is treated separately

¹²¹ *Id.* at 11-12.

¹²² *Id.* at 7.

¹²³ *Id.* at 3; David A. Hyman, *Health Care Fragmentation: We Get What We Pay For*, in THE FRAGMENTATION OF U.S. HEALTHCARE, *supra* note 29, at 21, 23 n.7 (citing Hoangmai H. Pham et al., *Care Patterns in Medicare and Their Implications for Pay for Performance*, 356 NEW ENG. J. MED. 1130, 1130 (2007)).

¹²⁴ Cebul et al., *supra* note 97, at 37, 55.

¹²⁵ *Id.* at 46.

¹²⁶ Hyman, *supra* note 123, at 23.

¹²⁷ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 3002, 124 Stat. 119, 363-66 (2010).

by each examining specialist. Due to disintegrated care, patients experience a single episode of illness effectively as a recurring one, as they travel to various physician offices and medical institutions for diagnosis or treatment and are handled anew each time. Billing also is separate and uncoordinated.

These social assumptions about equality and rationing, patient autonomy, high technology health care, and medical specialization paradoxically support social and legal structures that fragment health care—the very result patients seek to avoid. It is likely that these social assumptions influence lawmakers considering health care delivery and financing, though that is an empirical claim I do not seek to prove in this Article. What is clear is that these social views are reflected in health laws. So while lawmakers support laws that may be consistent with consumer (and some physician) preferences regarding equality, autonomy, technology, and specialization, these laws may not uphold patients' overall goal of adequate access to health care over a lifetime. Compounding the problem is that health laws, at a more foundational level, contain deeply entrenched assumptions about human functioning and health that support health care fragmentation. Lawmakers in fact embrace assumptions about the human condition and experience that directly cause fragmentation.

III. LEGAL ASSUMPTIONS ASSOCIATED WITH FRAGMENTATION

Lawmakers make at least three assumptions about health that result in laws that fragment the human experience of illness. Individuals are: (1) fully functioning over a lifetime, (2) capable of laboring for wages, and (3) able to form and to order preferences and to participate in the market. Each is examined in turn.

A. Individuals Are Fully Functioning Over a Lifetime

Lawmakers often assume that individuals are healthy and fully-functioning over a lifetime. Illness (and disability) is considered an exception to the typical human state, rather than a part of it. This results in a fundamental misperception about illness and human vulnerability, causing a skewed legal response.

Illness is not an exceptional state but part of the human condition because everyone is universally vulnerable to it. This alone means

that health care services must be present throughout the lifecycle to facilitate functioning to prevent illness, and, if not to prevent it, to support health. Thus, health care services should be available regardless of whether illness manifests and before an individual becomes a patient. Further, all individuals will experience illness at some point in their lives, whether temporary or chronic, and these individuals are vulnerable to further illness. Many people—particularly women—live with chronic illness.¹²⁸ And people may experience periods of extended illness at the end of life, due to terminal illness, or chronic illness or organ failure in old age.¹²⁹

Under current legal structures, illness is treated as a discrete occurrence to be remedied by bursts of health care. As a result, public and private health insurance is structured to support sporadic deviations from health rather than to provide health care services throughout the lifecycle. Insurance plans primarily address acute illness or changes in health status, such as the federal Social Security Disability Insurance program, which provides medical and wage supports to workers who become disabled.

Other laws addressing illness provide limited protections against discrimination based on health status (rather than vulnerability to illness) and establish targeted rather than universal health benefit programs. Discrimination is prohibited based on disability,¹³⁰ current health status, and pre-existing conditions, but discrimination in premiums premised on actuarially sound calculations remains legal,

¹²⁸ See *Women and Disability: Chronic Illnesses*, CTR. ON HUMAN POL'Y, SYRACUSE U., <http://thechp.syr.edu/women-and-disability-chronic-illnesses/> (providing an extensive bibliography on the topic) (last visited Sept. 25, 2015).

¹²⁹ Daniel Callahan, Letter to the Editor, *Costs of Medical Care at the End of Life*, N.Y. TIMES (Jan. 10, 2013), http://www.nytimes.com/2013/01/11/opinion/costs-of-medical-care-at-the-end-of-life.html?_r=0 (discussing costs of extended illness in old age due to chronic illness and organ failure).

¹³⁰ Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12112(a), (b)(4), 12132 (codified as amended as 42 U.S.C. §§ 12101-12213; Interpretive Guidance on Title I of the Americans with Disabilities Act, 29 C.F.R. § 1630.4(a)(1)(vi), (f) (2015). Insurance classifications cannot be used to exclude individuals with disabilities from receiving benefits. 29 C.F.R. § 1630, app. § 1630.5. Historically, a “disability-based distinction” has been illegal if it targets a particular disability, group of disabilities, or disability in general. *But see* 42 U.S.C. § 12201(c)(1) (providing a safe harbor provision for “underwriting risks, classifying risks, or administering such risks . . . based on or not inconsistent with State law”).

so long as it does not exceed certain thresholds.¹³¹

Health insurance coverage is limited to a patchwork of government and private health care programs. Enrollment in government programs often depends on age, income, federal employment, or military status. Some people with specific diseases also are covered, such as patients with end-stage renal disease who require dialysis. In the private realm, health insurance is targeted in the sense that most group plan insurance is contingent on employment, with 66% of United States citizens receiving health insurance through their employer.¹³²

Health insurance coverage within government programs is restricted further by inconsistent eligibility standards. For example, Medicaid has various plan options with different standards for eligibility, resulting in disparities in access to services. These plans include fully capitated (prepaid per individual), partially capitated (limited to certain services), and managed fee-for-service arrangements.¹³³ Children and adults with disabling illness face different eligibility criteria for Medicaid, even if they have the same condition.¹³⁴ Individuals in debilitating pain may not be considered under Medicare or Medicaid to be “truly and justifiably in need,” while other individuals with debilitating conditions are so viewed.¹³⁵ Additionally, insured individuals may not enjoy comprehensive benefits, and private health insurance coverage typically tracks the coverage of federal entitlement programs.

By failing to recognize universal vulnerability to illness and the

¹³¹ Patient Protection and Affordable Care Act § 1201; see 42 U.S.C. § 300gg (2012).

¹³² 2014 *Employer Health Benefits Survey*, KAISER FAM. FOUND. (Sept. 10, 2014), <http://kff.org/health-costs/report/2014-employer-health-benefits-survey/> (last visited July 26, 2015).

¹³³ 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); see also Cynthia R. Schuster et al., *Partially Capitated Managed Care Versus FFS for Special Needs Children*, 28 HEALTH CARE FIN REV. 109, 109 (2007).

¹³⁴ See SOC. SEC. ADMIN., 2015 RED BOOK: A SUMMARY GUIDE TO EMPLOYMENT SUPPORTS FOR PERSONS WITH DISABILITIES UNDER THE SOCIAL SECURITY DISABILITY INSURANCE AND SUPPLEMENTAL SECURITY INCOME PROGRAMS 5 (2014), available at <http://www.socialsecurity.gov/redbook/documents/TheRedBook2015.pdf>.

¹³⁵ Timothy S. Jost, *Public Financing of Pain Management: Leaky Umbrellas and Ragged Safety Nets*, 26 J.L. MED. & ETHICS 290, 290 (1998).

reality that all individuals will experience illness at some point in their lives, lawmakers contribute directly to health care fragmentation as I understand it—that is, to the misalignment between the lived and legally-recognized experience. Health insurance is structured to address discrete episodes of illness instead of maintaining health. Because illness is viewed as exceptional rather than as part of the human condition, anti-discrimination protections are limited, and health insurance is not universal. Health care may be interrupted because individuals are not eligible for certain governmental or private plans; their ability to purchase health insurance is limited by premium rates, deductibles, or co-insurance; or their plans do not cover needed services.

B. Individuals Are Capable of Laboring for Wages

Related to the legal assumption that most individuals are full-functioning over a lifetime is the assumption that individuals are capable of laboring for wages. The patchwork of health care coverage in the United States relies heavily on private firms to provide health insurance to their employees. Even after health care reform, most individuals in the United States will continue to obtain health benefits through their employer.¹³⁶ In fact, PPACA mandates employer-provided insurance for employers with over fifty full-time employees,¹³⁷ mandatory enrollment for employers with over 200 employees,¹³⁸ and penalties for some employers whose employees purchase health care in the health insurance exchanges in lieu of employer-provided plans.¹³⁹

Individuals with health or other functional impairments that restrict their ability to work may be disadvantaged in acquiring health care in a number of ways. If they are unable to work and they

¹³⁶ The employer mandate will cover 72% of working Americans. See Juliet Eilperin & Amy Goldstein, *White House Delays Health Insurance Mandate for Medium-Size Employers Until 2016*, WASH. POST (Feb. 10, 2014), available at http://www.washingtonpost.com/national/health-science/white-house-delays-health-insurance-mandate-for-medium-sized-employers-until-2016/2014/02/10/ade6b344-9279-11e3-84e1-27626c5ef5fb_story.html.

¹³⁷ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1513, 124 Stat. 119, 253-56 (2010).

¹³⁸ *Id.* § 1511.

¹³⁹ *Id.* § 1411(e)(4)(B)(iii). Small businesses may take part in the health insurance exchanges. *Id.* § 1311(b)(1)(B).

qualify, they are limited to Social Security health (and wage) benefits for disability. These benefits take into account medical improvement as well as financial and material assets.¹⁴⁰ If individuals are able to work part-time, it is unlikely they will qualify for Social Security benefits or be insured by their employer, as health benefits are not required for part-time employees under PPACA's employer mandates. If individuals are able to work full-time, but their condition impacts their work productivity, they may have difficulty retaining their jobs and therefore their health insurance (and have no legal recourse under the Americans with Disabilities Act (ADA), which assumes the ability to perform the "essential functions" of one's job and the capability to be productive).¹⁴¹ Illness and other functional impairments also may impact the type of work one is able to do, which may affect job options, or prevent movement to firms offering more comprehensive or otherwise suitable health insurance plans.

For individuals unable to work altogether or unable to work in the productive manner that legal protection requires, the actual and legally-recognized experience of illness are different. This brings about health care fragmentation as I define it. The problem is especially acute for workers who, due to illness, are less productive than other similarly situated employees. These individuals may be unable to retain a job and be legally terminated under the ADA but ineligible for Social Security assistance because they are not sufficiently impaired.

C. Individuals Are Able to Form and to Order Preferences and to Participate in the Market

The next assumption about the ability to participate in the marketplace has two parts. First, lawmakers assume individuals have the mental ability to form and to order preferences. Second, they assume that if individuals have this ability, they are unimpeded in participating in the market. Either or both of these assumptions may be false.

Not all individuals are able to form and to order preferences. This may be particularly true for individuals who are temporarily or

¹⁴⁰ SOC. SEC. ADMIN., *supra* note 134, at 9-10, 39, 43, 57.

¹⁴¹ 42 U.S.C. § 12111(8) (2012).

permanently incapacitated due to illness as well as for some individuals with mental illnesses or other mental impairments that inhibit their ability to think in certain ways. Individuals with mental impairments also may be excluded from the marketplace if they do not have and require guardians or others to assist them. This may have two implications: individuals may not be able to work and to obtain insurance through their employer (as discussed in the previous subsection), and they may be unable to identify, to select, and to purchase other competitive health plans or health-related services.

Alternatively, some individuals may have the mental ability to form and to order preferences but face substantial barriers to accessing the health care marketplace. One such barrier is physical incapacitation due to illness or disability. Another significant barrier is discrimination based on race, disability, gender, or sexual orientation, which may or may not be related to health status. Such discrimination may be based on animus, ignorance, or failure to accommodate different methods of functioning. Racial disparities in access to health care are well-documented.¹⁴² While the roots of such discrimination are disputed, evidence suggests that discrimination may occur regardless of health insurance status (which might affect perception of ability to pay and could serve as a racially-neutral reason for denying services) and socioeconomic class.¹⁴³ Discrimination in access to health care may occur for individuals with disabilities who are unable to use standard medical equipment, such as examination tables or mammography machines.¹⁴⁴

¹⁴² See generally *Disparities Policy*, KAISER FAM. FOUND., <http://kff.org/disparities-policy/> (last visited July 26, 2015); *Minority Health: Reports*, CDC, <http://www.cdc.gov/minorityhealth/reports.html> (providing resources about racial disparities in access to health care) (last updated Sept. 10, 2013).

¹⁴³ See, e.g., Andrew J. Epstein & Bradford H. Gray, *Racial and Ethnic Differences in the Use of High-Volume Hospitals and Surgeons*, 145 ARCHIVES SURGERY 179-86 (2010) (finding in a study of 133,821 patients that white patients were more likely to be treated by high-volume hospitals and surgeons than black, Asian, and Hispanic patients, regardless of health status, insurance coverage, proximity to high-volume hospitals, education, or income); see also INST. OF MED., *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE* (2002), available at <http://iom.nationalacademies.org/Reports/2002/Unequal-Treatment-Confronting-Racial-and-Ethnic-Disparities-in-Health-Care.aspx>.

¹⁴⁴ See Elizabeth Pendo, *Disability, Equipment Barriers, and Women's Health: Using the ADA to Provide Meaningful Access*, 2 ST. LOUIS U. J. HEALTH L. & POL'Y 15, 18 (2008), reprinted in

Often these barriers to accessing health care are viewed as important but outside the scope of health care reform because they invoke larger social problems or laws not directly related to the provision of health care. But the work of Dorothy Roberts and others has shown that the link between social inequality and poor health states may not be as remote as one might think.¹⁴⁵ Roberts argues, for example, that discrimination results in women of color being exposed more often to toxins and illness within their living, work, and other environments; long-term incarceration and then subsequent poor health care within prisons; and poor health care following births or abortions, which leads to their infertility.¹⁴⁶ Treating the social causes of this infertility is the most effective (and arguably efficient) way to promote fertility. Yet political energy is focused on treating infertility after it arises through greater access to Artificial Reproductive Technologies.¹⁴⁷

Part of the issue is perhaps a narrow understanding of preventative care (and health care generally) that fails to take into account environmental exposures, safety, and nutrition. These areas are traditionally covered by public health laws and measures, which have little overlap with laws and policies affecting health insurance, health care delivery, and health care financing. And because public

RIGHTS OF THE DISABLED (Sonia Katoch, ed., 2010).

¹⁴⁵ See, e.g., Dorothy E. Roberts, *The Social Context of Oncofertility*, 61 DEPAUL L. REV. 777 (2012) (discussing social inequality and infertility). Evidence of the relationship between social and environmental factors and health has been building for well over a century. See Rudolf Virchow, *Report on the Typhus Epidemic in Upper Silesia*, 96 AM. J. PUB. HEALTH 2102, 2103 (2006) (reproducing excerpts of the original report from 1848: "For there can now no longer be any doubt that such an epidemic dissemination of typhus had only been possible under the wretched conditions of life that poverty and lack of culture had created in Upper Silesia. If these conditions were removed, I am sure that epidemic typhus would not recur."); see also RICHARD WILKINSON & KATE PICKETT, *THE SPIRIT LEVEL: WHY GREATER EQUALITY MAKES SOCIETIES STRONGER* 26 (2009) ("For instance, differences in the quality of medical care have less effect on people's life expectancy than social differences in their risks of getting some life-threatening disease in the first place. And even when the various services are successful in stopping someone re-offending, in curing a cancer, getting someone off drugs or dealing with educational failure, we know that our societies are endlessly recreating these problems in each new generation. Meanwhile, all these problems are most common in the most deprived areas of our society and are many times more common in more unequal societies."); Michael Marmot, *Social Determinants of Health Inequalities*, 365 LANCET 1099 (2005) (discussing social determinants of health).

¹⁴⁶ See Roberts, *supra* note 145, at 796-97.

¹⁴⁷ *Id.*

health laws focus on certain populations and health care delivery laws on individuals, lessons from public health often do not translate into health care delivery. Vulnerability theory offers an interesting insight here: perhaps neither public health nor health care delivery laws should look at discrete populations or individuals, but rather universal vulnerability of the entire population.

Another problem related to a narrow understanding of health is the failure of most health care laws to take into account the whole patient, in the sense of examining the source of particular ailments rather than simply treating symptoms. While osteopathic doctors (DOs) by definition consider the whole patient, most medicine in the United States is provided by allopathic doctors (MDs) who focus on treating a particular, specialized problem. Further, with patient numbers increasing and doctors' time per patient decreasing, both MDs and DOs in standard clinics often have eight to ten minutes a patient, allowing little time to assess the ontology of an illness.¹⁴⁸

Barriers to addressing structural impediments to health also exist at the regulatory level. Federal agencies like HHS, the Centers for Medicare and Medicaid Services, the Centers for Disease Control and Prevention (CDC), the FDA, the United States Department of Agriculture (USDA), and the Environmental Protection Agency do not have the authority (and possibly the knowledge) to coordinate with each other to address system-wide issues such as food deserts, food and water contamination, and environmental hazards affecting health.¹⁴⁹ The agencies largely operate independently, and, even if they have limited authority to coordinate their responses, have different missions. For example, the FDA has a "neutral" mission to protect health,¹⁵⁰ and the USDA supports and represents the interests

¹⁴⁸ See Pauline W. Chen, *For New Doctors, 8 Minutes Per Patient*, N.Y. TIMES (May 30, 2013), available at <http://well.blogs.nytimes.com/2013/05/30/for-new-doctors-8-minutes-per-patient/>.

¹⁴⁹ See, e.g., U.S. GOV'T ACCOUNTABILITY OFF., GAO-15-180, FEDERAL FOOD SAFETY OVERSIGHT: ADDITIONAL ACTIONS NEEDED TO IMPROVE PLANNING AND COLLABORATION 2 (2014), available at <http://www.gao.gov/assets/670/667656.pdf> ("[Existing] mechanisms do not allow FDA, FSIS [USDA], and other agencies to look across their individual programs and determine how they all contribute to federal food safety goals.").

¹⁵⁰ See FOOD & DRUG ADMIN., STATEMENT OF FDA MISSION, <http://www.fda.gov/downloads/aboutfda/reportsmanualsforms/reports/budgetreports/ucm298331.pdf> (last visited July 26, 2015).

of agribusiness,¹⁵¹ though both agencies may need to respond to issues of food safety. Some collaboration is possible, though, under current rules. For example, the FDA and USDA are working together to reduce and to monitor antibiotics placed in animal feed to make animals healthier or grow larger when they are intensively confined in factory farms to produce cheaper meat.¹⁵² But such collaborative efforts are an exception to the norm.

Legal assumptions about patients' ability to function over a lifetime, to work, and to participate in the market, treat illness as an exception to the human condition rather than a part of it. These assumptions do not appreciate universal and constant vulnerability to illness and the need for health insurance (and possibly health care services) throughout one's life. They fail to reflect the reality of the end of life, when health care services are required for most people, as well as the life of individuals with chronic disease. They also do not recognize preventative care as necessary throughout the lifecycle. Further, such legal assumptions fail to account for barriers, such as discrimination, to participating in the health care insurance market and to accessing health care services once insured.

PPACA was passed in 2010 as a comprehensive health care reform package intended, in part, to combat the effects of health care fragmentation as traditionally understood, that is, as uncoordinated care and payment. PPACA also goes some distance in addressing health care fragmentation under my expanded definition, in order to align better the lived patient experience with the legally-recognized one. The next part addresses PPACA's legal assumptions about human functioning and illness and its reforms relevant to health care fragmentation.

¹⁵¹ See *Agribusiness and Cooperatives*, U.S. DEP'T AGRIC., http://www.usda.gov/wps/portal/usda/usdahome?navtype=AU&navid=AGRIBUSI_COOP (last modified May 15, 2015).

¹⁵² See Press Release, FDA, *FDA Takes Steps to Protect Public Health* (Apr. 11, 2012), <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm299802.htm> (discussing collaboration with USDA to reduce antibiotics) (last updated May 13, 2013); *National Antimicrobial Resistance Monitoring System for Enteric Bacteria (NARMS)*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/narms/> (discussing collaboration between CDC, USDA, FDA, and other governmental entities to monitor antibiotics) (last visited July 26, 2015).

IV. LEGAL ASSUMPTIONS WITHIN THE PATIENT PROTECTION AND AFFORDABLE CARE ACT

PPACA shifts, to some degree, legal assumptions about human functioning and illness. This part explores how PPACA alters these assumptions as well as the specific reforms it contains that address health care fragmentation. It also discusses areas where PPACA may exacerbate fragmentation.

A. Many Individuals Are Not Fully Functioning Over a Lifetime

PPACA assumes that only some individuals are fully functioning over a lifetime. Illness is viewed as affecting many people and is addressed through expanded, targeted benefit programs, including the voluntary Medicaid expansion up to 138% above the federal poverty level (133% with a 5% income disregard),¹⁵³ the continuation of the Children's Health Insurance Program (CHIP) until 2019,¹⁵⁴ the establishment of health insurance exchanges for individuals 133%–400% above the federal poverty level and small business of up to 100 employees,¹⁵⁵ and other health insurance subsidies, including cost-sharing subsidies like out-of-pocket maximums.¹⁵⁶

These access provisions are based on a fundamental shift in thinking about human health needs. As Chief Justice Roberts of the United States Supreme Court stated in *National Federation of Independent Business v. Sebelius*,¹⁵⁷ the Medicaid expansion was intended as “a shift in kind, not merely in degree.”¹⁵⁸ It was intended to cover all non-elderly, non-pregnant individuals not entitled to

¹⁵³ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 2001, 124 Stat. 119, 271-79 (2010).

¹⁵⁴ *Id.* § 2101. Federal funding is through 2015. *Id.* Eligible children unable to enroll due to caps may receive tax credits in the health insurance exchanges. *Id.* § 2101(b)(1).

¹⁵⁵ *Id.* § 1311. Public funding is available from 2011-2015. *Id.* § 1311(d)(5)(A). After 2017, businesses with more than 100 employees may purchase policies in the health insurance exchanges. At least two multi-state plans must be offered by each exchange. *Id.* §§ 1301(a)(1)(C)(ii), 1311(d)(2)(B).

¹⁵⁶ *Id.* §§ 1302(c)(1), 1402(c)(1). Individuals in community-assisted living would have received services and other supports through the CLASS Act, which was repealed. *Id.* §§ 8001-8002; American Taxpayer Relief Act of 2012, Pub. L. No. 112-240, § 642, 126 Stat. 2313, 2358 (2012).

¹⁵⁷ *Nat'l Fed'n of Indep. Bus. v. Sebelius*, 132 S. Ct. 2566 (2012).

¹⁵⁸ *Id.* at 2605.

Medicare, that is, childless adults, some parents, and some children. While the Court ruled mandatory expansion of state Medicaid programs unconstitutional, it recognized Congress's intent to consider illness as more than sporadic, if not universal.¹⁵⁹ If the Medicaid expansion had passed constitutional muster, an estimated sixteen to seventeen million people would have been covered by that alone; thirty-two million additional people would have been covered taking into account other health care provisions, resulting in total coverage of 94% of the non-elderly population.¹⁶⁰ While Medicaid expansion still is evolving, approximately 5.6 million adults at 138% or below the federal poverty level live in states that do not plan to extend Medicaid.¹⁶¹

PPACA contains other Medicaid expansions. It provides new options for home and community-based services for individuals with incomes up to 300% of the maximum Supplemental Security Income payment for disability and who have a higher level of need.¹⁶² These individuals are permitted a full range of Medicaid benefits.¹⁶³ It establishes the Community First Choice Option, which gives states an additional 6% to provide community-based attendant supports and services for individuals with disabilities who require institutional-level care.¹⁶⁴ And it creates the State Balancing Incentive Payments Program to increase federal matching funds for non-institutionally-based long-term care services.¹⁶⁵

Additionally, PPACA increases Medicare coverage. It includes value-based purchasing and payment adjustments for hospitals

¹⁵⁹ *Id.* at 2605, 2608.

¹⁶⁰ Robert Pear, *Administration Advises States to Expand Medicaid or Risk Losing Federal Money*, N.Y. TIMES (Oct. 2, 2012), available at http://www.nytimes.com/2012/10/02/us.use-advises-stats-to-expand-medicaid-or-risk-losing-funds.html?_r=0.

¹⁶¹ Matthew Buettgens, *Medicaid Expansion Could Make Health Insurance Affordable for 5.6 Million*, URBAN INST. (Oct. 2, 2015), available at <http://www.urban.org/urban-wire/medicaid-expansion-could-make-health-insurance-affordable-56-million>.

¹⁶² Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 2402(b), 124 Stat. 119, 302 (2010).

¹⁶³ *Id.*

¹⁶⁴ *Id.* § 2401.

¹⁶⁵ *Id.* § 10202.

providing inpatient care,¹⁶⁶ increases payments for preventative services,¹⁶⁷ and eliminates the “donut hole” (expenses between where initial coverage ends and catastrophic coverage begins) in prescription drug plans.¹⁶⁸ The Act also establishes some programs to reduce gaps in providing care by better coordinating and overseeing care and payment, including the “bundled payments” pilot program,¹⁶⁹ the Patient-Centered Medical Home pilot program,¹⁷⁰ and the Independence at Home Demonstration Program.¹⁷¹

PPACA improves eligibility for private insurance coverage as well. PPACA expands private insurance through employer mandates (addressed in the next subsection). Dependent coverage is extended under COBRA until age twenty-six.¹⁷² PPACA eliminates pre-existing condition clauses for adults and for children.¹⁷³ It removes lifetime limits¹⁷⁴ and most annual limits for essential benefits,¹⁷⁵ prohibits insurance rescissions,¹⁷⁶ and shortens group health plan waiting periods to ninety days or less.¹⁷⁷ Insurance companies are required to offer group and individual policies to every employer and person, respectively, who applies for coverage and to renew them at the option of each employer or insured.¹⁷⁸ Health plans are barred from discriminating on the basis of health status.¹⁷⁹

PPACA also alters other private health insurance market

¹⁶⁶ *Id.* § 3001.

¹⁶⁷ *Id.* § 1001.

¹⁶⁸ *Id.* §§ 3301, 3315.

¹⁶⁹ *Id.* § 3023.

¹⁷⁰ *Id.* § 3502.

¹⁷¹ *Id.* § 3024.

¹⁷² *Id.* § 1001; *see* 42 U.S.C. § 300gg-14 (2012).

¹⁷³ Patient Protection and Affordable Care Act § 1201; *see* 42 U.S.C. §§ 300gg-1, 300gg-3–300gg-4.

¹⁷⁴ Patient Protection and Affordable Care Act § 1001; *see* 42 U.S.C. § 300gg-11.

¹⁷⁵ Patient Protection and Affordable Care Act § 1001; *see* 42 U.S.C. § 300gg-11.

¹⁷⁶ Patient Protection and Affordable Care Act § 1001; *see* 42 U.S.C. § 300gg-12.

¹⁷⁷ Patient Protection and Affordable Care Act § 1201; *see* 42 U.S.C. § 300gg-7.

¹⁷⁸ Patient Protection and Affordable Care Act § 1201; *see* 42 U.S.C. §§ 300gg-1–300gg-2.

¹⁷⁹ Patient Protection and Affordable Care Act § 1201; *see* 42 U.S.C. § 300gg-4.

requirements. It places restrictions on premiums¹⁸⁰ and limits deductibles and co-insurance in individual and small group markets.¹⁸¹ It requires health plans to cover preventive services without cost-sharing, including United States Preventive Services Task Force recommended items, CDC recommended immunizations, breast cancer screenings, and Health Resources and Services Administration recommendations.¹⁸² Health status, medical conditions, claims experience, medical history, genetic information, and domestic violence cannot be taken into account in insurance coverage or premiums.¹⁸³

Further, PPACA contains a number of provisions directed at improving the patient experience and health outcomes within both public and private insurance. PPACA finances pilot programs to study ACOs, long-term care, and payment bundling for the same medical episodes.¹⁸⁴ It establishes the Center for Medicare and Medicaid Innovation to study, in part, payment and service delivery.¹⁸⁵ It establishes Medicare Pay-for-Reporting and Pay-for-Performance programs.¹⁸⁶ It creates incentives to promote primary care and prevention within Medicare, Medicaid, community clinic, and employer programs.¹⁸⁷

Medicaid enrollees are allowed to establish a health home if they have at least two chronic physical conditions, one such condition and are at risk of developing another, or have at least one serious and persistent mental health condition.¹⁸⁸ This program is especially interesting as it recognizes vulnerability to future illness by those who are already ill. The program provides participating states with 90% federal assistance for two years for home health-related services,

¹⁸⁰ Patient Protection and Affordable Care Act § 1201; *see* 42 U.S.C. § 300gg.

¹⁸¹ Patient Protection and Affordable Care Act § 1302(c).

¹⁸² *Id.* § 1001; *see* 42 U.S.C. § 300gg-13.

¹⁸³ Patient Protection and Affordable Care Act § 1201; *see* 42 U.S.C. § 300gg-4.

¹⁸⁴ Patient Protection and Affordable Care Act §§ 3022, 3024.

¹⁸⁵ *Id.* § 3021.

¹⁸⁶ *Id.* §§ 10326-10327.

¹⁸⁷ *Id.* §§ 4003, 4104-4108, 4201-4202, 4303, 5405, 5501, 10503.

¹⁸⁸ *Id.* § 2703.

including care management and coordination.¹⁸⁹

A number of other initiatives seek to improve patient care. PPACA charges HHS with improving health care quality, that is, health care delivery and health outcomes. It extends the Medicaid Money Follows the Person Rebalancing Demonstration through September 2016.¹⁹⁰ It allocates \$10 million per year for five years to continue the Aging and Disability Resource Centers initiatives,¹⁹¹ establishes the Community-Based Collaborative Care Network Program to coordinate and to integrate health care services for low-income populations,¹⁹² and creates Healthcare Innovation Zones for integrated care.¹⁹³ Additionally, it establishes the National Prevention, Health Promotion and Public Health Council to coordinate federal prevention and wellness activities.¹⁹⁴

Even if Congress recognized vulnerability to illness as universal and constant, PPACA stops short of responding to it as such, and, with the exception of Medicaid health homes, to responding to the fact that individuals who are ill are vulnerable to further illness. The former is evident on at least two fronts. First, PPACA excludes some people from coverage. An estimated twenty-three million people remain uninsured, including seven to eight million undocumented immigrants.¹⁹⁵ Second, PPACA allows some individuals to be charged higher premiums, such as individuals who use tobacco, so long as such premiums do not exceed certain thresholds (for tobacco, a one and a half to one ratio of the standard premium).¹⁹⁶

PPACA also appears to exclude some people with disabilities from consideration. The Act aims to reduce health care costs rather than to provide what is required for functionality. For example,

¹⁸⁹ *Id.*

¹⁹⁰ *Id.* § 2403.

¹⁹¹ *Id.* § 2405.

¹⁹² *Id.* § 10333.

¹⁹³ *Id.* § 3021.

¹⁹⁴ *Id.* § 4001.

¹⁹⁵ *Id.* § 1312(f). The Act treats undocumented immigrants as if they are not members of the United States community.

¹⁹⁶ *Id.* § 1201; see 42 U.S.C. § 300gg (2012). Responding to vulnerability in this context is trumped by Congress's desire to impose responsibility for behavioral "choices."

PPACA imposes taxes on “Cadillac” plans,¹⁹⁷ which might be necessary for some individuals with disabilities who have greater health care needs.¹⁹⁸ Similarly, strict adherence to a range of essential benefits—as opposed to functional benchmarks—could frustrate equal access to health care for individuals with disabilities (and possibly be counter-productive to reducing costs).¹⁹⁹ Individuals with disabilities also may not be able to access care if they live in a state that fails to adopt the Medicaid expansion or has reduced Medicaid benefits that they require, or they earn too much money to receive other federal insurance subsidies.²⁰⁰

Premiums based on wellness targets pose additional potential hurdles to health care access for individuals with disabilities.²⁰¹ PPACA allows exemptions from wellness targets based on physician certification,²⁰² but it is unclear whether these exemptions will be used to prevent premium discrimination against individuals with disabilities.²⁰³ If they are not, it is uncertain whether wellness programs could be challenged successfully under the ADA. It is unclear whether the definition of “disability” includes people who cannot meet wellness targets. Further, wellness programs may not entail illegal classifications based on disability, as they present nondiscriminatory reasons for premium differences. PPACA itself states that premium differences under wellness programs are not discrimination based on health status, which would be illegal under

¹⁹⁷ Patient Protection and Affordable Care Act § 9001.

¹⁹⁸ Anita Silvers & Leslie Francis, *Human Rights, Civil Rights: Prescribing Disability Discrimination Prevention in Packaging Essential Health Benefits*, 41 J.L. MED. & ETHICS 781, 788 (2013).

¹⁹⁹ *Id.* at 785, 788. Essential benefit plans also may vary by state. *Id.* at 788.

²⁰⁰ *Id.* at 788.

²⁰¹ Patient Protection and Affordable Care Act § 1201; *see* 42 U.S.C. § 300gg-4. But wellness programs need not be based on wellness targets (that is, “health contingent”). Some are “participatory” in nature and reimburse regardless of health outcomes, for example, for participation in a smoking cessation program regardless of whether one quits smoking. Patient Protection and Affordable Care Act § 1201; *see* 42 U.S.C. § 300gg-4.

²⁰² Patient Protection and Affordable Care Act § 1201; *see* 42 U.S.C. § 300gg-4.

²⁰³ Silvers & Francis, *supra* note 198, at 789. Wellness programs also may impact premiums of individuals who are obese but not necessarily disabled. *See* Lindsay F. Wiley, *Shame, Blame, and the Emerging Law of Obesity Control*, 47 U.C. DAVIS L. REV. 121, 154-56 (2013).

the Act.²⁰⁴

B. Most Individuals Are Capable of Laboring for Wages

PPACA furthers the assumption that most individuals are capable of laboring for wages. I say most and not all, since PPACA contains the voluntary Medicaid expansion and establishes health insurance exchanges, which may provide health insurance to some individuals who do not work.

PPACA creates employer-provider mandates for all but small employers.²⁰⁵ All employers with fifty or more full-time employees must offer health insurance to their employees or pay a penalty of \$2,000 per full-time employee, excluding the first thirty.²⁰⁶ Employers with 200 or more full-time employees must automatically enroll their employees in health insurance.²⁰⁷ Employers with more than fifty full-time employees who offer insurance coverage but who have at least one full-time employee receiving a premium tax credit must pay a penalty.²⁰⁸ The penalty is the lesser of \$3,000 for each employee receiving the credit or \$2,000 (excluding the first thirty) for each full-time employee.²⁰⁹ An exception is made for employees eligible for a voucher to purchase insurance in a health insurance exchange.²¹⁰ Such eligibility is measured by whether the employee has an income of less than 400% of the federal poverty level, and the employer-provided plan has a premium of 8%-9.8% of their salary.²¹¹

PPACA also creates incentives for some small businesses that fall outside the employer mandates. Small businesses may purchase insurance in a health insurance exchange,²¹² and employers with

²⁰⁴ Patient Protection and Affordable Care Act § 1201; *see* 42 U.S.C. § 300gg-4; *see also* Silvers & Francis, *supra* note 198, at 789.

²⁰⁵ Patient Protection and Affordable Care Act § 1513.

²⁰⁶ *Id.*

²⁰⁷ *Id.* § 1511.

²⁰⁸ *Id.* § 1513. This might occur if the premium is more than 9.5% of household income, or the offered health plan fails to cover at least 60% of the actuarial value of the cost of benefits. *Id.* §§ 1512, 10108(c).

²⁰⁹ *Id.* § 9001.

²¹⁰ *Id.* § 10108.

²¹¹ *Id.* § 10108(c)(1).

²¹² *Id.* § 1311(b)(1)(B).

twenty-five or less full-time employees who offer health insurance to their employees may receive a small business tax credit.²¹³

C. Many Individuals Are Unable to Form and to Order Preferences and to Participate in the Market.

Perhaps the greatest shift with respect to previous assumptions about health and illness is Congress's recognition that many individuals are not able to participate in the market. PPACA acknowledges and seeks to address discrimination based on health status. But PPACA does little to assist individuals with severe illness or disabilities who are unable to participate in the market due to physical incapacitation, cognitive impairment, or mental illness. The latter two groups of individuals may not be able to form and to order preferences. Additionally, PPACA does not speak to the social determinants of health discussed in Part III that inhibit participation in the market.

PPACA does recognize that all ill individuals are vulnerable to disadvantage, including discrimination, based on health status. The Act makes discrimination based on health status in determining eligibility for health insurance illegal.²¹⁴ It eliminates pre-existing condition clauses along with lifetime and most annual limits on health care spending.²¹⁵ A temporary high-risk pool even was created in 2010 to capture previously uninsurable individuals.²¹⁶

In addition to increasing eligibility for insurance, PPACA expands insurance options through tax credits, health insurance exchanges, mandatory employer plans, and the voluntary state Medicaid expansion.²¹⁷ PPACA also requires that essential benefits be provided by the exchanges and certain other health plans.²¹⁸ These include emergency, hospital, physician, preventative, mental health care, rehabilitative and habilitative, and laboratory services as well as

²¹³ *Id.* § 1421.

²¹⁴ *Id.* § 1201; *see* 42 U.S.C. § 300gg-4 (2012).

²¹⁵ Patient Protection and Affordable Care Act §§ 1001, 1201; *see* 42 U.S.C. §§ 300gg-1, 300gg-3-300gg-4, 300gg-11.

²¹⁶ Patient Protection and Affordable Care Act § 1101.

²¹⁷ *Id.* §§ 1311, 1331, 1401-1402, 1513.

²¹⁸ *Id.* § 1302.

prescription drugs.²¹⁹

While health care services for mental illness are included in “essential benefits”—which would seem to reach some individuals who are unable to form and to order preferences and to participate in the market—this mandate does not apply to large group or grandfathered plans.²²⁰ And under the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (Mental Health Parity Act), employers with fifty or more employees may choose not to offer mental health care services, if coverage raises plan costs by greater than 2% in the first year or by 1% each year thereafter.²²¹ Further, the Mental Health Parity Act does not mandate that an employer cover any particular range of mental health care services.²²²

Further, PPACA does not address the social determinants of health that may prevent individuals from participating in the market. Since structural inequality and personal or institutional bias may remain, PPACA may fail to improve health care for some²²³ and even exacerbate existing inequality for others.²²⁴ Some programs, such as those based on wellness targets, assume that poor nutrition, tobacco and other addiction, and additional harmful behaviors are based on choice—for which individuals should be held accountable—when they may not be.

For individuals who are unable to participate in the marketplace due to incapacitating illness, the individual mandate might prove quite harsh. It is to be phased in from 2014-16, and in 2016 will require that individuals purchase coverage or pay a penalty of either \$695 per adult and \$347 per child (up to \$2,085 per family) or 2.5% of

²¹⁹ *Id.* § 1302(b)(1).

²²⁰ See Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, § 2301, 124 Stat. 1081-82 (2010).

²²¹ Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008, Pub. L. No. 110-343, § 512(a)(3)(B), 122 Stat. 3881-82 (2008).

²²² *Id.* § 512(a)(4).

²²³ Rene Bowser, *The Affordable Care Act and Beyond: Opportunities for Advancing Health Equity and Social Justice*, 10 HASTINGS RACE & POVERTY L.J. 69, 112-17 (2013) (discussing structural inequality and race).

²²⁴ Ruqaiijah Yearby, *Breaking The Cycle of “Unequal Treatment” With Health Care Reform: Acknowledging and Addressing the Continuation of Racial Bias*, 44 CONN. L. REV. 1281, 1313-32 (2012) (discussing racial inequality and health care reform).

household income, whichever is greater.²²⁵ Some exemptions exist, but not for poor health status.²²⁶

D. Fragmentation Exacerbated by the Patient Protection and Affordable Care Act

In other ways, PPACA may exacerbate health care fragmentation under both the traditional and my expanded definition. One area of concern is PPACA's alteration of safety net financing for hospitals. PPACA reduces Medicare's Disproportionate Share Payments for hospitals providing uncompensated care.²²⁷ While hospitals are expected to recoup this loss through other savings under the Act, if they cannot, poor patients may go untreated. Despite the Emergency Medical Treatment and Labor Act, which requires all hospitals receiving Medicare payments and operating an emergency room to provide emergency medical care, patient dumping (which often involves shifting patients to more urban hospitals) still occurs.²²⁸ Hospitals struggling to provide uncompensated care may need to cut costs in other ways, creating gaps in care for different populations of patients. Some hospitals may go bankrupt, and closing the doors of a large urban hospital may be catastrophic for patients. Cuts to Disproportionate Share Payments could be a classic case of law recognizing one experience for patients (and hospitals), and reality imposing another.

The disjunction between the lived and legally-recognized patient experience also occurs with respect to accessing pharmaceuticals. PPACA does not contain many measures to control drug costs. When drug prices rise, insurers cover fewer drugs in an attempt to recoup costs. Reduced drug formularies may affect patient outcomes, even when drugs are similar, or, in some cases like allergies to inactive ingredients, when the active ingredients are the same. Some life-saving drugs may not be covered at all.

PPACA perpetuates the status quo under the 2003 Medicare Modernization Act (Part D Prescription Drug Benefit), which

²²⁵ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1501, 124 Stat. 119, 242-49 (2010).

²²⁶ See *supra* note 106 and accompanying text.

²²⁷ Patient Protection and Affordable Care Act § 3133.

²²⁸ Emergency Medical Treatment and Labor Act, 42 U.S.C. § 1395dd (2012).

prohibits the federal government from negotiating drug prices with pharmaceutical companies on behalf of Medicare. Given the costs of high technology health care discussed in Part II, this compromise may undermine health care savings under PPACA. This is especially so as personalized medicine evolves and places a focus on pharmaceuticals, and new last resort treatments continue to escalate in price into the tens and sometimes hundreds of thousands of dollars per treatment.

At the same time, PPACA contains provisions to foster greater drug access. The Act closes the “donut hole” in drug coverage, eliminates lifetime and most annual caps on essential benefits including drug coverage, and improves access to innovative medical therapies.²²⁹ The latter includes drug discounts for patients of rural referral centers and some children’s, critical access, free-standing cancer, and sole community hospitals.²³⁰

PPACA also contains provisions to bolster competition amongst drug makers for at least one new class of drugs—biologics—though it is unclear how these provisions will affect expenditures. The Act allows the FDA to license a product that is “biosimilar” to or interchangeable with an approved, licensed product after the original (reference) product has been on the market for twelve years.²³¹ Subsequent interchangeable products may be licensed a year later.²³² But since the passage of PPACA, no biosimilars have been marketed in the United States.²³³

Additionally, PPACA may exacerbate health care fragmentation for retirees by creating gaps in insurance coverage. The Act imposes more insurance costs on employers for current employees, which may restrict employer health plans for retirees.²³⁴ The effect of this

²²⁹ Patient Protection and Affordable Care Act §§ 1001, 3301, 7001-7103; see 42 U.S.C. § 300gg-11 (2012).

²³⁰ Patient Protection and Affordable Care Act § 7101(b).

²³¹ *Id.* § 7002.

²³² *Id.*

²³³ *News Hour: What's Keeping Less Expensive Biologic Drugs from the U.S. Market?* (PBS television broadcast Apr. 19, 2014), available at <http://www.pbs.org/newshour/bb/whats-keeping-generic-version-biologic-drugs-u-s-market/>.

²³⁴ Susan E. Cancelosi, *The Bell is Tolling: Retiree Health Benefits Post-Health Reform*, 19 ELDER L.J. 49, 97 (2011).

remains to be seen, however, since PPACA provides public options through the health insurance exchanges for early retirees and Medicare exists for other retirees, which may reduce gaps in coverage overall.²³⁵

V. ACCOUNTING FOR THE LIVED EXPERIENCE AFTER HEALTH CARE REFORM

Given the many facets of health care reform, it is difficult to speak generally about how to represent better the patient experience and to prevent fragmentation. Cutting across social and legal assumptions about the patient experience, three broad categories of issues emerge: concerns about health care access, delivery, and quality. Each may be broken down into subtopics.

Issues of access include lack of insurance (uninsurance or underinsurance), coverage of health care services, and availability of such services; prohibitive deductibles or co-insurance rates; and discrimination. Preventing discrimination requires better ways to enforce antidiscrimination laws and to address the sources of discrimination. Other access issues may be remedied substantially by universal health insurance or expanded targeted insurance programs that seek to provide care over a lifetime—before and after individuals become patients—rather than according to a time-slice view addressing only health crises. Under an expanded targeted program approach, additional support would be needed for institutions that provide uncompensated care to both documented and undocumented patients.

Issues with health care delivery include the failure to treat a single episode of care as one event for health services coordination and billing purposes. This not only fragments care in the traditional sense, it creates a misalignment between the patient's experience of a single episode of illness and insurance structures that treat it as separate events. Coordinating care and billing goes only so far in addressing this issue. Large structural impediments to more continuous care based on how medicine is practiced and managed must be eliminated. Physicians are independently organized, and under the corporate practice of medicine doctrine, medical

²³⁵ *Id.* at 108-16.

institutions cannot direct care. Patients' and lawmakers' assumptions about the patient experience also must be reshaped. In this context, the law reflects social assumptions about the value of physician specialization and CDHC, but fragments care for the patient. Less reliance could be placed on specialist care and more on holistic care. More traditional insurance models may better aid patient choice by defining (and narrowing) the range of covered services and promoting physician-patient dialogue about choice among them; they also would eliminate the need to negotiate prices.²³⁶

Problems with health care quality form another subcategory of issues to be addressed. In this instance, high technology health care does not always generate the best or desired patient outcomes. Thus, following social assumptions about the benefit of such health care services may not serve patients' overall goals with respect to health outcomes. Legal assumptions in this area parallel social ones, and lawmakers have the difficult task of reshaping legal assumptions in this and other areas. Each of these subtopics is addressed briefly below in the context of universal and targeted health care programs and changing legal assumptions. My hope is to begin a conversation about these different approaches to remedying health care fragmentation.

A. Creating Universal Programs

The only way to close gaps in formal access to a basic level of health care services completely is through universal health care coverage throughout the lifecycle that does not require an emergency event. PPACA is essentially a broader, targeted approach than previous government-funded options with some universal elements, for example, coverage for all individuals within certain employment or other categories. Historically, the United States has witnessed a gradual expansion of targeted government health care programs, including Medicare and Medicaid (1965), CHIP (1997), and Medicare Part D Prescription Drug Benefit (2003). One possibility is to reconsider a public option. The Federal Employee Health Benefit Program generally is successful and could be expanded to the United

²³⁶ Satz, *Toward Solving the Health Care Crisis: The Paradoxical Case for Universal Access to High Technology*, *supra* note 47, at 101-02.

States population. Regardless of which model is adopted, universal programs inherently reduce gaps in coverage and, at least on that front, better align the legal and lived patient experience. Targeted programs also may be modified to account better for the lived experience.²³⁷

B. Expanding Targeted Programs

The United States health care system is not actually one system but a patchwork of programs. One possibility for addressing fragmentation is to continue working within that paradigm, and to expand further targeted programs. A natural place to look—as Massachusetts did before PPACA—is to Medicaid. Further voluntary expansion of Medicaid could allow greater coverage for citizens as well as undocumented workers, who historically received some services, such as dialysis, through state Medicaid programs. Another way to work within a targeted program approach is to change legal assumptions about the patient experience that may cause fragmentation.

C. Changing Legal Assumptions About the Patient Experience

Addressing legal assumptions about health and illness that fragment health care need not involve an expansion of material benefits. In a number of areas, the law could be reshaped to reflect better the patient experience. And to the extent resources are involved, they may be shifted from one approach to another.

One area where PPACA appears to do the latter successfully is fostering greater access to community and home services for some individuals with illness or disabilities. In this context, community and home services allow less restrictive settings than institutions and may bring about better health outcomes. A number of famous examples illustrate that point, including Lois Curtis, one of the litigants in *Olmstead v. L.C.*,²³⁸ who went from living in a cement room in a mental health institution to living in a community-based setting

²³⁷ Of course even within universal health care systems, gaps may occur under rationing protocols, or the patient's lived and legally-recognized experience of coverage may not align due to waiting lists, as under the U.K.'s National Health Service.

²³⁸ *Olmstead v. L.C.*, 527 U.S. 581 (1999).

and thriving as an artist.²³⁹

On other fronts, PPACA is less successful in appreciating the lived experience. For example, the wellness initiatives under the Act fail to acknowledge that wellness may be relative to individuals regardless of personal health choices, and that some “choices” are not fully voluntary. Similarly, the Act does not account directly for the social determinants of health, including discrimination based on race, disability, and gender. Here it is possible to take a lesson from disability accommodation law: formal access does not equate with meaningful access. Health care laws could consider the causes of illness and its prevention in much broader terms. Similarly, they could recognize that some poor health states, even those stemming from negative health behaviors, may not be based on autonomous choice and are undeserving of less favorable legal treatment.

On a meta-level, PPACA also encounters difficulty appreciating the lived experience by providing health care resources largely after an individual becomes a patient, when health needs clearly begin prior to that time. A radical way of re-envisioning health care would be to shift the point at which a patient accesses health care services. Evidence suggests that providing services before someone finds themselves a patient is not only more economical, but likely to address vulnerability to illness at a more appropriate point. For example, providing wellness information (different from PPACA’s wellness programs, which often reward certain health states or behaviors) or preventative care earlier in patients’ lives could reshape insurance structures and improve patients’ health outcomes.²⁴⁰

Bill Sage has eloquently discussed the timing of medical interventions in terms of “upstream” and “downstream” health

²³⁹ See generally Robin Nelson, *Unlocked: The Lois Curtis Story*, DIXIE’S LAND (Nov. 27, 2010), available at <https://assignmentatlanta.wordpress.com/2010/11/27/unlocked-the-lois-curtis-story/>.

²⁴⁰ Kenneth L. Brigham, *Predictive Health: The Imminent Revolution in Health Care*, 58 SUPP. J. AM. GERIATRICS SOC’Y S298, S301 (2010) (reporting that after receiving corresponding wellness information a cohort of fifty-one patients experienced “statistically significant reductions in BMI, percentage of body fat, and systolic blood pressure,” and that “[f]itness (maximum oxygen uptake) improved significantly, fasting blood glucose decreased, and serum high-density lipoprotein concentrations increased...[s]tandardized instruments evaluating depression, anxiety, and stress also all improved significantly”).

care.²⁴¹ Downstream health care is that which begins once an individual becomes a patient.²⁴² Upstream health care is prior to that time, including everything from mobile health applications for smart phones to preventative health care services.²⁴³ Sage argues that upstream health care involves “redesigning communities and redeveloping the workforce to discourage unhealthy activities, reinforce healthy ones, and serve the sick and elderly where they live.”²⁴⁴

According to Sage, this reframing of health care is necessary for both health care innovation and cost-savings.²⁴⁵ But I believe the value of his insights extends well beyond these goals to include addressing the disparity between the lived and legally-recognized patient experience. Health is not the product of discrete health care services but of a lifetime of access to services and wellness information that shape physical resilience, behavior, and lifestyle. Sage alludes to this when he describes the upstream health sector as including “services delivered to people who are living their daily lives rather than people who have been plucked from those lives and labeled ‘patients.’”²⁴⁶

D. Rethinking Patient-Centered Care

Another way to address health care fragmentation and to account for the actual patient experience, ironically, may be to move away from current patient-centered care models. Given patient limitations in evaluating and choosing care under CDHC, the dispositional autonomy of patients likely is best protected by other insurance models. Further, patient choice of a range of services does not require CDHC, despite public perception.²⁴⁷ Rationing approaches

²⁴¹ See, e.g., William M. Sage, *Putting Insurance Reform in the ACA's Rear-View Mirror*, 51 Hous. L. R. 1081, 1113 (2014); William M. Sage & Kelley McIlhattan, *Upstream Health Law*, 42 J.L. MED. & ETHICS 535 (2014).

²⁴² Sage, *supra* note 241, at 1113; Sage & McIlhattan, *supra* note 241, at 535–36.

²⁴³ Sage, *supra* note 241, at 1113; Sage & McIlhattan, *supra* note 241, at 535–36.

²⁴⁴ See William Sage, *Preserving The Republic: Chief Justice Roberts' Affordable Care Act Opinion*, HEALTH AFF. BLOG (June 30, 2012), <http://healthaffairs.org/blog/2012/06/30/preserving-the-republic-justice-roberts-affordable-care-act-opinion/>.

²⁴⁵ See, e.g., Sage, *supra* note 241, at 1113.

²⁴⁶ *Id.*

²⁴⁷ Satz, *Toward Solving the Health Care Crisis: The Paradoxical Case for Universal Access to High*

could make a larger number of health care services available to eligible patients under more standard health insurance policies.²⁴⁸

CONCLUSION

PPACA addresses only some issues of fragmentation, as understood under both the traditional conception and my expanded notion. Fragmentation could be further remedied by increasing material benefits to reduce gaps in health care that frustrate the patient experience. Other reforms to address fragmentation might simply entail a better understanding of the patient experience and how resources are best directed. Since key social assumptions about health care paradoxically support fragmentation, the public must be educated about their own misperceptions. Lawmakers must then battle deeply-entrenched legal views about health and illness that fragment care, in order to bring about reform.

Technology, *supra* note 47, at 101–02.

²⁴⁸ *Id.*